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Emeline Brulé

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*Emeline Brulé*

# Understanding Visually Impaired Children's Experiences of Schooling

A FRENCH ETHNOGRAPHIC AND DESIGN INQUIRY



*This thesis is dedicated to  
Louisette Guienne,  
the giant on whose shoulders I stand.*

## *Remerciements*

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### *Notes on templating*

Short citations are placed on the right margin on the page and can be found in full at the end of the manuscript. Footnotes are placed in the right margin as well.

In excerpt from discussions 'E:' indicates my interventions.

In the text-body, the bold is use to **emphasize** concepts or propositions, while italic for *citations and field-notes*.

I chose to align the text on the left, rather than justify it, as it improves the readability of long paragraphs.

### *List of acronyms*

CDAPH: Disabled Persons' Rights and Autonomy Committee (Commission des Droits et de l'Autonomie des Personnes Handicapées)

DEPP: Direction for the Evaluation, Prospective and Performance of the Ministry of Education (Direction de l'évaluation, de la prospective et de la performance)

INSEE: French National Institute of Statistics and Economic Studies (L'Institut national de la statistique et des études économiques)

MDPH: Departmental Administration for Disabled People (Maison Départementale des Personnes Handicapées)

Ulis: Special education classroom within a general education school (Unité localisée pour l'inclusion scolaire)



## *Abstract*

In 2005, France passed a law on equal rights and opportunities, participation and citizenship of people with disabilities. It consecrated the right of all children to attend their neighbourhood school and re-organized the provision of services to this population, including the provision of assistive technologies. This research conducted a decade later between 2014 and 2017, investigates visually impaired children's experiences of schooling and the roles of technologies in supporting their well-being at school.

I developed a mixed-methods interdisciplinary approach, blending qualitative sociological research with Human-Computer Interaction experiments. Specifically, I conducted a two-years-long ethnographic study at a service provider for visually impaired children in the South of France, during which I made several design interventions. This field-work is contextualized by a critical review of the statistics on the schooling of visually impaired children provided by the Ministry of Education.

I use an ecological understanding of resilience to examine children's narratives about school, across different schooling modalities (e.g., mainstream and special education school) and sociodemographic characteristics. I discuss the resources and strategies children and their carers use to open opportunities for well-being at school, including uses of technologies. I contextualize these by investigating desirable schooling outcomes that define who is resilient and what resilience is for.

From there I propose to develop a non-visual approach to the (geography) curriculum inspired by the sensory turn. By changing what is considered as a valued way of learning, this thesis aims at providing opportunities to develop the sense of belonging and the perception of self-efficacy in the classroom. It informs us on the uses of hearing, smell, taste, and kinesthesia in geography; it supports pupils in reshaping of the learning activities and spaces; Finally, it opens opportunities for collective geographical knowledge rooted in experiences of social inequalities. More broadly, it opens a discussion on building collective well-being and resilience in schools.

**Keywords:** Meaning-making; Resilience; Geography; Geography Curriculum; Multisensory; Sensory turn; Sensory Knowledge; Disability; Education; School; Human-Computer Interaction; Design; Probes.

# 1

## *Introduction*

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### *1.1 Context*

Between 1945 and 1975, the United Nations set the basis for international policies supporting the rights of people with disabilities. Initially focusing on welfare, rehabilitation and prevention, it gradually took into account social and environmental barriers to participation. Following the disability rights movement born in the 1960s, the definition of disability shifted from disability as an individual characteristic, towards disability as a mismatch between individuals and the resources offered by their environment. This mismatch hinders participation in society. Disabled people should thus receive the necessary assistance and accommodation so as to get access to the same opportunities and rights. The UN Declaration on the Rights of Disabled Persons, adopted in 1975, reflects these efforts. It took 30 more years to become legally binding: the Convention on the Rights of Disabled Persons was adopted in 2006, and is now ratified by most countries worldwide.

The French laws on disability rights of 2002<sup>1</sup> and 2005<sup>2</sup> implement these principles. For disabled children, these policies greatly improved access to formal education and to, so-called mainstream, general education classrooms. Before the 2005 law, attending a general education classroom depended on the good will of local and school authorities. It was a familial matter. The law made it a requirement, reversing the responsibility of adaptation: previously, pupils could attend a mainstream school if they were able to adapt; since then, schools implicitly have to adapt to pupils, which was reinforced by the French education reform of 2013<sup>3</sup>.

This last reform enshrines the principle of inclusive schooling. Inclusion goes beyond the right to attend a general education school. It asserts that all children are different and teachers should adapt to their needs. In this perspective, abilities at school are more socially constructed through the curriculum and teaching practices than characteristics of individuals. In practice, the adaptation of general education schools to disabled pupils is not yet the norm. The number of disabled children attending them has doubled since 2006—but this statistic hides that the number of children in other educational institutions has remained stable<sup>4</sup>. Moreover, there are many overlaps between special and general education schooling modalities. Children may attend: a special education classroom within a general education school (called *Ulis*) full-time; a special education school and an *Ulis*; a general education classroom and an *Ulis*, etc. Schooling modalities are further differentiated by whether pupils have access to a human aid or to assistive learning technologies.

The outcomes of these legal evolutions are mixed. Parents of disabled children attending general education schools (all modalities confounded) are overall satisfied, although less so than the parents of non-disabled children<sup>5</sup>. But there are indications that families still struggle to get the state to respect disabled children's rights<sup>6</sup>. More generally, Ebersold argues current practices still exclude the children considered to differ too much from schooling norms<sup>7</sup>.

**But how do disabled pupils fare at school? What do *they* have to say about schooling experiences? How do the limitations of inclusion policies affect them?** This is little studied in France<sup>8</sup>. This lack of knowledge limits children's ability to participate in the decisions taken about their lives<sup>9</sup>. I thus set out to investigate children's experiences of schooling, focusing on visually impaired children.

This research was conducted between 2014 and 2017 in the South of France, at a service provider for visually impaired children. It was funded by a research project called *Accessimap*, focused on devel-

<sup>1</sup> *Loi n° 2002-2 du 2 Janvier 2002 rénovant l'action sociale et médico-sociale.*

<sup>2</sup> *Loi n° 2005-102 du 11 Février 2005 pour l'égalité des droits et des chances, la participation et la citoyenneté des personnes handicapées, Page 2353, JO n° 36 du 12 Février 2005.*

<sup>3</sup> *Loi n°2013-595 du 8 Juillet 2013 d'orientation et de programmation pour la refondation de l'école de la République.*

<sup>4</sup> Makkessi, "L'accueil des enfants handicapés dans les établissements et services médico-sociaux en 2010".

<sup>5</sup> Le Laidier and Prouchandy, "Pour la première fois, un regard sur les parcours à l'école primaire des élèves en situation de handicap".

<sup>6</sup> This is discussed as well as in: Lansade, "'La Vision Des Inclus' Ethnographie d'un Dispositif d'inclusion Scolaire à Destination d'adolescents et Jeunes Adultes Désignés Handicapés Mentaux"; Revillard, "La Réception Des Politiques Du Handicap: Une Approche Par Entretiens Biographiques".

<sup>7</sup> Ebersold, "Idéologie de La Réusite, Réinvention Des Institutions et Reconfiguration Du Handicap".

<sup>8</sup> Lewi-Dumont, "Blind Teen-Age Students' Expectations"; Coudronnière and Mellier, "Qualité de Vie à l'école Des Enfants En Situation de Handicap. Revue de Questions."

<sup>9</sup> UNICEF, "The State of the World's Children. Children with Disabilities".

oping assistive spatial and navigation technologies—both tools to ease teachers’ workload and devices to foster collaboration between pupils<sup>10</sup>. The funding is rooted in education policies encouraging the use of information and communication in the classroom—a trend that began in the 1970s in France<sup>11</sup>. Technologies in the classroom embody/materialize a promise of differentiated pedagogy for a personalized education in an inclusive schooling system<sup>12,13</sup>. They have the potential to empower disabled pupils, enabling them to access the same opportunities as their peers<sup>14</sup>. However, studies in context show using assistive technologies far from guarantees neither the development of a differentiated pedagogy, nor the opportunity to fully participate in classroom activities<sup>15</sup>. Furthermore, the ideal of autonomy through the use of technologies is to be taken with caution. Being assisted by someone does not necessarily mean losing autonomy. Personal assistance being costly, technologies can serve as an alibi for reducing it, sometimes without measuring the actual impact on outcomes<sup>16</sup>. For instance, when assistive technologies are evaluated, it usually is not against doing the task at hand with someone’s assistant, but against doing the same task alone<sup>17</sup>. Thus, in order to realize the full potential of assistive technologies, we still need to question the assumptions their design reflect. This entails a change of focus, from focusing on tasks and exercises, towards a focus on interactions with the environment—which requires studying children’s experiences of school.

Any research in this area is *politically charged*. Even if we discounted the values held by the researcher or underpinning the funding, a core of research ethics is the principle of *beneficence* to the participants<sup>18</sup>. There are different ways to design beneficial research. We could argue that simply knowing more about a situation is beneficial, as it can improve the implementation of the policies striving for a fair and inclusive educational system<sup>19</sup>. Given my background as a designer, the context of the research and the preferences of the participants, I chose rather to take a hands-on approach, focusing on visually impaired children’s well-being at school and how it could be supported using technology design.

## 1.2 Thesis overview

A decade after the passage of a law rendering access to general education classrooms the primary choice for disabled children in France, I investigate visually impaired children’s experiences of schooling. I now detail the research approach taken in this thesis.

<sup>10</sup> Christophe Jouffrais, *Innovation Biomédicale (DS0404) 2014. Projet AccessiMap. Les Cartographies (Open Data) Interactives, Collaboratives et Accessibles Pour Les Déficients Visuels*.

<sup>11</sup> Bernard and Ailincăi, “De l’introduction des TICE à l’École aux pratiques actuelles des jeunes.”

<sup>12</sup> McMillan Culp, Honey, and Mandinach, *A Retrospective on Twenty Years of Education Technology Policy*; Isaacs, *Transforming education: The power of ICT policies*.

<sup>13</sup> It is not without raising multiple conceptual and practical issues: See Chapter 8.

<sup>14</sup> Forgrave, “Assistive technology: Empowering students with learning disabilities”.

<sup>15</sup> Mithout, “L’inclusion Scolaire à l’heure Des TIC : Perspective Franco-Japonaise”; Metatla, Serrano, et al., “Inclusive Education Technologies: Emerging Opportunities for People with Visual Impairments”.

<sup>16</sup> E.g., Mithout cited above shows that equipping visually impaired pupils with assistive technologies in France sometimes justifies not to further help the pupil.

<sup>17</sup> Which is problematic. See: Agree et al., “Reconsidering substitution in long-term care: when does assistive technology take the place of personal care?”

<sup>18</sup> Graham, M. Powell, et al., “Ethical Research Involving Children”.

<sup>19</sup> Then, defining what is a fair educational system is not a small task. Dubet, *Faits d’école*.

### 1.2.1 *Research approach and Interdisciplinarity*

As implied so far, this is an interdisciplinary research in Sociology and Human-Computer Interaction (HCI). More specifically, I present a pragmatist inquiry into visually impaired children's experiences of school, through which the participants and I formulated a problem. What can, could or should be done to improve these pupils' well-being at school? Many interventions have been proposed in sociology to diminish educational inequalities (in experiences and outcomes), but they rarely focus on technologies. Meanwhile, HCI research addresses educational inequalities, but rarely discusses their assumptions about social class and educational inequalities, hence potentially limiting the impact of their prototypes and lacking a theoretical basis for the design process. Focusing on technologies is thus a way to expand the concerns of both these fields of research, and to provide a range of diverse resources to individuals, advocates and organizations trying to improve inclusion and inclusive practices in education.

The choice of research methods follows from the definition of the problem. To understand pupils' perceptions and experiences, the conditions that led to the situations I observed, ethnography became an evidence early on. Its inductive nature, the centrality of values and of researcher's reflexivity, its attention to emerging processes was consistent with the requirements from the field, the lab and the studio (Chapter 2).

Then, studying the multiple facets of this problem led me to borrow from multiple academic disciplines and from diverse bodies of studies. Both sociology and design are structured through fields. Sociology of childhood and youth, and of education, are the sociological fields I borrow the most from, and I am foremost influenced by the interactionist literature. In HCI, my work is more inspired by design research (than, for instance, interaction techniques). But I borrow from other social sciences, particularly geography, as well as from (cultural) studies, i.e. interdisciplinary fields of study focused on a specific topic, generally with an emancipatory aim: childhood, design, disability, gender, science and technology, and sensory studies. I identify in each chapter which field I borrow from and to which academic discipline I aim to contribute. Yet, as the frontiers of disciplines are permeable, each chapter can be seen as contributing to both fields to a certain extent. This is especially true because sociology is an existing perspective in the HCI field—and because sociology does not ignore our material environment, which HCI shapes.

As for the field work described and the data used in this thesis: I conducted a two-year long ethnographic study at a service provider for visually impaired children in the South of France, during which I made several design interventions. It involved about 50 children and 40 carers (e.g., teachers, therapists) with varying degree of participation, from long term observations and repeated interviews, participation to design activities to informal meetings. I contextualize my field-work with a critical review of the statistics on the schooling of visually impaired children provided by the Ministry of Education.

### 1.2.2 *Outline and contributions*

This thesis is driven by two main research goals: understanding visually impaired children's experiences of schooling, especially what supports or impedes their well-being; and identifying potential opportunities for interventions including technology design (with the aim of supporting their well-being).

The contributions of this thesis are primarily empirical and span across different disciplines: some belong primarily to social sciences, although they can be used for HCI and design research. Those are about the experiences of schooling of the population studied. Others more specifically focus on improving design practices for assistive learning technologies. They all aim at outlining opportunities for action and change. To reach these goals, the thesis is built in four parts.

	Sociology	HCI
<b>Part 1</b>		
Chapter 2	Constructing of the topic through the field-work and auto-ethnography (axiological framework).	Defining of design used in the thesis. Positioning the research in HCI as a field.
Chapter 3	Discussing definitions and models of disability and childhood, and their theoretical background. Questioning the categorization of users.	Discussing the implications of the definitions of disability for the design of technologies.
Chapter 4	Outlining the research approach:	Worldview, design, methods and ethics.
<b>Part 2</b>		
Chapter 5	Reviewing the literature on experiences of disabled childhood. Considering how experiences of violence may shape daily life and identity.	Discussing the implications for assistive learning technologies in the classroom.
Chapter 6	Discussing the statistics on visual impairments in childhood and modalities of schooling. Questioning the categorization of users.	-
Chapter 7	Contextualizing assistive learning technologies.	Discussing HCI research on assistive learning technologies for visually impaired children.
Chapter 8	Discussing implications for field work.	Discussing implications for design.
<b>Part 3</b>		
Chapter 9	Presenting the context of the field work. Discussing the impact of my gender and age on relationships in the field.	-
Chapter 10	Findings: discussing children's and carers' views on well-being and resilience at school.	-
Chapter 11	Findings: discussing children's and carers' views on the goals of schooling and how they shape the resources available to pupils.	Findings: framing how technologies can become material resources for resilience.
Chapter 12	Discussing the socio-demographic characteristics retained in analysis. Discussing how the findings contribute to the social relational model of disability.	-

Table 1.1: Overview of the academic discipline to which each chapter contributes primarily. Part 1 of 2.

	Sociology	HCI
<b>Part 4</b>		
Chapter 13	Critiquing the notion of visual substitution. Introducing the sensory turn in geography.	Discussing how learning technologies may address social inequalities. Establishing a design agenda.
Chapter 14	Exemplifying how parental practices are categorized and how it impacts what counts as learning.	Probe 1: audio-recorders. Examining non-visual geography field-trips and how to support them. Discussing how an artifact contributes to reshaping values and developing a non-visual culture at school.
Chapter 15	Exemplifying how social sciences may be taught using multisensory technologies.	Probe 2: multisensory map. Examining how pupils make sense of smellable and tastable material in geography. Discussing assistive learning technologies as tools to propose other ways to interact in a classroom.

### 1.3 Resulting publications

Table 1.2: Overview of the academic discipline to which each chapter contributes primarily. Part 2 of 2

The research presented in this thesis led to the following publications and presentations in research conferences:

Full-papers in conference proceedings:

- **Brulé, E.,** Bailly, G., & Gentes, A., Identifier les besoins des enfants en situation de déficience visuelle: état de l’art et étude de terrain. In *Proceedings of IHM*. ACM, 2015. 12 pages.
- **Brulé, E.,** Bailly, G., Brock, A., Valentin, F., Denis, G., & Jouffrais, C., MapSense: multi-sensory interactive maps for children living with visual impairments. In *Proceedings of CHI*. ACM, 2016. 14 pages.
- **Brulé, E.,** & Bailly, G., Taking into Account Sensory Knowledge: The Case of Geo-technologies for Children with Visual Impairments. In *Proceedings of CHI*. ACM, 2018. 12 pages.
- Spiel, K., **Brulé, E.,** Frauenberger, C., Bailly, G. & Fitzpatrick, G., Micro-Ethics for Participatory Design with Marginalised Children. In *Proceedings of the Participatory Design Conference*, ACM 2018. 10 pages.

Book chapters:

- **Brulé, E.,** & Jouffrais, C., Representing Children Living with Visual Impairments in the Design Process: A case Study with Personae.



In *Designing Around People: CWUAAT 2016*. Springer, Cham. 10 pages.

Full journal papers:

- Borsari, A., & **Brulé, E.**, Le sensible comme projet: regards croisés. *Hermès, La Revue*, 2016. 12 pages.
- **Brulé, E.**, Bailly, G., Brock, A., Gentès, A. & and Jouffrais, C., An Exploratory Study of the Uses of a Multisensory Map—With Visually Impaired Children, in *Multimodal Technologies and Interaction* 2.3, 2018. 22 pages.

Presentations and workshops:

- **Brulé, E.**, Bailly, G., & Gentès, A., Social Class, School and Visual Impairments: Reflections from the field. In *Interaction Design for Children*, 2017.
- **Brulé, E.**, & Bailly, G., Designing for inclusion: Examining Do-It-Yourself design activities. In *ALTER Conference*, 2017.

#### 1.4 Use of the expressions "visually impaired French children" and "disabled children"

During the writing of this dissertation and other research papers, I oscillated between using person-first and impairment-first language—children with visual impairments or visually impaired children, children with disabilities or disabled children. French presents a similar dichotomy of terms (*personne handicapée*, disabled/handicapped person; *personne en situation de handicap*, person with disabilities). There are good reasons for using both. Person-first language highlights that these children are first and foremost children. It is supposed to help focus on their *abilities* before their *disabilities* and to make disabilities external to the person (i.e., caused by the environment, to a person). However, there is no proof this is an efficient measure<sup>20</sup>. Meanwhile, impairments-first language can be used to reclaim disability as a non-stigmatizing yet defining characteristics. It is preferred, for instance, by d/Deaf<sup>21</sup> and autistic people who see disability as part of their identity and argue it should be recognized as a difference<sup>22</sup>. Scholars and activists have pushed for the use of the expression disabled people, pointing out that disability should be reclaimed as part of a person's identity<sup>23</sup>, that it cannot be separated. Finally, metaphoric expressions are also used—e.g., differently-abled, handicapable, special needs, challenged. These are not straightforward choices, where

<sup>20</sup> Louis, "Person-first labeling and stuttering".

<sup>21</sup> This notation is commonly used as it highlights the duality of deafness as an impairment and Deafness as a culture. See: Padden, Humphries, and Padden, *Inside deaf culture*.

<sup>22</sup> Kenny et al., "Which terms should be used to describe autism?"

<sup>23</sup> Liebowitz, *I Am Disabled: On Identity-First Versus People-First Language*.

one is inherently good or bad. Their uses depend on the historical, geographical and communication context<sup>24</sup>.

I took into account three main factors to decide over which terms to use:

1. The children I worked with almost never described themselves as disabled, as *malvoyants* (visually impaired) or *aveugle* (blind). When describing impairments, they used descriptions of the types of material help needed (e.g., "*the one who uses a yellow cane*"). In their discourses, what makes them similar to other visually impaired children are their schooling conditions and the stigmatization exerted by others. They however distinguished themselves from children with visual and additional impairments, considered more severe (in particular mental and physical impairments), by designating them as disabled;
2. Carers use *malvoyants* or *déficients visuels* (visually impaired) to designate the children they work with, because it designates the core aspect in the rehabilitation and services they provide. For instance, deaf-blind children were more often referred to by their visual impairment than by the combination of the two;
3. Disabled children/children with disabilities are a social group that is marked as different from others administratively, no matter whether children identify themselves as belonging to this group.

My first inclination was to follow the research participants: if children use "assistive-devices-based" language, similar to the expression people using wheelchairs, I should use their language. However, it obscured the fact that they do indeed identify as belonging to the larger group of children with visual impairments, which they find distinct from the group disabled children—the latter group including children who are taken care of by the same organization and have multiple additional impairments. However, carers make a different choice as they focus on what in their opinion has the most impact on everyday functioning. Children's and carers' categorizations and choices of language relate to the organization of care, which makes visually impaired children and disabled children as social groups, necessitating specific care and structures (see also chapter 9).

I began using visually impaired children after discussing with children participants how they considered visual impairments. Analysis suggested that children do not mention their impairments because they are part of who they are ("*there's no denying it, that's just how I am (...) it's not because I don't see that I get picked on, it's more like the others*

<sup>24</sup> Lunsford, "Seeking a Rhetoric of the Rhetoric of Dis/Abilities".

*don't like the disabled. So me I'm pretty okay, because I'm not like the disabled").* Distinguishing visual impairments from the person (children with visual impairments) thus seemed inadequate in the analysis. Deciding to homogenize and use disabled people instead of people with disabilities was a more complex decision. On one hand, some children distinguish what identifies them as disabled (e.g. assisted devices, being picked on) from themselves. On the other, they do so because they think that disability should be ascribed to some, but not to themselves. Hence, using disabled people as a term reflects my view—informed by the debates resumed above and by the definitions of disability outlined in chapter 3—rather than theirs. This is because I want to express that being identified and treated as disabled is not just something done by others to an impaired person, but can also be embraced as part of someone's identity. In other words, I also wanted to open the door to the children, who might benefit from identifying as visually impaired, or as disabled: this process of identification can help the sharing of concerns and efforts with other children subjected to the same exclusions.

## **Part I**

# **Constructing “visually impaired French children's experiences of schooling” as a research topic**



Part I of this thesis describes the construction of my research topic and its theoretical and methodological framework. My goal is to understand how visually impaired French children experience school, and how to design educational technologies improving these experiences, through a pragmatist lens relying primarily on sociology and Human-Computer Interaction research. Rather than presenting it as a preliminary choice, I prefer to discuss the many conditions that enabled this specific research topic to emerge. Though visually impaired French children seem a relatively clear and straightforward category of population, I demonstrate that it actually can be defined and approached in very different ways, leading to different research interests. Hence I need to clarify how my approach came to be, through two different but convergent perspectives.

In Chapter 3, I discuss the conditions that enabled this topic to emerge as a problem necessitating research, specifically the values brought by the different stakeholders: (1) the research project I was funded by, which itself was made possible by specific policies; (2) the organization's staff I was asked to observe; (3) my position within the academic field. They affect each other: for instance, the research conditions set by the participants changed the research literature I consulted and relied on and my subsequent position within academia. In other words, this chapter looks into the axiological background of my dissertation, i.e. the values and moral judgments that shaped the research.

I then dive more into the contemporary debates regarding the definition of disabled children, and how it informed my fieldwork. Chapter 3 offers a complementary perspective on my research topic. It focuses on the problematization of disabled childhoods in policies and the research literature. I outline the long history leading to the study of disabled children in social research. I highlight tensions and bridges between (1) French, American, Britannic or Nordic understandings of disabled childhoods and (2) the so-called **medical** and **social** models, including in the very definition of visual impairments. I then (3) discuss how they structure Human-Computer Interaction (HCI) research focusing on disability. This chapter describes the theoretical framework of the dissertation.

This dual approach to defining my research topic determined my research approach, i.e. how I decided to investigate the research topic after the first set of observations and interviews. Not that the topic and the approach can be fully separated, but they need to be consistent. Chapter 4 first describes the research approach in four aspects: worldview, design, methods<sup>25</sup>, and ethical framework. I then discuss the fieldwork itself. I specify how and when each of the methods pre-

<sup>25</sup> Following: Creswell, *Research Design: Qualitative, Quantitative, and Mixed Methods Approaches*.

viously described was used, and reflect on the ethical dilemmas that arose from my approach. This chapter elicits the epistemological and methodological framework for the dissertation.

In addition to describing the framework of my dissertation, this part aims to contribute to the growing body of work on the development of interdisciplinary research in sociology and design. In doing so, I make two additional contributions. The first is to bridge French and international research perspectives on disabled childhoods. The second lies in the ethical considerations that can be of use to other researchers involved in the same type of research.

### *Visual Overview*

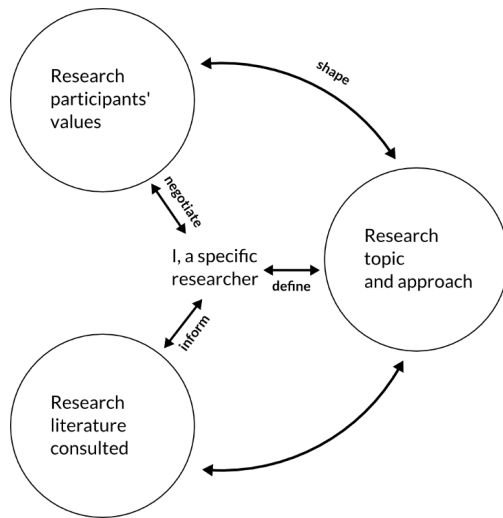


Figure 1.1: This figure illustrates the focus of the first part of the dissertation. I discuss how my research topic emerged as a negotiation I made between the values of the research participants, and the research literature on disabled childhoods.

## 2

# *Negotiating Values, Defining a Research Topic*

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The dissertation introduction contextualizes the research presented here within contemporary policies and research in the domain of education. It outlines how the very possibility of conducting this project depended on the perception of educational technologies as valuable, as a public interest. But this is far from being the only value shaping the research—value being hereby described as a judgment guiding human conduct following Dewey<sup>1</sup>. The values held by research par-

<sup>1</sup> Dewey, "The Logic of Judgments of Practice (1915)".



ticipants and conditioning their engagement with a researcher, the academic context of the researcher that deem certain topics and approaches more valuable than others, all influence theoretical and methodological choices. Yet, these values and their negotiations (i.e., the valuations<sup>2</sup>) are often undescribed, if noticed at all.

In the initial research project for instance, values were mostly implicit. They were expressed during formal and informal discussions with research participants, as well as in research documents (reports, statements). They were an object of research, described as determining the design of artifacts, but not fully acknowledged as part of the research process. In contrast, I argue that exposing them would actually enable evaluating the reliability of the research. Discussing values uncovers parts of the **hidden ethnography**<sup>3</sup>, i.e. the researcher's choices that necessarily impacted research but are often concealed for the sake of an illusion of objectivity. I further argue that on this research subject, attentiveness to values is crucial—which I contextualize in Chapter 4 within current ethical frameworks for research for technological innovation with children. Hence, this chapter aims at unpacking how values were negotiated between research stakeholders, myself including, and how it contributed to define the research topic and approach.

I focus on values expressed through moral commitments (e.g. "*we ought to ensure that everybody is participating*") by the different parties involved. In the first half of the chapter, I focus on the research team behind the initial research project, the teachers and the children. In the second half of the chapter, I reflect on the valuations I made in different spaces: the field, the studio, academia. I discuss the progressive integration of research stakeholders' values—and the interaction with my own values and experiences. I conclude by outlining the implications for the research topic and approach.

<sup>2</sup> Dewey, "Theory of Valuation.", p. 58.

<sup>3</sup> Blackman, "'Hidden Ethnography': Crossing Emotional Borders in Qualitative Accounts of Young People's Lives".

## Visual Overview

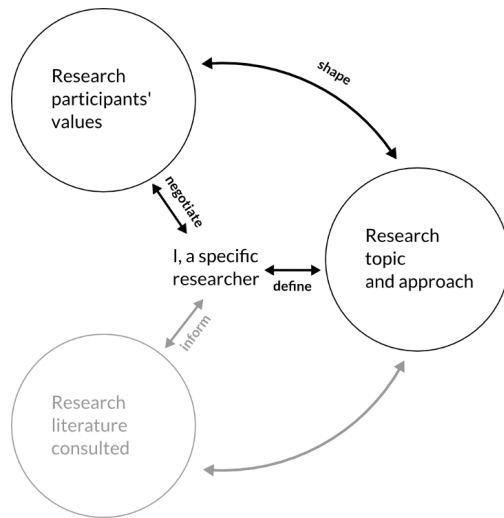


Figure 2.1: This figure illustrates the focus of Chapter 2: It looks into the values of all research participants, and how my specific position in the academic field shaped the multitude of negotiations I made to refine my research topic.

## 2.1 Study

### 2.1.1 Data Generation

This chapter is primarily based on the data generated in the early fieldwork period (October 2014 to February 2015). It consisted in interviews with the organization's employees focusing on their roles and perceptions of educational technologies, notes from the initial research project meetings and personal notes on the research process enabling auto-ethnography<sup>4</sup>. See chapter 4 and appendix A.3 for a presentation of the data generation and the carers interviewed.

<sup>4</sup> Ellis and Bochner, "Autoethnography, Personal Narrative, Reflexivity: Researcher as Subject".

### Interviews

The interviews were semi-directive, and structured as follow:

- Presentation of the researcher;
- Non-participant observations of the interviewees while working;
- Questions about the interviewees' professional history and training;
- Explanations, by the interviewee, of the activities previously observed;

- Discussion of the interviewee's activities, profession and how it relates to its colleague's, including the gathering of relevant documents they wished to share.

### 2.1.2 Data analysis

The initial analysis conducted was based on open coding the material by hand. I initially planned to follow a Grounded Theory approach. It consists in coding material iteratively, analyzing these codes to develop categories which both leads the emergence of a theory of the phenomena, and guides the next steps of the inquiry to strengthen the developing theory<sup>5</sup>. The dominant theme of these early months was the conflicts in values and priorities discussed in this chapter. However, there are many principles of Grounded Theory that did not fit my developing research, in particular data saturation<sup>6</sup>, which led me to adopt a different set of analysis methods (described chapter 4). Data saturation is a debated concept in Grounded Theory, but broadly refers to the time in the inquiry where the researcher is confident no new code could be added, that the theory is complete. However, I have first and foremost attempted to develop an empirical account of visually impaired children's experiences of schooling, not the development of a fully-fledged theory of these experiences. This is because I primarily aim at providing insights useful for action, and decided to develop a theoretical account after the end of my Ph.D.

As to how the analysis unfold, note that the opinions and values of the three groups of research **stakeholders** (the research team, the carers and the children) are expressed implicitly or explicitly. Indeed, in their discourse, carers distinguish themselves from the researchers (and vice-versa). As for the children, they are often described by carers as compliant or non-compliant with the care received, which highlights their divergences. Note that this should include parents and regulatory authorities (i.e., Ministry of Education, Health and Research). However, parents were little involved in the life of the organization, and the various governmental interests were evoked more through their impact on practices, e.g., funding awarded to develop tools to reduce costs. I thus assume here they were represented in the discourse of the research team and carers.

Then there is the question of how values are expressed, and what I identified as an expression of value<sup>7</sup>. Here, I mostly focus on verbal and written occurrences, and in Chapter 13 and 14 I discuss values as expressed through material means (e.g., artifacts). In the case of carers and the research project, they are often introduced in arguments about priorities. It was thus relatively easy to identify subjects that

<sup>5</sup> Charmaz, *Constructing Grounded Theory: A Practical Guide through Qualitative Analysis (Introducing Qualitative Methods Series)*.

<sup>6</sup> Charmaz, *Constructing Grounded Theory: A Practical Guide through Qualitative Analysis (Introducing Qualitative Methods Series)*, p. 113.

<sup>7</sup> Van Mechelen et al., "The GLID Method: Moving from Design Features to Underlying Values in Co-Design".

were attributed to the other group and deemed controversial. I would then re-introduce them during discussion, interviews or design activities, to confirm my interpretation or better elicit these values. In the case of children, this was rather more difficult: some children had limited verbal skills, and overall, children do not use the same type of discourses to express their needs. Hence, I focused on statements about **liking** or **disliking**, and as indicated in the previous paragraph, **refusal to comply**.

## 2.2 *Involved Parties' Values*

### 2.2.1 *The Accessimap research team and project*

In this first section, I focus on the research team and project, building upon the project description, formal and informal discussions throughout the research, results of a design workshop<sup>8</sup> and observations in the regular meetings.

<sup>8</sup> E. Brulé and C. Jouffrais, "Representing Children Living with Visual Impairments in the Design Process: A Case Study with Personae".

### **Description**

My Ph.D. was funded and conducted as part of a research project called *Accessimap*<sup>9</sup>, funded by the National Agency for Research (*Agence Nationale de la recherche – ANR*). *Accessimap* is a project primarily conducted by the *IRIT-Elipse* team. The team has several years of experience in designing interaction techniques for users with visual impairments, and developed a joint research structure, *Cherchons pour voir*, with the local care center dedicated to people with visual impairments (the *CESDV-IJA*). *Accessimap* derives from an analysis of user needs conducted during previous collaboration between the research team and the care center. Some of the participants from the care center also belongs to national non-profit organizations defending the rights of people with visual impairments. The project also involves: a software company, *Makina Corpus* (with the aim of developing a **product**, i.e. a device that can be distributed and commercialized); HCI or ergonomic specialists interns, completing their Master degree; my Ph.D. advisors, a social scientist and an HCI researcher, both affiliated with *Télécom ParisTech* at the beginning of the research project; and finally, me as a design research Ph.D. student. The project manager had already presented the research aims to the parents, to obtain their consent before my field study started.

<sup>9</sup> Christophe Jouffrais, *Innovation Biomédicale (DS0404) 2014. Projet AccessiMap. Les Cartographies (Open Data) Interactives, Collaboratives et Accessibles Pour Les Déficients Visuels*.

*Accessimap* aims at improving access to maps for people with visual impairments, through four main actions:

1. Facilitating the design and sharing of adapted maps, by developing design software using open data (e.g. OpenStreetMap).
2. Developing a prototype of an interactive map, enabling collaborative exploration.
3. Developing and evaluating novel, non-visual, interaction techniques (that may or may not be included in the prototype aforementioned).
4. Improving the knowledge available on spatial cognition, and Human Computer Interaction techniques.

According to the research project statement, in addition to its research objectives Accessimap was envisioned as a first step for the industrial production of an interactive technology providing access to paper tactile graphic documents to children with visual impairments attending general education classrooms and their families. It was described as a technical action research<sup>10</sup>. Action research is a common approach in education<sup>11</sup>. It is used to bridge the gap between theory and practice<sup>12</sup>, and enables teachers and other professionals to reflect on their practices and amend them when necessary. The CESDV-IJA's professionals were described as clients of experts (here the software engineers and the researchers) and as cooperative participants in the research<sup>13</sup>. It was envisioned that the experts would propose technological interventions yielding practical and theoretical knowledge, as well as pursue separately their own inquiries inspired by the field.

Within this project, my defined role was to understand users' and providers' needs regarding interactive maps in primary and secondary schools, using a Grounded Theory approach. Grounded theory is an inductive and iterative research methodology on a broadly defined research topic<sup>14</sup>. It consists of iteratively collecting and analyzing data dynamically to identify emerging concepts, which will then be related to one another and to the research literature to become a theory. This topic was investigated through four data collecting strategies:

1. Observations of classroom environments and their characteristics, such as teaching practices and philosophies;
2. Observations and analysis of the characteristics of current educational material;
3. Interviews and observations with visually impaired members of the community, on their existing uses of technologies, to learn about their preferences;

<sup>10</sup> Kemmis, "Action research as a practice-based practice".

<sup>11</sup> Nolen and Putten, "Action Research in Education: Addressing Gaps in Ethical Principles and Practices".

<sup>12</sup> McNiff, *Action Research: Principles and Practice*; Williamson and Prosser, "Action Research: Politics, Ethics and Participation".

<sup>13</sup> As exemplified by discourses about helping teachers to formalize their needs or formulate new needs based on the technologies available, so that they could be taken care of by the research team.

<sup>14</sup> Charmaz, *Constructing Grounded Theory: A Practical Guide through Qualitative Analysis (Introducing Qualitative Methods Series)*.

4. Interviews and observations with carers (in particular transcription specialists and teachers) regarding the production of accessible maps, to inform the software development process and propose improvements to the current map production processes.

Furthermore, the project was meant to "*have a positive impact on VI [Visually Impaired]’s autonomy and quality of life*" and to "*[deploy] a set of procedures and tools [...] to change practices by integrating new technologies*"<sup>15</sup>—which hints at the values embedded in the research project and supported by its team.

<sup>15</sup> Christophe Jouffrais, *Innovation Biomédicale (DS0404) 2014. Projet AccessiMap. Les Cartographies (Open Data) Interactives, Collaboratives et Accessibles Pour Les Déficients Visuels*.

## Values

I outline here expressions of values, which either qualified the kind of intervention to implement, or the way research should be conducted. As to the kind of intervention to implement, the values underlined by the research project differ between interventions meant for document makers or for visually impaired users. Document makers’ practices are only described as to be optimized, and partially automated. The priority for research on their practices is to increase productivity, by reducing the difficulties encountered in the production of tactile graphics, e.g. lack of sharing on a national levels, desirable functions lacking in the software used. This went hand in hand, in their discourse, with the necessity of helping organizations at many levels make the right technological choices. For instance: "*there’s so much money wasted in technos that no one uses. A device becomes fashionable, everyone wants one, then there’s a new one... Though it’s good for us, if people get interested in what we do*".

Regarding this concern for influencing the choices made by schools, we note that the maintainability of certain tools developed (the map editor and reader) was framed as a priority. For instance, at the beginning of the research project, a Ph.D. graduate from the HCI research team started working as an IT manager and maintainer at the CESDV-IJA. Interns in ergonomics were also solicited for creating content for the interactive map so as to avoid adding to the teachers’ workload and to help maintain their interest in the technologies proposed. The technologies developed are open source. Furthermore, a second funding was sought early in the research project to ensure its continuity. This contrasts with the short lifetimes of the prototypes that were used for the research itself. This sometimes created tensions—with carers hoping for some research prototypes to be adapted to their needs—but overall this value was shared by all.

On the other hand, research focusing on visually impaired users<sup>16</sup>

<sup>16</sup> For a critique of the notion of user, see: Baumer and Brubaker, "Post-Userism".

is framed as encouraging participation, in line with international and national policies for the integration of people with disabilities. Yet, we note that participation modalities described differ depending on the context. The research statement emphasized collaboration in the classroom. Whereas it focused on "*autonomy*" and "*quality of life*" at home or in mobility, through providing geo-localized information about activities and environmental features. Here, autonomy and collaboration are considered as lacking because of the absence of adequate technological support. I note, however, that most evaluations conducted by the research team focused on usability and attempting to improve spatial memorization, rather than collaboration in context or quality of life. This shows that although these are framed as values guiding design on the long term, they were not necessarily actively pursued during the research process and project. I outlined this as well in the results of a design workshop<sup>17</sup>: the users described and envisioned by the research team were primarily defined by their impairments, leaving other characteristics such as gender or social class unaddressed. This is consistent with a research focus on controlled environments.

As for values underlying the conduct of research itself, the ethical framework used was based on standard deontology rules ensured with administrative tools, e.g. consent forms for participating in experiments, signed by parents as minors are not considered to be legally able to give informed consent. This was grounded in their disciplinary background, psychology applied to Human Computer Interaction. *Accessimap* did not seek ethical approval to an ethics board for my observations in the classroom, as the American Psychological Association (APA) does not require it<sup>18</sup>.

Furthermore, discussions within the research team suggested that researchers framed the project and the resulting device as a way of giving voice<sup>19</sup>, which motivated the inclusion of practitioners in the research process. Indeed, the *Accessimap* research statement mentioned that the research would be participatory: "*We will use a method of participatory design including users, but also specialized teachers*". However, the importance given to participation, its configuration<sup>20</sup> in the research, was unclear. For instance, children's views were not solicited: only carers's were. Participation was most often framed as ensuring adoption of the final device, and fostering motivation to participate in research experiments by being morally rewarded. It was also advocated as positive for researchers, as a way to increase creativity of interaction techniques or use scenarios. In this spirit of participation, there were multiple public presentations on the research, progress and devices developed. However, priorities and

<sup>17</sup> E. Brulé and C. Jouffrais, "Representing Children Living with Visual Impairments in the Design Process: A Case Study with Personae".

<sup>18</sup> American Psychological Association, "Ethical Principles of Psychologists and Code of Conduct", p. 8.05.

<sup>19</sup> For a discussion of the dangers of this notion, see Alper in her eponym book. To summarize her argument, framing assistive technologies as giving voice often perpetuates structural inequalities. M. Alper, *Giving Voice*.

<sup>20</sup> Vines et al., "Configuring Participation: On How We Involve People in Design".

what is considered a desirable intervention, remained preemptively and primarily set by researchers according to the necessity of obtaining measurable research outcomes (published articles), with the assent of community's representatives (association leaders, employees' representatives, the organization's supervisor).

As for the industrial partner of the research, Makina Corpus, they were chosen for their commitment to maintainability (through open sourcing the software developed, and using open data)<sup>21</sup>. Although they participated in the requirements gathering from time to time, their planning depended on the IRIT research team. Finally, they also had an interest in developing technologies that can be applied to other contexts, and strengthening their relations with local public administrations that may later require their services. For instance, they were the main organizers of mapping parties<sup>22</sup> about local accessibility. They therefore focus on immediately implementable actions.

<sup>21</sup> <https://makina-corporus.com/valeurs>

<sup>22</sup> A mapping party is an event dedicated to add information about environmental features, generally on digital open source maps. See also: [http://wiki.openstreetmap.org/wiki/Mapping\\_parties](http://wiki.openstreetmap.org/wiki/Mapping_parties)

### 2.2.2 Carers

#### Description

Three carers from the studied organization (a document maker, a special education teacher, and an orientation and mobility specialist) were directly involved in the research team. They participated in research meetings and were asked to provide their opinion on software features, to propose scenarios etc. They had dedicated time for this mission (although it raised conflicts, as their employer sometimes considered it too costly). Other carers expressed their interest in the research or collaborated punctually with other researchers or me. Parents, on the other hand, were not involved in the research project, except for being invited to the public presentation of progress and results.

I distinguish between five groups of carers throughout the dissertation: teachers, assistants to teachers (e.g., the librarian, document makers, school assistant), educators, therapists and parents. I discuss this categorization further in Chapter 10. For now, I merely point out that I have found that they express different priorities regarding care, and distinguish themselves as belonging to one group in particular.

#### Values

Carers emphasized multiple values and priorities. Social justice



was the main theme—many volunteer and engage in various civic activities. They all made multiple references to children's rights as determined by law, and the failures in their implementation, as well as to the inequalities children face in general. Of the 37 carers I interviewed, only three thought the socioeconomic background of children did not matter, and one had no opinion. Several carers stated they considered the socioeconomic background to be more determining than impairment itself regarding academic performance ("*with the assistance we provide, they perform pretty much like their able-bodied peers... and they have the same other issues*" [a therapist]). Others suggested the socioeconomic context had an impact on the severity of impairments. Some further argued that new technologies, given how inclusion in schools is currently designed, could not do much to address these issues ("*considering very partially their individual specificity, with untrained human aids*" [an educator]). Finally, they expressed criticisms on which children were included and which were left out of the research: they initially felt that participation was too restricted to children without additional impairments or academic difficulties, therefore contradicting social justice principles. The early interviews reveal much about the way the public policies aiming at integration are perceived by the professionals affected.

Furthermore, they insisted on the differences between their priorities and those of the researchers. Some refused to participate as they estimated that research would always prioritize abstract results over pragmatic change ("*I've been asked to talk to you, so I'm going to do that, but then I don't want to have anything to do with it, been there done that, loss of my time, for which I'll never get anything back, and moreover [THE CHILDREN]'ll never get anything back*" [a therapist]). On the other hand, many carers later recognized they found value in having researchers interested in their practices, and that this collaboration in itself help them develop new activities or skills. For example: "*even if we do not get any actual software or a commercialized interactive map, it was, it still is, interesting to get the head out of the everyday tasks*" [an assistant to teachers]. Overall, carers prioritized the development of research with concrete and direct impact on the quality of education and therapy, that could be shared within their professional network.

### 2.2.3 *Children*

My early interactions with children mostly involved observations and informal discussions. Later in the research, I attempted to give children the means to shape my research objectives, through more focused interviews or design activities. I build upon this material in

this section.

## Description

The children involved in this research receive services from the organization involved in the research project. It provides a broad range of services to visually impaired children and their families. The children I worked with constitute a very heterogeneous group in terms of age, socioeconomic context, impairments, etc. The research project envisioned children as informers and testers<sup>23</sup>. As for me, I instead tried to involve them as co-designers<sup>24</sup>).

<sup>23</sup> Druin, "The Role of Children in the Design of New Technology".

<sup>24</sup> I discuss this further in Chapter 4 and 9.

## Values

From the very first week of observations, when asked about what they found essential for me to know, the children repeatedly reported feeling unheard by the many adults in their lives, which is consistent with Lewi-Dumont's previous studies on blind teenagers<sup>25</sup>. These statements could be dismissed on the basis that children do not know what is right for them—and it often is, in their stories. Initially, children's views were not central to the research project. In contrast, I decided to take their narratives seriously. Specifically, children expressed not being believed (for instance, about being tired), being dismissed (for example, being told that bullying was not a big deal), or as not having valuable opinions (for instance, about what should be their rights). On the other hand, children are encouraged to express opinions if they coincide with those of adults: for instance, a child asked for after-school tutoring, and his teacher encouraged him to take it to the headmaster of the school. In this specific case, children's opinions may have more weight than adults.

<sup>25</sup> Lewi-Dumont, "Blind Teen-Age Students' Expectations".

The second most repeated theme was the relational problems they encountered with other children. Children also demonstrated a vivid perception of unfairness, or discrimination, which echoes carers' insistence on social justice. For instance, a child referred to the law guaranteeing equal rights to disabled people to reclaim a tactile earth globe (non-tactile earth globes being available to her peers). Another referred to a teacher refusing to let him participate in classroom activities, because of his impairments. Overall, the preoccupations they shared revolved around their well-being—in particular at school (e.g. "*not liking to go to school*"; "*not feeling safe at school*"). When asked about what they would like to change if they could do so, priority was given to practical change to improve their well-being (e.g. "I would like [my special education teacher] to always be with me at

school because... she's very gentle with me."). As a counterpoint, the same teacher emphasized the need for this child to "toughen up".

However, children did not manifest interest in research objectives, beyond practical interventions. For instance, they mostly refused to be involved in the analysis of the results. Note that this is not an unprecedented situation in the research literature<sup>26</sup>—which has ethical implication I discuss in Chapter 4. It contrasts with their carers, who saw value in the knowledge produced by researchers to improve their practices.

<sup>26</sup> See: J. Sanders, *Subject Child: The Everyday Experiences of a Group of Small Town Aotearoa/New Zealand Children*, p. 117.

#### 2.2.4 Discussion

This overview of the values expressed by the different research stakeholders highlights six aspects of the research, on which the groups differ: The priority given to immediate practical application; life-duration of the prototypes developed; the actions that may contribute to a social justice agenda<sup>27</sup>; taking into account immediate well-being; the importance of developing formal knowledge; and lastly, research that aims at giving voice may not mean for their participants feeling that they are heard. The following table summarizes, very succinctly, the importance associated to each of these aspects by the different groups of research participants.

The values expressed by research participants, including the discourses of children, build on policies aiming at the integration of disabled people. The main point of disagreement lies in how this can be achieved: who should be heard, and what are the priorities for action between practical interventions and research outcomes. This is a well-known issue in action research<sup>28</sup>, which I will further discuss at the end of this chapter. I also observe that the design of the research project took into account conflicts in values, negotiating a middle ground to ensure participation from the carers. Researchers focused on academic outcomes based on short-lived prototypes, but also facilitated the development of technologies that could be used in the long term and eventually commercialized.

Nevertheless, carers sometimes met me with opposition or defensiveness in the field, which suggests that these negotiations were not sufficient. Furthermore, I brought my own values and abilities, opening new opportunities for children and carers. Hence, the second part of this chapter focuses on the valuations I made during the research process, and how they shaped how I refined the research topic and defined a research approach.

<sup>27</sup> I am aware of the different definitions of social justice in research, which is outside the scope of this dissertation. I use this term because it was used by several carers to explain their action to ensure equality of choices or a better integration in society for the children in their care. For discussions on social justice in the domain of education, or for disabled people, see: Dawson, "Social Justice and Out-of-School Science Learning: Exploring Equity in Science Television, Science Clubs and Maker Spaces"; Liasidou, "Intersectional Understandings of Disability and Implications for a Social Justice Reform Agenda in Education Policy and Practice".

<sup>28</sup> McKay and Marshall, "The Dual Imperatives of Action Research"; Frauenberger, Good, Fitzpatrick, et al., "In Pursuit of Rigour and Accountability in Participatory Design".

	Research team	carers	Children
Immediate practical application	+ Necessary to guarantee the participation. Only sometimes an object of research.	+++ Main perceived benefit of the research.	+++ Main perceived benefit of the research.
Social justice	+ Primarily framed a result of the technologies developed from the research.	+++ The current technologies should be included in all others activities aiming towards social justice.	++ Getting access to better/equal resources is a subject often discussed. Yet this is not framed as enabling inclusion.
Well-being	+ Evaluations primarily target cognitive gains.	++ Described as necessary for good academic performance.	+++ Primary request.
Developing formal knowledge	+++ Main perceived benefit of the research.	++ Interested some carers and not others. Potential for training of their younger peers	+ Low interest in participating in this aspect of research.
Giving voice	++ Described as necessary to guarantee the involvement of carers. But quite limited when it comes to children.	+ Dispositions are taken to help children expressing their needs on a variety of subjects, but not on the research itself.	+ Giving voice is both the counterpoint and complement of being heard. One can want to "give voice" when one is already heard. It thus is not something expressed by children.
Being heard	+ Concern for influencing technological choices in education.	+++ Concern of being heard by researchers, by the organization, and in local/regional/national policies	+++ Being heard by adults if the main concern expressed by children.

### 2.3 *Researcher's Values and Valuations*

With this second section, I further contextualize the research presented in the rest of this dissertation. But I also aim to contribute to the literature on action research with a case-study. The oppositions regarding priorities between pragmatic change oriented towards social justice and the production of scientific content<sup>29</sup> and the concerns over who is given a voice in research<sup>30</sup> described in the first part of this chapter are well described in the literature. However, the specificity of doing social sciences research as a designer is rarely addressed<sup>31</sup>. When it is indeed discussed, it mostly focuses on importing methods from design, rather than questioning how being trained as a designer may influence how we undertake observations or field-work in social sciences<sup>32</sup>.

In this section, I thus reflect on how my research unfolds in three different spaces (the studio, the field, volunteering space) and the valuations I had to make when navigating from one to the other. I then discuss their articulation with my position in the academic field. I outline the implications for the research in the final section.

Table 2.1: Values associated with participation in the research, as expressed in terms of intensity, on a scale from + (not often expressed) to +++ (described as fundamental), with comments summarizing the differences between each groups.

<sup>29</sup> Frideres, "Participatory Research: An Illusionary Perspective"; McKay and Marshall, "The Dual Imperatives of Action Research".

<sup>30</sup> DeMeulenaere and Cann, "Activist Educational Research"; Bang and Vosoughi, *Participatory Design Research and Educational Justice: Studying Learning and Relations within Social Change Making*.

<sup>31</sup> Lupton, "Towards Design Sociology".

<sup>32</sup> R. Cole et al., "Being Proactive: Where Action Research Meets Design Research".

### 2.3.1 *Navigating between the studio, volunteering spaces, the field...*

To account for how I handled the field work, I outline how the research presented here was influenced by my training and professional past as a designer, and my experience as a volunteer and activist<sup>33</sup>. I argue that considering the training in design is important for three reasons. (1) It develops a skilled vision<sup>34</sup> (for shapes, colors, etc.) that makes a designer particularly attune to such characteristics. (2) It also provides a number of tools (e.g., mood boards, brainstormings, sketching) and (3) values subjective ways to know about the world, such as empathy and intuition—what Cross calls the “designerly ways”<sup>35</sup>. As discussed later in the chapter, it’s a mindset that can conflict with criteria of validity in academia.

As for my experience as a volunteer and activist, it raised a political consciousness and gave me a variety of skills, such as specific communication techniques<sup>36</sup>, as well as sensitization to specific matters (e.g., family violence against youths). The danger is the temptation to use field-work as a way to prove a given political issue exists, instead of understanding it<sup>37</sup>. This is why acknowledging this specificity and disentangling it from the research is important.

I propose to achieve this through auto-ethnography<sup>38</sup>, reflecting on the values I mobilized throughout my Ph.D. research project. I focus on conflicts, and their negotiations, between my design, volunteering and research activities. Auto-ethnography requires researchers to present their experiences analytically, in connection to the research literature. It acknowledges that how the researcher feels and develops relations is of primary importance in how qualitative research unfolds<sup>39</sup>. I alternate passages consigned in a research journal (in blue) with their analysis.

November 2014 -- the field.

"It hurt, listening to this child telling me he feels miserable [...] I didn't expect this [...] I feel bad I know so much about them, and they don't know the tenth of it about me. It's hard to distinguish between the discussion and the research."

March 2015 -- volunteering spaces.

After a volunteers' meeting during which I was called out: not being visually impaired, I was told I had no legitimacy to talk about a disability-related topic directly connected to my research, and that I should be ashamed of receiving funding to research this topic: "I don't know if I should be the one doing this research [...] How do I do as well as possible now that

<sup>33</sup> Schematically, the volunteer undertakes direct action to relieve everyday problems, while the activist attempts to push structural changes by a broad range of means (e.g., publicizing a specific issue so as to change the law). The frontiers between the two can be porous. See: Eliasoph, *The Politics of Volunteering*.

<sup>34</sup> Grasseni, *Skilled Visions: Between Apprenticeship and Standards*.

<sup>35</sup> Cross, "Designerly Ways of Knowing".

<sup>36</sup> Communication training is usual before the admission of volunteers. See for instance: Worthington, "Communication Skills Training in a Hospice Volunteer Training Program."

<sup>37</sup> Barthe et al., "Sociologie Pragmatique: Mode d'emploi".

<sup>38</sup> Ellis and Bochner, "Autoethnography, Personal Narrative, Reflexivity: Researcher as Subject".

<sup>39</sup> Holland, "Emotions and Research".

I've stepped in? [...] It feels like being watched at every step I take on eggshells, with the threat of being lynched if I stumble."

March 2015 -- the field.

"Weird discussion at lunch. I was explaining I wanted to make a series of 3D printed globes because they seemed to have so much success with children (and I'm interested in how "special" artifacts affect stigma management). A. stated it encouraged fetishism in objects, and not the right kind of learning, and that I shouldn't listen too much to them because they're capricious. It sounds a lot like the guy who advocated that 'we shouldn't give money to these families because they spend it the wrong way and they don't want to get out of poverty' last week [at another volunteers' meeting]. It was very uncomfortable; I don't like thinking of children as not to be trusted, or as acted in ways that need to be constantly corrected."

April 2015 -- the studio.

"Spent the last three days and most of the weekend at the Fablab. The 3D printer got stuck and stuck again---I even feared I had broken it. I'm not sure if this is doing research at all, or merely design stuff. I kind of fear having to report on what I did this week, as I'm supposed to write this article, and the deadline is coming up."

These four events occurred within the first six months of my research. The fragments evoke difficulties well-known to ethnographers, such as concerns regarding the differential of power<sup>40</sup> and engagement<sup>41</sup> between the researcher and the researched. They also underline the importance of emotions in identifying what would become a research question. Encountering children recounting feeling hurt attuned me to their experiences and their narratives, both because of the content of their stories, and because I was not expecting this to happen upfront, without the time necessary to build trust<sup>42</sup>. More specifically, these extracts illustrate how different parallel activities (research, volunteering/activism<sup>43</sup>, design) in different sites (the field, the non-profit organization, the studio), and the values associated with each activity and sites, all inform my research<sup>44</sup>.

When entering each of these spaces, values are re-evaluated. The research context provided me with arguments and knowledge that could be made useful in a volunteering/activism context. But this

<sup>40</sup> Yvonna S Lincoln, Lynham, and Egon G Guba, "Paradigmatic Controversies, Contradictions, and Emerging Confluences, Revisited".

<sup>41</sup> Duncombe and Jessop, 'Doing Report' and the Ethics of 'faking Friendship'. Holland, "Young People and Social Capital".

<sup>42</sup> See also Chapter 9.

<sup>43</sup> Eliasoph, *The Politics of Volunteering*.

<sup>44</sup> Procter, "Exploring the Role of Emotional Reflexivity in Research with Children".

knowledge was considered illegitimate, because of the priority given by other volunteers to first-hand accounts of experiences. On the other hand, discourses made and criticized in a volunteering context proved useful to reflect on power issues between children and adults<sup>45</sup>. Furthermore, there are many ways through which volunteers and activists build upon academic research<sup>46</sup>, which would suggest that the research I was undertaking would not always be considered illegitimate in that sphere. Indeed, in the second fragment, activists used a specific understanding of the standpoint theory (i.e., the attention to the point of view during the development of knowledge<sup>47</sup>) to assert the epistemological primacy of the lived experience. But other activists supported my research aims and practices.

A similar process can be found when going from the studio and the design field to the academic field, as the last extract hints. What research participants or other designers value might not be considered valuable in academic spaces.

### 2.3.2 *And in academic spaces*

Consider the following excerpts:

March 2016 - the lab.

After a research discussion with a colleague on the current framing of my dissertation: "His argument is simple: I'm a female, and a designer, so I get emotional as well as too empathetic with children. Thus, I'm doing bad research, driven by feelings instead of a more detached, objective, approach to research [...].

It's true that I'd probably be more efficient, if I didn't care as much. But if everything I do is depreciated because I care, and I can't not care, where does that leave me?"

June 2016 - the lab. During an evaluation of my research progress by external researchers. Transcript: "What I see, is that you've been dutiful [...] beyond duty even. What I don't see however is [...] how can others learn from it? You think like a designer [not like a researcher] [...] What I ask my students is: why do you care? Why do you do the research you do? [...] Who wants to learn about this?"

Journal: "It's frustrating, I still can't articulate why I'm both eager and concerned to include a reflexion on caring in the definition of my research question. It feels important, yet I'm not sure what it impacts."

<sup>45</sup> Andy West, "Power Relationships and Adult Resistance to Children's Participation".

<sup>46</sup> Akrich, "From Communities of Practice to Epistemic Communities: Health Mobilizations on the Internet".

<sup>47</sup> Hartsock, "The Feminist Standpoint: Developing the Ground for a Specifically Feminist Historical Materialism".

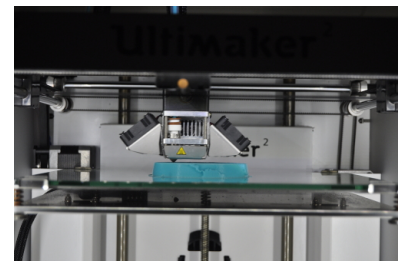


Figure 2.2: A 3D printer in Télécom Paristech's fablab: hereby named the studio.

What underpins the frustration expressed in the first extract is that a significant proportion of my colleagues and peers repeatedly attributed attentiveness to values and valuations to my supposedly innate female identity. Even doing qualitative research in HCI was conflated with "*girl stuff*."<sup>48</sup> Some criticized this approach as hindering or biasing research work, but others encouraged embracing it in my attempts to refine my research question. Both fragments point to the entanglements of epistemological and ethical considerations: what is the kind of knowledge produced? For whom, for what purpose? Both researchers evoked in those excerpts aimed at helping me disentangling contradictory values. They made me face that defining a research question was yet another valuation process. Within a given material with multiple emerging threads, what are the threads that mattered, to which research community? Design research in particular, as a relatively young discipline, remains very concerned with the type of knowledge thus produced and the role of artifacts in its production<sup>49</sup>; a knowledge that may be developed for designers, engineers or social researchers<sup>50</sup>.

Recognizing that academic research and findings emerge from convergent interests and specific positions within academia or different worlds is far from new<sup>51</sup>. However, there are different ways to engage with these interests. Values and valuations may be hidden, or more or less disclosed as variables influencing the findings. For instance, the disclosure of funding sources is a practice aiming to provide readers with indications regarding the potential conflicts of interest. In this particular case, there are two main reasons for reclaiming situated valuations as a legitimate way to define a research topic. First, it made the field-study possible, as discussed in the first section of this chapter. Second, it may open new perspectives on the overall subject—here the education of children with visual impairments.

Regarding how my position in the academic field influenced my definition of a research topic, I note two main aspects. The first is that both of my supervisors greatly encouraged writing in English for an international community, rather than writing in French and building upon the French research literature<sup>52</sup>—for instance in Communication and Information Sciences, the discipline of my first Ph.D. supervisor. Furthermore, they had not previously worked on design and disability. It required me to build a **Frankenstein** theoretical framework from different bits of themes I had identified during the field-work, rather than building on a well-identified body of work.

This oriented the type of literature research I did, and the research communities I tried to participate in or to learn from, following

<sup>48</sup> This is particularly ironic, given that there is an important gender imbalance in the design industry, in favor of male designers. See for example: [www.designweek.co.uk/issues/17-23-april-2017/women-studying-design-female-creative-directors](http://www.designweek.co.uk/issues/17-23-april-2017/women-studying-design-female-creative-directors).

<sup>49</sup> Binder and Redström, "Exemplary Design Research"; Fallman, "The Interaction Design Research Triangle of Design Practice, Design Studies, and Design Exploration"; V. Margolin and S. Margolin, "A 'Social Model' of Design: Issues of Practice and Research"; Forlizzi, Zimmerman, and Evenson, "Crafting a Place for Interaction Design Research in HCI".

<sup>50</sup> Hutchinson et al., "Technology Probes"; Dow, Ju, and W. Mackay, "Projection, Place and Point-of-View in Research through Design".

<sup>51</sup> Becker, "Whose Side Are We On".

<sup>52</sup> Which, on the subject of disability in social sciences, is anyway quite skewed, as will be discussed in the next section and Chapter 5.



emerging patterns. Specifically, I participated in the design research and participatory design communities in Human-Computer Interaction (HCI)—my second supervisor researching interaction techniques in that field) and learned from the new sociology of childhood and American or British disability studies communities. Only later in the process did I try to identify a potential **French framing** (and subsequent approach) of this topic.

The second is that valuations are an essential part of the design activity. Considering design practices as future oriented<sup>53</sup>, designers need to question the possible futures they open. These futures are constituted through practice(s): those of the designer, those of **users**<sup>54</sup>. In other words, if I want to study how to design in this context, being reflexive on the valuations made are part of the knowledge to be transmitted: they are design principles that should not be neglected<sup>55</sup>.

Furthermore, as these design principles evolve during their deployment in the field, they may reveal new or previously unnoticed aspects of experiences of school. Indeed participants developed new knowledge about their practices, hence new material and perspectives for research. I came to reckon that my naive<sup>56</sup> research approach as a designer denotes a pragmatist worldview—defined as "*a general philosophical orientation about the world and the nature of research that a researcher brings to a study*"<sup>57</sup> which I discuss in details in Chapter 4.

To summarize the different valuations that made my research possible. First, there was a public interest in educational technologies and a perceived lack of knowledge on the spatial cognition of people with visual impairments in the research literature. Hence the Accessimap project, in which core members were primarily interested in the second aspect but very willing to support the dissemination of a prototype of their device. Second, carers resisted researchers' priorities. Third, children related adversarial experiences, to which I was particularly attentive because of my involvement in volunteering activities on that theme. Finally, I came to acknowledge their experiences of school could be valuable as a research topic because research communities were sharing this attention to values and the study of experiences.

<sup>53</sup> Dow, Ju, and W. Mackay, "Projection, Place and Point-of-View in Research through Design".

<sup>54</sup> Akrich, "Comment Décrire Les Objets Techniques?"

<sup>55</sup> Friedman, "Value-Sensitive Design".

<sup>56</sup> I do not mean that pejoratively. As outlined earlier in this chapter, I had no previous experience of academic work, and had decided on an inductive approach.

<sup>57</sup> Creswell, *Research Design: Qualitative, Quantitative, and Mixed Methods Approaches*.

## 2.4 *Implications for the Definition of the Research Topic and Approach*

In addition to the implications for the research worldview (philosophical background), the valuations I made have consequences for the research topic and its methodological approach. First, they progressively refined the focus of the study, towards children's experiences. Second, they led me to turn to the literature on activism and research, to elicit more clearly the part activism could (or not) play in my research. Third, they modified the design rationale underpinning my interventions and the type of knowledge I aimed to produce.

### 2.4.1 *Focusing on children's experiences*

Because of my interest in how adults frame and describe children (see above) and my questioning on whether there was a French approach to the study of disabled childhood, I conducted a separate bibliographic research of French academic literature. It revealed a strong focus on teachers' and carers' practices and conceptual accounts of education (e.g., debates on special and inclusive education). Children's views were under-represented<sup>58</sup>, whereas it has generated much interest in the American, British and Scandinavian contexts<sup>59</sup>. Not only there were power issues between children and carers in the field (see also next chapter), but it coincided with an understudied area in French research.

As I rearticulated my research topic around children participants' views, it raised new provisional research questions: How do children with visual impairments experience school? What are the contextual factors (policies, conceptual models of disability advocated by their carers, local norms of care, individual education projects but also children socio-demographic characteristics) influencing their experiences of school? Could design interventions improve these experiences? In this perspective, children's narratives about negative experiences at school became a primary subject of interest, both as a phenomenon to understand, as potentially generating new concepts, and as a site for action.

### 2.4.2 *Delineating activism in research*

Action (in) research have political implications<sup>60</sup>. I outlined that carers and children emphasize social justice issues, how I used skills built during my volunteer/activism experiences, as well as the cir-

<sup>58</sup> See Chapter 5

<sup>59</sup> Stalker, Abbott, et al., "Researching the Lives of Disabled Children and Young People."

<sup>60</sup> Williamson and Prosser, "Action Research: Politics, Ethics and Participation".

ulation of knowledge between academia and volunteering/activist groups. These two aspects, as well as the disability studies literature<sup>61</sup>, led me to posit early in my research that disabled people constitute an oppressed group<sup>62</sup>. This oppression, disablism, should be understood in interaction with other components of their identities<sup>63</sup>. It should not occlude the issues faced by all children<sup>64</sup>. Indeed, children have limited legal rights, little political representation, etc<sup>65</sup>. Furthermore, they are often described as diminished adults rather than as social actors<sup>66</sup>.

Once this oppression is acknowledged, there are different ways a research project can be designed and led. One recommendation is for researchers to confer with activists to develop material supporting political claims<sup>67</sup>. However, this can compromise the validity of the research<sup>68</sup>, in addition to exclude diverging voices<sup>69</sup>. My position is to: 1) provide academic skills when asked by activists; 2) promote diversity in academia by providing advice to disabled students eager to engage in research; 3) use my design skills as a way to provide needed material assistance, both in and outside of my scope of research; 4) exposing the values underlying this research; and 5) taking the too often overlooked children's accounts and experiences as a research starting-point to counterbalance the power differential between adults and children.

#### 2.4.3 Redefining the design interventions rationale

Finally, in line with the participatory design principles, I questioned which values were incorporated into the design rationale. Whereas I was first asked to gather data for informing the design of technologies focusing on activity limitations (i.e., access to maps), my actual interventions were conducted with the primary goal of providing pleasant experiences in the classroom with educational technologies. But this needed to engage teachers as well, hence to be considered useful for learning. Furthermore, given the fact that an overarching value is to reduce the marginalization of disabled children, improving learning is not sufficient. There is a need to design for the recognition of a diversity of ways to learn and know. Or in other words, to contest some educational norms, based primarily on a visual paradigm. In this perspective, design is a way to improve material conditions, but also to produce symbolic meaning, which in turn may decrease marginalization<sup>70</sup>. This is in line with carers' emphasis on social justice, their attentiveness to children' motivation, and children' emphasis on their well-being. I also emphasize robustness and focus on issues of maintenance after intervention (through

<sup>61</sup> Victor Finkelstein, *Attitudes and Disabled People: Issues for Discussion*; Liasidou, "Intersectional Understandings of Disability and Implications for a Social Justice Reform Agenda in Education Policy and Practice".

<sup>62</sup> Young defines oppression as five faceted: exploitation, marginalization, powerlessness, cultural imperialism and violence. Cultural imperialism refers to the fact a person is not adequately represented, or preemptively attributed negative characteristics. Whereas powerlessness points out that, even with the will to change one's environment, one does not have the power to do so—which may contribute to self-imposed barriers as well. I. M. Young, "Five Faces of Oppression".

<sup>63</sup> Vernon, "Multiple Oppression and the Disabled People's Movement".

<sup>64</sup> Connors and Stalker, "Children's Experiences of Disability – Pointers to a Social Model of Childhood Disability".

<sup>65</sup> James, *Childhood Identities: Self and Social Relationships in the Experience of the Child*.

<sup>66</sup> James and Prout, *Constructing and Reconstructing Childhood: Contemporary Issues in the Sociological Study of Childhood*.

<sup>67</sup> M. Oliver, "Emancipatory Disability Research: Realistic Goal or Impossible Dream?"

<sup>68</sup> Nick Watson, "Researching Disability".

<sup>69</sup> Danieli and Woodhams, "Emancipatory Research Methodology and Disability: A Critique".

<sup>70</sup> Hamraie, "Designing Collective Access: A Feminist Disability Theory of Universal Design".

open access and documentation sharing), maintenance strongly relating to the values of care<sup>71</sup>—which is well consistent with the ethical framework described in Chapter 4.

<sup>71</sup> S. J. Jackson, “11 Rethinking Repair”.

## 2.5 *Summary*

This chapter described the definition of my research topic, within a larger research project aiming at developing new technologies to provide access to tactile graphics (and maps in particular). My Ph.D. research began with a field study, using a Grounded Theory approach, in an organization providing services to children with visual impairments. This study aimed at understanding the different contexts of use for the type of educational technologies envisioned and produce design guidelines for partner researchers. However, conducting fieldwork required to renegotiate the research values and priorities. I described these negotiations as valuations<sup>72</sup>, which engaged every research stakeholders, myself included. It resulted in giving priority to children’s well-being—with a concern to design for supporting a plurality of experiences and ways of knowing. It refined the research topic and the design rationale guiding my interventions. Lastly, these valuations anchored my research in pragmatism: I build my research on a problem, that of adversarial experiences of school for this particular group of children, knowing that as a designer, I had tools that might be useful to investigate and maybe improve it.

<sup>72</sup> Dewey, “Theory of Valuation.”



# 3

## *Defining Visually Impaired Children*

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The previous chapter focused on the initial research project, the values it embodied, and the negotiations necessary to conduct fieldwork on the subject of school and children with visual impairments. It described how I chose to focus on children's views and experiences—which converges with a part of the research literature on disabled childhoods, spanning from disability studies scholars. This chapter contextualizes my research within the different theo-

retical frameworks used to study disabled children. In line with my pragmatist worldview, I did not a priori discarded or adopted any of them. But as I gradually integrated the research literature in my analysis, my observations were necessarily influenced by these definitions, and vice-versa—ways of thinking affect ways of seeing—and thus the topic and associated theoretical framework of this dissertation.

Contrasting definitions of disability, childhood and visual impairments is important for grounding and contextualizing my research. Arguably, disabled childhoods are more likely to be looked at through a medical/psychological lens, as specialists carers such as therapists and doctors play an important role in their early years. Hence, it is even more crucial to contest a naive definition of disabled children in general and visually impaired children in particular.

This chapter attempts to articulate the different research disciplines and fields of research concerned with visually impaired children's experiences of school, and the roles of learning technologies play in it. Specifically, this dissertation belongs to social sciences, here broadly defined as the study of society and relationships between individuals. I rely primarily on sociology research and additionally mobilize references from history, education, political sciences and psychology research. But I also use social sciences to inform Human-Computer Interaction (HCI) research.

I begin by providing a socio-historical account of the problematization of disabled children in Social Sciences and policies. I then discuss more precisely what is at stake when defining disability, children and visual impairments. Specifically, I focus on the long-lasting opposition of the medical and social models of disability, as well as the differences between international and French research on that subject. I conclude with a discussion of their appropriation in design research.

## Visual Overview

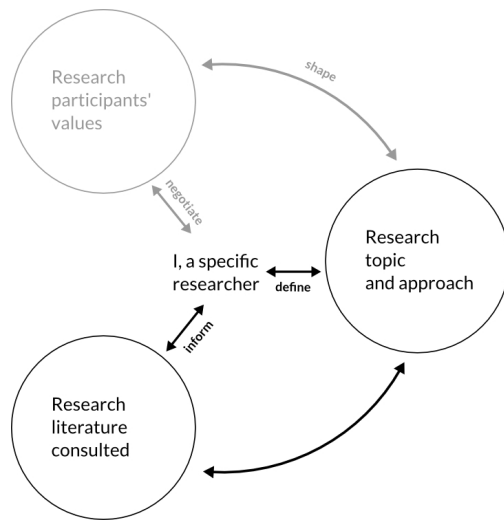


Figure 3.1: This figure illustrates the focus of Chapter 3: It too discusses the construction of my research topic and approach, but this time by taking the research literature as a starting point.

### 3.1 Constructing Disabled Childhoods

The category "disabled children" is not stable in time or space: what is considered as an impairment, or the age at which we leave childhood depends on the context. This section aims at giving some context on how disabled childhoods became a research subject—which highlights two main tensions, one between a social and medical approach (or structural and individual), the other between the French, and English research literature.

#### 3.1.1 A short history of ideas

Knowledge about disabled children could be described as a complex interplay between knowledge about children and disability in general, and knowledge about specific groups of disabled children. In Europe, after some pioneering work in the Renaissance period<sup>1</sup>, the Enlightenment in the XVIII<sup>th</sup> century marked increased interest in the rehabilitation of disabled people<sup>2</sup>, mainly in order to be able to put them to work<sup>3</sup>. People deemed impaired were furthermore greatly affected at the turn of the XX<sup>th</sup> by the **Social Darwinism** movement. Thinkers from this movement advocated for the withdrawal from society or the sterilization of disabled people. Disability was considered to be a deviance, and a danger for the future of humanity<sup>4</sup>. It

<sup>1</sup> See for instance the work of Spicker on Juan Luis Vives, who argued in the XVI<sup>th</sup> century to put an end to charity for disabled people, and enable them to earn a living: Spicker, *The Origins of Modern Welfare: Juan Luis Vives, De Subventionne Pauperum, and City of Ypres, Forma Subventionis Pauperum*.

<sup>2</sup> P. L. Safford and E. J. Safford, *A History of Childhood and Disability*; Braddock and Parish, "An Institutional History of Disability".

<sup>3</sup> Weygand, *Vivre sans Voir: Les Aveugles Dans La Société Française, Du Moyen Age Au Siècle de Louis Braille*.

<sup>4</sup> Morss, *The Biologising of Childhood: Developmental Psychology and the Darwinian Myth*.



consecrated a medical model of disability: knowledge about impairments and disability were confined to the realm of "natural" sciences, in particular medicine and psychology, and their corollary, rehabilitation sciences<sup>5</sup>. And with the increase in disability rates caused by industrialization and the first World War, rehabilitation became a state matter: France, for instance, passed a law to provide compensation to workers disabled in the workplace in 1898, and two laws to compensate and reintegrate disabled soldiers in 1919 and 1924<sup>6</sup>.

Similarly, children's development and education increasingly became a preoccupation of Western states during the XIX<sup>th</sup> century, in part because of the Enlightenment utopian thinkers such as Rousseau depicting them as **natural beings**, yet to be marked by culture<sup>7</sup>. Policies increasingly described children as fragile, in need of protection. The government became more involved in early life stages through the subvention of child care and educational institutions. Private philanthropic organizations of all kinds destined to **save** children thrived. Meanwhile, parental literature publicizing norms of good care developed<sup>8</sup>. These norms required a scientific basis: From the XIX<sup>th</sup> century onward, educators, psychologists and doctors created an important body of work about children's **natural development** and how to sustain it<sup>9</sup>. From there, theories diverge: whereas Piaget attempted to define universal stages of development, Vygotsky emphasized the role socio-cultural relations in cognition<sup>10</sup>. Among other consequences, these norms were often not compatible with poverty, making poor families the primary target of state interventions.

There were similar attempts to measure and standardize disabled children and their care. But not all impairments were treated equally. D/deaf and blind children were considered educable quite early (the first school for the blind was opened in France in 1786<sup>11</sup>, at the same period as the first school for the D/deaf), but only in special education settings. Children with learning disabilities or mental impairments remained in hospices and asylums.

Until late in the XX<sup>th</sup> century, biological views of children's development tended to hide social factors (gender, class, ethnicity etc.). They were risks, factors that may impede education—and ultimately, access to the workforce. But gradually another discourse on children emerged: one based on their agency, and on their civil rights, on their competencies and rights to participate in civil life<sup>12</sup>. The UN declaration of the rights of the child illustrates this (discussed later in this chapter). This discourse supports and is supported by the sociologists invested in the study of children's views from the 1980s onward<sup>13</sup>. The focus in research, especially in the English literature, was greatly displaced towards children's experiences and narratives,

<sup>5</sup> For a concrete example of the dynamics between the epistemology of disability and care organizations and policies: Hayhoe, "The Epistemological Model of Disability, and Its Role in Understanding Passive Exclusion in Eighteenth and Nineteenth Century Protestant Educational Asylums in the USA and Britain".

<sup>6</sup> publique, *Chronologie, La Politique Du Handicap*.

<sup>7</sup> P. K. Smith and C. H. Hart, *The Wiley-Blackwell Handbook of Childhood Social Development*.

<sup>8</sup> Vandenbroeck and Bie, "Children's Agency and Educational Norms: A Tensed Negotiation".

<sup>9</sup> Noon, "The Evolution of Beasts and Babies: Recapitulation, Instinct, and the Early Discourse on Child Development"; Aries, *Centuries of Childhood: A Social History of Family Life*.

<sup>10</sup> E. K. M. Tisdall and Punch, "'Not So 'New'?: Looking Critically at Childhood Studies' Children's Geographies".

<sup>11</sup> The *Institut royal des Jeunes Aveugles*, founded and funded by Valentin Haüy, with the help of patrons. In 1785, he wrote a book on his educational methods and supports. His school was nationalized in 1791 and renamed the Institution Nationale des Jeunes Aveugles (INJA). The education provided primarily focused on providing youngsters with practical and manual skills. Only a few activities, such as weaving, were considered to be accessible to them. Weygand, "Les aveugles dans la société française".

<sup>12</sup> Vandenbroeck and Bie, "Children's Agency and Educational Norms: A Tensed Negotiation"; Ørholt and Trine, "Small Is Powerful: Discourses Onchildren and Participation in Norway"; E. K. M. Tisdall and Punch, "'Not So 'New'?: Looking Critically at Childhood Studies' Children's Geographies".

<sup>13</sup> W. A. Corsaro, *The Sociology of Childhood*.

or childhood cultures, and the impact of a variety of social factors (e.g., gender, ethnicity, social class, place), and question normative assumptions about children.

In the domain of disability, one can pinpoint this social turn (in the English literature) to the 1970s, with the pioneering work of UPIAS<sup>14</sup> and civil rights movements. Although symbolic interactionists also made significant contributions to the study of social aspects of mental illnesses<sup>15</sup> in the 1960s—and there is, of course, the foundational work of Durkheim on suicide as caused by lack of social integration<sup>16</sup>. These strands of sociology (of childhood, and of disability) converge in disabled childhood studies<sup>17</sup>, a body of work growing since the end of the 1990s<sup>18</sup>. Access to services and rehabilitation remains an important topic in this literature, in order to contribute to shape better policies: The research developed is more often applied than theoretical<sup>19</sup>. But similar topics are re-interrogated from a different perspective. For instance, instead of evaluating services on the basis of professional or standardized tests outcomes, scholars may inquire as to what children consider successful life outcomes<sup>20</sup>.

### 3.1.2 *At the crossroad between disciplines and countries*

There are two main difficulties when attempting to define and situate academically visually impaired French children's school experiences as a research topic. First, the scientific field concerned with the education of disabled children is structured very differently in France than in the international literature. The international literature can itself be subdivided between a civil rights framework mainly used in the UK and the US, a Nordic social relational approach<sup>21</sup>, and a critical approach held by scholars studying the Majority world where concepts of participation or agency are defined very differently.

For instance, American and British social research on disability and childhood is often conducted in homonymous **studies** and dedicated research centers, which enables to shortcut disciplinary differences or to more easily create sub-disciplines (e.g., child geographies). In France, however, the organization of research differs significantly: this topic may be studied in education sciences, the sociology of education, or in non-specialized sociology departments interested among other things in disability, childhood and education<sup>22</sup>. If I were to summarize their differences, the first is concerned with defining pedagogical and didactic issues, and focuses on practices; whereas in sociology, some scholars choose to specialize in a given subject (here education), and others to switch from a domain to another.

<sup>14</sup> UPIAS, "Fundamental Principles of Disability".

<sup>15</sup> Goffman, *Stigma: Notes on the Management of Spoiled Identity*; Goffman, "Asylums: Essays on the Social Situation of Mental Patients and Other Inmates".

<sup>16</sup> Mucchielli and Renneville, "Les Causes Du Suicide: Pathologie Individuelle Ou Sociale? Durkheim, Halbwachs et Les Psychiatres de Leur Temps (1830-1930)".

<sup>17</sup> Although one may ask to which point disabled childhoods are taking into account in the mainstream Sociology of Childhood—see for instance the editorial of the special issue of *Children & Society* on disabled children for a discussion Stalker, Abbott, et al., "Researching the Lives of Disabled Children and Young People."

<sup>18</sup> Connors and Stalker, "Children's Experiences of Disability – Pointers to a Social Model of Childhood Disability"; Stalker, Abbott, et al., "Researching the Lives of Disabled Children and Young People."; Ytterhus, "Everyday Segregation Amongst Disabled Children and Their Peers: A Qualitative Longitudinal Study in Norway"; Rabiee, "Choice: What, When and Why? Exploring the Importance of Choice to Disabled People"; A. Cocks, "Researching the Lives of Disabled Children. The Process of Participant Observation in Seeking Inclusivity".

<sup>19</sup> Stalker, Abbott, et al., "Researching the Lives of Disabled Children and Young People."

<sup>20</sup> Rabiee, Sloper, and Beresford, "Desired Outcomes for Children and Young People with Complex Health Care Needs, and Children Who Do Not Use Speech for Communication".

<sup>21</sup> This is not an impermeable frontier. See for instance: Connors and Stalker, "Children's Experiences of Disability – Pointers to a Social Model of Childhood Disability"; Traustadóttir et al., *Childhood and Disability in the Nordic Countries: Being, Becoming, Belonging*.

<sup>22</sup> Dutercq, "Sociologie, Sociologie de l'éducation et Sciences de l'éducation".

Research interests and definitions thus tend to differ from one geographic area to another, according to local political needs, for example<sup>23</sup>. I discuss the differences in the theoretical frameworks and subsequent preferred research approaches of children and disability in French social and human sciences in the following sections. But to close this section, I should summarize why I turned to foreign research literature instead of building upon research by French scholars. I pointed out in chapter 2, this was initially motivated by my supervisors advocating for writing in English. It was quite simply more convenient to build this dissertation on an English-written body of research. Additionally, the French sociological literature on disabled childhoods was quite scarce when I began my PhD (see chapter 5). The involvement of, and with, research participants rendered necessary by the field-study is a little-used approach to this domain in France. Second, as French policies are adjusting to international conventions on children and disability (see below), it seems legitimate to study how research tools developed for this new paradigm by scholars of the "*New Sociology of childhood*" in other countries may be fruitful. Third, it seemed worthy to attempt to bridge these different perspectives, to contribute to the current debates regarding the international applicability of the sociology of childhood<sup>24</sup>.

### 3.2 *Defining Disability*

This section expands the historical outline provided above by looking more specifically into the definition(s) of disability, first in research, then in policy.

#### 3.2.1 *The stakes of defining disability*

The definition of disability has varied in the last century, from an individual model of disability (i.e., disability as a feature of the individual that reduces its capacities) to a "hybrid" model (i.e., disability as the interaction between the individual's embodiment and the environment). I first describe the individual model, before moving on to a discussion on the variety of ways scholars have proposed to take into account the environment in the definition and study of disability.

<sup>23</sup> Gary L Albrecht, "American Pragmatism, Sociology and the Development of Disability Studies".

<sup>24</sup> E. K. M. Tisdall and Punch, "'Not So 'New'?: Looking Critically at Childhood Studies' Children's Geographies".

### Issues with an individual model of disability

By individual model of disability, I refer to the distinction made by Oliver<sup>25</sup>, Finkelstein<sup>26</sup> and others<sup>27</sup> between a definition of disability as a feature of a person and disability as a series of activity restrictions due to the interaction of a person and an inadequate environment. It is also termed the **medical model**. The main consequence of such a model of disability is that it frames the individual as foremost in need to be repaired—which is the work of rehabilitation professional. Disability is then assimilated to a personal tragedy<sup>28</sup>, which requires the charity of the community, the State, or the Church. As a corollary, disabled people are disqualified as lesser, and stigmatized<sup>29</sup>. Furthermore, it renders community organizing more difficult: if disability is an individual issue, that needs to be compensated for or rehabilitated at the individual level, why organize against such stigmatization?

Furthermore, in this perspective, expertise on disability is primarily detained by medical and rehabilitation specialists. Such discourse tends to impose a normative framework on abilities and interventions. Rehabilitation aims at making the body conform to the **norm** as much as possible. An example is the treatment of deafness: one could argue that proposing cochlear implants to deaf children implements a medical model of deafness. In contrast, D/deaf people advocate the recognition of D/deafness as a variation, and as a different culture, using alternative means of communication (e.g., American Sign Language).

### How to take into account the environment?

Opposed to the individual model is the social model of disability<sup>30</sup>. The term, coined by Oliver<sup>31</sup>, emerged from the civil rights movement and the UPIAS group. It reframes disability as being separated from the impairments, and in addition to them<sup>32</sup>. In this perspective, disability is 'the disadvantage or restriction of activity caused by a contemporary social organization which takes no or little account of people who have [...] impairments and thus excludes them from the mainstream of social activities'<sup>33</sup>. It follows that disability is foremost an oppression, that disabled people are a marginalized group, and that research should focus on empowering disabled people in their fights for equality<sup>34</sup>.

The social model acts as an umbrella term for various definitions of disability, and was adapted to answer the specificity of different contexts<sup>35</sup>. Rather than a theory, it is a heuristic tool to attract atten-

<sup>25</sup> Mike Oliver, *Social Work with Disabled People*.

<sup>26</sup> Victor Finkelstein, *Attitudes and Disabled People: Issues for Discussion*.

<sup>27</sup> Ennuyer, "Définir Le Handicap : Une Question Sociale et Politique?"; Stiker, *Corps Infirmes et Sociétés: Essais d'anthropologie Historique*.

<sup>28</sup> Mike Oliver, "The Individual and Social Models of Disability".

<sup>29</sup> Goffman, *Stigma: Notes on the Management of Spoiled Identity*.

<sup>30</sup> Gill, "A New Social Perspective on Disability and Its Implications for Rehabilitation".

<sup>31</sup> Mike Oliver, *Social Work with Disabled People*.

<sup>32</sup> C. Thomas, "How Is Disability Understood? An Examination of Sociological Approaches".

<sup>33</sup> UPIAS, "Fundamental Principles of Disability".

<sup>34</sup> M. Oliver, "Emancipatory Disability Research: Realistic Goal or Impossible Dream?"

<sup>35</sup> Pfeiffer, "The Conceptualization of Disability".

tion to the role of the environment<sup>36</sup>. Indeed, if we were to consider it as a theory, four main issues would arise from a strict separation of impairments from disability:

1. It downplays the embodied experiences of disability<sup>37</sup>, and the activity restrictions arising from impairments themselves<sup>38</sup> (e.g., fatigue);
2. It overlooks that discrimination against people with impairments would not occur if impairment were not suspected or observed<sup>39</sup>;
3. It obscures that abilities vary from one person to the other and that we are only temporarily able-bodied<sup>40</sup>, and;
4. It does not take into account the impact that lack of access and restrictions of activity have on a person (e.g., psycho-emotional consequences)<sup>41</sup>.

Furthermore, a number of British scholars using the social model of disability opposed the use of personal experiences in scholarship (i.e., **experience-near perspectives**<sup>42</sup>), in order to avoid fueling the view that disability is a personal matter<sup>43</sup>. Some scholars have proposed taking a critical realism lens, framing disability in an interdisciplinary fashion by synthesizing the influence of the different strata on a given situation<sup>44</sup>. Finally, a number of people adopt a post-modernist theoretical frameworks and approaches, to complement or supplement those above<sup>45</sup>. For instance, they propose a phenomenological account of bodily experiences<sup>46</sup>, or focus on disability representations and expression in language through time<sup>47</sup>.

Although all these different models of disability have nurtured this research, it is the social relational model of disability, also adopted by some scholars interested in disabled children<sup>48</sup>, that I found the most useful. Proposed by Thomas<sup>49</sup>, it posits the interaction of impairments and disability—and that the exclusion disabled people must face contributes to internalized and externalized barriers-to-being and barriers-to-doing.

Barriers-to-doing refers to material limitations in activities (e.g., lack of access because of stairs, marginalization or exploitation); while barriers-to-being ensues from the psycho-emotional effects (e.g., lack of self-esteem or confidence) of these material barriers, adversarial and violent attitudes from others because of the disability (i.e., stigma)<sup>50</sup>, or of cultural norms (i.e., not being included in the norm)<sup>51</sup>. This model does not negate that disabled people are dis-

<sup>36</sup> Vic Finkelstein, "The Social Model of Disability Repossessed".

<sup>37</sup> Hughes and Paterson, "The Social Model of Disability and the Disappearing Body: Towards a Sociology of Impairment".

<sup>38</sup> Tom Shakespeare, "The Social Model of Disability".

<sup>39</sup> Tremain, "On the Subject of Impairment".

<sup>40</sup> Tremain, "Critical Disability Theory".

<sup>41</sup> C. Thomas, *Sociologies of Disability and Illness: Contested Ideas in Disability Studies and Medical Sociology*.

<sup>42</sup> Gustavsson, "The Role of Theory in Disability Research-Springboard or Strait-Jacket?"

<sup>43</sup> C. Thomas, "How Is Disability Understood? An Examination of Sociological Approaches".

<sup>44</sup> Following Bhaskar and Danermark, Watson proposes the following levels of analysis: Physical; biological; psychological; psycho-social and emotional; socio-economic; cultural; normative. Nick Watson, "Theorising the Lives of Disabled Children: How Can Disability Theory Help?"

<sup>45</sup> Corker and Tom Shakespeare, *Disability/Postmodernity: Embodying Disability Theory*.

<sup>46</sup> Garland-Thomson, "The Story of My Work: How I Became Disabled".

<sup>47</sup> Devlieger, "Generating a Cultural Model of Disability".

<sup>48</sup> Connors and Stalker, "Children's Experiences of Disability – Pointers to a Social Model of Childhood Disability"; Ytterhus, "Everyday Segregation Amongst Disabled Children and Their Peers: A Qualitative Longitudinal Study in Norway"; Hanisch, "Psycho-Emotional Disablism: A Differentiated Process".

<sup>49</sup> C. Thomas, "Rescuing a Social Relational Understanding of Disability".

<sup>50</sup> Hanisch, "Psycho-Emotional Disablism: A Differentiated Process"; Goffman, *Stigma: Notes on the Management of Spoiled Identity*.

<sup>51</sup> Reeve, "Psycho-Emotional Disablism and Internalised Oppression".

criminated against materially<sup>52</sup>, but takes into account the effects it can have on individual self-perceptions, much like Young's model of oppression. Definitions of disability in policies are consistent with this model, which can be criticized as a Western-centric point of view, based on societies where care is centralized by the State, thus not necessarily adapted to other contexts<sup>53</sup>.

### Social sciences and disability in France

In a meta-review of research on disability in France, Albrecht *et al.*<sup>54</sup>, note that in contrast with other countries, there is a much stronger focus on historical perspectives on disability, which includes a focus on the evolution of policies. Furthermore, most American or British concepts do not coincide with those used in French sociology (e.g., the concept of minority has a different meaning). Similarly, there is little uptake of the disability model, and there has not been as much convergence between activists and researchers as in the US or UK. The focus has rather been on questioning norms of care<sup>55</sup>, observing disability policies' design and deployment<sup>56</sup>, or in a post-modern fashion on expanding the normal<sup>57</sup>. Though there is a recent turn to biographical research, interested in the near-experience<sup>58</sup>.

#### 3.2.2 Definitions in policies

I outline in this section the two definitions relevant to my study: the one adopted by the World Health Organisation (WHO), which informs policies worldwide and provide consistency to research in transnational contexts; the definition adopted by the 2005 French law for equality of rights and chances, participation and citizenship of disabled people<sup>59</sup>, which directly regulates the services to which the children I studied have access.

#### The WHO's definition of disability

In 1980 the World Health Organisation (WHO) published the *International Classification of Impairment, Disability and Handicap* (ICDH). Based on the work of Brown, this classification adopted a three-fold typology: "*Impairment any loss or abnormality of psychological, physiological or anatomical structure of function; Disability any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being; Handicap a disadvantage for a given individual, resulting from an impairment or disability, that limits or prevents the fulfillment of a role that is normal*

<sup>52</sup> Reindal, "A Social Relational Model of Disability: A Theoretical Framework for Special Needs Education?"; I. M. Young, "Five Faces of Oppression".

<sup>53</sup> Kalyanpur, "Inclusive Education Policies and Practices in the Context of International Development: Lessons from Cambodia"; Brégain, *Pour une histoire du handicap au XXe siècle: approches transnationales (Europe et Amériques)*.

<sup>54</sup> Gary L. Albrecht, Ravaut, and Stiker, "L'émergence Des Disability Studies : État Des Lieux et Perspectives".

<sup>55</sup> E.g., Hennion and Vidal-Naquet, "La Contrainte Est-Elle Compatible Avec Le Care ? Le Cas de l'aide et Du Soin à Domicile".

<sup>56</sup> E.g., Baudot, "Figures de l'État local. Une approche relationnelle des politiques du handicap".

<sup>57</sup> A body of work in the wake of Canguilhem and Foucault for instance. Canguilhem, *The Normal and the Pathological*.

<sup>58</sup> E.g., Revillard, "La Réception Des Politiques Du Handicap: Une Approche Par Entretiens Biographiques"; Dufour, *L'Expérience Handie*; Winance, "Mon Fauteuil Roulant, Mes Jambes". De l'objet Au Corps"; Lansade, "La Vision Des Inclus" Ethnographie d'un Dispositif d'inclusion Scolaire à Destination d'adolescents et Jeunes Adultes Désignés Handicapés Mentaux".

<sup>59</sup> Loi n° 2005-102 du 11 Février 2005 pour l'égalité des droits et des chances, la participation et la citoyenneté des personnes handicapées, Page 2353, JO n° 36 du 12 Février 2005.

(depending on age, sex and social and cultural factors) for that individual."

It implies that intervention is needed on different aspects: medical, functional, social, environmental etc. There were several versions of this classification. Today, the WHO provides a classification of diseases (ICD)<sup>60</sup>, and one of functioning (ICF). The latter is used to describe and measure disability. It defines disability as: "*an umbrella term for impairments, activity limitations and participation restrictions. It denotes the negative aspects of the interaction between an individual (with a health condition) and that individual's contextual factors (environmental and personal factors).*"<sup>61</sup>"

In this definition:

- Impairments are "*problems in body function and structure such as significant deviation or loss;*"
- Activity limitations are "*difficulties an individual may have in executing activities;*"
- Participation restrictions are "*problems an individual may experience in involvement in life situations;*"
- Environmental factors are "*the physical, social and attitudinal environment in which people live and conduct their lives.*"

<sup>60</sup> Current version is ICD-10: <http://apps.who.int/classifications/icd10/browse/2016/en>. ICD-11 should be published in 2018.

<sup>61</sup> World Health Organization, *International Classification of Functioning, Disability and Health: ICF*.

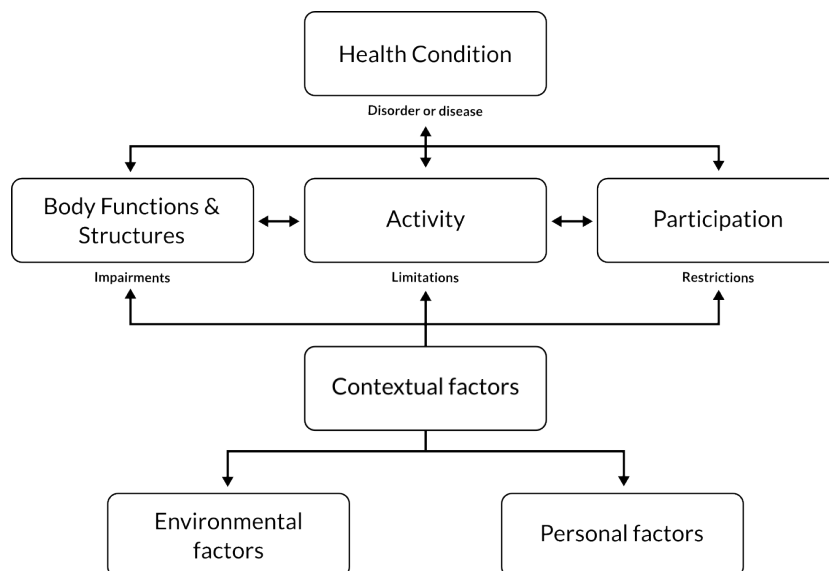


Figure 3.2: This schema, adapted from the ICF, describes the relationship between the different aspects of disability. A health condition and contextual factors determine body functions and structure, activity limitations and participation restrictions, which also shape one another.

The WHO thus adopts a definition of disability recognizing the role of the environment in disabling people. However, some have criticized the fact that this classification is too centered on the individual and its aptitude to adapt and not enough on environmental aspects (as evidenced by the term biopsychosocial<sup>62</sup> often used to describe it), and make Western-centric assumptions about what is participation, the importance of work and productivity etc<sup>63</sup>. This focus on the individual can also be found in national policies.

<sup>62</sup> Engel, "The Clinical Application of the Biopsychosocial Model".

<sup>63</sup> Barnes and Mercer, "Theorising and Researching Disability from a Social Model Perspective".

### The French 2005 law on integration

Although there have been laws to protect disabled workers and soldiers since the end of the XIX<sup>th</sup> century, the first law granting full civil rights to disabled people was voted in 1975<sup>64</sup>. It recognized the right to an education and to be, *when possible*, cared for in their communities. It established that different institutions would be responsible or disabled people under and over 20 years old. That same year, the UN adopted the first declaration of rights of disabled people.

<sup>64</sup> See: La Politique du Handicap, Chronologie. [http://www.vie-publique.fr/politiques-publiques/politique-handicap/chronologie/#sommaire\\_1](http://www.vie-publique.fr/politiques-publiques/politique-handicap/chronologie/#sommaire_1), as well as: Ennuyer, "Définir Le Handicap : Une Question Sociale et Politique ?"

In 2002, this law was revisited to include, among other things, the notion of a co-decided "yearly personal project" guiding the services and aids received by a disabled person. Finally, the 2005 law for equality of rights and chances, participation and citizenship of disabled people (**loi pour l'égalité des droits et des chances, la participation et la citoyenneté des personnes handicapées**) further reinforced civil rights<sup>65</sup>. Among other things, it imposed the physical accessibility of all public spaces and transportation systems before 2015 (which was then delayed for up to ten years, and new exceptions were recently announced), made new provisions for enabling access to human assistance in the classroom and the inclusion of disabled children and created the MDPH, the departmental organization tasked with deciding the needed adaptations and services, and managing service providers. This law defines disability as follows:

<sup>65</sup> See also: Stiker, "Les Métamorphoses Du Handicap de 1970 à Nos Jours".

*"Within the meaning of this Act, disability constitutes any activity limitation or participation restriction to society experienced by a person in their environment, when caused by a substantial, lasting or definitive alteration of one or more physical, sensory, mental, cognitive or psychic functions, by severe multiple disabilities, or by a debilitating health disorder"*<sup>66</sup>.

This definition uses key components of the WHO's, i.e. activity limitation and participation restriction. However, disability in this definition is caused by impairments, rather than emerging from the interaction between a person and the environment as it was the case in the previous version of the law<sup>67</sup>. This difference does not

<sup>66</sup> Translation is mine. Original formulation: "Constitue un handicap, au sens de la présente loi, toute limitation d'activité ou restriction de participation à la vie en société subie dans son environnement par une personne en raison d'une altération substantielle, durable ou définitive d'une ou plusieurs fonctions physiques, sensorielles, mentales, cognitives ou psychiques, d'un polyhandicap ou d'un trouble de santé invalidant."

<sup>67</sup> Ennuyer, "Définir Le Handicap : Une Question Sociale et Politique ?"



necessarily affects the provisions of care or accessibility. Finally, let's note that the inclusion at school was consecrated by the 2013 bill on education<sup>68</sup>. Beyond the integration of disabled children, the law focuses on the adaptation of school to all children regardless of their characteristics.

<sup>68</sup> *Loi n°2013-595 du 8 Juillet 2013 d'orientation et de programmation pour la refondation de l'école de la République.*

### 3.3 Defining Visual Impairments

Defining visual impairments can also be a source of debate, with tensions close to those found in the definition of disability: Is the main issue not being able to undertake given activities, or conform to a given diagnosis? Visual impairments can be defined by visual abilities, functional abilities, or both. Moreover, the criterion and thresholds determining visual impairments can be contested<sup>69</sup>. Several classifications co-exist, all of which distinguishing blindness and low vision.

<sup>69</sup> L. Dandona and R. Dandona, "Revision of Visual Impairment Definitions in the International Statistical Classification of Diseases."

#### 3.3.1 Visual abilities

The description adopted by the World Health Organization as described by the International Classification of Diseases (ICD-10)<sup>70</sup>. In this classification, visual impairments are defined by acuity after correction. Perfect acuity is a 1; visual impairment describes an acuity inferior to 0.3 in the better eye after correction. Visual loss can apply to one or both eye (monocular or binocular visual impairment). Let's acknowledge that people characterized as blind may have residual visual abilities, such as seeing colors, or distinguishing between light and darkness. It recognizes different degrees of visual impairment, illustrated in the Table 3.1:

<sup>70</sup> World Health Organization, *International Classification of Functioning, Disability and Health: ICF.*

Category	Presenting distance visual acuity	
	Worse than:	Equal to or better than:
0 Mild or no visual impairment		3/10 (0.3)
1 Moderate visual impairment	3/10 (0.3)	1/10 (0.1)
2 Severe visual impairment	1/10 (0.1)	1/20 (0.05)
3 Blindness	1/20 (0.05)	1/50 (0.02)
4 Blindness	1/50 (0.02)*	Light perception
5 Blindness	No light perception	
9	Undetermined or unspecified	

\* or counts fingers (CF) at 1 meter.

Table 3.1: This table depicts the thresholds used by the WHO to classify visual impairments. Note that the term blindness does not infer that there are no visual perceptions.

The thresholds of visual impairments may differ from country to

country, and change with time<sup>71</sup>. France mostly follows the WHO's classification but defines visual impairments in children by a visual acuity inferior to 0.4. Being visually impaired gives children access to specific care services. Children with a visual acuity superior to 0.4 may also have access to these services if they have visual field restrictions (<20°)<sup>72</sup>. However, the capacity to use these visual abilities differs from one child to another.

<sup>71</sup> L. Dandona and R. Dandona, "Revision of Visual Impairment Definitions in the International Statistical Classification of Diseases."

<sup>72</sup> Catherine Arnaud et al., "Déficits Visuels: Dépistage et Prise En Charge Chez Le Jeune Enfant".

### 3.3.2 *Functional abilities*

A diagnosis also needs to evaluate functional abilities to evaluate the specific adaptations needed and to detect better difficulties in everyday life associated with functional vision issues. For instance, one legally blind child we worked with never used a cane, while all others children within the same range of visual abilities did. Some organizations, such as the NGO European blind union, thus define a person with visual impairment as someone "for whom the reduced vision affects one or several of the following activities: 1) Reading and writing; 2) Orientation and mobility; 3) Activities of daily life; 4) Communication; 5) Maintenance of any visual task."<sup>73</sup> Self-administered questionnaires often focus on these functional abilities<sup>74</sup> to assess visual impairments. Indeed, people may not be diagnosed, or may not use the label "visual impairment." With a categorization based on functional abilities, being visually impaired becomes a characteristic that calls for assistance in activities considered indispensable that require vision.

<sup>73</sup> Union, *EBU Policy Statement on Low Vision*.

<sup>74</sup> E.g., Sander et al., "La Population En Situation de Handicap Visuel En France: Importance, Caractéristiques, Incapacités Fonctionnelles et Difficultés Sociales. Exploitation d'enquêtes HID 1998/99".

In this dissertation, I use "disability" and "visual impairments" primarily to refer to the administrative categories they represent. This shapes and is shaped by the type of field-work I undertake, that inquires about visually impaired children who are identified as such, to get access specialized care. It does not presume that they identify themselves as disabled or visually impaired, and it does not summarize their functional abilities. However, the relation between the two terms is best described by the social-relational model of disability: Even if visually impaired children do not identify as such, they experience disability in various contexts, because they encounter different types of barriers.

## 3.4 *Defining Children*

I outlined the difficulties of defining disability, and my leaning towards a social relational understanding of disability, well in line with

my pragmatist worldview. This enables me to reconcile micro and macro perspectives when defining disability and when trying to understand disability experiences. I now focus on defining children.

We use "children" as a term to distinguish the youngest part of the population from adults. But the definition of childhood is context sensitive. How exactly do they differ from adults, and how does this difference affect their experiences of the world (and in our case, of disability)? To address these questions, I need to contest a purely biological and developmental view, which frames children as lacking in abilities which they must acquire to become adults and that they acquire by stages defined by age<sup>75</sup>; and adopt a definition of children closer to that of the (new) Sociology of Childhood<sup>76</sup> which recognizes that children are not an homogeneous group, and the relativity of the attribute of youth. From this perspective, I argue for considering children as competent social agents with their own cultures, without negating their needs for specific types of support nor the influence of adults on their lives. Finally, I distinguish teenagers, because we observed a specific conjuncture<sup>77</sup> marking teenage years, which makes the experiences different.

### 3.4.1 Children as Defined in Laws

"Ways of seeing children affects ways of listening to children"<sup>78</sup>.

The United Nations Convention on the Rights of the Child<sup>79</sup> describes children as people under the age of eighteen, except if the local law defines an earlier age. The legal majority in France is also set at 18 years-old and marks the beginning of full legal responsibility<sup>80</sup>. However, minors can be held responsible in a court of law, they can be emancipated, and many countries progressively grant them new legal rights. They can often work before their majority (France: under certain conditions, 14 years old<sup>81</sup>). Additionally, the UN uses the term Youth or Young people to refer to people between 15 and 24 years-old<sup>82</sup>.

The WHO, however, distinguishes between children (under ten years old) and adolescents (from ten to nineteen years old) as two populations with different health-related needs (e.g., teenagers need to receive sexual health attention). It also uses the term young people in the same way as the UN<sup>83</sup>. But it also points out that these definitions fluctuate depending on the context, e.g. average age for having a first child etc.

In this dissertation, I use "children" as a generic term to refer to people under 18 years of age then receiving a higher education, or

<sup>75</sup> Borland, Hill, and J. Brown, *Middle Childhood: The Perspectives of Children and Parents*.

<sup>76</sup> S. H. Matthews, "A Window on the 'New' Sociology of Childhood".

<sup>77</sup> Jeffrey, "Geographies of Children and Youth I: Eroding Maps of Life".

<sup>78</sup> Samantha Punch, "Research with Children: The Same or Different from Research with Adults?", p. 322.

<sup>79</sup> Office of the United Nations High Commissioner for Human Rights, *Convention on the Rights of the Child*.

<sup>80</sup> *Loi n° 74-631 du 5 Juillet 1974 fixant à dix-huit ans l'âge de la majorité*.

<sup>81</sup> Service-Public.Fr, "À partir de quel âge peut-on travailler ?"

<sup>82</sup> United Nations Department of Economic and Social Affairs, "FAQ: Definition of Youth".

<sup>83</sup> Sawyer, "Optimising Learning: Implications of Learning Sciences Research"; World Health Organization, "Adolescence: A Period Needing Special Attention. Recognizing adolescence".

under 20 and still attending high school. I chose this criterion to fit the institutional practices observed. When reaching 20 years-old, children with disabilities are supposed to receive services from a different organization or branch. However, those attending a public university after high school receive services and support there. Furthermore, this distinction was very present in the children's discourse, distinguishing themselves from their same-age peers who get support and disability services from the adult-focused branch.

### 3.4.2 *The New Sociology of Childhood*

This section engages with the so-called New Sociology of Childhood, born in the 1980s<sup>84</sup>. It presents its foundational principle, then discusses three issues relevant to this dissertation: the tensions around agency, its moderate success in French Sociology, and the place of adolescence in this field.

#### **Positing children as competent agents**

The foundation of the so-called New Sociology of Childhood, is the observation that children are often ignored as social agents<sup>85</sup>, and thus rarely studied in social sciences<sup>86</sup>. The study of children, they argued, had been the realm of psychology for too long. By focusing on natural developmental landmarks that should be reached at specific ages, psychology obscured social factors shaping childhood, such as the family socioeconomic context<sup>87</sup>. Sociologists thus focused on demonstrating how these stages embed social norms that can be contested<sup>88</sup> and studying the agency of children<sup>89</sup>. Rather than describing them as "less than adults", scholars show the multiple communication strategies established by children from a very young age, and how they create specific peer cultures, shaping their everyday worlds<sup>90</sup>: children as beings, rather than becomings. This view of childhood has both shaped and been shaped by the policy work that led to the UN Declaration of the Rights of the Child<sup>91</sup>.

The implication for research is two-fold. First, it means that children's views should not be ignored when investigating a childhood-related subject. Not that all studies on childhood should solely research their opinions and experiences, but they should be a subject of interest and may help reframe findings made about their caregivers<sup>92</sup>. Second, if children as competent agents, who can express their preferences and make decisions, they may do so with different means of communication. The research should thus adapt the methods deployed, and make careful ethical decisions<sup>93 94</sup>.

<sup>84</sup> W. Corsaro, *Friendship and Peer Culture in the Early Years*.

<sup>85</sup> Stafford et al., "'Having a Say': Children and Young People Talk about Consultation".

<sup>86</sup> Holloway and Valentine, "Spatiality and the New Social Studies of Childhood".

<sup>87</sup> Malcolm Hill and K. Tisdall, *Children and Society*; J. Sanders, *Subject Child: The Everyday Experiences of a Group of Small Town Aotearoa/New Zealand Children*.

<sup>88</sup> Prout, "Taking a Step Away from Modernity: Reconsidering the New Sociology of Childhood"; Qvortrup, "Introduction"; James and Prout, *Constructing and Reconstructing Childhood: Contemporary Issues in the Sociological Study of Childhood*; Vandebroek and Bie, "Children's Agency and Educational Norms: A Tensed Negotiation".

<sup>89</sup> P. Christensen and Prout, "Working with Ethical Symmetry in Social Research with Children"; Vandebroek and Bie, "Children's Agency and Educational Norms: A Tensed Negotiation".

<sup>90</sup> W. Corsaro, *Friendship and Peer Culture in the Early Years*; Malcolm Hill and K. Tisdall, *Children and Society*.

<sup>91</sup> Moran-Ellis, "Reflections on the Sociology of Childhood in the UK".

<sup>92</sup> Qvortrup, "Introduction".

<sup>93</sup> P. Christensen and Prout, "Working with Ethical Symmetry in Social Research with Children".

<sup>94</sup> See also Chapter 2.

### Reconciling embodiment, social factors, and youth cultures

Indeed, considering children as agents is not to say that youth cultures are not influenced by the adults surrounding them. Many studies thus focus on children-adult interactions, and how children incorporate and negotiate discourse and norms from their family and community (i.e., social factors). According to Sanders<sup>95</sup>, key themes are the uses of power (generally to constrain children<sup>96</sup>, but also how children may resist it<sup>97</sup>); the generational order, or how children and adults perceive and identify to one group or the other; children and their parents (and carers or adults in general); children at school<sup>98</sup>; and patterns of activity, or uses of space and time. In addition to this topic, I would add youth cultures, broadly understood as how children appropriate media and representations to forge their interests, material that is usually made for them by adults.

Considering children as agents is not to say either that children can be fully autonomous or legally responsible for their actions, or that they are independent, nor that there is not a specific vulnerability in the period of childhood<sup>99</sup>. Children may not understand all the consequences of their actions. Lack of experience outside their family and community may lead them to consider some situations as acceptable, even though they are abusive. They have different boundaries and different concepts of privacy than adults. So, researching children does raise acute ethical, methodological and theoretical issues. But those are present with other groups as well—care ethics positing, for instance, that we are all dependent (and not only children), or more precisely, that we are all interdependent.

### Children in French sociology

Whereas the English-written Sociology of Childhood focused on children as competent agents and a specific culture from the 1980s on, a French sociologist stated in 2002 that "*for sociologists (in France particularly), the child in itself does not exist.*"<sup>100</sup> He further explains that children's voices are most often ignored in French sociology, in favor of the study of how different groups of young people are situated in different parts of society, and of the structures supporting it<sup>101</sup>. In this perspective, children's voices and views are the matter of psychology (or psychoanalysis), not of sociology. They may be present in education sciences, but a lot less in the sociology of education<sup>102</sup>. There are, of course, exceptions, such as the work of Dubet on teenagers' narratives about school<sup>103</sup>, or Delalande's anthropology of childhood<sup>104</sup>. But fifteen years later, it seems that few things have changed: the sociology of childhood was still considered a frag-

<sup>95</sup> J. Sanders, *Subject Child: The Everyday Experiences of a Group of Small Town Aotearoa/New Zealand Children*.

<sup>96</sup> Mayall, *Children's Childhoods: Observed and Experienced*.

<sup>97</sup> Beresford, "Working on Well-Being: Researchers' Experiences of a Participative Approach to Understanding the Subjective Well-Being of Disabled Young People."

<sup>98</sup> Which requires to overcome the dichotomy between being and becoming outlined above A. Quennerstedt and M. Quennerstedt, "Researching Children's Rights in Education: Sociology of Childhood Encountering Educational Theory".

<sup>99</sup> S. H. Matthews, "A Window on the 'New' Sociology of Childhood".

<sup>100</sup> Gausson, "Le jeu de l'enfant et la construction sociale de la réalité".

<sup>101</sup> Ebersold and Detraux, "Scolarisation Des Enfants Atteints d'une Déficience: Configurations Idéologiques et Enjeux".

<sup>102</sup> "Sociologie, Sociologie de l'éducation et Sciences de l'éducation".

<sup>103</sup> Dubet, *Faits d'école*.

<sup>104</sup> Delalande, "Comment le groupe s'impose aux enfants".

mented field of research in 2010<sup>105</sup>; the interest for the sociology of childhood has only increased since, but is far from having reached the breadth of English-written research. Furthermore, as outlined in the previous section, the same observation can be made for sociological research on disability. For more information on French sociological research on disabled children, the reader can consult Appendix A.2, which compiles the sources I reviewed.

### Distinguishing teenagers

I use the term "teenagers" to specifically designate children over 12 years old. This threshold is higher than the age proposed by the UN and the WHO<sup>106</sup>, as I do not aim at pointing specific health-related needs. This threshold corresponds, loosely, to their entrance in secondary education<sup>107</sup>. Teenagers report distinct patterns of technology use<sup>108</sup> and media consumption. For instance, teenagers report having greater and less supervised access to a computer or a smartphone, but also using technology for communicating with peers—whereas younger children mainly report using technologies for playing and media consumption mainly, or for communicating with adults of the family, and under adults's supervision.

The choice of definition is again informed by my research: Twelve is the age corresponding in participants' discourse to the passage to a different group of peers, to a different culture<sup>109</sup>. However, they still identify as belonging to the larger children group, as opposed to the other youths cared for by the organization<sup>110</sup>, but also as opposed to their same age sighted peers. Indeed, they pointed out they rarely had free time or freedom of movements, and being subjected to a higher level of surveillance—whereas adolescence is often associated with independent access to youth spaces<sup>111</sup>.

## 3.5 Defining Disabled Children with Visual Impairments

I summarize the above discussion on the different categories and analysis frameworks, primarily stemming from disability and childhood studies, that might be applied to children with visual impairments, as well as the reasons that led me to adopt a specific theoretical framework. I then outline the bodies of design research literature using similar frameworks.

### 3.5.1 In sociology

In a society that considers some tasks requiring vision, e.g. reading, as fundamental, visually impaired people are considered disabled. This leads to their marginalization. In a society in which children have limited rights, visually impaired children's views are further

<sup>105</sup> Sirota, "French Childhood Sociology: An Unusual, Minor Topic or Well-Defined Field?"

<sup>106</sup> For these organizations, teenagers are people between 10 and 19 years-old. [apps.who.int/adolescent/second-decade/section/section\\_2/level2\\_3.php](https://apps.who.int/adolescent/second-decade/section/section_2/level2_3.php)

<sup>107</sup> The usual age is 11 years-old. However, visually impaired children were more likely to repeat a grade. Furthermore, they were often described as in need for more childhood time, either to compensate for rehabilitation or to solidify "educational basics."

<sup>108</sup> Lenhart et al., *Teens and Mobile Phones over the Past Five Years: Pew Internet Looks Back. Pew Internet & American Life Project.*

<sup>109</sup> Berndt and Perry, "Distinctive Features and Effects of Early Adolescent Friendships."

<sup>110</sup> People who lose their sight after turning eighteen are taken care of in a different service, even though they might be the same age than teenagers from the children group.

<sup>111</sup> Gillies, "Young People and Family Life: Analysing and Comparing Disciplinary Discourses".

dismissed, and thus marginalized. Visually impaired children are defined in relation to the norms they differ from (sighted, adults), which establishes specific power dynamics.

These dynamics can be studied in various ways. The social model (or minority model, or oppression model) suggests that the people who constitute the norm, i.e. non-disabled, or more generally those who do not present risk factors that in a given society affect life outcomes generally considered as desirable, have an interest in discrediting those who are not, e.g. conserving and expanding power. Hence the social model calls for research that supports those who are not in a position of power, to reverse that process. If unveiling cultural norms can be a purely intellectual pursuit, it also enables us to contest them. In fact, all of the theoretical frameworks described in this chapter have been weighed for their usefulness, most often outside of the field of social sciences—usefulness to policy, to the rearing of children, to rehabilitation, to contest the naturalness of norms used to justify inequalities, etc. By focusing on visually impaired children's experiences of school in a French context, I aim to understand how these norms are produced and sustained in everyday interactions and practices.

Although I chose to focus on children's experiences, I do not limit my inquiry to their views, in order to propose a more trustworthy account. This contrasts with the method advocated, for instance, by Connors and Stalker<sup>112</sup>. As in Chapter 2, I prefer to focus on negotiations and oppositions, a pragmatist approach, in the sense that it focuses on human interactions to understand a problem—adversarial experiences at school—and that I use research to propose and go towards a more desirable state<sup>113</sup>. Design is here a way of seeing<sup>114</sup> and a tool to investigate how research participants may reconfigure their material environment and develop new practices.

### 3.5.2 *In Human-Computer Interaction research?*

Accessibility has long been a topic in Human-Computer Interaction (HCI), design research and design. They are hereby understood as:

- HCI: the overarching field in which interactions with technologies are proposed and studied;
- Design research: the study of design processes and artifacts, some of these artifacts falling under the umbrella of HCI, e.g., interactive devices—the difference being that design research in HCI tends to focus on experience rather than usability;

<sup>112</sup> Connors and Stalker, "Children's Experiences of Disability – Pointers to a Social Model of Childhood Disability".

<sup>113</sup> Here I should note that this may refer to different research traditions. Interactionism and the school of Chicago, public sociology, and French pragmatic sociology, which, among others, build upon pragmatism philosophy. They do not inherently contradict each other. I use "pragmatism" to describe the research worldview in which researchers have to engage with audiences beyond academia, i.e. public sociology, as well as to describe the scale of inquiry, interactions as they unfold. Yet, and my concern with design and material environment could be associated with French pragmatic sociology which primarily focus on how people engage with their material environment, borrowing greatly from Actor-Network Theory. Finally, I do not adopt a pragmatic perspectives focused on how actors construct meanings, which I would rather described as constructivist: I operate many value choices, including in the vocabulary I use, which is not the one used by the participating children. See also: Thévenot, "Pragmatic Regimes Governing the Engagement with the World".

<sup>114</sup> This was previously discussed in Chapter 2

- Design: the practice of design, e.g. graphic design, industrial design.

For instance, designers concerned with ergonomics published guidelines to design for wheelchair users in the 50s<sup>115</sup>, Mace published Universal Design principles in 1985<sup>116</sup>, and there is a long history of research on assistive technologies<sup>117</sup>. Yet, most research specifically on technologies for disabled children, rather than the eventual adaptation to an educational settings of generic assistive technologies, is recent (most date from the last ten years<sup>118</sup>).

In these HCI projects, the same tensions as in social research about disabled children emerge. Children may be granted more or less agency and may be considered as users, testers, informants or design partners<sup>119</sup>. Disability may be framed as an individual problem to be corrected through technologies, or as a social-relational issue, addressed preferably through novel interaction techniques and devices, or community building projects. This latter body of research is most often conducted in a participatory fashion with transformative aims<sup>120</sup>. This is a community that has repeatedly emphasized the need for the designer/researcher's empathy, for taking into account the many and conflicting values at play<sup>121</sup> and often builds on a pragmatist understanding of experience<sup>122</sup>.

### 3.6 Summary

In this chapter, I outlined the construction of disabled childhoods as a research subject, before diving into the theoretical issues at stake when defining disability, children and visual impairments. I summarized current debates surrounding each of these definitions—as well as the different perspectives developed to study them, in international and French sociology. It describes the theoretical background of my dissertation.

Regarding the definition and study of disability, the main tension surrounds the influence attributed to the environment. Regarding childhood, this translates into debates on children's agency. For some the environment plays a central role in defining visual impairments: should we prefer make diagnosis in controlled or naturalistic settings? In any case, different perspectives suggest different research topics. Structural perspectives argue for the social model of disability or the study of the norms of childhood. Individualistic perspectives rarely contextualize disability, or propose accounts of childhood isolating children from the adult world. This is not a black-and-white matter, as there are initiatives to develop more dynamics accounts

<sup>115</sup> Dreyfuss, *Designing for People*.

<sup>116</sup> Mace, *Universal Design, Barrier Free Environments for Everyone*.

<sup>117</sup> Depending on the definition of technologies, we might as well date the beginning of this history to the first braille writing machines, or to Apple Adaptive systems in 1977 as the IEEE does: <http://theinstitute.ieee.org/tech-history/technology-history/timeline-the-evolution-of-assistive-technologies>

<sup>118</sup> E.g., McElligot and van Leeuwen, "Designing Sound Tools and Toys For Blind and Visually Impaired Children"; Guha, Druin, and Fails, "Designing with and for Children with Special Needs: An Inclusionary Model"; Frauenberger, Good, and Keay-Bright, "Designing Technology for Children with Special Needs: Bridging Perspectives through Participatory Design"; R. Holt, Moore, and Beckett, "Together Through Play"; Carrington, Hurst, and Shaun K. Kane, "Wearables and Chairables: Inclusive Design of Mobile Input and Output Techniques for Power Wheelchair Users".

<sup>119</sup> Druin, "The Role of Children in the Design of New Technology".

<sup>120</sup> Frauenberger, Good, and Keay-Bright, "Designing Technology for Children with Special Needs: Bridging Perspectives through Participatory Design".

<sup>121</sup> Van Mechelen et al., "The GLID Method: Moving from Design Features to Underlying Values in Co-Design"; Steen, "Upon Opening the Black Box of Participatory Design and Finding It Filled with Ethics".

<sup>122</sup> P. Wright and McCarthy, "Empathy and Experience in HCI".



(e.g. the social relational model of disability), trying to articulate a comprehensive understanding of how norms are negotiated and reinvented in action.

I primarily define my research topic through the valuations I made with the different research stakeholders. But I could as well have defined it from a review of the current bodies of research literature interested in the study of disabled children's experiences, in social sciences and in HCI/design. Indeed, this suggests that (disabled) children's views are understudied in France, highlights the importance of studying experiences of school, and shows the thriving research around the involvement of disabled people in HCI research

In summary, this chapter challenges naive definitions of children with visual impairments, and contextualizes my research topic (and attached theoretical framework) among the many different research traditions used to study disabled children in sociology and HCI. In-scribing this dissertation in the pragmatist and interactionist research tradition, enables me to take into account the marginalization of disabled children, and children's narratives.

# 4

## *The Research Approach*

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The first two chapters of Part 1 outline the construction this dissertation's topic, first through an empirical study of the research project I was involved in, second through a review of the research literature on disabled children, in social sciences and design research in HCI. I outlined the pragmatist and interactionist roots of my topic. This chapter describes the research approach I thus developed.

I follow Creswell<sup>1</sup>'s three-fold structure to describe a research project: worldview, design and methods. I work within a pragmatist worldview, an embedded mixed-methods design, using a mosaic of methods (e.g., ethnographic observations, interviews, design probes, exploitation of existing quantitative data). In addition, I detail the ethical frameworks that guided the fieldwork: the UNICEF's guidelines on ethics in research with children<sup>2</sup>, and the European Responsible Research and Innovation framework<sup>3</sup>. I highlight the importance given to the researcher in these frameworks, especially the

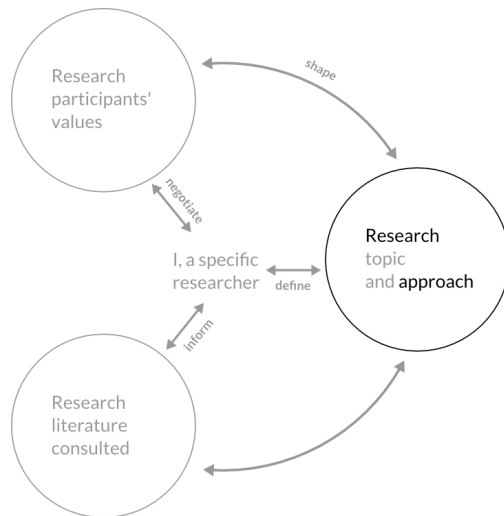
<sup>1</sup> Creswell, *Research Design: Qualitative, Quantitative, and Mixed Methods Approaches*.

<sup>2</sup> Graham, M. Powell, et al., "Ethical Research Involving Children".

<sup>3</sup> Owen, "Responsible Research and Innovation: Options for Research and Innovation Policy in the EU".

importance given to their caring skills—which leads me to articulate them through the ethics of care<sup>4</sup>.

### Visual Overview



<sup>4</sup> J. Morris, "Impairment and Disability: Constructing an Ethics of Care That Promotes Human Rights".

Figure 4.1: This figure illustrates the focus of Chapter 4: the definition of a suitable research approach.

## 4.1 Research Approach

This research approach aimed at answering the research questions formulated by the end of chapter 2: How do French visually impaired children experience school? Could we develop assistive learning technologies explicitly trying to support well-being at school, and if so, how? To achieve this, I adopted a research approach focused on developing empirical insights and concrete opportunities for action.

### 4.1.1 Worldview

*"Social constructivists believe that individuals seek understanding of the world in which they live and work. Individuals develop subjective meanings of their experiences—meanings directed toward certain objects or things. These meanings are varied and multiple, leading the researcher to look for the complexity of views rather than narrowing meanings into a few categories or ideas."*<sup>5</sup>

Social constructivism is arguably the most influential worldview in the new Sociology of Childhood<sup>6</sup>. Researchers adopting this perspec-

<sup>5</sup> Creswell, *Research Design: Qualitative, Quantitative, and Mixed Methods Approaches*, p. 37.

<sup>6</sup> James and Prout, *Constructing and Reconstructing Childhood: Contemporary Issues in the Sociological Study of Childhood*.

tive focus and represent children's voices<sup>7</sup> to investigate the meanings children give to their environment. Although children's views and experiences are both the starting point and an important part of the research presented here, the overall project is closer to pragmatism<sup>8</sup>, and in particular in Dewey's view of pragmatism<sup>9</sup>.

*"There are many forms of this philosophy, but for many, pragmatism as a worldview arises out of actions, situations, and consequences rather than antecedent conditions (as in positivism). There is a concern with applications—what works—and solutions to problems. Instead of focusing on methods, researchers emphasize the research problem and use all approaches available to understand the problem."*<sup>10</sup>

In contrast to social constructivism, pragmatism is interested in problems, and the inquiry as a "productive"<sup>11</sup> intervention, aiming to enhance life quality by different means. Pragmatism may be led by the wish for a better future (utopian), but can also be put to use for critical purposes<sup>12</sup> or for solving a very restrained problem—thus reconciling the three *points-of-view* of research through design<sup>13</sup>. I address the challenges raised by a pragmatism worldview regarding validity below. But I first expose key aspects of Deweyan pragmatism for my research topic and approach:

1. **PARTICIPATION AND DEMOCRACY:** Central to Dewey's conceptualization of inquiry<sup>14</sup> is the active engagement of research participants. As phrased by Bohman: "*Not only must science be democratically organized, Dewey argues, but democracy must also be a form of social inquiry.*"<sup>15</sup> Although Dewey supported the separation of cognitive labor (i.e., that some expert knowledge are not accessible by citizens), pragmatism can be the support of a more participatory research.
2. **DEFINITION OF EXPERIENCE.** This ensues from his concept of experience as an always active process, an interaction, between habits and a situation<sup>16</sup>. Habits have themselves been determined by previous situations, and can both change a new situation and being changed by it. It follows, Dewey argues, that worthy educative experiences are those who build upon past experiences, can be transformed to have a positive influence on future experiences (e.g., he gives the example of reading, which opens new possibilities to acquire knowledge). He also highlights the importance of processes that enable children's engagement<sup>17</sup>, e.g., activity planning. This concept of experience spans multiple bodies of literature I draw on, e.g. HCI<sup>18</sup>, education sciences or sociology of

<sup>7</sup> Eldén, "Inviting the Messy: Drawing Methods and 'Children's Voices'".

<sup>8</sup> Which also legitimizes the study of everyday experiences and biographical trajectories to understand the interaction between individuals and their milieu. C. W. Mills, *The Sociological Imagination*.

<sup>9</sup> L. Hickman, Neubert, and Reich, *John Dewey between Pragmatism and Constructivism*.

<sup>10</sup> 39 Creswell, *Research Design: Qualitative, Quantitative, and Mixed Methods Approaches*.

<sup>11</sup> L. A. Hickman, *Philosophical Tools for Technological Culture: Putting Pragmatism to Work*.

<sup>12</sup> Forester, "On the Theory and Practice of Critical Pragmatism: Deliberative Practice and Creative Negotiations".

<sup>13</sup> I.e., pragmatic and centered on everyday problems, utopian or critical Dow, Ju, and W. Mackay, "Projection, Place and Point-of-View in Research through Design".

<sup>14</sup> D. L. Morgan, "Pragmatism as a Paradigm for Social Research".

<sup>15</sup> Bohman, "Democracy as Inquiry, Inquiry as Democratic: Pragmatism, Social Science, and the Cognitive Division of Labor", p. 590.

<sup>16</sup> Dewey, *Experience and Education*, pp. 35 & 42.

<sup>17</sup> Dewey, *Experience and Education*, p. 58.

<sup>18</sup> P. Wright and McCarthy, "Empathy and Experience in HCI".

education<sup>19</sup>, and disability studies<sup>20</sup>—and is consistent with how carers envision education (see Chapter 14).

3. **SITUATEDNESS.** Dewey proposes that truth is always contingent to a historical and geographical context. More specifically, truth is what works in a given context and given conditions<sup>21</sup>. It is a temporary construction and one should always strive towards improving this truth (with the purpose to improve human experience).
4. **PLURAL AND RELATIVISTIC ETHICS.** Similarly, ethical matters can only be solved locally and dynamically<sup>22</sup>. Although in this view, philosophy should aim at attaining democratic consensus, it acknowledges that frictions are inevitable and that ethics should be actively discussed and negotiated. This is in line with the ethical frameworks I build upon, as well as with the operations of valuation presented in the first part of this chapter.
5. **AGNOSTICISM REGARDING THE NATURE OF REALITY.** Pragmatism does not presuppose the nature of reality. As such it enables to work with bodies of literature built on differing assumptions, e.g. critical realism and radical constructivism.
6. **DISCIPLINARITY.** Because of pragmatism' focus on problems and the effects of ideas, it is particularly suitable for interdisciplinary research (see also Chapter 3) and mixed-methods research<sup>23</sup>.

The worldview influences the type of inquiry strategy. Although it is rather the constraints and potentialities of the object of study that determined the strategies I initially deployed, determining a final research design led me to incorporate new sources of data.

#### 4.1.2 Design

The second aspect of Creswell' description of the research approach is the design or the type of inquiry led. He argues that there are three main designs: qualitative, quantitative and mixed-methods (qualitative and quantitative). In mixed-methods, there are different ways to articulate quantitative and qualitative data. For instance, they may be sequential, with survey results explained by qualitative inquiries, or qualitative inquiries used to design surveys. The design is defined by the topic.

<sup>19</sup> Dubet and Martuccelli, *À l'école ; Sociologie de l'expérience Scolaire*; Lake, "Dewey, Addams, and Beyond"; Kolb, *Experiential Learning: Experience as the Source of Learning and Development*; Daniels, M. Cole, and Wertsch, *The Cambridge Companion to Vygotsky*.

<sup>20</sup> Reindal, "A Social Relational Model of Disability: A Theoretical Framework for Special Needs Education?"

<sup>21</sup> Seigfried, *Feminist Interpretations of John Dewey*.

<sup>22</sup> Pappas, *John Dewey's Ethics: Democracy as Experience*.

<sup>23</sup> R. B. Johnson and Onwuegbuzie, "Mixed Methods Research: A Research Paradigm Whose Time Has Come".

For this dissertation, I knew I wanted to understand French children with visual impairments' views on schools, and their experiences at schools. This type of inquiry into meaning-making processes and experiences generally uses a qualitative design. This is especially necessary in this case, as only limited literature was available<sup>24</sup>. Thus, most of my research could be described as a qualitative ethnography design. However, I also exploited quantitative data and their reports on children with disabilities, produced by the Ministry of Education. This data is useful in two ways. First, in the definition of the research subject, as it provides a structural perspective on the inequalities children with disabilities face in France and insights on how institutions defined "disabled children." I also use it to test qualitative insights from the field. As such, I embedded quantitative data within a larger qualitative inquiry.

#### 4.1.3 Methods

Within this design, I used a variety of methods. They had to be adapted to children and to be adequate to understand longitudinal effects of design interventions. These methods can be separated into two categories:

1. Data generation<sup>25</sup> methods, which refers to the methods used in the field, such as interviews and observations of various kinds, the gathering of documents and artifacts made by participants and used by participants, and probes and prototypes;
2. Different analysis methods, of qualitative inspiration. As a reminder of chapter 2, I had initially planned to use Grounded Theory. However, I found it incompatible. I thus decided to use thematic and multimodal analysis at the end of the field-work period, for reasons discussed below.

This **mosaic of methods** is well in line with the literature in Disabled Childhood Studies<sup>26</sup>—as well as the triangulation advocated by Mackay for HCI researchers<sup>27</sup>. For each method, I first explain their aims and why I chose it. I then describe their deployment in the relevant chapters. But first, an overview of the research timeline.

<sup>24</sup> Revillard, "La Réception Des Politiques Du Handicap: Une Approche Par Entretiens Biographiques".

<sup>25</sup> Following Graue and Walsh, I use the term data generation rather than data collection: indeed, I played an active role in making phenomena emerge, by introducing new artifacts for instance. Generation better depicts this process than collection. Graue and Walsh, *Studying Children in Context: Theories, Methods, and Ethics*.

<sup>26</sup> Underwood et al., "Understanding young children's capabilities: Approaches to interviews with young children experiencing disability".

<sup>27</sup> W. E. Mackay and Fayard, "HCI, Natural Science and Design: A Framework for Triangulation Across Disciplines".

## Overview

The field work presented in this dissertation spanned over a year and a half. It began in November 2014 and ended in June 2016 (with intermittent contact and collaboration since, and a posteriori interviews with two carers in 2017). I isolate specific sub-studies or themes that I conducted during it in the following chapters, but I first outline their overarching, common aspects. It was organized as follows: I was present every month except during holidays, for at least a few days, but generally for a school week (Monday to Friday). I would sometimes coordinate with the carers and children to assist with specific events, but mostly the dates chosen reflected a will to be there regularly without my presence becoming a burden.

Most of the time, other researchers were working with the same organization: graduate students in ergonomics, making and studying interactive maps and their impact on cognitive performance; and a post-doc researcher using electronic boards to build low-cost interactive devices at the demand of carers<sup>28</sup>.

I kept two digital diaries during the time of my PhD. One lists all actions related to the study (including a list of emails and meetings with the research team for instance) as well as my observations and the content of the interviews, the other thoughts and reflexions related to the field study and the research work in general. I used the second to reflect on ethical dilemmas, retrace the context that influenced my choice of themes for analysis; to identify how the field-work shaped me and how I shaped the field-work. Excerpts of this second journal are used in Chapter 2 for my auto-ethnographic perspective.

<sup>28</sup> Giraud and Christophe Jouffrais, "Empowering Low-Vision Rehabilitation Professionals with "Do-It-Yourself" Methods".

## Data generation methods

**OBSERVATIONS (FROM PARTICIPANT TO PASSIVE).** Conducting observations is the main method in ethnography. Observations can be made with different degrees of participation<sup>29</sup>, from being part of the community studied to having no direct contact. My observations were of three types: participant (the observer share the observed' practices), semi-participant (the observer may propose activities to make observations) or passive (the observer shares the space but does not get directly involved). Observations are useful for understanding practices in context. Furthermore, they are often framed as particularly useful in research with children, and as Cocks<sup>30</sup> points out, with children with disabilities:

<sup>29</sup> K. M. DeWalt, B. R. DeWalt, and Wayland, "Participant Observation".

<sup>30</sup> A. J. Cocks, "The Ethical Maze: Finding an Inclusive Path towards Gaining Children's Agreement to Research Participation."

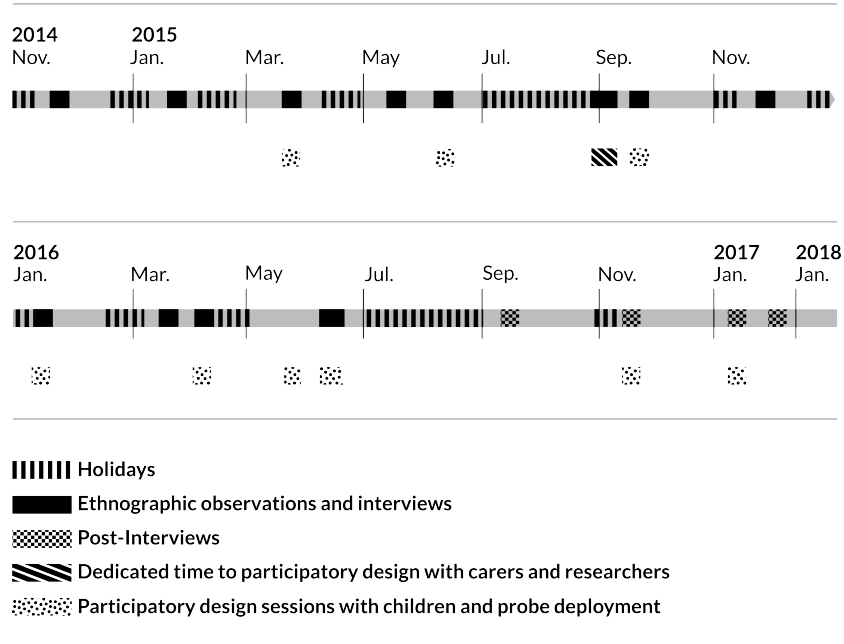


Figure 4.2: This figure illustrates the fieldwork timeline.

"First, it is viewed as being empowering for both those observed and for the researcher. Second, it is a 'study of behaviour in its natural settings'<sup>31</sup>, therefore contextualizing culture<sup>32</sup>. It also responds to a *variety of abilities*<sup>33</sup>." (Emphasis is mine.)

I conducted observations throughout the field study. My approach evolved. Overall, observations were increasingly participatory (either as a carer, a designer to collaborate with, or an "other kind of adult"—see Chapter 9 for a discussion on roles). However, I often would not participate in rehabilitation sessions (e.g. psycho-motricity, low vision rehabilitation, occupational therapy etc.), as these were one-on-one sessions and my participation would have been disruptive.

I kept detailed written records of my observations. I took notes during the day, regularly, and completed them in the evening. I made intensive use of photography for documenting places, prototypes, artifacts and pedagogical supports. In a few occasions, I used video recordings as well, with the consent of participants (see also multi-modal analysis below). This was also useful for class activities the teacher wanted to be able to reflect on, but to which I could not assist physically. However, I avoid using it as much as possible: although children seemed to mostly enjoy recording video and audio themselves, being videotaped by someone else most often made them

<sup>31</sup> Grieg, J. Taylor, and Vanobbergen, "Doing Research with Children".

<sup>32</sup> Graue and Walsh, *Studying Children in Context: Theories, Methods, and Ethics*.

<sup>33</sup> Ward, *Seen and Heard: Involving Disabled Children and Young People in Research and Development Projects*.



uncomfortable, even if by another child. Finally, I used drawings, particularly to examine participants' body attitudes I had noticed and that I wanted to convey alongside my textual notes.

Finally, I was particularly inspired by sensory ethnography scholars, and Morris's<sup>34</sup> work on sensory ethnography with young adults with visual impairments. I attempted to be particularly attuned to children's, and to my own, sensory experiences. My notes thus include observations on the level of noise, the weather, the textures and material, the constraints created by the built environment etc.

#### INTERVIEWS.

Interviews can be structured (using a strictly pre-defined set of questions), semi-structured (the interviewer has a general outline, but may ask different questions) or unstructured (the interviewer only has a generic theme, this type of interviews being common in ethnographic research)<sup>35</sup>. Interviews are useful complements to observations: they increase understanding the actors' views and opinions, to explain past events and situations, as oral accounts are: *"a linguistic device employed whenever an action is subjected to evaluative inquiry. Such devices are a crucial element in the social order since they prevent conflicts from arising by verbally bridging the gap between action and expectation"*<sup>36</sup>.

Interviews are often used in research with children<sup>37</sup>. They help elicit children' perspectives and opinions on a variety of subjects, but also to identify themes that are important to them<sup>38</sup>. They are also suitable for understanding identity construction<sup>39</sup>. Recommendations include trust-building activities, conducting group interviews with older children, conducting interviews as discussions, and more generally to be careful to adapt to children' styles and competencies in communication<sup>40</sup>. Some advocate complementing interviews with visual prompts and methods, such as photography or drawings<sup>41</sup>, to provide children with alternative means of expressing themselves. The visual modality was not adapted to my research field, but I did investigate alternative means of inquiry—such as probes, discussed below. Finally, interviews are always an interaction: as such, the way researchers present themselves, react verbally and non-verbally etc., play a role in how interviews unfold and the knowledge they generate<sup>42</sup>. Hence, interpretation of interviews should be carefully considered (see also Chapter 9 & 10), and when possible crosschecked with interviewees. Crosschecking was easier with adults than with children.

Interviews, depending on the preferences of the interviewee, were

<sup>34</sup> C. Morris, "Making Sense of Education: Sensory Ethnography and Visual Impairment".

<sup>35</sup> Fontana and Frey, "The Art of Science".

<sup>36</sup> Scott and S. M. Lyman, "Accounts", p. 46.

<sup>37</sup> Einarsdóttir, "Research with Children: Methodological and Ethical Challenges".

<sup>38</sup> O'Reilly and Dogra, *Interviewing Children and Young People for Research*, p. 170.

<sup>39</sup> Bamberg, De Fina, and Schiffrin, "Discourse and Identity Construction".

<sup>40</sup> Gibson, "Interviews and Focus Groups with Children: Methods That Match Children's Developing Competencies"; Einarsdóttir, "Research with Children: Methodological and Ethical Challenges".

<sup>41</sup> Zartler, "Photo Interviews with Children: Relating the Visual and the Verbal from a Participation Perspective".

<sup>42</sup> Fontana and Frey, "The Art of Science".

either audio-recorded or transcribed through notes. In the latter case, the notes were then reviewed with the interviewees. For more details about the interviewees, see Appendix A.3.

*Interviews with children.* I did not pre-select interviewees participants further than restricting them to the children receiving services in this particular organization. Indeed, I chose to let child-initiated discussions (first half of 2015) and only then proposed interviews to explore specific themes with more details. Details about adapting to children's communication needs can be found in section ethic.

I interviewed 20 boys and 12 girls, aged between 7 and 18 (see Appendix A.3). Eight belong to ethnic-minority families. All live with visual impairments, and sixteen of them have additional diagnoses: two were also Deaf (communicating orally), twelve were identified as having learning disabilities, two were speech impaired, one had physical impairments, and one was autistic. The medical diagnosis was not often mentioned by children, nor by their carers, who instead gave indications on "functional" abilities, and sometimes of the time of onset (prenatal, during birth, during infancy). These youngsters came from southern France, rural, suburban or urban areas, and attended either special, inclusive (general education classrooms) or integrated classrooms (special education classroom localized within general education schools). They participated in the study because they receive care at the service provider involved in the Accessimap research project.

Some interviews were biographical, focusing on children daily experiences (38 interviews in total, including six repeated interviews). When children expressed the will to talk to me for the first time, they often started by talking about school. I would quickly re-introduce myself and the purpose of my research (*"I want to help adults to understand you, and other children"*). I would ask about a typical day, their family situation (e.g. *"Do you have siblings? Where do you live?"*), on their trajectory within or between service providers and modalities of schooling (e.g. *"Since when do you come here?"*; *"Where do you go to school?"*), on "significant events" (*"What did you do for your birthday?"*) and on everyday activities (e.g. *"What do you like doing on weekends?"*). I also included a so-called magic wand question, inspired by the work of Connors and Stalker<sup>43</sup> (*"If you were a powerful magician, and had a magic wand: what would you change in your life?"*) This question most often prompted detailed answers on subjects regarding school, which contributed to my focus on their experiences in this context in particular. These interviews lasted between 20 minutes and an hour (the longest interviews were with teenagers). The repeated interviews were used to understand the changes in children's lives after the

<sup>43</sup> Connors and Stalker, "Children's Experiences of Disability – Pointers to a Social Model of Childhood Disability".

type of schooling they receive had changed or was changing (from part-time to full-time inclusion in an inclusive school for instance).

I also conducted thematic interviews on the use of technologies (26 interviews, most of them between November 2014 and March 2015, as well as additional interviews between January and June 2016). These were often conducted to complement observations I had just made of children using various devices: video-games, MP3 players, braille notepads, computers, smartwatches, smartphones or tablets. Similarly, I would remind them of my research and the possibility of not answering. We would then discuss their technology use mostly at school and at home. Finally, I conducted interviews as part of design activities (21 interviews in total, for different design inquiries, see the section about probes below).

*Interviews with carers.* To get context and understand the multiple perspectives on, and in, my observations, I also conducted: 9 repeated interviews with staff members from the care center (teachers, therapists, document maker specialist); 11 interviews with other staff members (educators, psychiatrist, therapists); 3 informal interviews with parents, on their perceptions of their child's educational project and the services they receive. Finally, I interviewed a special education teacher in geography from the national school for the blind. This is an addition to informal discussions.

Additionally, I collected public testimonies during events presenting the services and/or the research project to the public, most of them in June 2016. One was a parent's, on the life trajectory of the family, three from teachers from general education schools attended by children receiving services in the same center, four from various local state officials in charge of the education policy.

#### COLLECTION OF DOCUMENTS AND ARTIFACTS.

inspiration<sup>44</sup>. I gathered documents and artifacts produced or referred to by the participants<sup>45</sup> which became a basis for some later interviews, when I asked to elicit intentions behind their use for instance. They were also a way to convey tacit knowledge, e.g. during an interview, a teacher: "*wait, I don't know how I can explain that, but I can show it to you! [...] you should photograph it, you'll remember better*". Documents such as professional literature can complement observations and interviews by revealing how carers form or formalize their knowledge<sup>46</sup>.

I collected four main categories of artifacts: written professional documents, objects used in rehabilitation and pedagogical supports in general, objects and representations used to teach Geography, and

<sup>44</sup> Zimmerman and Forlizzi, "The Role of Design Artifacts in Design Theory Construction".

<sup>45</sup> Sensitization or presentation leaflets and websites, a documentary they found interesting and pointed out, museum adaptations I should see, the professional literature they use, artifacts they make for the children etc.

<sup>46</sup> See the chapter on artifacts in: Given, *The Sage Encyclopedia of Qualitative Research Methods*.

artifacts produced by carers using digital fabrication technologies and related documentation. The collection of professional documents was opportunistic (they were given or mentioned by carers), because that was not my primary concern. I collected photographs and references to rehabilitation props and pedagogical supports mainly for design inspiration—although I also use them as part of my analysis of carers' design practices<sup>47</sup>. I was much more systematic regarding objects and representations used in Geography, as I wanted to make a typology of this material, both for design inspiration and to complement my observations of learning activities. Finally, because I was interested in understanding carers' uses of digital fabrication tools, as they appeared during my field-study, and I tried to support them. They were also useful to understand carers' design rationale, or to fuel later interviews (e.g., "so, *why did you this that way?*").

Although the collection of artifacts was most often prompted by another inquiry (e.g. observing a new type of classroom), there were a few times where following artifacts prompted new inquiries. Artifacts can be followed, from where/when they are discussed, designed, produced, moved around, etc. They can also provide a new perspective, or enable meeting new actors<sup>48</sup>. For instance, photographs of artifacts do not seem to be enough for document makers: they sent each other, from one organization to the other, the things they built.

#### DESIGN AND TECHNOLOGY PROBES.

This method is unconventional in ethnographic research. Probes is an umbrella term in Human-Computer Interaction and design research, referring to artifacts or tools designed to generate data to inspire future designs. The original cultural probes, proposed by Gaver<sup>49</sup> are "*designed objects [...] containing open-ended, provocative and oblique tasks to support early participant engagement with the design process.*"<sup>50</sup> In some ways, they are similar to the props that may be used in interviews. For instance, at the beginning of my field research, I gave my audio recorder to a child who then played a reporter interviewing himself. It became a useful prop for the interview, but also revealed the potential of self-generated audio cues in learning, which inspired design propositions later in the research. As such, it could also be described as a cultural probe.

Technology probes, as proposed by Hutchinson *et al.*,<sup>51</sup> "*are simple, flexible, adaptable technologies with three interdisciplinary goals: the social science goal of understanding the needs and desires of users in a real-world setting, the engineering goal of field-testing the technology, and the design*

<sup>47</sup> Discussed in Part 4 and in: Brulé and Bailly, "Designing for inclusion: Examining Do-It-Yourself design activities".

<sup>48</sup> Mol and Mesman, "Neonatal Food and the Politics of Theory: Some Questions of Method".

<sup>49</sup> Gaver, Dunne, and Pacenti, "Design".

<sup>50</sup> Boehner *et al.*, "How HCI Interprets the Probes", p. 1.

<sup>51</sup> Hutchinson *et al.*, "Technology Probes".

*goal of inspiring users and researchers to think about technologies.*" Technology probes retain the inspirational goal of cultural probes, but are also envisioned as a tool for social inquiry. They give shape to different design rationales, enabling to observe how they are received, and the kind of reactions they elicit. Compared to commercialized devices, they do not have to be as robust: although being robust enough is often a key to obtaining interesting results<sup>52</sup> (except if one wants to understand the reaction to failure). In other words, cultural probes are a way to get an understanding of a phenomenon, or of someone's experiences to generate design inspiration, in an inductive fashion, whereas technology probes are both abductive: they generate phenomena to study; and deductive: they embed hypotheses to be tested. Throughout the research, I deployed a number of probes of both types, both to elicit requirements for classroom technologies, and as a way to understand how classroom dynamics may evolve when taking my defined approach to technologies in this context.

As indicated in the overview at the beginning of this section, I deployed probes at the end of February, May, and September 2015, as well as in February and June 2017. I made a few other artifacts, more to help out rather than for research. The list and description of probes is in Appendix A.4—and those directly relevant to the argument developed in the dissertation are more precisely described in the fourth part of the dissertation. This annex also proposes more details about the implementation of methods.

### Other data used

In complement to my qualitative field-work undertaken, I researched available quantitative data about visually impaired schooling in France. They are few<sup>53</sup>. The findings from the most comprehensive and first cohort study was published in 2016 and is conducted by the Ministry of Education<sup>54</sup>. Additionally, an epidemiological study published in 1998<sup>55</sup> includes information about the schooling of the group studied at 11 years old. I review and discuss in Chapter 6 these quantitative insights to help confirming the validity of insights from the field-study, especially the importance of studying how social class affects the experience of visual impairments.

<sup>52</sup> Hutchinson et al., "Technology Probes", p. 5.

<sup>53</sup> Revillard, "La Réception Des Politiques Du Handicap: Une Approche Par Entretiens Biographiques".

<sup>54</sup> Le Laidier and Prouchandy, "Pour la première fois, un regard sur les parcours à l'école primaire des élèves en situation de handicap".

<sup>55</sup> C. Arnaud et al., "Visual Impairment in Children: Prevalence, Aetiology and Care, 1976-85."

## Analysis

The "raw" data generated by all the inquiry methods presented above presents several challenges when it comes to analysis. (1) The data has different forms: text, drawings, photographs, artifacts etc. Moreover, the same item can be present in various forms. For instance, an artifact can be represented by different photographs or a video, by a textual description of its physical properties and functions, by the notes pertaining to its uses in context by different document related to its design, which are all artifacts in themselves. (2) The material is very dense<sup>56</sup>, and I needed to be able to analyze each corpus separately and to draw links between them. Finally, (3) the material is used for very different purposes: understanding children's experiences versus producing relevant designs. To address these challenges, I chose to rely primarily on inductive thematic analysis, as it can be conducted on (1) a variety of material<sup>57</sup>, thus (2) giving a coherence between each of my corpus, while (3) enabling to conduct separated analysis as this method is accepted in both HCI research<sup>58</sup>, and research with children<sup>59</sup>.

### INDUCTIVE THEMATIC ANALYSIS.

Thematic analysis consists of describing the research material, by associating codes with chunks of data<sup>60</sup>. It is inductive when significant themes are derived from these codes, rather than by predefined research questions. It unfolds as follows: (1) The researcher familiarizes herself with the data. (2) The researcher precisely labels the data using codes. The same content may have several labels, to identify who, and what, is involved in a given scene for instance, as well as what is communicated (e.g., to describe a specific interaction in the classroom "*raised-line map*," "*one-on-one-teaching*," "*4th grade*," "*encouragement*," "*hug*"). Once these elements are identified across a corpus of observation notes and interviews, a second reading enable to identify analytical codes, e.g. "*children's self-esteem*," "*concern for students*"<sup>61</sup>. This coding is done iteratively, as more data from the field-work is generated.

Using the codes thus generated, the researcher begins to research categories and patterns. To do so, I probed the data with different questions: Are children' accounts similar or dissimilar in structure and themes? What are the most recurrent theme in children/carers' accounts? New patterns and categories emerge with new generated data, new engagements with the data<sup>62</sup>, and the iterative integration of the research literature. A key to my process is to be attuned to inconsistent events, which may offer new insights. Once the codes

<sup>56</sup> Which is often considered as positive: it provides a thick description, as advocated by Geertz: Geertz et al., "Thick Description: Toward an Interpretive Theory of Culture".

<sup>57</sup> Byrne, "Visual Data in Qualitative Research: The Contribution of Photography to Understanding the Mental Health Hospital Environment".

<sup>58</sup> A. Adams, Lunt, and Cairns, "A Qualitative Approach to HCI Research".

<sup>59</sup> Joffe and Yardley, "Content and Thematic Analysis".

<sup>60</sup> Braun and Clarke, "Using Thematic Analysis in Psychology".

<sup>61</sup> Gibbs, *Analysing Qualitative Data*.

<sup>62</sup> Coffey and Atkinson, *Making Sense of Qualitative Data: Complementary Research Strategies*.

and categories used are stabilized, they form a coding scheme that enable to re-examine previously coded material<sup>63</sup>.

From November 2014 to June 2017, I coded the data iteratively, first using a digital notepad, then with *Nvivo*<sup>64</sup>. Coding had many different purposes. First, it was first a way of ordering the data in a way that could then be displayed thematically, with their relations clearer. In this endeavor, I used both written memos and schematics of relationships between people, artifacts, and institutions mentioned. In this sense, coding is in itself an analysis<sup>65</sup>. Parts of my work, in particular, Part 3 on children's experiences of school, is representative of this aspect of coding: I identified key themes, I compared different settings and different children to identify commonalities and divergences. My interpretation emerges quite straightforwardly from the coding.

Second, it was also a generative activity: it inspired design projects, my reflexion around design values, on sensory experiences, etc. In this sense, coding provides a reflective experience on the field-work, and helps thinking about it. Until late in my third year of PhD, I continued to identify new patterns and to refine the codes used, because my understanding of the data was still evolving.

#### MULTIMODAL ANALYSIS.

To complement thematic analysis, I used multimodal analysis of specific classroom events. Multimodal analysis is an approach born from social semiotics, and aims at systematically including the multiple resources chosen by actors in a given situation to construct meaning, e.g. gaze, gestures, utterances, graphic representations<sup>66</sup>. Concretely, this type of analysis begins with the systematic descriptions of the semiotic resources used in a given interaction. The purpose is to understand how these resources are used to produce meaning and to communicate with others, as well as the "the potentialities and constraints"<sup>67</sup> of a given mode of communication<sup>68</sup> (e.g., gestural) or a device. The analysis is then developed iteratively, similarly to thematic analysis, to identify meaningful patterns<sup>69</sup>.

<sup>63</sup> Saldana, "An Introduction to Codes and Coding".

<sup>64</sup> A qualitative data analysis software

<sup>65</sup> Miles, Huberman, and Saldana, "Qualitative Data Analysis: A Method Sourcebook".

<sup>66</sup> Kress, *Multimodality: A Social Semiotic Approach to Contemporary Communication*; Bezemer and Jewitt, "Multimodal Analysis: Key Issues".

<sup>67</sup> Carey Jewitt, "Multimodal Methods for Researching Digital Technologies".

<sup>68</sup> Carey Jewitt, "Multimodal Methods for Researching Digital Technologies", What qualify as a mode is a source of debate: "One definition of a mode is that it has to comprise a set of elements/resources and organizing principles/norms that realize well-acknowledged regularities within any one community. That is something which can only be recognized as a mode when it is a known/usable system of communication within a community."

<sup>69</sup> See also: Van Mechelen et al., "The GLID Method: Moving from Design Features to Underlying Values in Co-Design".

Multimodal analysis is often used in learning sciences<sup>70</sup>, for instance to analyze small units of interaction<sup>71</sup> via observations or videos<sup>72</sup>. It is also used to better comprehend children's inputs and opinions during design activities<sup>73</sup>. Therefore, it complemented thematic analysis well in all design-related activities. Note that there are discussions about the theoretical compatibilities of ethnography and multimodality analysis. Pink argues that multimodality is compatible with only certain schools of thoughts in ethnography, as it aims at producing data to describe a so-called objective reality. Whereas sensory ethnography, for instance, primarily emphasizes empathy, and does not primarily seek to generate data to analyze. Given the pragmatist orientation of my work, I rather belong to the multimodality paradigm.<sup>74</sup>

In June-July 2016, I used it to look into determined episodes, involving the use of two probes, MapSense, an interactive map, and interactive bracelets designed with children for field trips. This was consistent with the teacher's need to understand how each sensory modality and their combinations could be used—as well as with my own attentiveness to sensory experiences.

This concludes the description of my research approach. Each aspect presents a number of challenges. Some were discussed individually in the above sections. The next section is about the generic issues of a qualitative and pragmatist approach, and the actions I undertook to address them.

#### 4.1.4 Challenges

##### General challenges in qualitative inquiries

Instead of focusing on reliability and validity as criteria for evaluating research, qualitative inquiries should be evaluated on their trustworthiness<sup>75</sup>. Trustworthiness has four major aspects: Credibility, transferability, dependability and confirmability.

1. **CREDIBILITY** refers to the confidence that findings are true, and can be enhanced by using long periods of observations, checking with participants, and triangulation (for instance of methods and types of data). All of these mechanisms were used in my research;
2. **TRANSFERABILITY** refers to the likelihood that findings may be used in a different context. It can be ensured by thick descriptions

<sup>70</sup> Carey Jewitt, "Teacher's Pedagogic Design of Digital Interactive Whiteboard Materials in the UK Secondary School".

<sup>71</sup> Tang, Delgado, and Birr Moje, "An Integrative Framework for the Analysis of Multiple and Multimodal Representations for Meaning-Making in Science Education".

<sup>72</sup> Hackling et al., "Methods for Multimodal Analysis and Representation of Teaching-Learning Interactions in Primary Science Lessons Captured on Video."

<sup>73</sup> Malinverni, Mora-Guiard, and Pares, "Towards Methods for Evaluating and Communicating Participatory Design: A Multimodal Approach".

<sup>74</sup> See: Pink, "Multimodality, Multisensoriality and Ethnographic Knowing: Social Semiotics and the Phenomenology of Perception".

<sup>75</sup> Y. Lincoln and E. Guba, *Naturalistic Inquiry*.



of the field work;

3. **DEPENDABILITY** refers to the consistency of the findings. It can be ensured for instance by the examination of the same material by another researcher. This can sometimes enter in conflict with privacy matters, as research participants should also have the right to choose who is going to learn about their stories. This is partially achieved, as many parts of my material are not disclosed in this dissertation. However, the thick descriptions proposed should be enough to ensure dependability, and;
4. **CONFIRMABILITY** refers to the need to ensure that the research is not distorted by the researchers, to shape their own interests for instance. To address this issue, results were crosschecked with research participants, and I offered a detailed reflexive account of my positioning, values and the theoretical research that informed my research.

### Challenges of a pragmatist worldview

There is one major challenge ensuing from choosing a pragmatist world view: The research is **normative** i.e., it focuses on what ought to be. As it promises to improve a given problematic situation, researchers need to prove their interventions indeed had positive outcomes. Moreover, the values underlying the research should be made clear, and be consistent throughout. Indeed, within pragmatism, one should always be careful about "the difference it makes to define the problem one way rather than another"<sup>76</sup> and how this defines a line of action. In addition to the previous criteria, there is thus the challenge of accountability to research participants.

Regarding accountability to research participants, one should ask: Could the same (or better) outcomes for the research participants could have been achieved using a different approach and sets of methods? As pointed out, interventions by the researcher and an inductive/abductive approach can not be conducted while guaranteeing formal informed consent<sup>77</sup> as recommended by most ethics committees. However, this approach gave more room for children to shape the research focus in a way that may be profitable to them. Indeed, my inquiry into sensory knowledge changed my partner-teacher's practices, in a way that the children involved described as positive.

<sup>76</sup> D. L. Morgan, "Pragmatism as a Paradigm for Social Research", p. 1047.

<sup>77</sup> Informed consent refers to the process through which researchers outline the type of research done, its risks and benefits, before asking potential research participants if they agree to participate. The proof of informed consent generally is a signed form. Legally only parents can consent for minors.

However, speculation on the outcomes of other research approaches is just this: speculation. What I propose, to discuss accountability, in addition to the outline of the values embedded in the research in Chapter 2, is two-fold. In the next section I discuss the ethical dilemmas I faced, for others to examine; and, in the dissertation discussion on the research impacts.

#### 4.2 *Ethics*

I introduced in Chapter 2 the Accessimap ethical framework, grounded in the APA's guidelines and an anticipatory approach of ethics based on deontology rules. I pointed out observations in educational settings do not require informed consent, according to the APA code of ethics, and that consent from parents was sought before my arrival. Furthermore, there was no requirement at the time I started my research to get approval from an ethics committee — in fact, there was no ethics committee for social sciences research in my university. The corollary of anticipatory ethics is the consent form, is often more for the advantage of the researcher than the researched<sup>78</sup>. Furthermore, as the research project implied intervention, it could hardly predict outcomes for all participants. In order to develop an approach explicitly taking values into account within the research team, I turned to available ethical frameworks for research.

Ethics in research refers to a set of norms determining the acceptable conduct. In addition to general rules (e.g. ethical attribution of authorship), there are norms that vary by disciplines, research objects and geographical zones. Studies involving human subjects, or people who are considered vulnerable, require particular precautions. These norms can answer to different logics: for instance, the principle of "do no harm" illustrates a consequential view of ethics, which assesses the level of risks of a particular action (but not always of inaction); a virtue-based view rather emphasizes the researcher's situated responsibility and accountability.

I first discuss care ethics, a virtue-based ethics, as an overarching ethical approach of ethics in this research. I then articulate it to the two frameworks relevant to my subject—research with children, and research with innovation purposes. In the second half of this section, I discuss key ethical dilemmas that arose in the field.

<sup>78</sup> As discussed above and in: Weis and M. Fine, *Speed Bumps: A Student-Friendly Guide to Qualitative Research*, p. 42.

#### 4.2.1 Ethical framework

##### Care ethics

Care ethics postulate that all beings are interdependent<sup>79</sup>. This approach aims at highlighting the often hidden or under-valued relations of care. It places emphasis and values in the inter-relationships that constitute society, and challenge a consequential ethics of justice. Care supposes being attentive to the needs, taking responsibility of responding to this need, being skilled in providing care, while being mindful of the potential abuses of care and of the subjective perspectives of others. Care ethics is virtue-based: ethical thinking and reasoning is rooted in individual characters; it aims at developing virtues in the individuals themselves rather than at developing a fixed set of rules (i.e., deontology), or at reasoning from the consequences of different courses of action (i.e., consequential ethics). However it cannot be reduced to an innate empathy with users. Care is political, asks what is the kind of life we want to lead, the kind of risks and uncertainties we want to live with, and assess risks against this background<sup>80</sup>. In this framework, what is a **good** or **desirable** outcome depends on the position, and needs to be re-negotiated as needed.

Care ethics can be contested and challenged. In the case of disability, Morris<sup>81</sup> calls for carers to promote human rights. Indeed, there is a concern that placing too much emphasis on inter-dependency may pave the way for more abuse, rather than emphasizing civil rights (e.g., living autonomously). However, I argue that care ethics: provide a solid theoretical background to address ethical dilemmas as they arise and reflect on the decisions taken; is a needed support in ethnography, in which the researcher is an instrument which raises emotional issues<sup>82</sup>; and encompasses the UNICEF's guidelines for ethics in research with children and the Responsible Research and Innovation framework.

##### UNICEF's guidelines for ethics in research with children

The UNICEF's guidelines on ethical research with children<sup>83</sup> is underpinned by three key ethical principles, central to research in ethics since the Belmont report<sup>84</sup>: respect, benefit and justice. These principles can be summarized as follows:

1. RESPECT "*implies valuing children and the context of their lives, and recognition of their dignity,*" knowing "*who the child is; what cultural context they are living in; how culture shapes their experiences, capabilities and perspectives*"<sup>85</sup>."

<sup>79</sup> Tronto, *Moral Boundaries: A Political Argument for an Ethic of Care*, pp. 126–136.

<sup>80</sup> Groves, "Logic of Choice or Logic of Care? Uncertainty, Technological Mediation and Responsible Innovation".

<sup>81</sup> J. Morris, "Impairment and Disability: Constructing an Ethics of Care That Promotes Human Rights".

<sup>82</sup> Holland, "Emotions and Research".

<sup>83</sup> Graham, M. Powell, et al., "Ethical Research Involving Children".

<sup>84</sup> Protection of Human Subjects of Biomedical and Research, "The Belmont Report: Ethical Principles and Guidelines for the Protection of Human Subjects of Research".

<sup>85</sup> Graham, M. Powell, et al., "Ethical Research Involving Children", p. 15.

2. **BENEFIT** implies not doing harm but also doing research "*likely to have (positive) impact*" both for participants and their communities and the social group of children. It also implies avoiding "*harm as a consequence of exclusionary research practices*." It sometimes implies to carefully consider the balance between children's protection and rights participation<sup>86</sup>.
3. **JUSTICE** "*requires researchers to attend to the power differences inherent in the adult/child research relationship*." It defines the balance between "*perceived benefits of the research and perceived burdens placed on the participants*"<sup>87</sup>. It involves to carefully consider the power differential between the different stakeholders, to negotiate between empowerment and burden.

Furthermore, these guidelines emphasize the relational and personal aspects of ethics. "*Ethical principles and issues cannot be disconnected from researchers' attitudes, values, beliefs and assumptions about children and childhood, since these invariably shape our decision-making and underpin important matters of power and representation*"<sup>88</sup>. They call for researchers skilled in caring for children, and in providing them with the resources necessary to support their participation in research. They also emphasize the need for ongoing reflection on ethics during the research process, to address issues as they arise. In other words, an ethical approach challenges the researcher's assumptions. Their views evolve, as they establish a dialog with their participants<sup>89</sup>.

The notion of participation becomes central in these approaches, which has ethical implications different from those of Action Research. Indeed, participation of members of a community can contribute to isolate them from their communities when a taboo subject is research; participation could expose minority participants more than other types of research; and participation can be a way to involve communities who usually prefer not to be investigated—which can then expose them to negative consequences, even though researchers have taken the necessary ethical precautions<sup>90</sup>. So, how can the researcher take responsibility in the case of design?

<sup>86</sup> Graham, M. Powell, et al., "Ethical Research Involving Children", p. 16.

<sup>87</sup> Graham, M. Powell, et al., "Ethical Research Involving Children", p. 17.

<sup>88</sup> Graham, M. Powell, et al., "Ethical Research Involving Children", p. 18.

<sup>89</sup> Graham and Fitzgerald, "Progressing Children's Participation: Exploring the Potential of a Dialogical Turn".

<sup>90</sup> Bergold and S. Thomas, "Participatory Research Methods: A Methodological Approach in Motion".

## The Responsible Research and Innovation framework

Researchers in the field of Design and Human-Computer Interaction (HCI) are increasingly concerned with the ethical implications of their work<sup>91</sup> and with values in design<sup>92</sup>. Participatory design, a process "filled with ethics"<sup>93</sup> with an emancipatory aim<sup>94</sup> has gained a lot of attention. However, participation can not guarantee safety from all harms, as outcomes are not predictable, and as the collection of data can be accidental, and as different stakeholders (e.g. children, carers, researcher) have different priorities.

Frauenberger<sup>95</sup> proposes to use the European Responsible Research and Innovation (RRI) framework as a basis for ethics in HCI:

*"A succinct definition is offered by Stilgoe et al., (2013)<sup>96</sup>: "Responsible innovation means taking care of the future through collective stewardship of science and innovation in the present." [...] It highlights the difficulties of defining the central normative anchor points for what society wants research and innovation to do. Stilgoe et al. (2013) identify four central dimensions to RRI: (1) anticipation—active engagement with possible futures and their implications; (2) reflexivity—the capacity of actors and institutions to critically reflect; (3) inclusion—the involvement of stakeholders or the public; and (4) responsiveness—the ability to adapt in response to changing circumstances or new insights. Grimpe et al. (2014)<sup>97</sup> have investigated the relationship between RRI and HCI [and advocated] a continuous strive for shared responsibility."*

However, this framework does not define the values to be held important for the future. For instance, valuing individual rights, or choosing to focus on care can lead to radically different choices<sup>98</sup>. Whereas the first consists in evaluating risks and uncertainties to regulate them, the second consists in asking collectively if we want to live with these uncertainties and risks. Although care ethics, as discussed above, does not mean we can avoid to consider power issues between participants<sup>99</sup> (e.g., carers have more power over children than the reverse).

Frauenberger, Rauhala, and Fitzpatrick therefore advocates the development of a project ethos, or a set of co-defined (i.e. by participants and researchers) ethical statements on which the research project is built and that can be used to reflect on ethical difficulties and research situations. These statements can also be renegotiated during the project—which is consistent with Dewey's take on valuation. Frauenberger, Rauhala, and Fitzpatrick gives examples of such statements, such as a commitment to gender equality or open access, which determines what type of research is being conducted and how to conduct it. He also advocates for the development of

<sup>91</sup> Munteanu et al., "Situational Ethics: Re-Thinking Approaches to Formal Ethics Requirements for Human-Computer Interaction"; Benford et al., "The Ethical Implications of HCI's Turn to the Cultural"; Waycott et al., "The Challenge of Technology Research in Sensitive Settings: Case Studies in 'Sensitive HCI'".

<sup>92</sup> Friedman, "Value-Sensitive Design"; Mankoff, Hayes, and Kasnitz, "Disability Studies As a Source of Critical Inquiry for the Field of Assistive Technology"; Van Mechelen et al., "The GLID Method: Moving from Design Features to Underlying Values in Co-Design".

<sup>93</sup> Steen, "Upon Opening the Black Box of Participatory Design and Finding It Filled with Ethics".

<sup>94</sup> Light, "The Unit of Analysis in Understanding the Politics of Participatory Practice".

<sup>95</sup> Frauenberger, Rauhala, and Fitzpatrick, "In-Action Ethics".

<sup>96</sup> Stilgoe, Owen, and Macnaghten, "Developing a Framework for Responsible Innovation".

<sup>97</sup> Grimpe, Hartwood, and Jirotko, "Towards a Closer Dialogue between Policy and Practice: Responsible Design in HCI".

<sup>98</sup> Groves, "Logic of Choice or Logic of Care? Uncertainty, Technological Mediation and Responsible Innovation".

<sup>99</sup> Held, *The Ethics of Care: Personal, Political, and Global*.

self-regulatory mechanisms, to enable ethical reflections throughout the research process. In this framework, ethical dilemmas should be documented and continually reflected upon to refine the approach. It emphasizes the importance of researchers' accountability (including what happens as a consequence of the intervention), and their answers to unexpected outcomes.

Within both these frameworks (i.e., the UNICEF guidelines and the RRI), and in an ethics of care perspective, the agency of the researchers is key to the ethical decisions made. Ethics of care frame researchers as a caring (and cared for) agent. The UNICEF's guidelines call for competent carers, the RRI suggests that researchers should actively engage with the consequences of their research, and with those impacted.

#### 4.2.2 *Ethical precautions and dilemmas*

In this section, I describe and reflect on my ethical decisions and the ethical dilemmas I dealt with, in relation with my ethical framework. In other words, if the first half of this section was theoretical, this is its application. I discuss key ethical and legal matters regarding children and carers, and the steps taken to prevent conflicts. Before concluding with the limitations of my approach.

##### **With children**

**PROTECTING PRIVACY.** I have kept transcription of participant observations and interviews with children to myself. I also anonymized the identity of the children involved in the field-study in my presentation of results. One limitation is that other researchers, other employees or parents could probably recognize which child is testifying in certain cases if the quotes used were linked to a demographic profile. Although it is not a sensitive issue for observations in the classroom (as their use for research was discussed and validated with the participants), this is sensitive for their accounts of personal experiences. As a result, I chose not to include the content of children's testimonies on their non-school related experiences in my dissertation, even though it nurtured my analysis and opened numerous of the research questions to be explored I point out throughout this dissertation. I argue that to be presented here, I should have presented my research to children as aiming to understand their daily lives and conduct my research differently.

It also happened that carers disclosed sensitive information on children's lives to me (in team meetings for instance). This posed a number of challenges: When this information is useful for analysis, should I disclose it to the child to obtain consent to use it—as this is at least as much informative on adults and their practices that on the child? Do I have the right to risk causing distress by evoking painful moments? I chose not to disclose the content, but rather to tell the children involved I heard from a carers they were having a difficult time. In each of these sensitive cases, children immediately confirmed they knew what the carers had told me about. In some cases they wanted to tell me more about it, in others, they expressly said they did not want to talk about it. In any case, I do not report these testimonies here, as for the above reasons, I do not think that anonymization is sufficient to ensure that benefits are more important than risks<sup>100</sup>.

**OBTAINING CONSENT.** Consent is informed, and necessitates disclosure to research participants about the aims, methods and expected participation in research before they decide to get involved. Assent is an informal consent obtained during research from the participants, their participation evolving with time<sup>101</sup>. Due to the exploratory nature of my research, this posed a particular challenge: Hypothesis and research goals emerged throughout the research process, and I aimed at enabling the participants to intervene in the research process, which changes the risks they are exposed to. I therefore could not fully inform the participants beforehand about what exactly I was going to do. However, if I had chosen to stick with the original research plan, I argue that it would have contributed to silence children<sup>102</sup>, as there is a drastic need for more research on disabled children's experiences in France<sup>103</sup>. Additionally, the notion of informed consent would have excluded some children of the research (especially children with communication impairments or mental disabilities). Furthermore, it is very likely that some children felt somewhat compelled to participate (see limitations below) in some parts of the research, especially at the beginning, when it involved observations and interventions in the classroom.

In terms of practical actions, I made sure to remind the children every time we interacted that I was a researcher and my research subject, and that they could choose not to talk to me. I was attentive to children's body language, and interrupted interviews and observations if they seemed distraught or uncomfortable. Whenever it was possible<sup>104</sup>, I asked children whether I could use quotes from their interviews. Finally, my choice to conduct long term observations was

<sup>100</sup> However, children's experiences of violences in this context should be more thoroughly investigated.

<sup>101</sup> A. J. Cocks, "The Ethical Maze: Finding an Inclusive Path towards Gaining Children's Agreement to Research Participation."

<sup>102</sup> Alderson, *Listening to Children : Children, Ethics and Social Research*.

<sup>103</sup> Revillard, "La Réception Des Politiques Du Handicap: Une Approche Par Entretiens Biographiques".

<sup>104</sup> Some children moved away, while others clearly stated that they did not care discussing about it—see also next section.

in part motivated by my will to give children the time to define how they wanted to interact with me<sup>105</sup> (see also Chapter 9).

Still, a few events were ethically fuzzy. For instance, I once asked a child if he would like to discuss with me about a course he had taken a few days before. He refused, and asked if we could go outside so he could try riding my folding bicycle instead, which we did. After a while, he decided that he wanted to talk about that course after all. Even though I reminded him he had no obligation to do so and that I was happy to just let him try the bicycle, he insisted. I cannot be entirely sure he did not feel somewhat constrained to give me something back. On the other hand, this happened towards the end of my observation period, at which point I also assume he was comfortable enough to make his own decisions.

PROTECTING WELL-BEING. First, there is the necessity for the researcher to have a clear policy when children testify about dangers they may be exposed to. Second, the researcher must ensure that the burden of the research does not affect children's well-being. Regarding the former, children reported violence they had experienced that I was legally bound to report on several occasions. When this was the case, I explained this legal obligation to them and asked which adults I should talk to about these events. In most cases, they reported that educators or teachers had already been informed. Risks were thus handled by the care center's carers<sup>106</sup>.

Regarding the latter, the children involved in this research had a very busy schedule. In addition to school and extracurricular activities, they have rehabilitation sessions, medical appointments, additional support by teachers, they spend time commuting to these activities etc. Observations during their time in school and various care services are one way not to add to this burden. But I was surprised by the refusal of most children to participate in the verification of my research. At different steps of the observations and on-going analysis, I proposed to participants, individually, to present them my findings so we could discuss them, following the methodology often advocated in participatory research in the domain disability and childhood studies<sup>107</sup>. The participants most often refused. I thus proceeded to discuss whether they were still interested in participating in the research, and if they had felt uncomfortable or burdened by our previous encounters. But they confirmed they did want to be part of the research, and still wanted to. Some of them separated their participation from "*my job*," stating that I would know or do better at the analysis. Others said they did not want to take time to do so, but that we agreed during the interviews, suggesting that I

<sup>105</sup> W. Corsaro, *Friendship and Peer Culture in the Early Years*.

<sup>106</sup> Carers' practices and representations regarding neglect and abuse deserve a more thorough investigation as well.

<sup>107</sup> J. Sanders, *Subject Child: The Everyday Experiences of a Group of Small Town Aotearoa/New Zealand Children*.



use the interview content. One outlined that it was different if I used what we had discussed about school (*"that should be told"*) from what she had said about herself (that should not be talked about).

There may be different reasons for their refusal to get involved in the analysis. They may fear to *"fail"* at doing a *"good job,"* if they associate participating in research with doing some sort of school work. Although I have extensively discussed the fact that there were no right or wrong answers, and that I would be the only one knowing their personal opinion, I cannot entirely eliminate this hypothesis. Hypothetically, the research aims may not currently be of importance to them. However, given their eagerness to participate, this is unlikely. My third hypothesis is that they were, quite simply, not interested by that part of the process. I would point that this is not an unprecedented situation in the research literature<sup>108</sup>. Hence I did the analysis mostly by myself, cross checked my analysis about carers's practices with the the carers the most involved in the research, and elaborated a research account based on the different perspectives I had encountered.

As a final note on this topic, I tried to reciprocate the time and energy children put in the research, by designing and providing artifacts they wished such as 3D printed tactile globes, giving them the probes they liked etc. Teenagers often asked, in return, advice on IT related subjects (e.g., one wanted to get introduced to coding, which I did before introducing him to Scratch<sup>109</sup>; another wanted advice on Wordpress plugins<sup>110</sup>, a third on online libraries of audio material etc.). These exchanges happened after their interviews, as I did not wanted this reciprocity to become an inducement.

#### ADAPTING TO CHILDREN'S COMMUNICATION NEEDS.

I faced different difficulties regarding providing all children with the means to participate in the research. During my second day of observations, I was warned by a carer that I could not trust what many children I would meet would tell me, not because they were children but because many of them used **verbalism**. Verbalism refers to the use of words without understanding their meaning. Something can be heard and remembered, but not understood. One example is the plane: two children with blindness had told me planes fly in the air. But at some point in the discussion, it turned out they thought planes were similar to aerial subways. This was described by Hatwell<sup>111</sup>, for instance. Verbalism, I was told, would also be used to tell stories about everyday lives. Many children would repeat stories they heard from others (one of the explanation I was provided is that

<sup>108</sup> E.g., Mason and Falloon, "Some Sydney Children Define Abuse: Implications for Agency in Childhood"; Mayall, *Children's Childhoods: Observed and Experienced*, pp. 8 & 104.

<sup>109</sup> A popular educational game to learn the basics of programming. <https://scratch.mit.edu/educators/>

<sup>110</sup> Wordpress is a Content Management System enabling to build blogs and websites

<sup>111</sup> Hatwell, *Privation Sensorielle et Intelligence*, p. 35.

it helped children maintaining their self-esteem).

This is much more to say about the language strategies used by visually impaired children<sup>112</sup>. First, if verbalism was described to me as a particularity of children with visual impairments, using words without understanding their meaning is not uncommon in sighted children. Telling stories heard elsewhere instead of one's story is not surprising either, and a strategy not limited with children. The literature also suggest that young adults with visual impairments particularly like playing with language<sup>113</sup>. Last but not least, many of the children I have met had limited verbal proficiency—but common alternative techniques, such as drawings or image sorting, are not possible either. I was thus attentive to this issue and its potential consequences for data generation and analysis.

I addressed communication difficulties in different and complementary ways: I asked carers for children's communication preferences, and observed their communication strategies. I adapted my language and vocabulary to each of them. On a methodological level, during interviews, when I was unsure of how I should interpret a child's account, I used simple questions to clarify their testimony (e.g., "*did this happen to you, or to someone else?*"). Additionally, it constituted a central problematic while I was developing my methodology. In addition, I developed specific research tools (such as probes), so as to vary their modes of engagement.

### **With carers**

Regarding observations and interviews with carers, it raised fewer ethical dilemmas. The three carers I was most often in contact with had volunteered to be part of the research project. They negotiated their involvement, depending on their time and interest for the different aspects of the research. One teacher was interested in learning more about the literature, a carer wanted to know more about design, etc. I tried as much as possible to provide services, from 3D printing or laser cutting model they needed, to producing the needed interactive maps or helping in brainstorming adaptations. Many of my design interventions targeted difficulties I could (at least partially) help solve. Given that most of the hours they gave to the research project were outside their usual schedule, and paid as supplementary hours, they were not coerced into participating by their employer either. However, I need to acknowledge that their participation had mixed outcomes for them, as they were given new professional assignments as a consequence of the Accessimap research project.

<sup>112</sup> Lewi-Dumont, "Langage".

<sup>113</sup> Carrière, "Résilience et Humour Chez Des Étudiants Déficients Visuels".

Complementary to the issues related to changes in their professional responsibilities as the outcome of their participation, I argue that the most crucial ethical regarding their involvement is the risk of institutional backlash for their participation and for voicing their opinions. In this particular case, although they had some disagreements about management practices, they mostly praised how everything was handled within the care facility. Most of their criticisms aimed at the state's management practices (e.g. lack of training in the case of AVS/AESH, lack of assistive technologies), resulting in discriminations against students with visual impairments.

The main ethical dilemmas I faced were related to episodes where carers's and children's interest conflicted. An example is a child crying in the classroom because he was not feeling well and had difficulties finishing an exercise. Crying was considered by the carers as necessary for the child's education and something to grow out of by becoming stronger, rather than something denoting an issue that maybe could be addressed. This goes against the ethical framework outlined above. On the other hand, the literature points to the difficulties of the work of care. Hennion<sup>114</sup> for instance, asks whether constraints are compatible with care, and shows the strategies developed by carers and care-receivers to negotiate the gestures and practices of care. In some cases, the choices made by care-receivers' can go against the over-arching principle of "Do-no-harm." In others, the norms that constitute good care may not always be applicable due to material constraints. Finally, these norms may differ from a carer to the other, and are in complex interactions with the conceptual models that carers hold of a **good education** and **disability**. Pointing out values underlying such practices allows to discuss them. However, it can also induce guilt in carers. It also placed me in an uncomfortable situation: should I intervene? Can I intervene? When confronted to such events, I mostly addressed it retrospectively, by discussing the event with the carer (and the children), which richly elicited the values associated with education, emphasizing resilience (see Part 3). I once tried to help a child to deal with his feelings, but was barred from it by another carer. I remain unsure of how to best handle such events in this configuration.

Finally, I took a few other practical steps, to protect carers' privacy. I anonymized carers' identities in my research account, and do not refer to them individually: I only refer to the group they belong to. They were well informed of the progress of my research, through quarterly presentations, occasional demonstrations of the design developed, and regular discussions around my analysis of their practices. One teacher also commented on parts of my thesis. As with

<sup>114</sup> Hennion and Vidal-Naquet, "La Contrainte Est-Elle Compatible Avec Le Care ? Le Cas de l'aide et Du Soins à Domicile".

the children, they disclosed personal information to me during the research process and it influenced the data generated and its analysis, but I do not use these testimonies in my dissertation. As with the children, this would have required to clarify from the start it would be the subject of my research.

### Assessing ethics and limitation

The strategies I adopted to address ethical issues arising throughout my research need to be further discussed on different grounds. As mentioned earlier, the active participation in research may not always allow to protect from all kinds of harm. There may be conflicts of interest between participants (e.g. parents and children; children and teacher; institution and employees; researcher and participants). Additionally, even though research participants may agree with research findings, they may feel hurt by what they feel it says about them. In any case, power relations do not disappear, and my research posture is to address them—in particular by giving a centrality to children's own accounts.

One pragmatic way to look at it is to ask the participants themselves, considering consent as a process<sup>115</sup>. This is a complex issue with children: First, the nature of observations means that I incidentally observed children with whom I could not have first negotiated their involvement, and who I would not see again. This was the case during observations in general education schools, for instance. There are also limitations due to the frame in which I was allowed to do research (i.e., a mandatory school). On the other hand, I observed that children were eager to try and comment on the artifacts I built, and stated at numerous points that it made them feel heard. I would also argue that it gave them more agency in the classroom, in line with my objectives (see Chapter 15 for instance). It is less of an issue for research with carers: I remained in contact with two of the most involved carers long after the field-study has ended. I also asked them directly if they had felt constrained or burdened to participate—their answer was negative. They also demonstrated, in several occasions, that if they did not want to get involved, they would turn down research-related requests.

Due to the research subject, the participation modalities, I did not conduct as many observations with all the children attending this care facility as I would have liked. Indeed, the organization studied also provides services to children with profound and multiple impairments. I should have included them from the start. However, this raised multiple difficulties. To interact with them, I needed to get the assent of educators, by proposing structured activities. On

<sup>115</sup> Lareau, *Unequal Childhoods: Class, Race, and Family Life*.

several occasions, children boarded in this service tried to interact with me, but were held back by their carers, taken back to their common living room or to another activity. During further discussions with their carers, it appears that my presence was feared to be disruptive in the everyday routine, and thus potentially harmful. They also feared interacting with these children would be an inconvenience for me. I nevertheless had the occasion to participate in their artistic or sporting activities, to observe therapy sessions (e.g., psychomotor rehabilitation), and on a few occasions at the documentation center, to discuss their preferences regarding technologies. There is much more to be investigated: In particular the ways **abilities** and **aptitude to attend a general education classroom** are defined. My observations suggest that behavioral issues and difficulties to express oneself orally are more likely to be interpreted as requiring institutionalization than physical impairments. They also suggest that behavioral difficulties are either associated by carers to a precondition, or to traumatic experiences, rather than to the environment. **Capacities, skills, behaviors** and **potential** are characterized, assessed, re-examined, and contested (by children or parents) in this context should be studied in more details.

### 4.3 *Summary*

In this chapter, I presented the research approach I developed to investigate visually impaired children's experiences of school. It is anchored in a pragmatist worldview, using primarily a qualitative and ethnographic research—but I also use quantitative data to confirm certain findings. I used a diverse set of data generation methods (observations, interviews, artifacts gathering, probes) and two analysis methods (thematic and multimodal analysis). A diverse set of methods is useful for working with diverse groups, as well as to improve the reliability of the research.

The second part of this chapter outlines the ethical issues arising from this research approach, how they echo the concerns discussed in the Chapter 2, and how I addressed them. Through care ethics, I articulate a UNICEF framework for research with children with the Responsible Innovation framework proposed by the EU. It provides both pragmatic guidelines, topics to be careful about, as well as a larger moral of action—which is not without dilemmas. I discuss these dilemmas, and the shortcomings, which affords some accountability to the research stakeholders and peers.

### *General Conclusion of Part 1*

In this part of the thesis, I described the construction of my research topic and approach. Specifically, I outlined the emergence of visually impaired French children's experiences of school as "a problem" through the inductive analysis of my field-work material and the consideration of the power dynamics at stake (with some points of view valued and listened to more than others). I then discussed the literature on disabled childhoods. And I highlighted tensions between the study of norms of childhood and disability, and constructionist analysis of children-as-actors's views, each tied to specific national contexts, impacted by recent change in international policies. Though these research traditions, or research agendas, are often opposed, I pointed out that listening to and studying children's experiences can help us understand their "own views" as well as identifying underpinning norms. The objective is to understand how these norms are formed and sustained in practice.

I situate my research in a pragmatist and interactionist theoretical framework, which I argue is akin to the socio-relational model of disability. It does not presume which aspects are relevant to understand experiences, or to improve a situation framed as problematic. It starts from a co-defined problem—here a complex technical-cognitive-socio-emotional issue articulated by the research stakeholders. It investigates the situations where the identified problem arise, by observing and interpreting multiple perspectives—here using a mosaic of methods from design and sociology.

Finally, I quickly summarize the role of "design" in the definition of research topic and approach. I described it as a **skilled vision**, making me attentive to possibilities to design and to the material culture more generally (textures, materials, aesthetics). I framed a participatory design approach as a commitment to pragmatic intervention for and with research stakeholders. I also pointed out its epistemological and methodological value: producing artifacts is a way to involve participants differently, as well as to investigate how they may reconfigure the situations studied. But some design productions, as will be discussed later in the dissertation, are also valuable in themselves, opening design spaces. It illustrates the many ways an interdisciplinary research including design can be led.



## **Part II**

**Related work. What we  
know about...**





The first part of the dissertation discussed the construction of the research topic and approach, and situated it among the many perspectives used to study disabled children. The second part critically reviews the findings and hypothesis made in these bodies of research regarding disabled children's experiences of school. The purpose is triple: enabling the reader to compare how my findings converge or diverge from those made elsewhere; providing a complementary, macro and quantitative perspective on visually impaired French children and their schooling modalities; and last but not least, grounding my argument that designers should look beyond assistive learning technologies as a way to give access to visual-based representations.

The goal of Chapter 5 is to describe how the fact that children are considered disabled reconfigure their relations with others: (1) At school, (2) in relation with other social dynamics (e.g., class and gender), and (3) in terms of risk to experience violence. For each of these topics, I focus on disabled children in general, as they are not necessarily studied as a group. But this assumes again that visually impaired children belong to the group of disabled children, an affiliation they may reject.

As a complement, Chapter 6 focuses on visually impaired French children to better characterize this population and provide comparison points to my study. This characterization is made through the review and interpretation of two quantitative studies (1) on epidemiology of visual impairments in children; (2) on the schooling modalities and factors affecting it

This is extended in Chapter 7, which proposes a complementary perspective on educational technologies: their designers'. (1) What are the technologies available and developed for visually impaired people in general? (2) What are the technologies proposed to support the learning of geography specifically? (3) What are the design approaches commonly adopted?

Which leads me in Chapter 8 to discuss the representations of users guiding their elaboration. How does it converge or diverge with what the social sciences literature say of disabled children? What are the other possibilities?

The primary contribution of this part resides in the attempt to articulate the different factors affecting school experiences, if and how they are considered in design, and points on which they can be contested. A secondary contribution is the synthesis of the different sources of data enabling to characterize visually impaired French children.



# 5

## *Disabled childhoods*

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This chapter attempts to summarize what, through the many approaches discussed in Chapter 3, we know about disabled children's experiences of school. It explains where this dissertation can contribute to the literature. When possible I review research on visually impaired and/or French children, thus assuming that among disabled children, visually impaired children may have specific experiences, and that France can be an adequate dimension of analysis, given its specific organization of healthcare and education.

In the first section, I articulate how being considered disabled can reconfigure children's experiences at school. Specifically, I discuss:

The "good life"<sup>1</sup>, or what are considered good life conditions by children, and their carers, which contributes to define what is expected of school; Modalities of services; Peers and family relationships; And experiences of technologies. This is the occasion to point out that visual impairments alone do not seem to greatly affect academic attainments in mandatory schooling, though they seem to affect children's relationships with others. In the second section, I consider how these different aspects of experience differ depending on other characteristics, namely place, class, gender and ethnicity. This is the occasion to point out that these other characteristics seem to have a much higher impact on academic attainments (particularly in the case of social class). In the third section (3) I attempt to outline micro and macro perspectives on the violence more likely to be experienced by disabled children. This, I propose, is central to understand how visually impaired children experience school—and it echoes the socio-relational model of disability.

These themes are similar to those of Childhood studies in general (as discussed in Chapter 3), although we note a specific focus on access to services<sup>2</sup> and what constitutes a good life when it comes to studying disabled children. This similarity is not surprising: disabled children are children, what is important is to understand how they are differentiated in and across various contexts, by studying how they are socialized and act creatively in this socialization. The concern with socialization and differentiation is underpinned by a concern for ensuring equal chances to reach desired outcomes. Hence, the overall impression remains that disabled children are described in research as perpetually at risk. This does not well represent children's opinions, who mostly see themselves as similar to their peers (see below Good life). Yet, this is a perspective that cannot be overlooked, as it often underpins carers' actions (see Chapter 10).

### 5.1 *Experiences of School*

This section summarizes social research conducted on disabled children's experiences of school and views of education. It articulates the tensions in what constitutes a good education with choices of educational modalities, personal relationships with academic attainments in any education modalities, and points out the double function of assistive technologies in making disabled children **the same** and **different** from their peers.

<sup>1</sup> Beresford, "Working on Well-Being: Researchers' Experiences of a Participative Approach to Understanding the Subjective Well-Being of Disabled Young People."; Rabiee, Sloper, and Beresford, "Desired Outcomes for Children and Young People with Complex Health Care Needs, and Children Who Do Not Use Speech for Communication".

<sup>2</sup> Priestley, "Childhood Disability and Disabled Childhoods Agendas for Research".

### 5.1.1 Framing the "Good Life" (thus the "Good Education")

Today, compulsory schooling for children is the norm in Western societies. Beyond the necessity to look over children, schooling is defined by its aims—be they economic, social or intellectual<sup>3</sup>. These aims shape and are shaped by contemporary understanding of what is needed to live a **good life**, and generally, to ensure that it recognizes children's merits in a fair way<sup>4</sup>. As diplomas are more and more necessary to enter the workforce, intellectual and economic goals are sometimes conflated, i.e. school is first and foremost supposed to provide individuals with skills the workforce needs, and underachievement at school is described as necessarily impairing economic outcomes<sup>5</sup>, which in turn lower other outcomes such as health.

What constitutes a good life, or living well, is a normative question belonging to the field of moral philosophy—and it is too wide of a literature to be fully reviewed here<sup>6</sup>. I however underline that in many theories addressing this question, bad health is framed as inherently problematic. This is the case in some stances of the capability approach<sup>7</sup>, an influential framework to address this question. On the other hand, the capability approach also enables evaluation of which capabilities are important to individuals, and see if they are supported in acquiring them<sup>8</sup>. In this view, bad health or disability do not necessarily hinder the ability to live a good life, but it might change people's expectations. This is why Trani et al.<sup>9</sup> highlight the need to compare the aspirations of disabled people with those of non-disabled people in the same community, arguing that being neglected may lead individuals not to consider more positive outcomes, to settle for a given, unfair situation.

So, what do children consider to be positive outcomes or life perspectives? Rabiee et al.<sup>10</sup> researched the opinions of youngsters with complex health care needs due to non-degenerative conditions (life threatening or not). They outline "*fundamental outcomes*," such as well-being, not being in pain, living a long life, being able to communicate; and "*higher outcomes*:" such as making choices, learning new skills, having friends, being independent, and having a good self-image. She underlines that many of these desired outcomes are identical to those of non-disabled children—other studies confirm this latter finding<sup>11</sup>. But they also insist that "*not being in pain*" is a primary requirement—while this is most often taken for granted for non-disabled children. They further demonstrate that the same outcome (e.g., friendship) means very different things depending on the child (e.g., being present in a room with friendly people or be-

<sup>3</sup> Tyack, "Ways of Seeing: An Essay on the History of Compulsory Schooling"; Dubet, *Faits d'école*.

<sup>4</sup> Tenret, "L'école et La Croyance En La Méritocratie".

<sup>5</sup> Epstein, *Failing Boys?: Issues in Gender and Achievement*, It is a lot more complicated interactions. See:

<sup>6</sup> Griffin, "Well-Being: Its Meaning, Measurement, and Moral Importance"; J. Rachels and S. Rachels, *The Elements of Moral Philosophy*.

<sup>7</sup> Nussbaum for instance states explicitly that anyone should "(be) able to live to the end of a human life of normal length; not dying prematurely, or before one's life is so reduced as to be not worth living. (Be) able to have good health, including reproductive health." Nussbaum, *Creating Capabilities*, p. 33.

<sup>8</sup> Trani et al., "Disabilities through the Capability Approach Lens: Implications for Public Policies".

<sup>9</sup> Trani et al., "Disabilities through the Capability Approach Lens: Implications for Public Policies".

<sup>10</sup> Rabiee, Sloper, and Beresford, "Desired Outcomes for Children and Young People with Complex Health Care Needs, and Children Who Do Not Use Speech for Communication".

<sup>11</sup> E.g., Connors and Stalker, "Children's Experiences of Disability – Pointers to a Social Model of Childhood Disability"; V. Tadić et al., "Seeing It My Way: Living with Childhood Onset Visual Disability".

ing able to participate in specific activities). Investigating emotional and psycho-social aspects of children's lives is thus paramount to understanding what children consider as satisfying social participation or desirable lives<sup>12</sup>, along with considering how environmental characteristics (gender, familial environment etc) contribute to this appreciation<sup>13</sup>.

### 5.1.2 Modalities of Schooling and Services

All children spend a considerable amount of time at school and other educational environments (e.g., daycare). If international recommendations and treaties advocate clearly for the schooling of disabled children in general education classrooms, national implementations differ greatly. Furthermore, it is to be expected that such policies are received differently in different contexts (e.g., countries, grade, type of school etc). Hence, a consequent literature on disabled childhoods focuses on carers' practices and understanding of policies<sup>14</sup>, and disabled children's experiences of schooling. Yet, Carpenter and MacConkey<sup>15</sup> argue that disabled children's voices have had only marginal influence on policies and services practices.

One question is to understand and compare the benefits of special education or inclusive schools<sup>16</sup>. These studies often highlight a tensions between best practices for ensuring the best academic and social outcomes, which are both expected of schooling, during and after mandatory education. Regarding academic outcomes, the efficiency of different pedagogical practices such as the need for one-on-one tutoring, content adaptations etc, remains studied and debated by experts<sup>17</sup>. It is generally supposed that children learn better in inclusive environment, where they would be more stimulated, but this is not always the case<sup>18</sup>. Moreover, studies on academic achievement in the UK suggest that, when other social factors such as socioeconomic status are taken into account, visually impaired children (with no additional impairments) perform academically quite as well as their sighted peers<sup>19</sup>.

Regarding social integration, it seems to improve academic persistence and attainment, and to be correlated with well-being<sup>20</sup>. However, whereas some find that children with visual impairments report increased peer support and well-being in special education schools<sup>21</sup>, others argue that an inclusive setting improves social integration and lessens abusive behaviors against disabled children in general<sup>22</sup>.

<sup>12</sup> Nick Watson, "Theorising the Lives of Disabled Children: How Can Disability Theory Help?"; E. J. Hutcheon, "Crippling" Resilience: Generating New Vocabularies of Resilience from Narratives of Post-Secondary Students Who Experience Disability.

<sup>13</sup> Wagner et al., "Perceptions and Expectations of Youth with Disabilities. A Special Topic Report of Findings from the National Longitudinal Transition Study-2 (NLTS2). NCSER 2007-3006."

<sup>14</sup> E.g., Nind and Wearmouth, "Including Children with Special Educational Needs in Mainstream Classrooms: Implications for Pedagogy from a Systematic Review"; Reindal, "A Social Relational Model of Disability: A Theoretical Framework for Special Needs Education?"; Douglas et al., "International Review of the Literature of Evidence of Best Practice Models and Outcomes in the Education of Blind and Visually Impaired Children".

<sup>15</sup> Carpenter and McConkey, "Disabled Children's Voices: The Nature and Role of Future Empirical Enquiry."

<sup>16</sup> Ferrell, "Issues in the field of blindness and low vision".

<sup>17</sup> D. Hatton, "Current Issues in the Education of Students with Visual Impairments"; D. D. Hatton, "Advancing the Education of Students with Visual Impairments Through Evidence-Based Practices".

<sup>18</sup> Schuman, "Segregation, Inclusion and the Transition to Adulthood for Students with a Visual Impairment".

<sup>19</sup> Chanfreau and Cebulla, "Educational Attainment of Blind and Partially Sighted Pupils".

<sup>20</sup> Kuh et al., *What Matters to Student Success: A Review of the Literature*, Another hypothesis is that differences in expectations (e.g., less accentuation of academic attainments) can explain differences in social integration and well-being. See:

<sup>21</sup> Schade and Larwin, "The Impact of Visual Impairment on Perceived School Climate."; V. Tadić et al., "Seeing It My Way: Living with Childhood Onset Visual Disability".

<sup>22</sup> Bunch and Valeo, "Student Attitudes toward Peers with Disabilities in Inclusive and Special Education Schools".

Lewi-Dumont's research on school experiences of small groups of blind French teenagers in 1999<sup>23</sup> and 2009<sup>24</sup> confirm these findings. She found that teenagers had very different experiences of general and special education classrooms, which implies that there are no one-size-fits-all approach to schooling modalities for blind children<sup>25</sup>. She also found that children felt they were not listened to regarding their schooling modalities, and that this affected negatively their experiences. Furthermore, current well-being is often weighed against later expected well-being: early integration in a general education setting is often argued to better prepare for autonomy in adulthood<sup>26</sup>, but some visually impaired young adults disagree<sup>27</sup>.

As for what enables or hinders integration in a general education classroom, many mechanisms at play are described in previous studies. For example, we know that human assistants' and teachers' attitudes impact the formation of peer relationships, in particular by preventing interactions considered normal at a given age<sup>28</sup>. V. Tadić et al. also points out that age of onset affects how children perceive their impairments and its effects (with late onset associated with more difficulties to cope and relate to others). But those mechanisms are rarely integrated to form typologies to be applied or challenged elsewhere. There is thus the need for further research, to understand ever more precisely how different school systems or localization, or children's characteristics, may produce different experiences and relationships at school.

### 5.1.3 Experiences with/of Assistive Technologies

Among these factors we know to be influencing the formation of relationships at school are assistive technologies:

"The term "assistive technology device" means any item, piece of equipment, or product system, whether acquired commercially, modified, or customized, that is used to increase, maintain, or improve functional capabilities of individuals with disabilities."<sup>29</sup> The assistive technologies used by visually impaired children range from adapted tools, e.g. braille ruler, the use of note-taking devices, e.g. computer, braille Perkins machine or electronic notetaker, and to smartphones and smartwatches. They are more or less visible by design, and in different situations, e.g. if the whole classroom uses computers, it is quite different than to be the single user.

<sup>23</sup> Lewi-Dumont, "Moi Je n'ai Pas Envie de Prendre Ce Qui Reste. Proclamation de l'identité et de l'altérité Chez Des Adolescents Déficients Visuels".

<sup>24</sup> Lewi-Dumont, "Blind Teen-Age Students' Expectations".

<sup>25</sup> Note this could be argued for non-disabled children as well.

<sup>26</sup> Mithout, "L'inclusion Scolaire à l'heure Des TIC : Perspective Franco-Japonaise".

<sup>27</sup> Lewi-Dumont, "Blind Teen-Age Students' Expectations".

<sup>28</sup> V. Tadić et al., "Seeing It My Way: Living with Childhood Onset Visual Disability"; Davis and Hopwood, "Including Children with a Visual Impairment in the Mainstream Primary School Classroom".

<sup>29</sup> S. Alper and Raharinirina, "Assistive Technology for Individuals with Disabilities: A Review and Synthesis of the Literature", This is the definition used in the Technology-Related Assistance for Individuals with Disabilities Act (Tech Act). Used for instance in this meta-review of the impacts of assistive technologies:



A number of studies focus on widely used assistive learning technologies for this group<sup>30</sup> and conclude to the potential benefits of education, technologies for participation and autonomy in general education classrooms—but outline usability and accessibility problems, as well as potential backlash effects. These effects include: lack of adaptation from teachers (who might see assistive technologies as enabling participation in themselves, thus overlooking the needs for didactic or pedagogical adaptations—which seems to be too often the case in France<sup>31</sup>); children pointed out as different because of their use of technologies in the classroom, hence refusing to use them; and more generally, a disinterest in using technologies, whether it is due to the inadequacy of the device or not.

However, we lack data on other types of assistive technologies. This is the case for mobility and orientation aids, such as using a white or yellow cane. On this topic, findings about wheelchairs can be helpful<sup>32</sup>: It shows how some youngsters embrace these devices as part of who they are, whereas others were excluded for using such devices, resulting in underuse, or in negative subjective experiences of their use. We know little on the use of mainstream technologies for assistive purposes at school too. How does the surrounding digital culture influence the perception of technologies in the classroom, and the formation of peer relationships? For a start, see Chapter 11.

#### 5.1.4 Community, Peers and Family Relationships

Regarding social participation, or the engagement in a number of relationships with members of the community, peers and family. Scholars study these relationships to understand how they influence children's development and outcomes<sup>33</sup> (e.g., academic, professional, well-being, self-esteem<sup>34</sup>), although one should not overlook they are worthy in themselves for the people living them.

How people form and sustain relationships is age and context specific, or in other words varies with socio-demographic characteristics. Peer relationships enable to learn how to develop shared meanings and activities in the first years, and to find intimacy and emotional security later on<sup>35</sup>. Furthermore, the relationships we are able to develop can be considered a capital<sup>36</sup>, as they enable or preserve social positions and vice-versa<sup>37</sup>. Social participation is presumed to be more difficult for disabled children (both because of individual features and their stigmatization by others), while their ability to develop relationships is framed as a protective factor—although Hanisch for instance found that good peer relationships at school does not prevent bullying<sup>38</sup>.

<sup>30</sup> Douglas, "ICT, Education, and Visual Impairment"; Bocconi et al., "ICT Educational Tools and Visually Impaired Students"; Mithout, "L'inclusion Scolaire à l'heure Des TIC : Perspective Franco-Japonaise"; Popescu, "Accessible Learning Environments: When Care Meets Socio-Technological Innovations for Pupils with Disabilities"; Rony, *Information Communication Technology to Support and Include Blind Students in a School for All An Interview Study of Teachers and Students' Experiences with Inclusion and ICT Support to Blind Students*.

<sup>31</sup> Mithout, "L'inclusion Scolaire à l'heure Des TIC : Perspective Franco-Japonaise".

<sup>32</sup> Østvik, Balandin, and Ytterhus, "A "Visitor in the Class": Marginalization of Students Using AAC in Mainstream Education Classes"; Connors and Stalker, "Children's Experiences of Disability – Pointers to a Social Model of Childhood Disability"; Winance, "Universal Design and the Challenge of Diversity: Reflections on the Principles of UD, Based on Empirical Research of People's Mobility"; M. Alper, *Giving Voice*.

<sup>33</sup> Gillies, "Young People and Family Life: Analysing and Comparing Disciplinary Discourses".

<sup>34</sup> Huurre, Komulainen, and Aro, "Social Support and Self-Esteem among Adolescents with Visual Impairments."; Papadopoulos et al., "Social Support, Social Networks, and Happiness of Individuals With Visual Impairments".

<sup>35</sup> W. A. Corsaro and Eder, "Children's Peer Cultures".

<sup>36</sup> Holland, "Young People and Social Capital"; Edwards, J. Franklin, and Holland, *Families and Social Capital: Exploring the Issues*.

<sup>37</sup> R. D. Conger, K. J. Conger, and M. J. Martin, "Socioeconomic Status, Family Processes, and Individual Development".

<sup>38</sup> Hanisch, "Psycho-Emotional Disablism: A Differentiated Process".

In any case, a number of factors seem susceptible improve or hinder social participation as children (and related outcomes). This includes the difficulties encountered by children with different types of impairments when forming friendships<sup>39</sup>. In the case of visually impaired children it seems that the inability to pick-up non-verbal clues and body languages is detrimental<sup>40</sup>; that they have poorer socio-communicative language skills when they enter school<sup>41</sup>; but that pre-school groups of children with visual impairments are useful to develop their social skills<sup>42</sup>.

Other difficulties arise from differing from the norm in terms of independence and mobility<sup>43</sup>, thus being denied access to extra-curricular activities. Which points out the importance of parents' attitudes and support of their children's independence<sup>44</sup>—but emphasizing parents' resilience in policies and practices may obscure structural factors at play, such as poverty<sup>45</sup>. Furthermore, the way disabled children appropriate or reject parental expectations remain rather under-investigated<sup>46</sup>, particularly in the case of children with disabilities. This is a topic that emerged during my analysis and will thus be discussed, as parental expectations regarding social and academic participation shape their involvement.

To summarize, school can be described with two main aims: social integration (through access to work and citizenship) and the acquisition of academic skills and knowledge. Being integrated in a general education classroom is generally supposed to be more beneficial than a special education environment to achieve these goals. But qualitative studies suggest that this is not always true, and depends on the situation (e.g., quality of support, classroom ambiance) and that children have different preferences regarding their modalities of schooling. Furthermore, we should be attentive to other characteristics of children that are known to affect school experiences. Indeed, the literature suggests that visual impairments alone do not seem to affect academic performances.

## 5.2 *Intersectionality with Class, Gender, Place and 'Ethnicity'*

Intersectionality is a notion developed by Crenshaw to characterize discrimination occurring when an individual belongs to two discriminated groups of population (e.g., in her argument about black women, gender and 'race')<sup>47</sup>. She demonstrates that the impacts of each category can not be evaluated separately: companies may not discriminate against black men, or women in general, but may well discriminate against black women specifically. Since then, scholars

<sup>39</sup> Egilson, "School Experiences of Pupils with Physical Impairments over Time"; Callus, "Being Friends Means Helping Each Other, Making Coffee for Each Other": Reciprocity in the Friendships of People with Intellectual Disability", E.g.,

<sup>40</sup> Coates, "Visual Impairment, Blindness and Social Interaction".

<sup>41</sup> Valerie Tadić, Pring, and Dale, "Are Language and Social Communication Intact in Children with Congenital Visual Impairment at School Age?"

<sup>42</sup> Lewi-Dumont, "Regrouper Des Jeunes Enfants Déficients Visuels d'école Maternelle Pour Favoriser Apprentissages et Construction de l'identité Sociale".

<sup>43</sup> Lampert, *Social Participation: Perspectives on the Lived Experiences of Adolescents Who Have Visual Impairments*, E.g.,

<sup>44</sup> Huurre, Komulainen, and Aro, "Social Support and Self-Esteem among Adolescents with Visual Impairments."

<sup>45</sup> Val Gillies, "Meeting Parents' Needs? Discourses of 'Support' and 'Inclusion' in Family Policy".

<sup>46</sup> Holmes, *Influences of Parental Expectations and Involvement on Academic Success*.

<sup>47</sup> Crenshaw, "Mapping the Margins: Intersectionality, Identity Politics, and Violence against Women of Color".

from various fields have used, or referred to, this notion more generally to describe the interplay of gender, social class and race that constitute specific social inequalities. In the case of disability, because it remains perceived as a biological feature, these intersections tend to be under-researched. I use intersectionality as a heuristic, both to guide my literature research, and as a reminder that the children I worked with belong to multiple groups, from which they acquire different dispositions and resources.

I review four bodies of literature: three of them are usual in the intersectionality literature (class, gender and race). To this I added place, because this dimension was clearly important in my study. The first focuses on how social class impacts impairments prevalence and disability severity. The second is the intersection with gender, which echoes some considerations developed in the section peers and relationships. The third addresses the impact of 'ethnicity' (or 'race', understood as a social construction). The fourth outlines the impact of place, and resonates with the section on school and services. I close with general remarks on the difficulties stemming from the proliferation of variables to take into account—and the implications of choosing one over the other in an explanation.

### 5.2.1 *Social class, impairments, and disability severity*

First, I define social class as a concept referring to the social stratification of society: groups of people with similar characteristics share. A given social class is an umbrella term for different factors: household income, occupational status of family members, inherited wealth, education or cultural preferences. It can be studied through one or several of these factors, their meaningfulness often depending on the context. For instance, in relation to education outcomes, it is the occupational status of the household reference person that is most often taken into account in France, as it is supposed to encompass both sufficient material resources, a positive attitude towards school and social resources encouraging to study. However, there can be significant income, inherited wealth or education differences within each of the four categories used (from disadvantaged to highly advantaged).

We know there is a the relation between social class and impairment prevalence in childhood, because of a variety of factors: e.g., stress, lack of access to care, environmental risks. For instance in the United Kingdom cerebral palsy is more prevalent in disadvantaged families, because children from these families are more likely to be born with a low birth weight<sup>48</sup>. Disadvantaged mothers are more likely to be exposed to environmental risks causing prenatal

<sup>48</sup> Dowding and Barry, "Cerebral Palsy: Social Class Differences in Prevalence in Relation to Birthweight and Severity of Disability."

impairments<sup>49</sup>. Hence, it would not be surprising to find that visual impairments are more likely to occur in disadvantaged families (see also Chapter 6 for an exposé on the causes of visual impairments).

Then there is the question of the impact of the environment on the perceived severity of disability (i.e., differences in stimulation and care quality can account for differences in outcomes). For instance, the literature suggests that both disabled children and their parents experience multiple disadvantages and lower well-being<sup>50</sup>. This may be attributed to the fact of having a disabled child... and to the initial environment. Emerson<sup>51</sup> sheds light on this matter in the case of the UK and Australia, both countries with a state-run and low out-of-pocket costs, healthcare system:

*"[W]hen we take into account differences in exposure to common environmental adversities (e.g. household poverty, living in deprived neighbourhoods, exposure to adverse life events) between families who are and are not supporting a disabled child, we find that the differences in parental outcomes either disappear or are very significantly reduced in magnitude."*

*"[W]e have estimated that increased exposure to low socioeconomic position/poverty may account for: (i) 20–50% of the increased risk for poorer physical and mental health among British children and adolescents with learning disabilities, (ii) 29–43% of the increased risk for conduct difficulties and 36–43% of the increased risk for peer problems among Australian children with learning disabilities or borderline learning functioning, (iii) a significant proportion of increased rates of self-reported antisocial behaviour among adolescents with learning disabilities and (iv) 32% of the increased risk for conduct difficulties and 27% of the increased risk for peer problems among a nationally representative sample of three-year-old British children with developmental delay."*

In other words, children from disadvantaged families not only are more likely to live with an impairment, but they are also more likely to experience accrued difficulties such as poverty<sup>52</sup>, which socio-emotional or behavioral effects may be attributed to the impairments by carers. In the case of learning disabilities in particular, social class participates to the construction of the disability label<sup>53</sup>: when children do not conform to school's expectations, they are more likely to be labeled as disabled to access services even though they may lose this label later. More generally, there is an important literature on how social class affect children's experiences of school, inspired by the concept of cultural capital. Three main strands of research focus on: (1) how the curriculum and organizations are designed and whose interests they support; (2) how parental norms differ between class, and parents with higher social status engage in

<sup>49</sup> Weinhold, "Environmental Factors in Birth Defects: What We Need to Know".

<sup>50</sup> Feizi et al., "Parenting Stress among Mothers of Children with Different Physical, Mental, and Psychological Problems".

<sup>51</sup> Emerson, "Understanding Disabled Childhoods: What Can We Learn From Population-Based Studies?."

<sup>52</sup> Read, Blackburn, and Spencer, "Disabled Children and Their Families: A Decade of Policy Change."

<sup>53</sup> J. Powell, "Constructing Disability and Social Inequality Early in the Life Course: The Case of Special Education in Germany and the United States".

concerted cultivation with schools, proposing activities destined to improve children's performance. They also have more school choices and more information to make those choices; and (3) how at a micro-level, in examining how children acquire traits enabling or preventing them to fit in a given context, e.g. from feeling legitimate at school to displaying the right markers, such as verbal skills, in an interview<sup>54</sup>. Note that children too are active in this process: they can actively differentiate themselves from their peers, and they need to adjust emotionally and interest themselves in school activities<sup>55</sup>. Thus, children's socioeconomic and cultural context should be taken into account when studying their experiences, because it may impact their peer relationships (and reinforce the segregation of special education classrooms), and their schooling opportunities.

### 5.2.2 Disability and gender

Gender interacts with disability in various ways. For instance, boys are more likely to be identified as disabled than girls, in part because boys are over-diagnosed<sup>56</sup> with learning and behavioral disorders<sup>57</sup>. In turn, it contributes to fuel the widespread (but quite unfounded) perception that "schools fail boys"<sup>58</sup>. Whereas actually boys' class and 'ethnicity' have more impact than their gender, and if girls perform well at school, it does not mean that it strictly leads to better economic outcomes, or even to better educational opportunities<sup>59</sup>.

On the other hand, gender seems to affect the peer relationships of disabled children, we should first note that this is often overlooked by carers and schools<sup>60</sup>. The fact that gender is not taken into account impacts peer relationships, because disabled children do not fit easily in their age group, which is often separated by gender:

*"It was common to find special school classes which comprised one girl and nine or ten boys. [...] Disability provision also conflicted with gender norms, when an [assistant] was shared between two or more pupils: this could result in boys and girls being forced together, which went against the peer group culture, and was disliked by the children."*

Furthermore, non-disabled children's attitudes towards their disabled peers seem to vary with gender: *"disabled girls reported that non-disabled girls were less likely to be discriminatory than non-disabled boys."* Indeed, children raised as girls are encouraged to focus on relationships and the care of others<sup>61</sup>. A probable consequence is that disabled girls are more likely to have positive relationships with their peers at school. However the impact of gender and disability on peer relationships vary with age. In the early years, the fact that

<sup>54</sup> Scott Davies and Jessica Rizk, "The Three Generations of Cultural Capital Research: A Narrative Review".

<sup>55</sup> Marlies Kustatscher, "Young Children's Social Class Identities in Everyday Life at Primary School: The Importance of Naming and Challenging Complex Inequalities"; Holland, "Young People and Social Capital".

<sup>56</sup> Or girls under-diagnosed. Given the fact that the diagnosis gives access to resources, the positive and negative impacts of a diagnosis should be weighted.

<sup>57</sup> Oswald et al., "Trends in the Special Education Identification Rates of Boys and Girls: A Call for Research and Change".

<sup>58</sup> Epstein, *Failing Boys?: Issues in Gender and Achievement*.

<sup>59</sup> Hey et al., "Boys' Underachievement, Special Needs Practices and Questions of Equity".

<sup>60</sup> TW Shakespeare, Watson, and Cunningham-Burley, *Life as a Disabled Child: A Qualitative Study of Young People's Experiences and Perspectives*.

<sup>61</sup> Halldén, "Establishing Order. Small Girls Write about Family Life".

the gendered dimension of children is overlooked impacts the possibility for children to develop friendships. Whereas during teenage years, the cultural de-sexualisation and fetishism of disabled people<sup>62</sup> that plays in the (generally expected) romantic relationships. Disability may thus impact gender, by requiring them to develop non-traditional gender identities<sup>63</sup>. Yet of course, gender differences do not stop there: later in the lifecourse, disabled women are confronted with greater job discrimination than disabled men<sup>64</sup>.

From this, I identify two main points of interest for my research: are children aware of these dynamics and what kind of strategies do they develop to create or maintain peer relationships? Are girls aware of the specific discrimination they may experience in the professional world, and does that change their perceptions of school?

### 5.2.3 'Ethnicity' or 'race': on colonialism and racism at school

"Race" is hereby defined as a social construct othering people due to their origins or skin color<sup>65</sup>. It is more often referred to in France under the term "ethnicity," which is why I prefer the use of this term, conceptual differences is a debate beyond the scope of this dissertation. Ethnicity is probably the axis of difference I examined the least over the course of this research project. In part because of the low number of children of color cared for by the organization studied, and maybe because of my initial lack of awareness of this topic—discussed in Chapter 8. It is an under-researched topic in research on disabled childhood in general<sup>66</sup>. However, French colonization impacted care practices long after the wars of independence<sup>67</sup>. For instance, as attested by the administrative documents consulted during the field-study, the organization studied had boarding pupils from French ultra-marine territories (which are remnants of the colonial empire) until the end of the nineties.

<sup>62</sup> McRuer and Mollow, *Sex and Disability*.

<sup>63</sup> Dufour, *L'Expérience Handie*.

<sup>64</sup> Practices that seem tied to specific impairments however.

<sup>65</sup> Chapman and Frader, *Race in France: Interdisciplinary Perspectives on the Politics of Difference*.

<sup>66</sup> Ali et al., "Disability, Ethnicity and Childhood: A Critical Review of Research".

<sup>67</sup> This subject was investigated by Brégain, who points out how the circulation of various actors (e.g. blind students and community leaders) between the metropole and the colony overhauled care practices. For instance, blind children were previously instructed orally in Coranic schools, while French institutions supported the development of special education schools teaching braille. Brégain, "Colonialism and disability".

The literature suggests that disabled children of color's experiences of disability differ from their white counterparts<sup>68</sup>. Ali et al. argue that disability is perceived differently from one community to another: some communities may hold beliefs about disability requiring specific attention from service providers. They also remind us that language can be a barrier when trying to obtain care services; that cultural specificity and needs are not often considered in care practices; and that children may experience racist reactions from their peers and carers. Furthermore, a number of studies (mostly led in the US) suggest that children from (racial and ethnic) minorities were more likely to be over-diagnosed with learning disabilities or emotional and behavioral disorders due to biased or discriminatory assessments. However, later research point out that discrepancy between the percentage of white children and children of color diagnosed with a learning disability is most probably due to children's socioeconomic status, rather than ethnicity directly<sup>69</sup>. Minority children may also be under-diagnosed regarding emotional and behavioral disorders<sup>70</sup>, thus not having access to the same services than their white counterparts<sup>71</sup>.

#### 5.2.4 *Place: rural and urban schools; distance and opportunities*

By the term place, I refer to a particular nexus of space and time, to which is attributed a specific meaning and affective qualities<sup>72</sup>. The place where children grow up should not be overlooked, and should be studied in relation with specific impairments<sup>73</sup>. Rural and urban schools tend to provide very different experiences: while rural schools tend to have smaller classes with children of multiple age, urban schools are more likely to have more pupils, separated by year of birth most of the time, and to have a special education classroom within the school. Both types of organizations impact socialization possibilities and modalities, and therefore the development of emotional relationships—but this is, yet again, under-researched<sup>74</sup>.

There are larger spatial dynamics to take into account. Access to services is more difficult in rural areas<sup>75</sup>, which may isolate families. On the other it also means that a number of children may have to undertake rather long journeys regularly, to access specific care (e.g., hospitals). Similarly the spatial distribution of cultural infrastructures or public services is highly unequal. This limits possible extracurricular activities and the number of alternative places of socialization. Incidentally, it may entice a family to move to access better services, thus changing school outside of usual transitions (e.g., moving to secondary/middle school), hence severing relationships with their

<sup>68</sup> Ali et al., "Disability, Ethnicity and Childhood: A Critical Review of Research".

<sup>69</sup> Ali et al., "Disability, Ethnicity and Childhood: A Critical Review of Research".

<sup>70</sup> Note that criteria characterizing a child with such disorders are heavily debated, as well as the positive or negative effects of such diagnosis. But this is not the point here.

<sup>71</sup> P. L. Morgan and Farkas, "Evidence and Implications of Racial and Ethnic Disparities in Emotional and Behavioral Disorders Identification and Treatment", p. 201.

<sup>72</sup> Massey, *Space, Place and Gender*, See the Chapter "A place called home" in:

<sup>73</sup> For instance, the lack of access to public transportation services and the frequent traffic jams can make Paris a lot less accessible and degrade the quality of life of people using wheelchairs, compared to the countryside. But if autism in rural areas is often examined as an issue to access services, it might also provide a calmer and more appropriate environment for some families.

<sup>74</sup> L. Holt, "Children's Sociospatial (Re)Production of Disability within Primary School Playgrounds".

<sup>75</sup> Iezzoni, Killeen, and O'Day, "Rural Residents with Disabilities Confront Substantial Barriers to Obtaining Primary Care".

peers<sup>76</sup>. Note that, moreover, this region seems to have attracted family in search for adequate care since the 1970s<sup>77</sup>.

### 5.2.5 *A short discussion on the use of intersectionality*

This long enumeration of the impact of different characteristics on the experience of disability, an *inventaire à la Prévert* can seem more overwhelming than helpful. If we were to consider all possible intersections, we would probably end up with an extremely fractured account of experiences, or a scale of who is the less advantaged, hence inconclusive and difficult to compare. But it highlights that no aspect of disability can be considered as "non-social". A child's context influences the prevalence of impairments, or the inclusion in a diagnosis, even before it impacts their access to services.

However, this review of the scholarship is the occasion to lay out the complexity of analyzing children's experiences—as well as the relative lack of consensus on which characteristic(s) leads to which outcome(s) in which environment, or how they interact with each other in respect to a number of subjects, such as experiences of school. But my focus will rather be to build a typology of which intersections of these aspects were the more fruitful to explain children's narratives and interaction dynamics in my field-study, this review of literature helping to understand specific cases.

To summarize, I discussed factors pertaining directly to the school environment and shaping disabled children's experiences of school in the first section of this chapter. I point out the enduring stigmatization of disabled children, which is fundamental for understanding their experiences of school. Visual impairments alone do not seem to affect standard academic achievements (health status, or other impairments may). However, when we contextualize these experiences, by considering how wider social dynamics affect academic achievements, we find that these factors are more interesting to understand variations in outcomes. Indeed, we find that lower socio-economic status increases the presence and the perceived severity of impairments, and thus their access to equal educational opportunities. We also find that minority boys, or working class boys are more likely to be diagnosed with behavioral disorders or learning disabilities<sup>78</sup>.

<sup>76</sup> L. Holt, "Children's Sociospatial (Re)Production of Disability within Primary School Playgrounds"; J. Sanders, *Subject Child: The Everyday Experiences of a Group of Small Town Aotearoa/New Zealand Children*.

<sup>77</sup> C. Arnaud et al., "Visual Impairment in Children: Prevalence, Aetiology and Care, 1976-85."

<sup>78</sup> As a reminder, diagnosis can also be sought out to gain access to resources—which then can have positive or negative impacts. See for instance: Garcia, *À l'école des dyslexiques: Naturaliser ou combattre l'échec scolaire?*



On the other hand, girls may more easily develop relationships at school, but face more discrimination later in life. This does not always create adversarial experiences of school for children. However, it does point out that disabled children are "at risk", more specifically I at risk of experiencing increased violence.

### 5.3 Risk factors and experiences of violence

This topic runs across all the themes previously discussed in this section: for instance, there are gendered and age specific forms of violence, I hinted at experiences of violence at school and in peer relationships (bullying). The concept of structural violence (i.e., institutions not providing needed resources) has been very fruitful in the past to understand barriers to being and doing oppression<sup>79</sup>.

Violence is used as an umbrella term for many different phenomena, with different scales and reproduction mechanisms. Furthermore, the notion of what constitutes violence against a child has greatly evolved, from condemning physically violent parents to condemning non-benevolent parenting, that does not support children's agency<sup>80</sup>. But the extent to which this latter norm is widespread can be debated: Abuse against children is still widespread in occidental countries<sup>81</sup>. I refer here to French statistics on violence against children in general, as this topic in particular is well documented and studied, before going on the international literature on violence against disabled children (which is little studied in a French context).

Educative corporal punishments remain allowed to this day, and there is a strong opposition against attempts to change the legislation. Violence against children is pervasive<sup>82</sup>. For instance, in a recent population-based study, most sexual assaults reported have occurred before legal majority. At least 5% of French women (0.83% of men) were sexually assaulted by family members and immediate circle during their lives, and a large majority of them (between 80 and 90%) were assaulted before the age of fifteen<sup>83</sup>.

While we lack French population-based studies on violence against disabled people in general and disabled children in particular (see next chapter for a discussion of available data), the research literature suggests that children who are disabled are more likely to experience all kinds of interpersonal violence. Disabled children are more likely to be bullied at school<sup>84</sup>. Furthermore, a study by Sentenac, Gavin, et al. suggests that disabled children are more likely to be bullied in France than in Ireland, which could hint at a national specificity.<sup>85</sup> Disabled people also are at higher risks of intra-familial violence<sup>86</sup>,

<sup>79</sup> I. M. Young, "Five Faces of Oppression".

<sup>80</sup> Vandenbroeck and Bie, "Children's Agency and Educational Norms: A Tensed Negotiation".

<sup>81</sup> Adamson et al., *A League Table of Child Maltreatment Deaths in Rich Nations*.

<sup>82</sup> Tursz and Gerbouin, *Enfants Maltraités—Les Chiffres et Leur Base Juridique En France*.

<sup>83</sup> Hamel, Debauche, E. Brown, et al., "Viols et Agressions Sexuelles En France: Premiers Résultats de l'enquête Virage".

<sup>84</sup> Hanisch, "Psycho-Emotional Disability: A Differentiated Process"; Chatzitheochari, Parsons, and Platt, "Doubly Disadvantaged? Bullying Experiences among Disabled Children and Young People in England".

<sup>85</sup> Sentenac, Gavin, et al., "Victims of Bullying among Students with a Disability or Chronic Illness and Their Peers: A Cross-National Study between Ireland and France".

<sup>86</sup> Sobsey et al., "Violence and Disability".

and of experiencing sexual violence<sup>87</sup>. On an institutional level, they are more likely to be marginalized and imprisoned<sup>88</sup>, and to be denied their civil rights to mobility and education<sup>89</sup>, which can be experienced as violent. The risks and types of violence seems to depend on the type of impairment<sup>90</sup>; varying with gender (sexual for girls vs physical for boys<sup>91</sup>); and with socioeconomic status and origins<sup>92</sup>. This shows the importance of an intersectional approach in research.

There are several reasons behind these increased risks of violence, from oppression<sup>93</sup>. Many co-exist<sup>94</sup>. Children who are abused are more likely to develop a disability. Disabled people's and children's testimonies of violence are often overlooked, thus making them more vulnerable to violence. Parents who lack resources and support may be overwhelmed and more likely to resort to violence, or to not be able to answer to their needs (neglect). Finally cultural norms frame disability as an undesirable state<sup>95</sup>, or as a burden<sup>96</sup>, which creates or sustains their stigmatization by others<sup>97</sup>. In this respect, examining the models of disability held by the community, peers and carers can be insightful<sup>98</sup>. Carers' attempts to protect children from harm may be experienced as violence.

#### 5.4 Summary

This chapter reviews the literature on disabled children's experiences in social sciences, focusing when possible on visually impaired children. I attempted to contextualize them in research and policy preoccupations, e.g. on schooling modalities, and within wider social forces, e.g. social class. It highlights tensions in the expectations held about school, between immediate social integration, desirable academic outcomes and long term integration in society, which differentiate between children who only have a visual impairment, and those who have additional impairments (particularly, regarding learning and behavior).

The key findings from the literature can be summarized as follow: (1) Disabled children assert their similarity with their able-bodied peers, which makes generic childhood studies research relevant (Section 5.1.1). Furthermore, visually impaired children are likely to perform academically quite as well as their sighted peers during their mandatory schooling period (Section 5.1.2)—other characteristics, such as social class, affect more clearly their academic attainments (Section 5.2). (2) Visually impaired children can be excluded from learning opportunities when they are perceived as unlikely to achieve the same goals, and they remain stigmatized by their peers and un-

<sup>87</sup> Stalker and McArthur, "Child Abuse, Child Protection and Disabled Children: A Review of Recent Research."; Brownridge, "Partner Violence against Women with Disabilities: Prevalence, Risk, and Explanations".

<sup>88</sup> Elwan et al., *Poverty and Disability: A Survey of the Literature*.

<sup>89</sup> Galbally, "SHUT OUT: The Experience of People with Disabilities and Their Families in Australia".

<sup>90</sup> Jaudes and Mackey-Bilaver, "Do Chronic Conditions Increase Young Children's Risk of Being Maltreated?"

<sup>91</sup> Stalker and McArthur, "Child Abuse, Child Protection and Disabled Children: A Review of Recent Research."

<sup>92</sup> Svensson, Bornehag, and Janson, "Chronic Conditions in Children Increase the Risk for Physical Abuse—but Vary with Socio-Economic Circumstances".

<sup>93</sup> See the discussion of Young's oppression model, in *Delineating activism in Research*, Chapter 2.

<sup>94</sup> Corr and Santos, "Abuse and Young Children With Disabilities: A Review of the Literature".

<sup>95</sup> Munyi, "Past and Present Perceptions towards Disability: A Historical Perspective".

<sup>96</sup> Lero, Pletsch, and Hilbrecht, "Introduction to the Special Issue on Disability and Work: Toward Re-Conceptualizing the 'Burden' of Disability".

<sup>97</sup> Goffman, *Stigma: Notes on the Management of Spoiled Identity*.

<sup>98</sup> Woolfson, "Family Well-Being and Disabled Children: A Psychosocial Model of Disability-Related Child Behaviour Problems."

heard by adults (Sections 5.1.2, 5.1.3 and 5.1.4). (3) Because they are identified as disabled, they are more likely to face challenges such as bullying at school and intra-familial violence. They also continue to face significant access restrictions, and policies are still not designed to accommodate their needs, especially if they belong to a minority (Sections 5.2 and 5.3). These are both barriers to being (violence can be psycho-emotional) and barriers to doing, ultimately undermining their well-being.

Another characteristic of the literature is the lack of integration in research of the many dimensions of children's experiences of disability. Each aspect is likely to be studied separately which does not allow well for understanding how one influences the other in social interactions. Furthermore, disabled children are quite likely to be studied as a group, which seems problematic in a context where care remains organized based on the classification of impairments—and the experiences of visually impaired children, especially the youngest, are not often investigated specifically<sup>99</sup>. Therefore, cross-national comparisons are difficult to make, even though a number of studies suggest the interest of such comparisons, to understand experiences in relation with structural factors, e.g. organization of care.

<sup>99</sup> Which is also due to their low numbers.

## 6

# *Visually Impaired French Children*

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This chapter critically reviews quantitative studies of visually impaired children and their modalities of schooling. It is articulated around sources rather than themes. This is because this review of the material available had not been done previously and constitutes a contribution. The two main sources of quantitative data on visually impaired French children are an epidemiological study of childhood visual impairments conducted in the 1990s, and the data provided by a cohort study on disabled children led by the Ministry of Education on their modalities of schooling. I interpret this data for the purposes of this dissertation, with two main goals: (1) Confirming findings made in other contexts, especially regarding the influence of gender and socioeconomic status on academic trajectories and achievement; and (2) Arguing that the group of children I worked with well represents this population, hence complementing my interactionist approach with a more structural perspective.

## 6.1 *Epidemiology of Visual Impairments in French Children*

I define in Chapter 3 visual impairments and children, which include biological, functional and sociological aspects. I now focus on the epidemiology of children with visual impairments in France (prevalence, causes and associated impairments). This enables me a (very cautious) comparison with the epidemiology of the children I worked with.

### 6.1.1 *Prevalence of visual impairments in children*

France lacks precise data on the number of children with visual impairments. Visual impairments are correlated with aging, have a low prevalence among children<sup>1</sup>, which can be estimated using epidemiological data (often generated for the Ministry of Health) or statistics on schooling (often commissioned by the Ministry of Education).

Regarding epidemiological data, I draw on a study on prevalence conducted in France, on cohorts of 9 years old children, born between 1976 and 1985, and tested in 1992-1993<sup>2</sup>. To my knowledge, this is the most recent study on the subject. C. Arnaud et al. suggest a prevalence of 0,28‰ for blindness, and 0,52‰ for low vision (acuity < 0.3). They also point out that male children were more affected than their female counterparts. These numbers should be used with caution because the prevalence increases as children grow older, and because other studies suggest different percentages<sup>3</sup>. However, they are consistent with the ranges used in comparative studies on the subject in Europe<sup>4</sup>.

According to the National Institute of Statistics and Economic Studies (INSEE), there are 14 826 128 people under eighteen years-old as to the 1st of January 2017. If we apply the estimated prevalence to this population, we obtain an estimate of 4151 children with blindness and 7710 children with low vision, and a total of 11861 children living with visual impairments.

However, the estimated prevalence is inconsistent with the number of children receiving specific care for visual impairments. According to a 2016 report by the Direction de l'évaluation, de la prospective et de la performance (DEPP), a service attached to the Ministry of Education, only 2 516 children in primary education and 2 550 in the secondary education are reported to have visual impairments. An additional 488 children receive education in medico-social organizations (special education schools or hospitals). This gives a total of 5554 children<sup>5</sup>, a number slightly higher than the one of visually im-

<sup>1</sup> World Health Organization, *Visual Impairment and Blindness Fact Sheet N° 282*.

<sup>2</sup> C. Arnaud et al., "Visual Impairment in Children: Prevalence, Aetiology and Care, 1976-85."

<sup>3</sup> Catherine Arnaud et al., "Déficits Visuels: Dépistage et Prise En Charge Chez Le Jeune Enfant".

<sup>4</sup> Kocur and Resnikoff, "Visual Impairment and Blindness in Europe and Their Prevention".

<sup>5</sup> Direction de l'Évaluation, de la Prospective et de la Performance, "Repères et Références Statistiques 2017. Enseignements. Formation. Recherche.", p. 21.

paired children recensed by the Ministry of education in 2009 (5462, of which 840 receive education in medico-social organizations)<sup>6</sup>, or in 2004<sup>7</sup> (4 760 children, of which 450 receive education in medico-social organizations).

Arnaud <i>et al.</i> (1992-93)	Report to the Ministry of Labor (2004)	Ministry of education (2009)	Ministry of education (2016)
11861 children	4750 children	5462 children	5554 children

Why is there a discrepancy between the estimations made from epidemiology and the numbers provided by the Ministry of Education? This may be explained by different factors: First, children who do not attend primary or secondary school because they are too young (under 6 years old) or too old (over 16 years old, schooling is not mandatory anymore), or because they are schooled in private settings uncontrolled by the state, are not included in these numbers. Second, as discussed below in Causes and Associated impairments, visual impairments may be one of multiple impairments. A part of this population may thus not be described in education statistics as living with visual impairments, but rather as with multiple impairments<sup>8</sup>. Third, despite mandatory screening for visual impairments at school, some visual impairments are only detected late in life<sup>9</sup>, or parents may not ask the state to recognize their child's impairments. As for the augmentation of the number of visually impaired children in schools between 2007 and 2016 sources, it can probably be attributed to the effects of the 2005 law of integration. Finally, there might have been a decrease in the prevalence of visual impairments, as this study was conducted more than 20 years ago<sup>10</sup>. In any case, this shows how two definitions of children with visual impairments may yield very different results.

### Causes (aetiology)

The causes of visual impairments are often classified by the period of onset: prenatal, peri- and neonatal (from birth to the 28th day) and the infant/juvenile period (until 18 years old). In the same prevalence study<sup>11</sup>, 48% of visual impairments were due to antenatal causes (e.g. genetic factors, exposition to chemicals), 21.6% appeared during the perinatal period (e.g. pre-due births), 9.1% during the infant/juvenile period (e.g. traumatic or tumoral causes), while 21.3% had unspecified causes. The study also points out that low vision was more likely to be caused by antenatal causes, while blindness and unspecified vision loss were more likely to be caused by perinatal aetiologies.

<sup>6</sup> Blanc, *La scolarisation des enfants handicapés*.

<sup>7</sup> Montagné, "L'inclusion Des Personnes Aveugles et Malvoyantes Dans Le Monde d'aujourd'hui".

<sup>8</sup> Compare for instance the tables on page 12 and 13 of Blanc's report. The number of visually impaired children receiving schooling is higher than the reported total number of visually impaired children. Hence a need to distinguish between medical categories of impairments and children receiving services from organizations specializing in providing related services. Blanc, *La scolarisation des enfants handicapés*.

<sup>9</sup> Catherine Arnaud et al., "Déficits Visuels: Dépistage et Prise En Charge Chez Le Jeune Enfant"; Tanet and Ouss, "Mal Voir et Ne Pas Le Savoir: Comment Grandit-on Avec Un Trouble Neurovisuel?"

<sup>10</sup> Kocur and Resnikoff, "Visual Impairment and Blindness in Europe and Their Prevention", However, I note the consistency with the rates found in other West-European countries.

<sup>11</sup> C. Arnaud et al., "Visual Impairment in Children: Prevalence, Aetiology and Care, 1976-85."

**A note on maltreatment:** maltreatment is one of the juvenile causes of visual impairments (e.g., shaken baby syndrome). Although to my knowledge there is no data on the prevalence of this cause, we know that visually impaired children are two to three times as likely as able-bodied peers to be fostered, suggesting severe abuse or neglect<sup>12</sup>. In 2015, this was the case of 0.8% of visually impaired children born in 2001 and 1.2% of those born in 2005 (respectively 0.3% and 0.4% of children the same age)—see Chapter 5 Section 5.3 for a discussion of these numbers.

<sup>12</sup> Le Laidier, "À l'école et au collège, les enfants en situation de handicap constituent une population fortement différenciée scolairement et socialement".

### 6.1.2 *Associated impairments (co-morbidity)*

55.7% of the children involved in this prevalence study had at least one severe additional impairment. Learning disabilities were not included. The association of visual, mental and motor impairment was the most common. Only 27.9% of children with blindness had no additional impairment (81.8% for low vision, 13.3% for unspecified vision loss). The association of multiple impairments was more likely to occur when visual impairments were the result of perinatal or juvenile causes. Children with an additional hearing impairment were rare (0.7% of total).

### 6.1.3 *Parallel with my field-study*

Causes of visual impairments were not always mentioned during my observations and interviews. Instead, caregivers focused on actual visual and functional abilities during their discussions (e.g. "*let's say, he sees shapes, but no details at this distance;*" "*she has no trouble in the day, but without luminosity she's lost*"). Many explained causes were rarely relevant for their work. Two main arguments emerged. First, the causes were not known in a number of cases, making it a somewhat unreliable information (e.g., "*there are over ten thousands possible causes for visual impairments, sometimes they tell us 'that's the reason', and then the diagnosis change;*" "*they think he has an orphan syndrome, so he has to be tested every months, but it's similar to an Usher syndrome*").

Second, they outlined that the actual diagnosis had little importance to them compared to functional abilities (e.g., "*It's like 'he has syndrome X, or 'he's a preemie [a premature baby].'* Great. But one child with syndrome X is not going to develop like another child with syndrome X, if they didn't receive the same care and so on. Similarities between children are not that often deducible from the cause [of impairments]. It can be useful to know, for sure, because we can try what worked with a children with the same syndrom, but it's much more informative to know what

*visual abilities they have or how they use their vision*"). They would however very often comment on the care history—as well as on juvenile causes because they often denoted environmental factors (e.g. "he's blind because of the Shaken Baby Syndrom. You know what that means. . .") [Previous discussions with the same caregivers suggested this remark meant additional impairments, but also psychological difficulties]). For ethical reasons, I did not ask about the children's medical diagnosis (this would have required a different vetting process). Some children disclosed it anyway, others did not.

Hence I cannot compare statistics precisely. However, my data on the 50 children I interviewed or observed suggests a similar distribution<sup>13</sup>, and I met at least one child in each category (blind/low vision with/without additional impairments, all types of additional impairments, and varied types of causes). To the best of my knowledge, the children I met were thus quite representative, in terms of type of impairments, of this group in France.

Finally, note that this prevalence study underlined the impact of access to services. They confirm that children with a visual impairment without associated impairments, regardless of the severity of the vision loss, were likely to have academic attainments in primary school similar to their sighted peers. However, a lack of access to care before reaching the age of 5 years old negatively impacted children's academic trajectory, which hints at the impact of environmental conditions. A similar argument was made by caregivers during my field study—although they also struggled to understand counter-examples, children who had received adequate care but did not reach the outcomes considered as positive (see Part 3).

<sup>13</sup> The transcription services provides adaptations of educational supports for about 70 children attending general education schools, 15 to 20 of them using braille (which represents 20 to 30%). But the children with multiple impairments I met were more likely to be blind. Chapter 9 summarizes the information about the children participating in my research.



## 6.2 *Children with visual impairments at school*

The statistical department of the Ministry of education (DEPP) provides numerous insights on the educational trajectories of children with impairments in its yearly reports<sup>14,15</sup>. Furthermore, since 2013 the DEPP have assembled a representative<sup>16</sup> panel of parents of children with impairments born in 2001 or 2005, who answer a yearly questionnaire on children's current type of schooling, household structure and socioprofessional characteristics, as well as various questions such as satisfaction with the school attending and the teaching quality<sup>17</sup>. In 2015 and 2016, the DEPP published data on the educational modalities and academic attainments of children living with impairments, as well as on their sociodemographic characteristics.

### 6.2.1 *Modalities of schooling*

France has special, integrated and inclusive schooling modalities for children with visual impairments. Pupils can:

- Attend a general education classroom, with or without a personal assistant (individual inclusion);
- Attend a special education classroom within a general education school, today called "Ulis", with or without a personal assistant (group inclusion);
- Attend a special education classroom, in a special education school<sup>18</sup>.

Additionally, children may access the national distance education service, some schools have a service dedicated to support children with a specific kind of impairment, and there can be a mix of two modalities (e.g., 4 days in a general education classroom, one day in a special education classroom to acquire specific skills). In secondary education, there is a split between pre-vocational and vocational education (some students will continue in higher education) and general or technological education.

Inclusion, either individual or grouped, is the norm since the 2005 law on equal rights for disabled people. However, as the multiple modalities of schooling demonstrate, this does not mean that all children have equal access to formal education<sup>19</sup>.

The DEPP reports show that most children with visual impairments attend general education schools, and are integrated individ-

<sup>14</sup> Direction de l'Évaluation, de la Prospective et de la Performance, "Repères et Références Statistiques 2017. Enseignements. Formation. Recherche."

<sup>15</sup> For some perspectives on higher education, see: Handi-U, "Recensement Des Étudiants en situation de Handicap Année Universitaire 2014-2015 et Évolutions".

<sup>16</sup> Representative in the sense that all types of impairments are represented in proportion to the rate of impairments found in disabled children receiving some sort of formal schooling. This is not necessarily representative of the disabled children population in general.

<sup>17</sup> Laidier, « *La scolarisation des jeunes handicapés* »; Le Laidier, "À l'école et au collège, les enfants en situation de handicap constituent une population fortement différenciée scolairement et socialement"; Le Laidier and Prouchandy, "Pour la première fois, un regard sur les parcours à l'école primaire des élèves en situation de handicap"; Le Laidier, "Les enfants en situation de Handicap - Parcours scolaires à l'école et au collège".

<sup>18</sup> Ministère de l'Éducation nationale, "La Scolarisation Des Élèves En Situation de Handicap".

<sup>19</sup> France is somewhat notorious for exiling autistic children in Belgium, because of the lack of services on a national level. Furthermore, the seemingly augmentation of the number of disabled children attending general education schools seems to be rather due to the widening of disability definition. See: Ebersold, "Idéologie de La Réussite, Réinvention Des Institutions et Reconfiguration Du Handicap".

ually. Compared to children with other impairments, they are more likely to attend the same grade than their sighted peers at the end of primary school: in 2015-2016, 61% of 10 years-old visually impaired children attended 5th (CM2) grade on time<sup>20</sup> (non-disabled: 91%). 16% were in 4th grade (CM1). 12% attended a special classroom (Ulis) within a general education school, while 9% attended a socio-medical organization (special school or hospital). 2% were in unspecified settings. At 14 years old, 53% of children attended 9th grade on time. 17% were in 8th grade or below. 5% schools preparing to enter vocational education (1.6% for non-disabled children). 14% attended a special education classroom within general education school (Ulis), while 9% attended school in a socio-medical organization. 2% were in unspecified settings.

In other words, a majority of visually impaired children attend general education classrooms, and a small majority of them do not go through grade repetition. They are the group of disabled children the most likely to have a schooling career considered as standard. They go to classrooms preparing for vocational education at a similar rate as other groups of disabled children. Although the rate of children attending special schools is steady throughout primary and secondary education, 7% of the children attending a general education classrooms in primary schools are oriented towards vocational education (SEGPA/ULIS) in secondary school. Grade repetition is mostly used in primary school—at a time when a diversity of specific skills (braille reading, orientation mobility) are developed. Among all disabled children, girls to avoid repeating a grade<sup>21</sup>.

In 2015-2016, 48,8% of children with visual impairments in primary school work with a human assistant (8.6% full-time, 28.1% part-time, 10.1% share their assistant with other children), a number that decreases in secondary school to 39.8%<sup>22</sup>. This is higher than the average (30%) percentage of disabled children having a human assistant. In secondary school, 14,7% work with a special teacher part-time<sup>23</sup>, which is much higher than for other groups of disabled children, except children with auditory impairments or Deaf. In 2014, the majority of parents of disabled children were satisfied or satisfied enough with the school attended by their children, with rates becoming more similar to parents of non-disabled children over time. 4.7% remain very unsatisfied, which is more than twice the rate of dissatisfaction of parents of non-disabled children. However, their satisfaction with the quality of teaching is much lower: 12.9% of parents of visually impaired children are dissatisfied with the education received (3.9% in the general population)<sup>24</sup>.

<sup>20</sup> Direction de l'Évaluation, de la Prospective et de la Performance, "Repères et Références Statistiques 2017. Enseignements. Formation. Recherche.", p. 85.

<sup>21</sup> Direction de l'Évaluation, de la Prospective et de la Performance, "Repères et Références Statistiques 2017. Enseignements. Formation. Recherche.", p. 18.

<sup>22</sup> Direction de l'Évaluation, de la Prospective et de la Performance, "Repères et Références Statistiques 2017. Enseignements. Formation. Recherche.", p. 123.

<sup>23</sup> This information was not available for primary school pupils.

<sup>24</sup> Le Laidier, "À l'école et au collège, les enfants en situation de handicap constituent une population fortement différenciée scolairement et socialement".

This means that among disabled children, visually impaired children are more likely to have a dedicated human assistant or specialized teacher, which may explain why they are more likely to be on-time academically than other groups of disabled children. This may either reduce peer interactions (as it increases the surveillance they are subjected to) or encourage them (if they create opportunities for social interaction). The parents' perception of the school their children attend is more positive than the actual quality of education received. This suggests that support and adaptations remain insufficient. Finally, this data reveals changes in schooling modalities for children who started attending school after the 2005 law on disability rights was passed. In contrast with their elders, they were more likely to attend their neighborhood school.

### 6.2.2 *Assistive technologies in the classroom*

The DEPP also provides insights about human and technological aids in the classroom. Their 2012 report<sup>25</sup> reports the percentage of provision by the state of an assistive device or tool, called "*adapted pedagogical material*" or "*technical aid*" (e.g. magnifiers, computers with vocal synthesis, braille note-takers etc). 47% and 70% of the pupils respectively attending primary and secondary education were provided with assistive technologies. They are more likely than any other group to be provided with assistive technology. The data does not specify the type of technologies used. In 2015-2016 this rate was lower: 40.2% and 66.4%, respectively. In any case, the fact these rates are much higher than for other children makes research on assistive technologies for this population specifically valuable.

<sup>25</sup> Laidier, « *La scolarisation des jeunes handicapés* ».

### 6.2.3 *The impact of social class*

The intersection of coming from a disadvantaged family and disability generate a number of specific inequalities, highlighted by the DEPP's surveys. The DEPP reports suggest that visual impairments are not equally distributed in families with different socioeconomic status and that children from disadvantaged families are less likely to attend general education schools (either general or in special education classrooms). In their panel, visually impaired children are more likely to be of disadvantaged **social origin** than children in the general population<sup>26</sup>. I compare it below to the general children population.

**Social origin** here refers to the occupational category to which the household reference person<sup>27</sup> belongs. Disadvantaged includes:

<sup>26</sup> Le Laidier, "Les enfants en situation de Handicap - Parcours scolaires à l'école et au collège".

<sup>27</sup> Definition: "The household reference person is determined from the family structure of the household and the characteristics of the component persons. More often than not, it is the family reference person when there is one, or the oldest man, with priority to the oldest active person." From: [www.insee.fr/en/metadonnees/definition/c1192](http://www.insee.fr/en/metadonnees/definition/c1192)

parents who are inactive or retired, and blue collars. Middle class includes: employees, agriculture workers, artisans. Advantaged includes: intermediary professions except for teachers, retired executives. Highly advantaged includes: executives/managers and "higher intellectual professions," teachers and business of more than 10 employees owners.

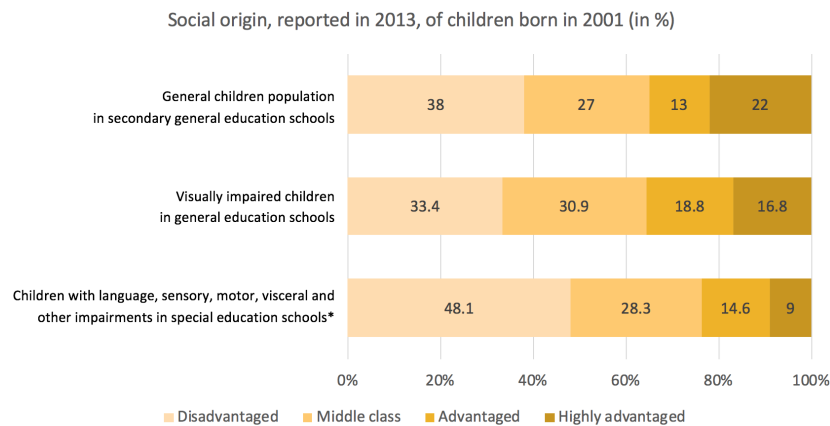


Figure 6.1: How to read: 22% of children born in 2001 and attending a general secondary education school in 2013 come from a highly advantaged family, but that is the case of only 16.8% of visually impaired children born in 2005 attending a general education school, and of 9% of children attending special education schools. [\* Data obtained through the DEPP, thanks to Sylvie Le Laidier, aggregates visually impaired children with other groups of disabled children sharing similar characteristics in terms of schooling modalities.]

The available data, depicted in Figure 6.1, suggests that children with visual impairments are less likely to come from highly-advantaged families. Children from this background represent 22% of the secondary school students, but only 16.8% of visually impaired children in general education school and only 9% of those attending a special education schools. Furthermore, no matter the year of birth and the type of impairment, disabled children from advantaged and highly-advantaged families are the most likely to have a "normal" schooling<sup>28</sup>, in a general education classroom, without repeating a grade.

If we compare the panel of visually impaired children born in 2001 to the one of children born in 2005, we note that visually impaired children remain less likely to come from highly advantaged families, but the rest of the distribution changes, particularly for those in special education schools. Children from highly advantaged family are more represented in special education than before, but the overall rate is lower. This could be partly explained by a parental preference for the national special school for the blind (INJA), which schools 3.6% of visually impaired children in France and has a 100% of success rate at secondary-level diplomas. Meanwhile, the children surveyed are more likely to come from disadvantaged families than before. In any case, this is far from conclusive, especially given the quality of the sample is difficult to evaluate: there were 362 chil-

<sup>28</sup> Le Laidier, "Les enfants en situation de Handicap - Parcours scolaires à l'école et au collège", p. 45.

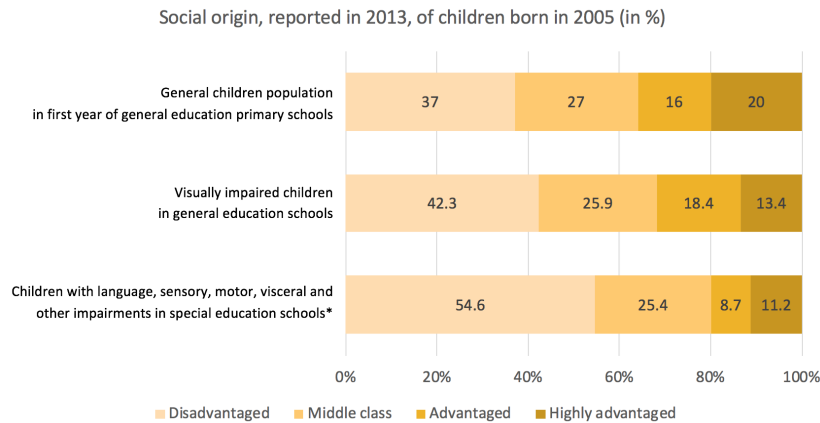


Figure 6.2: How to read: 20% of children born in 2005 and attending the first year of primary school in 2011 come from a highly advantaged family, but that is the case of only 13.4% of visually impaired children born in 2005 attending a general education school, and of 11.2% of children attending special education schools. [\* Data obtained through the DEPP, thanks to Sylvie Le Laidier, aggregates visually impaired children with other groups of disabled children sharing similar characteristics in terms of schooling modalities.]

dren involved for the cohort born in 2001; and 381 the cohort born in 2005. This represents a considerable percentage of this population, but there might be participation biases. Some children with impairments do not attend school, and highly advantaged parents may have the opportunity to take care of their children without asking for a disability statement from the state. In both cases, they would not be included in the DEPP panel. There might be variations with time, and there might be biases in the parents recruited for the panel. However, both the national<sup>29</sup> and international research literature suggests that disadvantaged families are more likely to have a disabled child, and that these children are more likely to attend special education schools<sup>30</sup>.

The correlation between social inequalities and the prevalence of impairments in children is not yet fully explained<sup>31</sup>. Note that the inequalities identified by the DEPP reports may differ from those reported in the literature cited above: indeed, social origin here serves as a proxy for social class and is defined by the highest occupational status of an adult family member. A definition based on family income would better show disparities due to a parent stopping to work for care for their children<sup>32</sup>. In contrast, the definition used by the DEPP could simply show that parents make different occupational choices because they have a visually impaired child, not that visually impaired children are more likely to be born in disadvantaged families.

<sup>29</sup> This report was published in the last week of my PhD, it is not fully exploited here: Etchegaray, Bourgarel, and Mazurek, *Géographie de La Population En Situation de Handicap En France Métropolitaine*.

<sup>30</sup> See above and: Mormiche and Boissonnat, "Handicap et Inégalités Sociales: Premiers Apports de l'enquête «Handicaps, Incapacités, Dépendance»".

<sup>31</sup> Read, Blackburn, and Spencer, "Disabled Children and Their Families: A Decade of Policy Change."; Emerson, "Understanding Disabled Childhoods: What Can We Learn From Population-Based Studies?."

<sup>32</sup> Which is widespread, especially in early years, and for mothers. Le Laidier, "À l'école et au collège, les enfants en situation de handicap constituent une population fortement différenciée scolairement et socialement".

To conclude, visually impaired French children are likely to have different schooling experiences, due to diverging modalities of schooling. According to the DEPP, schooling modalities of children with visual impairments resemble (but do not equal) those of Deaf and hard-of-hearing children, children with visceral or language disorders and children with motor or other impairments. This highlights the need for studies based on specific groups of disabled children

### 6.3 *Summary*

This chapter characterizes visually impaired French children. To do so, I drew on two main sources: an epidemiology study of visual impairments in childhood, and surveys made for and by the Ministry of Education. It demonstrates out that this category covers a large variety of situations in terms of visual functioning, health status and other functional characteristics, as a high percentage of visually impaired children live with additional impairments. It also suggests that in France, parents with high occupational status are less likely to have children with visual impairments, and might be more able to enable them to attend general education schools. This might be due to different factors, including parents' and children's involvement and strategies and teachers' perception of children's potential. However, almost 75% of visually impaired children attend general education classrooms individually, and that 50% experienced no delays in their schooling, which points to a positive effect of the 2005 law on inclusion. This distinguishes them from other groups of disabled children, who perform less well academically. Finally, they are very likely to have an assistive educational technology—the design and characteristics of which we discuss in the next chapter.



# 7

## *Assistive Learning Technologies*

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This chapter: (1) summarizes existing HCI research on assistive learning technologies for visually impaired children, (2) questions assumptions made in most of these projects and formulate a different approach. I define Assistive Learning Technologies, with examples of systems drawn from the literature, organized along three axes: (1) material characteristics, (2) their aims, and (3) the steps taken to improve their uptake. I then propose an analysis of the limitations of these systems, and highlights opportunities for design.

### *7.1 Definition*

#### *7.1.1 Legal definitions*

Different definitions of assistive technologies and assistive learning technologies co-exist. For instance, the ISO norm, used in American legislation: *“The term “assistive technology device” means any item, piece*



*of equipment, or product system, whether acquired commercially, modified, or customized, that is used to increase, maintain, or improve functional capabilities of individuals with disabilities.”<sup>1</sup>*

The WHO proposes the following definitions:

*"Assistive technology is the application of organized knowledge and skills related to assistive products, including systems and services. Assistive technology is a subset of health technology. Assistive products: Any external product (including devices, equipment, instruments or software), especially produced or generally available, the primary purpose of which is to maintain or improve an individual's functioning and independence, and thereby promote their well-being. Assistive products are also used to prevent impairments and secondary health conditions."*

The French disability rights law of 2005 refers to "technological innovations" to "reduce [disabled people]'s incapacities" in various domains, without defining them more precisely<sup>2</sup>.

### 7.1.2 Typologies

#### Classifying by activity domain

In a meta-review, Hersh and Jognson<sup>3</sup> propose a categorization based on the activities in which assistive technologies are involved:

1. Mobility;
2. Communication and Access to information;
3. Daily living, and;
4. Education and Employment and Recreational Activities.

They also propose a model to take into account the context, such as the user's attitudes towards technology or employment status, that are framed as affecting self-esteem and trust in assistive technologies. As for the assistive devices themselves, they are analyzed in terms of activity specification, design approach, system technology issues and end-users issues. They each have characteristics of their own e.g., design issues encompasses design approach (e.g., philosophy and strategy) and technology selection (e.g., based on criteria such as cost—see Figure 7.1).

<sup>1</sup> This is the definition used in the Assistive Technology Act Technology-Related Assistance for Individuals with Disabilities Act (Tech Act). It is consistent with the norm ISO 9999 on assistive technologies, and used for instance in this meta-review of the impacts of assistive technologies uses: S. Alper and Raharinirina, "Assistive Technology for Individuals with Disabilities: A Review and Synthesis of the Literature".

<sup>2</sup> Loi n° 2005-102 du 11 Février 2005 pour l'égalité des droits et des chances, la participation et la citoyenneté des personnes handicapées, Page 2353, JO n° 36 du 12 Février 2005.

<sup>3</sup> Hersh and M. A. Johnson, *Assistive Technology for Visually Impaired and Blind People*.

## Classifying by Impact on Activity

**Assistive learning technologies** for visually impaired people, with a focus on children is a subset of the Education and Employment and Recreational Activities used in Hersh and Johnson<sup>4</sup>'s review. According to McKnight and Davies<sup>5</sup> they can be classified in two groups:

1. **Remedial** technologies, "*which are intended to help by 'fixing' a problem (for example software to provide training in specific skills which are lacking);*"
2. **Compensatory** technologies, "*are those while compensatory technologies are those that help by accommodating for it, in order to move towards a more equal environment for learners (for example text-to-speech software for those that struggle to read, or speech-to-text software for those that struggle to write.)*"

This distinction Gori et al.<sup>6</sup> in their meta-review of assistive technologies for improving the spatial skills of visually impaired people. They distinguish between technologies for rehabilitating impaired cognitive ability, i.e. that are **remedial**, and technologies for accessing content usually presented visually, i.e. that are **compensatory**. However, compensatory technologies for learning are about more than accessing content<sup>7</sup>. Instead, they can be used to change the material presented. Indeed, whereas research on **accessibility** aims at enabling the use of a system in a normal way, through adaptations or by design, "*assistive technology aims specifically to support and aid users<sup>8</sup>*" in their own best way of learning.

## 7.2 Examples of Assistive learning technologies

In this section, I review assistive learning technologies as used in primary and secondary formal education, either already used in classrooms or proposed in research. They can be characterized by their material characteristics, activities targeted (aims) and design approaches. Below are two tables of examples used. They come from the reviews proposed by McKnight and Davies<sup>9</sup> and Hersh and M. A. Johnson<sup>10</sup>, as well as from my review of HCI research (using the ACM and Springer libraries). The goal is not to make an exhaustive reviews of research focusing on assistive learning technologies, but rather to outline which problems are addressed in the classroom and in the literature and provide an overview of common approaches.

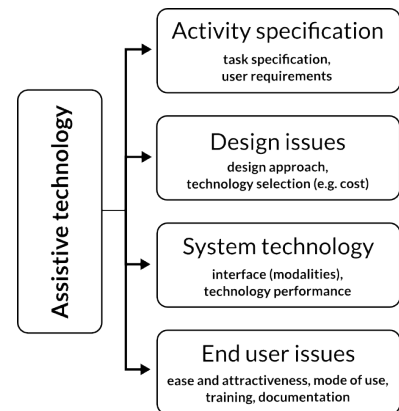


Figure 7.1: Attributes of assistive technologies, adapted from Hersh and M. A. Johnson.

<sup>4</sup> Hersh and M. A. Johnson, *Assistive Technology for Visually Impaired and Blind People*.

<sup>5</sup> McKnight and Davies, "Current perspectives on assistive learning technologies. 2012 review of research and challenges within the field".

<sup>6</sup> Gori et al., "Devices for Visually Impaired People: High Technological Devices with Low User Acceptance and No Adaptability for Children".

<sup>7</sup> McKnight and Davies, "Current perspectives on assistive learning technologies. 2012 review of research and challenges within the field"; Rose and Meyer, *Teaching Every Student in the Digital Age: Universal Design for Learning*.

<sup>8</sup> McKnight and Davies, "Current perspectives on assistive learning technologies. 2012 review of research and challenges within the field", p. 14.

<sup>9</sup> McKnight and Davies, "Current perspectives on assistive learning technologies. 2012 review of research and challenges within the field".

<sup>10</sup> Hersh and M. A. Johnson, *Assistive Technology for Visually Impaired and Blind People*.

Example	Material characteristics	Activities targeted	Design approach
Braille notetakers or displays	<i>Hardware:</i> Braille cells: raised pins displays <i>Software:</i> various screen readers often integrated to exploitation systems <i>Modality:</i> Haptic (tactile)	Reading	Focus on accessibility Focus on blind users
Speech synthesizers	<i>Software:</i> various screen-readers, sometimes integrated to computer operating systems <i>Modality:</i> audio	Reading	Focus on pupils with learning difficulties Modular design
On-screen magnifiers	<i>Software:</i> adaptation of mainstream applications or specialized software handling screen reading preferences (e.g. Jaws) <i>Modality:</i> visual	Reading, accessing images and schema (Science, Technology, Engineering and Math—STEM, geography, history)	Focus on users with low-vision Modular design
Equipment to make tactile graphics	<i>Hardware:</i> E.g. swell form machine and special paper, braille embosser <i>Modality:</i> Haptic (tactile)	Accessing images and schema (STEM, geography, history)	Focus on blind users Community-based
Braille printers	<i>Modality:</i> Haptic (tactile)	Reading, accessing schema	Focus on blind users Community-based
Talking calculators	<i>Modality:</i> Visual, audio	Mathematics	Focus on all visually impaired users
Computer Assisted learning	<i>Software:</i> Use of adequate markup <i>Modality:</i> Audio, haptic (tactile)	Wide range of documents	Modular
Conversion tools and specific file formats	<i>Software:</i> E.g., mathematics documents made with latex, converted with Duxbury Braille Translator, Braille 2000, Optical Character Recognition <i>Framework:</i> E.g., DAISY specification for read-aloud books	Mathematical notations Read-aloud books Wide range of documents	Focus on blind users Between universal and modular design

Table 7.1: Assistive technologies common in Western education

Example	Material characteristics	Activity targeted	Design approach
Buehler et al., Investigating the Implications of 3D Printing in Special Education (2016)	<i>Hardware:</i> 3D printers <i>Software:</i> CAD 3D software, parametric design to customize <i>Framework:</i> Reflection on the management of these tools (e.g., library, formation) <i>Modality:</i> haptic (tactile and proprioceptive)	Representing STEM concepts	Do-It-Yourself Community based Concern for maintainability
Miele, Landau, and Gilden, Talking TMAP: automated generation of audio-tactile maps using Smith-Kettlewell's TMAP software (2006)	<i>Software/Framework:</i> Web-based generation of map outlines and audio tags <i>Hardware:</i> Touch screen <i>Modality:</i> Haptic (tactile) and audio	Producing and accessing images and schema (STEM, geography, history)	Accessibility (focus on blind users) Community-based (mentions schools, libraries etc for implementation) Concern for maintainability
Yu, Ramloll, and Brewster, Haptic graphs for blind computer users (2001)	<i>Hardware:</i> Phantom, a forced-feedback <i>Software:</i> Ghost SDK toolkit <i>Modality:</i> Haptic (proprioception)	Accessing graphs	Focus on blind users
McGookin, Robertson, and Brewster, Clutching at Straws: Using Tangible Interaction to Provide Non-visual Access to Graphs (2010)	<i>Hardware:</i> Various objects, cameras <i>Software:</i> custom, recognizing tangibles <i>Modality:</i> Haptic (tactile, proprioception)	Accessing graphs	Focus on blind users
Rasmus-Gröhn, Magnusson, and Efring, Iterative Design of an Audio-haptic Drawing Application (2007)	<i>Hardware:</i> Phantom, regular mouse <i>Software:</i> Reachin API software (haptic), FMod Ex (sound) and Microsoft SAPI (speech synthesis). <i>Modality:</i> haptic, audio	Drawing, geometry	Focus on collaboration
Pielot et al., Tangible User Interface for the Exploration of Auditory City Maps (2007)	<i>Hardware:</i> stylus with tablet; or tracking cameras, tangible pawn, environmental auditory display <i>Software:</i> OpenCV, 3D sound library <i>Modality:</i> audio, haptic	Exploring a map	Focus on blind users
Bussell, Touch Tiles: Elementary geometry software with a haptic and auditory interface for visually impaired children (2003)	<i>Hardware:</i> Logitech Wingman Force Feedback Mouse, keyboard, computer with audio output <i>Modality:</i> haptic, audio	Manipulating geometry shapes at a primary school level	Focus on blind children)
Albert, Math class (2006)	<i>Hardware:</i> Refreshable tactile graphic display GWP <i>Software:</i> Math programs (Maple and PlotExplorer), screen reader <i>Modality:</i> audio, haptic (tactile)	Accessing mathematical graphics	Focus on blind users Concern for open source Concern for cost
Buzzi et al., Playing with geometry: a Multimodal Android App for Blind Children (2015)	<i>Hardware:</i> Tablet <i>Software:</i> Custom, on Android, providing vibratory and audio feedback <i>Modality:</i> audio and haptic	Accessing mathematical figures	Focus on blind children
Winberg and Bowers, Assembling the senses: towards the design of cooperative interfaces for visually impaired users (2004)	<i>Hardware:</i> mouse, headphones, screen <i>Software:</i> Custom, a collaborative Hanoi Tower game <i>Modality:</i> visual, audio	Generic design considerations on collaborative tasks	Focus on collaboration Focus on blind and sighted pairs (adults) Focus on context and human-human interaction

Table 7.2: Technologies proposed or used in a limited number of places. Part one of two.

Example	Material characteristics	Activity targeted	Design approach
Tomlinson et al., Exploring Auditory Graphing Software in the Classroom: The Effect of Auditory Graphs on the Classroom Environment (2016)	<i>Hardware:</i> computer, headphone, mouse <i>Software:</i> GNIE (Graph and Number line Input and Exploration) <i>Modality:</i> audio	Accessing and editing graphs	Focus on blind users Focus on classroom interactions
Tanhua-Piironen et al., Supporting Collaboration between Visually Impaired and Sighted Children in a Multimodal Learning Environment (2008)	<i>Hardware:</i> Phantom force-feedback, Magellan space mouse, mouse and keyboard, visual display, loudspeakers <i>Framework:</i> MICOLE (Multimodal Collaboration Environment for Inclusion of Visually Impaired Children) <i>Modality:</i> haptic (proprioceptive), audio, visual	Access to STEM concepts (physics, astronomy)	Focus on collaboration (sighted and blind children)
A. M. Brock et al., "Interactivity Improves Usability of Geographic Maps for Visually Impaired People" (2015)	<i>Hardware:</i> Tablet (with a tactile overlay) <i>Modality:</i> audio, haptic (tactile)	Accessing graphics (specifically maps)	Focus on usability Focus on blind users Community-based (mentions schools and organizations for implementation)
Daunys and Lauruska, Maps Sonification System Using Digitiser for Visually Impaired Children (2006)	<i>Software:</i> XML parser and graphical rendering <i>Hardware:</i> Different types can be used (haptic input, gesture recognition) <i>Modality:</i> audio	Accessing graphics (specifically maps)	Focus on accessibility Low-Cost Open-source
L. B. Christensen and Stevns, Biblus – A Digital Library to Support Integration of Visually Impaired in Mainstream Education (2012)	<i>Software:</i> repository for shared educational material <i>Modality:</i> audio, haptic (tactile)	All types of educational material	Modular (can eventually serve all groups of children) Focus on collaboration between communities
Swaminathan et al., Linespace: A Sensemaking Platform for the Blind (2016)	<i>Hardware:</i> Modified 3D printer <i>Software:</i> Custom, prepares adequate outline of a given document <i>Modality:</i> Haptic (tactile)	Accessing graphics (specifically maps and more generally spatial representations)	Focus on blind users Focus on enabling access to different scales of representations
Stangl, Kim, and Yeh, Transcribing Across the Senses: Community Efforts to Create 3D Printable Accessible Tactile Pictures for Young Children with Visual Impairments (2015)	<i>Hardware:</i> 3D printer <i>Software:</i> Proposes an online creation tool <i>Modality:</i> Haptic	Accessing illustrated books	Community based Focus on visually impaired children
Plimmer et al., Multimodal collaborative handwriting training for visually-impaired people (2008)	<i>Modality:</i> Haptic (tactile and haptic), audio (non-speech)	Learning to recognize and write letters (e.g. for signature)	Focus on blind children

Table 7.3: Technologies proposed or used in a limited number of places. Part two of two.

Table 7.1 shows devices and systems used in the classroom that use of tactile and audio modalities (braille displays, speech synthesizers), with an increasing use of digital systems for the production and sharing of accessible documents (digital braille printers, screen magnifiers). The research literature proposes a wide range of possible tools and interactions techniques to accomplish standard classroom tasks.

As I proposed in the tables above and adapted from, these examples can be analyzed along various dimensions. I first discuss the material characteristics, corresponding in Hersh model to technology selection, performance and system interface. Second I examine the activities these propositions aim to enable or support. Third I reflect more broadly on the design approach, i.e. the framing of a problem underpinning the proposed devices.

### 7.3 *Material Characteristics*

In material characteristics, I include: (1) the sensory modalities and their combinations, and (2) how they are used to replace or augment visual interfaces. Unsurprisingly, the visual modality is little discussed, except for low-vision users or collaborative interfaces. However, much research have focused on haptic (not just tactile) and audio modalities.

The haptic modality is actually an umbrella term for many different types of interaction and sensations, and includes two modalities: "*tactile (sensations arising from stimulus to the skin—heat, pressure, vibration, slip, pain) and proprioceptive (which provides our knowledge of body positions, forces, and motions via end organs located in muscles, tendons, and joints*<sup>11</sup>." Haptic interfaces and interactions target one, the other or both. For instance, braille displays make use of the tactile modality. While tangible interactions, i.e. the use of physical objects to interact with digital information<sup>12</sup>, and more generally focus on interactions with the material environment, primarily make use of the proprioceptive modality, and to a lesser extent to the tactile modality. Moreover, most systems use multiple modalities, e.g. audio tactile, audio and proprioceptive, or to multiple types of interactions in one modality, e.g. speech and non-speech audio. Finally, although the field of olfactory and gustatory interfaces is growing<sup>13</sup>, olfaction and taste are not commonly used in this literature. The few occurrences of their use with disabled children were developed for a museum context<sup>14</sup>, and thus could qualify as assistive learning technologies.

Although the senses are separated, the sensory system is far messier. Different senses interact with one another, and what we

<sup>11</sup> MacLean, "Haptic interaction design for everyday interfaces".

<sup>12</sup> Ullmer and Ishii, "Emerging Frameworks for Tangible User Interfaces".

<sup>13</sup> Murray et al., "Olfaction-enhanced multimedia: A survey of application domains, displays, and research challenges".

<sup>14</sup> E.g., Hollinworth et al., "Interactive Sensory Objects for and by People with Learning Disabilities".

call "visual interfaces" also require proprioception (e.g., for moving a mouse). However, the primary modalities are useful for classification purposes.

The examples above can be categorized according to the primary system or device used:

1. Refreshable displays for braille and graphics: Composed of arrays of pins, that can be raised or lowered to create different combinations. Sizes vary from 6 pins for a braille cell, to hundreds of pins for a larger display, and enable access to text or to graphics (see Figure 7.2);
2. Force-feedback devices: The exertion of different forces, e.g. resistance to a given movement. Devices may exert forces on one or multiple axis. It enables access to graphical representations. For instance, the Phantom device is often used, and provides three axes that can guide the user's hand around complex shapes (see Figure 7.3);
3. Interactive touch surfaces, with or without a tactile overlay: They react to touch by delivering audio (speech or non speech) or haptic (through vibrations) content. They can be of different sizes, from tablet to tables. They enable access to text or to graphics (see Figure 7.8);
4. Audio systems: Systems taking a variety of inputs, e.g. fingers, keyboard arrows, or an object and delivering audio content. For instance, spatialized audio systems may enable access to graphics (especially maps), and shapes and graphs can be represented with variations in tone, pitch or sound level (see Figure 7.4);
5. Tangible interaction systems: Systems using objects to control access to information. Some use multiple building blocks (e.g. McGookin, Robertson, and Brewster), other use a single object has an input (e.g. Pielot et al.). Potentially any object can be used for those systems: they are most often recognized by cameras (see Figure 7.9), and;
6. 3D printing systems: 3D printers are digital fabrication tools producing three dimensional objects. They most often use an additive fabrication process: they add layers of a given material (e.g. plastic) until the piece is finished. They can also be used to make only outlines of a graphic (e.g. Swaminathan et al.), or tactile overlays. Some propose parametric 3D models to print (e.g., Buehler et al.): end-users can customize a model to fit their needs (see Figure 7.5).



Figure 7.2: A braille note-taker, using this system.



Figure 7.3: Use of the force-feedback Phantom device, by Plimmer et al.



Figure 7.4: Tomlinson et al.'s implementation of auditory graphs.



Figure 7.5: Picture of Stangl, Hsu, and Yeh's 3D printed tactile books.

## 7.4 Geography-Specific Technology

Most ALTs aim at providing access to graphics that are discipline-specific (e.g., geometric figures). The Accessimap project focus on geography, which includes a wide variety of interactive maps, that could replace the raised-line tactile paper maps currently used. Maps are useful for representing topology and spatialized data (e.g., census). The systems can be used for annotation or consultation. Note that I do not discuss here tools for assisted mobility or for the rehabilitation of spatial cognition<sup>15</sup>. Zeng and Weber<sup>16</sup> identify four main categories:

1. Virtual acoustic maps are entirely based on verbal and non-verbal audio output. E.g., moving an object (tangible interaction) or a finger creates audio feedback<sup>17</sup>.
2. Virtual tactile maps make use of haptic devices, and can include audio feedback. For instance, the user uses a joystick and feel resistance when finding a contour<sup>18</sup>, or a forced-feedback device guide the user's hand<sup>19</sup> and points of interest are indicated through audio;
3. Braille tactile maps are based on the use of dedicated raised-pin displays presented above. Depending on the cite, the map can be represented sequentially or fully<sup>20</sup> (see Figure 7.6);
4. Augmented paper-based tactile maps: a tactile map (3D printed or traditional paper raised-line map) used as an overlay of a touch-display screen enabling audio output. When the user finds a point of interest, the label is read aloud. There can also be a guidance option (see Figure 7.8), and;
5. Tangible maps, which consists in the construction of a map representations using tangible building blocks recognized by the system (see Figure 7.9).

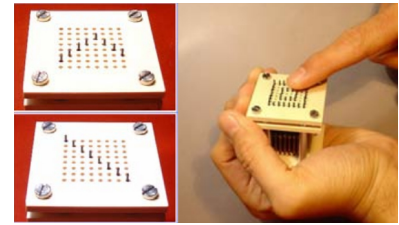


Figure 7.6: Refreshable tactile display, used to present sequences of a map, by Maingreud et al.

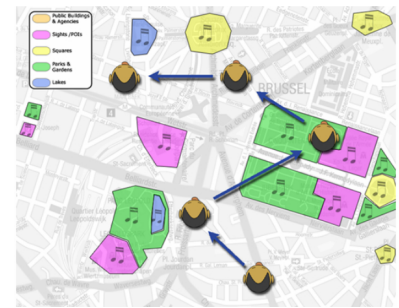


Figure 7.7: Representation of the virtual acoustic map proposed by Pielot et al.

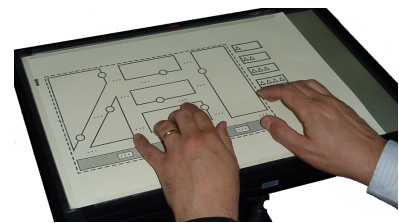


Figure 7.8: A touch surface with a tactile overlay, photo from A. M. Brock et al.

<sup>15</sup> For a review, see: Gori et al., "Devices for Visually Impaired People: High Technological Devices with Low User Acceptance and No Adaptability for Children".

<sup>16</sup> Zeng and Weber, "Accessible Maps for the Visually Impaired".

<sup>17</sup> Pielot et al., "Tangible User Interface for the Exploration of Auditory City Maps".

<sup>18</sup> Parente and Bishop, "BATS".

<sup>19</sup> Rice et al., "Design considerations for haptic and auditory map interfaces".

<sup>20</sup> Maingreud et al., "A dynamic tactile map as a tool for space organization perception: application to the design of an electronic travel aid for visually impaired and blind people".

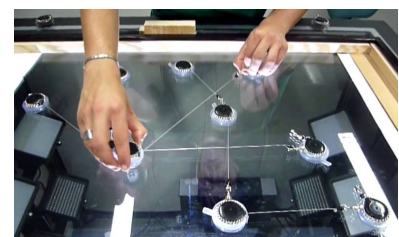


Figure 7.9: Ducasse et al.'s tangible interface to construct maps non-visually.



Additionally, research focuses on the automatic production of maps and their standardization, using SVG and XML to store spatial vectors and associated information allowing, e.g. for automatic simplification or conversion from GPS coordinates<sup>21</sup>. Overall, the propositions made for geography are good examples of the orientations of the general literature on assistive learning technologies for visually impaired children presented above, and they focus on the standardization or access to visual content.

### 7.5 On Design Approaches

Designers have implicit and explicit assumptions about their users and representations of what they do, that constrain the boundaries of the design space in which they work<sup>22</sup>. This *framing* includes some situations or problems but not others. Many studies motivate the work in terms of including visually impaired children in general education schools. Yet, the systems are often designed for individual use. Furthermore they are rarely evaluated in actual classrooms, where interactions between children, the device and the environment could be observed<sup>23</sup>. There are also few indications as to the pedagogical framework and activities in which they would fit. This is not surprising, since it requires interdisciplinary expertise, or multi-step studies, but there seems to be important discontinuity (e.g., research announcing follow-up studies, which remain unpublished). Despite ample research on how to structure and deliver information, we lack data on what happens during actual deployment<sup>24</sup>.

Some studies suggest the under-use or abandonment of assistive technologies. Barriers to long-term use include: high cost, inadequacy in regards to pedagogical needs, difficulties to maintain<sup>25</sup>, need for training, commercialized for a limited time<sup>26</sup> and negative feelings associated with their use<sup>27</sup>. To address these issues, others have developed open source and low-cost systems<sup>28</sup>, but highlighting the importance of maintainability and how it would fit in existing organizations<sup>29</sup>. For example, in the case of audio-tactile maps, Miele and Brock explain how their systems build upon available community resources (equipments to make tactile document).

Many studies focus on specific groups defined by their level of visual impairments (sighted, low-vision, and blindness). Fewer take a **modular** approach to design, i.e. focus on flexibility and adaptation to diverse group of users, on enabling customization, or on questioning the categories of users altogether. Interestingly, much research focus on multimodality but I found little literature citing Universal

<sup>21</sup> Daunys and Lauruska, "Maps sonification system using digitiser for visually impaired children"; Swaminathan et al., "Linespace: A Sensemaking Platform for the Blind"; Rice et al., "Design considerations for haptic and auditory map interfaces"; Wang et al., "Instant Tactile-Audio Map: Enabling Access to Digital Maps for People with Visual Impairment".

<sup>22</sup> Akrich, "User Representations: Practices, Methods and Sociology"; Baumer and Brubaker, "Post-Userism".

<sup>23</sup> With a few exceptions e.g., Tomlinson et al., "Exploring Auditory Graphing Software in the Classroom: The Effect of Auditory Graphs on the Classroom Environment".

<sup>24</sup> Kelly and D. W. Smith, "The impact of assistive technology on the educational performance of students with visual impairments: A synthesis of the research".

<sup>25</sup> Phillips and Zhao, "Predictors of Assistive Technology Abandonment".

<sup>26</sup> Gori et al., "Devices for Visually Impaired People: High Technological Devices with Low User Acceptance and No Adaptability for Children".

<sup>27</sup> Söderström and Ytterhus, "The Use and Non-use of Assistive Technologies from the World of Information and Communication Technology by Visually Impaired Young People: A Walk on the Tightrope of Peer Inclusion".

<sup>28</sup> Albert, "Math Class: An Application for Dynamic Tactile Graphics"; Daunys and Lauruska, "Maps sonification system using digitiser for visually impaired children".

<sup>29</sup> E.g., Stangl, Kim, and Yeh, "3D Printed Tactile Picture Books for Children with Visual Impairments: A Design Probe"; Buehler et al., "Investigating the Implications of 3D Printing in Special Education".

Design for Learning<sup>30</sup> of which it is a core principle—along with the concern to enable multiple means of engagement and expression. Moreover, there are also still little research involving children in the process<sup>31</sup>.

## 7.6 Summary

In this chapter, I discussed commercialized or proposed assistive learning technologies (ALTs), focusing on answering the needs of visually impaired children in the classroom. I reviewed the modalities commonly used and the afferent types of systems, such as the proprioception and audition for virtual tactile maps. Building on this review, I argued in the current state, ALTs and research on ALTs do not quite satisfyingly address the issues outlined so far in this thesis.

Furthermore, although there is an extensive literature on assistive learning technologies for visually impaired children, the systems proposed are rarely tested in classrooms, let alone for long periods. At the deployment stage, the lack of support, both technical and pedagogical, as well as the lack of long-term investment and maintenance, further prevents the use of ALTs—and their evaluation. The design and research communities, however, are well aware of these issues and have proposed a number of ways to address them, such as participatory design, or finding ways to involve a larger community. I discuss this further in the next chapter.

<sup>30</sup> Rose and Meyer, *Teaching Every Student in the Digital Age: Universal Design for Learning*.

<sup>31</sup> In a review of the Participatory Design literature, Halskov and Hansen did not identify assistive technologies as a domain in this body of work. See: Halskov and N. B. Hansen, “The Diversity of Participatory Design Research Practice at PDC 2002–2012”.



# 8

## *General Discussion of Part 2*

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With this discussion, I aim to tie together the different literatures I reviewed in this part of the dissertation, through a discussion about the current framing of visually impaired students' needs and the resulting design propositions for ALTs. It is two-fold: I begin with (1) considerations about how the learning context and pedagogies are taken into account; and I discuss (2) the different approaches previously developed to address this lack of awareness of the context, as well as further challenges. I highlight implications for design that ground my own design work.

### *8.1 How is the learning context envisioned?*

I point out in my discussion of design approaches in Chapter 7 that the type of pedagogies assistive learning technologies may support are little discussed. The same is true of the characteristics of the classrooms in which it is used.

### 8.1.1 *Designing for individual use*

Assistive systems are most often designed for individual use, to support student autonomy, sometimes reinforced by the idea it could lower the cost of human labor. But it overlooks the issues arising from use in context: malfunctioning, training time, forgetfulness of how the system works, integration in teacher's prepping or even requiring new skills and new specialists<sup>1</sup>, as well as the intervention of other children or the fact that assistants can enable joint autonomy: the fact that a child needs an assistant to perform parts of a task is not necessarily an issue<sup>2</sup>. Take for instance the drawing of geometric shapes: they serve to develop fine motor skills and geometrical reasoning. But if the pupil knows how to describe and manipulate them, some figures may be drawn for convenience and speed by the assistant without affecting the learning of geometry. Finally, school work is rarely fully individualized: a teacher alternates between work with the whole class, small groups, and individual work. In practice, teachers can not easily cater to the individual needs of children and the question might well be how to best cater to a (heterogeneous) group rather than, or in complement to, ALTs for individual use.

<sup>1</sup> E.g., for handling 3D printing needs Buehler et al., "Investigating the Implications of 3D Printing in Special Education".

<sup>2</sup> McKnight and Davies, "Current perspectives on assistive learning technologies. 2012 review of research and challenges within the field".

### 8.1.2 *Taking stigma into account*

If each child is different and each child's needs can be met, then the inclusion of disabled children would work. However, the use of assistive learning technologies consecrated by policies on inclusive schooling can be perceived as differentiated instruction and equalizer in itself<sup>3</sup>, obscuring other mechanisms of exclusion and stigma. Diep and Wolbring argue that assistive technologies often remain envisioned by disabled children as a way to "*fit in by not standing out*,"<sup>4</sup> as disability remains punished by their peers (e.g., adversarial attitudes or refusal to interact). In terms of design, it is often translated in a requirement that the device proposed should resemble mainstream ones—i.e. concerns over the device's aesthetic<sup>5</sup>. However, this is rather restricted: children may be stigmatized on the basis that they have access to a device in class, whichever this device may be. This is less a matter of aesthetic than a matter of how a given technology is going to be received in a given classroom.

<sup>3</sup> Mithout, "L'inclusion Scolaire à l'heure Des TIC : Perspective Franco-Japonaise".

<sup>4</sup> Diep and Wolbring, "Who Needs to Fit in? Who Gets to Stand out? Communication Technologies Including Brain-Machine Interfaces Revealed from the Perspectives of Special Education School Teachers Through an Ableism Lens".

<sup>5</sup> Bichard, Coleman, and Langdon, "Does My Stigma Look Big in This? Considering Acceptability and Desirability in the Inclusive Design of Technology Products".

## 8.2 Proposed alternative approaches

### 8.2.1 Adopting participatory design

Participatory design was born from a will to involve users in the decisions affecting them, but also from the fact that user participation in research enables to better understand the context of use. In education, it involves working with communities, being attentive to values, systematically addressing larger social dynamics, and characterizing what counts as learning and who decides on that<sup>6</sup>. Yet, Assistive Learning Technologies are not often developed using participatory design approaches, as if it escaped its political aims, as if this was a functional rather than a political design problem. Some scholars have tried changing this<sup>7</sup>. Although the long term impacts of participatory design projects can be questioned<sup>8</sup> as well as the implication of focusing mostly on small-scale interventions<sup>9</sup>, it offers resources to address the questions presented above. It is not necessarily a set of practical guidelines to be followed, but rather a mindset including the different questions I have asked in this section—and requiring the theoretical and empirical research of Chapter 5 and 6.

### 8.2.2 The contributions and limits of Universal Design

Envisioning collaboration in the design of ALTs raises the problem of conflicting needs: a tactile map with audio labels might be accessible to sighted and visually impaired children, but not to d/Deaf children. It requires a different design approach, one that is not centered around a group in particular but that can potentially include all of them. This is for instance the ambition of the Universal Design for Learning (UDL) framework<sup>10</sup>, briefly evoked in Chapter 7. UDL is the application of Universal Design<sup>11</sup> to learning. Universal Design is both a marketing and a design approach. It argues that simplifying products, so they can be used by a larger group of the population, provides the opportunity to increase accessibility—and profit from it<sup>12</sup>. In contrast, UDL advocates for more complex provisions, to provide all children with multiple means of representation (what), engagement (why) and expression (how)<sup>13</sup>. Multimodal representations, for instance, could include tactile, visual, and audio representations. Varying the types and forms of exercises provided, or segmenting tasks differently provides multiple means of expression. Taking examples culturally and socially relevant, meaningful to children or supporting reflection and self-assessment falls under multiple means of engagement. Whereas providing a variety of means of

<sup>6</sup> Bang and Vossoughi, *Participatory Design Research and Educational Justice: Studying Learning and Relations within Social Change Making*.

<sup>7</sup> E.g., Shaun K Kane et al., “Collaboratively designing assistive technology”.

<sup>8</sup> Björgvinsson, Ehn, and Hillgren, “Participatory Design and Democratizing Innovation”.

<sup>9</sup> Steen discusses the ethical frameworks mobilized in different types of design approaches. In participatory design, care seems central. Thus, it is probably unsurprising that the focus is placed on individuals and communities, rather than say, policies. But we also find here the distinction made by Eliasoph between activists and volunteers, and the permeability between the two. Steen, “Upon Opening the Black Box of Participatory Design and Finding It Filled with Ethics”; Eliasoph, *The Politics of Volunteering*.

<sup>10</sup> Rose and Meyer, *Teaching Every Student in the Digital Age: Universal Design for Learning*.

<sup>11</sup> Mace, *Universal Design, Barrier Free Environments for Everyone*.

<sup>12</sup> Aimi Hamraie. “Universal Design and the Problem of “Post- Disability ” Ideology”. In: *Design and Culture* (2016)

<sup>13</sup> [http://www.udlcenter.org/aboutudl/udlguidelines\\_theorypractice](http://www.udlcenter.org/aboutudl/udlguidelines_theorypractice)

expressions refer to the efficient use of assistive technologies, the use of different forms of exercises and assessment and of scaffolding (for the same task, one student may need more scaffolding than another).

UDL focuses on material and curriculum features, but it is theoretically close to the theory of Differentiated Instruction<sup>14</sup> which advocates for finding personalized ways of teaching based on children's interests and learning style (e.g., preference for audio over the visual). However, I should note that there is little evidence of the efficiency of learning styles in practice<sup>15</sup>. Conceptually, it might be a problematic understanding of how the senses work, as it tends to separate them and assume that a preference is fixed in time. Yet, these approaches remain interesting as they offer a way out of a fixed separation of abled and disabled children, where the former would not have access to an audio-based curriculum and tools, but the latter could.

In turn, UD risks reinforcing discourses about what kinds of bodies are considered better, more fitted for the world. In this view, that we espouse, design should also focus in proposing a multiplicity of ways to access<sup>16</sup>, be considered able<sup>17</sup> and know<sup>18</sup> the world. Or as phrased by Winance:

*"The guidelines that explain the principles tend towards taking into consideration the diversity of abilities and characteristics. But this consideration is limited to certain abilities and attributes that are only mentioned because they have a limiting effect on functioning. (...) There is a second paradox in the UD approach concerning the way it understands abilities. On the one hand, these abilities are considered as existing by themselves, as acquired abilities (or inabilities) and characteristic of an individual person. In the design process, these in/abilities determine the shape of the interaction between the person and the future object. With this perspective, UD is no different from the medical model insofar as abilities are implicitly considered as linked to the physical or mental attributes of individuals."<sup>19</sup>*

To address these blind spots in the literature, I first expose my findings about experiences of schooling (Part 3) and then propose a new design approach for assistive learning technologies with and for visually impaired students.

<sup>14</sup> T. Hall, Strangman, and Meyer, "Differentiated instruction and implications for UDL implementation. Wakefield, MA: National Center on Accessing the General Curriculum".

<sup>15</sup> Coffield et al., *A Critical Analysis of Learning Styles and Pedagogy in Post-16 Learning: A Systematic and Critical Review*.

<sup>16</sup> Mingus, "Changing the framework: Disability justice"; Hamraie, "Designing Collective Access: A Feminist Disability Theory of Universal Design".

<sup>17</sup> Wobbrock et al., "Ability-based design: Concept, principles and examples".

<sup>18</sup> Harris, *Ways of Knowing: Anthropological Approaches to Crafting Experience and Knowledge*.

<sup>19</sup> Winance, "Universal Design and the Challenge of Diversity: Reflections on the Principles of UD, Based on Empirical Research of People's Mobility".

### *General Conclusion of Part 2*

With the first part of the dissertation describing the construction of my research question (how visually impaired French children's experiences of school can enable to rethink assistive educational technologies as a mean to support well-being at school), I attempted in this part to critically review the research literature, developing my argument for taking into account more than supposed functional/cognitive differences of visually impaired children. It overlooked fundamental aspects of visually impaired children's experiences: the risks of violence, well present at school and in general; and the fact that not all visually impaired children underachieve at school. Hence the need to take into account how larger social dynamics (e.g. gender and social class) affect these children's interactions in the classroom.

Reviewing the data available on the schooling modalities of visually impaired French children suggests the particular importance of taking into account the interaction of disability and social class—as evaluated by occupational status of the head of the family. Compared to the general population, visually impaired children are less likely to come from families where one parent has a high occupational status. Those who do might be less likely to attend segregated classrooms. This dissertation aims to provide a more precise picture of how it may affect visually impaired children's experiences.

Finally, I argue these findings contest assumptions made about visually impaired users in the design of Assistive Technologies for education. Indeed, these technologies primarily aim at translating visual representations in another modality. To do so, studies group users by type and severity of impairments, and look at the ability for an individual to better accomplish a task with or without the device. But the actual learning situations and children's other characteristics are not often taken into account. This is why the next part of this dissertation dives into my findings on experiences of school, proposing to reconceptualize Assistive Learning Technologies (ALTs) and their roles and uses in the classroom. It is the core of my argument for proposing ALTs could be a way to support non visual-based learning in certain contexts and in doing so, supporting visually impaired children in developing more satisfying classroom experiences. I develop this argument in Part 4.





## **Part III**

# **At School: Being Resilient, Being-Well**



The first two parts of this dissertation outline the constitution of children's experiences and well-being at school as a research topic, and highlight previous works in this domain. This part attempts to articulate micro-interactions at school, including assistive learning technologies, with larger social factors. I argued the literature suggests that academic differences in achievements should less be attributed to visual impairments alone than to other sociodemographic factors, such as social class. Additionally, I pointed out that disabled children's experiences might well be distinctive from their peers because of their risks to experience violence. This part prolongs and expands on these topics.

I present and discuss my findings about children's experiences of school from interviews and observations. Specifically, I focus on well-being: As a reminder of Chapter 2, it was a prominent concern and priority of children. I propose to take a closer look at how children fare at school, and what they perceive as school's functions—as well as at carers' views on the same topics and the way it shapes their interventions. I examine these findings using the Social Ecology of Resilience Theory, that focus on resources needed for people and groups to sustain their well-being. It posits that resilience is evaluated against locally defined norms and can be defined as the ability to navigate and negotiate needed resources to reach these norms.

My overall argument is three folds: (1) children often experience mainstream schools as adversarial or exclusionary spaces; metaphors used to describe it are often related to the lexicon of **battle** (Chapter 10). (2) Carers perceive emotional resilience as necessary to academic achievement, and identify poor parental practices and belonging to socially disadvantaged group as main negative factors for resilience. Both carers and children strongly adhere to school as a meritocratic apparatus, but in doing so establish a hierarchy of disability that further exclude those who do not adhere to these norms, or can not reach them (Chapter 10). (3) Children (and carers) can only partially negotiate both norms and resources. I examine more in depth technological resources and show that children can use them for asserting their competence, notably in relations with peers (Chapter 11). This provides the ground for the fourth and last part of the thesis, that focuses on the prototypes I developed and deployed as a mean to support children to assert competency and a non-visual culture.

To achieve this, I first contextualize the field-work (Chapter 9). I describe the organization observed to provide points of comparison for future work on this topic. I then discuss the impact of my own characteristics and how it shaped my relationships with the partici-

pants and ultimately what could be told to me. It also contributes to the body of work on the researcher's embodiment in research relationships<sup>20</sup>.

In Chapter 10, I examine how children and carers describe how children feel at school. Children describe school either as **exhausting** and trying, as a **battle** or as **painful**. They describe visible and less visible barriers, and the relational resources they mobilize. Meanwhile, carers define children suffering as the limiting factor of integration in mainstream schools. It suggests the same dichotomy identified in the literature between academic attainments and social integration, and their interdependence. I analyze children's experiences using Ungar<sup>21</sup>'s theory of resilience. This chapter particularly highlights the emotional resources mobilized by carers and children so as to complete mandatory education and their unequal distribution.

Chapter 11 complements this by examining what children and carers describe as the functions of schooling. It both defines the standard against which someone is considered resilient in a given context, and gives worth to efforts to navigate, negotiate and provide resources. I show that carers and children quite strongly adheres to the meritocratic idea, and to academic performance from an early age as particularly important for disabled children, given fears over future lack of support and disablist work market. I highlight the range of resources mobilized by children and provided by carers, and focus specifically on how children use technologies to assert competence at school.

Finally, I discuss these findings in light of the literature in Chapter 12. I reflect on how they fit within the research agenda for a social relational theory of disability—as well as how they open the possibility to redefine Assistive Learning Technologies as resources to reshape perceived competence among children.

The main contribution in this part is the empirical account of visually impaired French children's experiences of school and my theoretical interpretation. Its second contribution is to the field of ethnography, in which I aim to contribute to the current body of work interested in the multi-faceted negotiations of identity when collecting data<sup>22</sup>.

<sup>20</sup> Hillyard, *Gender Identity and Research Relationships*.

<sup>21</sup> Ungar, "The Social Ecology of Resilience: Addressing Contextual and Cultural Ambiguity of a Nascent Construct".

<sup>22</sup> Hillyard, *Gender Identity and Research Relationships*.

Visual Overview

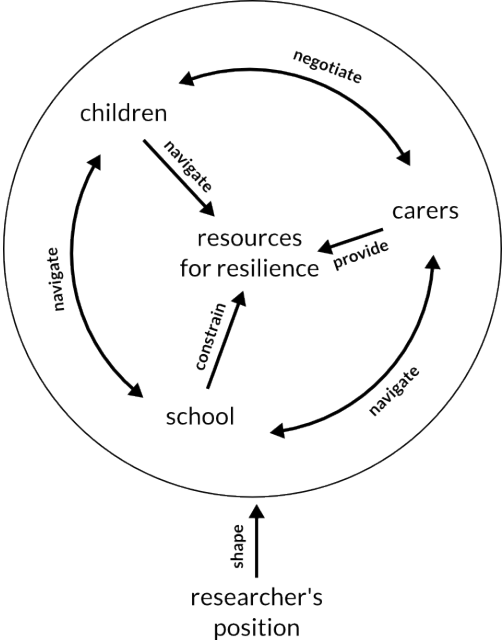


Figure 8.1: This figure illustrates the focus of Part 3.



# 9

## *Ethnographic Fieldwork: Context and roles*

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This chapter aims at answering the following research question: What are the specificities of my inquiry that might affect the results obtained during the fieldwork? This is motivated by several aims: reinforcing the trustworthiness of the results by clarifying how my identity have affected my whole ethnographic; contextualizing the analysis on children's experiences of schooling in the next two chapters; enabling to explain differences between that organization and others, as well as providing a point of comparisons for future in-



quiries. Here, I am particularly interested in the co-construction of norms of care and the architectural and material environment, as well as in the challenges it poses to the researcher.

*Visual Overview*

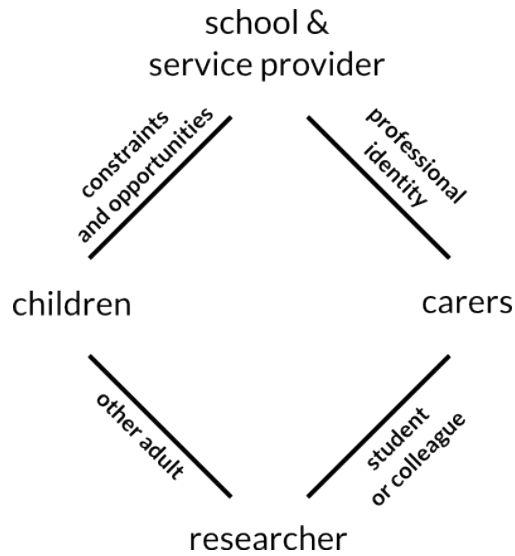


Figure 9.1: This figure illustrates the focus of Chapter 9: I discuss how the environment and the roles I undertook during the field-inquiry shape the discourse and views of carers and children.

## 9.1 *Study*

### 9.1.1 *Data Generation*

This chapter builds on interviews with carers about their professional roles (see Appendix A.3 and Chapter 4), and the longitudinal observations of the work practices of the partner document maker (P1). It also uses two of the documents gathered, a book about the history of the IJA written by its current director, compiling some of its archives, and published for its 150th anniversary; the organization's presentation leaflets. Finally, it uses my observations reports and my reflexive diary.

### **Interviews**

The interviews were semi-directive, and structured as follow:

- Presentation of the researcher;
- Non-participant observations of the interviewees while working;
- Questions about the interviewees' professional history and training;
- Explanations, by the interviewee, of the activities previously observed;
- Discussion of the interviewee's activities, profession and how it relates to its colleague's, including the gathering of relevant documents they wished to share.

### 9.1.2 *Data Analysis*

Following the thematic analysis approach introduced in Chapter 4, I coded the material described above using Quirkos. From the interviews with carers, I identify the characteristics of the organizations they find to be influencing their practices, namely the historical and spatial characteristics of the organization, as well as its current organization and its position within France's landscape of care for disabled children. This is the first theme I develop, "context," which I expanded by using my observations and the documents presenting the organization. While working on interviews for this theme, much of the material I was coding referred to "professional identity," either as a group or as an individual. This became my second theme. I thus decided to look more closely at my own professional identity

in the field work, probing observations, interviews and my reflexive diary for references by others or by myself to my role in the organization. I called this theme: “shifts in roles.” I analyze how these shifts occurred and how they can be explained.

### 9.1.3 Data Presentation

In accordance with the ethical choices described in Chapter 4, I identify carers by their identification to a group, and not by their identification number.

## 9.2 The Organization Studied

In this section, I provide contextual elements on the organization studied, the CESDV-IJA of Toulouse. I situate it within the current structure of services and resources providers, and argue it embodies quite well the French history of the education of visually impaired children. It may contribute to distinguish the care practices in the IJA<sup>1</sup> from those in more recent organization. Furthermore, it explains the spatial characteristics that shape current work practices. Interestingly, this tension between the local specificity and national level is also present in the discourses of carers.

<sup>1</sup> This is the part of the acronym most often used by the research participants.

### 9.2.1 The provision of resources and services in France

In this section, The French care system for people living with impairments is territorialized on a departmental level. Once children are identified as having an impairment by their pediatrician, their file is sent to the Departmental Administration for Disabled People (*Maison départementale des Personnes Handicapées*, MDPH), which judges of the extent of the resultant disability. MDPH are coordinated on the regional (i.e., county level) by the Regional Agency of Health (*Agence Régionale de Santé*, ARS), which role is to define the funding, number of places available in each care center, as well as to audit their practices<sup>2</sup>.

<sup>2</sup> Baudot, “Figures de l’État Local. Une Approche Relationnelle Des Politiques Du Handicap”.

Commissions within the MDPH, called Disabled Persons’ Rights and Autonomy Committee (*Commissions des droits et de l’autonomie des personnes handicapées*, CDAPH), determine which services, devices, or adaptations (e.g., in a building) the child is entitled to<sup>3</sup>. The MDPH also provides a list of legitimate service providers in the area. Service providers can have a long waiting list, given the limited number of places allocated (and funded for) by the ARS. Once the

<sup>3</sup> Revillard, “Social Movements and the Politics of Bureaucratic Rights Enforcement: Insights from the Allocation of Disability Rights in France”.

child accepted by the service provider, an educative project (*Projet Personnalisé de Scolarisation*, PPS) is defined and updated every year by the team of professional carers, the family and a special education teacher from the MDPH. It may add or withdraw services and devices, and specify the child's schooling modalities (e.g., full time inclusion in a general education classroom).

Services can be provided in ambulatory care setting or within dedicated spaces. For visually impaired children, services are often provided or managed by organizations that were historically special schools for the blind. The only such school that kept its this status is the National School for the Blind (*Institut National des Jeunes Aveugles*, INJA). The others developed new modalities of care following the evolution of policies and norms of care. This is the case of the organization I studied.

### 9.2.2 History of the organization studied

To understand the current norms and environment of care, I find interesting to take a detour through history to see how they evolved. The material used in this section mostly comes from the administrative archives presented by the director of the organization and interviews<sup>4</sup>.

With the framing of blind people as educable subjects by philosophers of the Enlightenment (see also Chapter 3), a number of special schools opened. This particular organization was established in 1867 by a Catholic congregation on the model of the National School for the Blind opened in Paris in 1785<sup>5</sup>. It was funded by the Catholic Church, private sponsors and local authorities. It occupies the same building since 1871. Children could stay several years without seeing their parents and families. Education was based on the Catholic religion. Children were given some formal education (reading, writing, counting, geography and music), but most often proposed to learn a manual trade.

This organization was not organized to care for children with multiple impairments until recently. The first changes towards this direction dates of 1971 and reflected the change in policies: The notion of **care** (in addition to education) begins to appear in the missions entrusted to the institution. In 1974, it opened a service to care for children with multiple impairments<sup>6</sup>, as the number of children with visual impairments alone reduced (antenatal and juvenile causes were better prevented, while perinatal causes such as premature births, most often correlated with associated impairments<sup>7</sup>, increased). An-

<sup>4</sup> Montauriol, *L'institut Des Jeunes Aveugles de Toulouse, Petite et Grande Histoire*.

<sup>5</sup> Depending on the sources, the date used is 1784 or 1785. I use the date chosen by Zina Weygand, a French historian specialized in the history of blindness in France. See: Weygand, "Les aveugles dans la société française".

<sup>6</sup> This follows the apparition of the new category of disabled children in France, those with so-called rare disabilities. See: Winance and Barral, "From 'Ineducability' to 'Rare Disabilities'. Evolution and Emergence of Political Categories Involved in Shaping the French Medico-Social Sector".

<sup>7</sup> Catherine Arnaud et al., "Déficits Visuels: Dépistage et Prise En Charge Chez Le Jeune Enfant".

other major change occurred in 1975: nuns stopped running the institution, to retain the funding of the Ministry of Health. However, it remained a private school, which deprived it from some resources allotted to public and secular institutions.

At this time, the institution was still a boarding school, but gradually developed part-time boarding. It also provided training in piano tuning and receptionist work. In the 1990s, the organization evolved greatly: it developed services to adults and to children with multiple impairments. This leads to the the apparition of new professional functions: health care personnel, psycho-motor therapy, mistress of the house (*maîtresse de maison*) a worker who accompanies children in their activities and handle logistic issues<sup>8</sup> as well as orientation and mobility specialists. Low vision therapy, even if legally blind children could have benefited from it, was not well implemented before the 90s. Social educators were more and more involved too. This is consistent with a shift in policies: All aspects of the children's lives were considered to be part of the organization's missions. It mainly provided special education and care, until the 2000s. In 1989, six children attended a general education school while 56 attended the special education school. In 1998, the numbers were five to 28. But in 2003, the proportion reversed: 29 children attending a general education school compared to 12 in special education setting. The shift thus occurred before the 2005 law consecrating inclusion in a general education school as the norm, which consolidated it, except in practice for children with additional impairments... and to some extent, from disadvantaged families. This is consistent with the data provided by the Ministry of Education, analyzed in Chapter 6. Since the 2000s, ambulatory services have developed, boarding being reserved for children living too far away, or coming from neglecting families.

In summary, this organization well embodies the history of French special education, having evolved following each new policies for 150 years<sup>9</sup>. This history is further visible in the spatial changes of the organization.

### 9.2.3 *Spatial features and interactions*

Which themselves shape care practices and micro-interactions. The main building itself is an example of monastic architecture: rectangular shape, on three levels plus the basement, with a patio in the middle and a chapel<sup>10</sup>. Its interior design changed with the norms of care. Before 1970, it was a special education school with a strict separation by gender (boys in the right aisle, girls in the left). The first disability rights law in the 1970s had a direct effect on children ac-

<sup>8</sup> Fruchard, "Maîtresse de Maison, Quels Métiers?"

<sup>9</sup> Weygand, *Vivre sans Voir: Les Aveugles Dans La Société Française, Du Moyen Age Au Siècle de Louis Braille*.

<sup>10</sup> As is the National School for the Blind. See: Hottin, *L'Architecture Des Établissements d'enseignement Supérieur*.

commodations. Dormitories of 20-bed were transformed into rooms for 3 or 4 children with adjuncts bathrooms (bathrooms which previously were in the basement). The building was expanded in 1993, to add residency rooms, separate children from adults, and provide a space for children with multiple impairments. These services are still separated spatially, within the building. It was renovated and reorganized in the 2000s, and since host a nursery. Despite opposition, the chapel was cut in half to accommodate for sports activities—hinting both at a long attachment to this history and at a contemporary detachment. Ambulatory services are now separated in two branches, in different cities, to serve the different parts of the region.

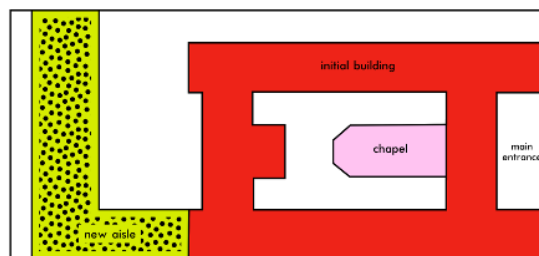


Figure 9.2: A satellite image of the CESDV-IJA (from Google Maps), and its schematic representation.

On an interaction level, the size of the building and its current organization (only one entrance for the children, separation of living areas from therapy rooms, organization of living areas in function of age, few stairs to go up and down, provoking encounters) facilitates certain interactions and not others. For instance, I rarely saw children under six outside of their dedicated space (as it is both a living and learning space). On the other hand, older children freely walk around during their time there, interacting with adults and carers if one or the other want to.

As carers work with children of various ages, they have to go from the living space dedicated to one group to the other to see the children they need to see, and to their own office. As a result, carers have the opportunity to hail one another to coordinate their actions about specific children, a common informal knowledge being developed in corners to keep the corridor clear for people walking. Finally, it enables for certain kinds of surveillance, and not others. For instance, going in and out of the building can be monitored, but walking from a bedroom to another can not, if there is only one point of surveil-

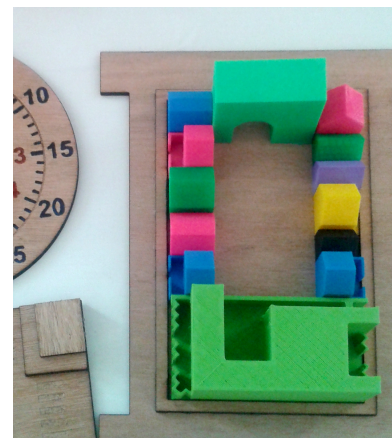


Figure 9.3: A 3D-printed and manipulation representation of the block in which the IJA is situated. The green building at the bottom is a simplified representation of the IJA's building described above.

lance. To paraphrase Whyte<sup>11</sup>, one could describe it as a **corridor corner society**.

<sup>11</sup> Whyte, *Street Corner Society: The Social Structure of an Italian Slum*.

Carers may also use the facility and its neighborhood for formal and informal learning activities with children, such as taking the stairs, conversing, or reading a tactile map. Children and adults benefiting are often seen developing their orientation and mobility skills in the neighborhood. Sometimes on the road, rather than on sidewalks. They may learn how to independently shop there as well. They all know the nearby museum and its mummy, the park and the garden. It provides a variety of urban experiences in a context considered as safe. This is evolving too, as interventions are more and more conducted in the children's community, school and home.

#### 9.2.4 *Services provided*

The care center provides services to children with visual impairments and their families, from birth to 20-years-old. It consists of four main branches: early infancy support, education support for children attending general education schools full or part-time, therapeutic and educational services for children with multiple impairments or so-called rare disabilities, and professional training (initial formation or rehabilitation). The main services provided to children are: document adaptations (braille, tactile pictures), orientation and mobility, psychomotor therapy, psychological support, low vision rehabilitation, occupational therapy, educational support (in the family home or in the facilities), assistance in general education schools and specialized teaching interventions, artistic activities, and taxi services. Some of these services were specifically developed for people with visual impairments. It includes: orientation and mobility specialists, who focus on mobility techniques and spatial awareness; low vision specialists, who train children to use even the slightest remaining visual abilities. Other therapists are not specific to visual impairments, and include: Psychomotor specialists intervene since early in life to develop body image, coordination and overall well-being; Occupational therapists work on fine motricity and help the children to develop strategies for conducting everyday life activities autonomously (e.g. eating); speech and language therapists, etc. The organization may keep providing services such as document adaptation if children attend private universities (public universities have the obligation to provide support).

### 9.2.5 *Children receiving services*

The children receiving services from this organization constitute a largely heterogeneous group in terms of age (from 0 to 20 years old), background, modalities of schooling, and impairments (i.e., types of visual impairments and associated impairments). The institute cares for about 140 children and 14 adults. The transcription services provides daily adaptations of educational supports for about 70 children, 15 to 20% of them using braille. This means that half of the children in care do not attend a general education school requiring these adapted documents, either because they primarily attend a special education classroom in which a special education teacher provides adapted documents (about 35), vocational education (about 18), or too young (about 10). With 35 places reserved to children with additional impairments, the rate seems lower than the 60% found by<sup>12</sup> on the national level. However, here it designates children who can not attend a general education school most of the time, rather than the severity of disability. Note that definitions of visual impairments and children are discussed in Chapter 3 and 6.

<sup>12</sup> C. Arnaud et al., "Visual Impairment in Children: Prevalence, Aetiology and Care, 1976-85."

### 9.2.6 *A local identity?*

To better understand carers' points of view, this section expands on how they express their professional identity, and their relations to the aforementioned organization. I focus on the expressed local and historical expertise, explained by the political leaning in the management of resources and a claimed collective identity. I am not concerned here with measuring whether this is true, or can be measured. It simply seems useful to understand their practices and views—and eventually to understand differences with other organizations. The material used here comes from informal discussions and formal interviews.

A topic often initiated was the local development of expertise, nurtured by the long history of the organization. People raising this point were all considered specialists of visual impairment—it did not arise in my discussion with the organization's taxi drivers for instance. Their initial formation is either not focused on visual impairments (e.g., occupational therapy), or in their opinion misses critical points. In this context, the fact that this is a well established organization in this domain gives them an advantage on other service providers<sup>13</sup>.

Teacher: *"There's not a too-big of a turnaround, and it's not like this is a young organization. It gives perspective, you know? You can try new*

<sup>13</sup> I distinguish between five groups of carers throughout the dissertation: teachers, teacher assistant (e.g., the librarian, document makers, children's assistants), social educators, therapists and parents.



*things, but there's no need to jump on that new thing. So it's pretty stable, and that's good for our children."*

Therapist: *"The thing is, we're not going to change our specialty suddenly. With the SESSAD [ambulatory service providers] you can never know when they're going to change their focus, because they don't have enough children, or simply because the newly hired prefer working on other impairments."*

Therapist: *"I feel like we're particularly into new technologies and the such... Like I'm definitely the only occupational therapist, as far as I know, to try establishing guidelines and documentation for the uses of smart-phones... (...) I've only managed to scrape two hours per week for that! But it changes all the time, you have to update and maintain everything, that's completely overlooked."*

On the other hand, some point this feeling of legitimate expertise as limiting:

Therapist: *"I used to work at [redacted for anonymization purposes] and they are so far ahead from us, because it's younger, and they started working after ambulatory services became the norm, so they could invent something new, whereas we adapt, and that always takes more time."*

Whereas, over coffee and alone in a room, it can be completely contested:

Teacher: *"We're always saying that we're better, that there are good organizations and lesser ones, but that's easy to say. We may be doing a better job on some aspects, but we're lagging on others. (...) Anyway there's only so much we can do with the budget we have. Maybe there's a certain, erm, political spirit, but it seems to me it's pretty standard in the medical-social milieu and it's certainly really useful to make us work more without paying what our time is worth. And I don't always mind that, because it's for the children, though sometimes they're really messing with us."*

This local expertise, according to some, has to do with management practices:

Social educator: *"The core thing is that the organization's supervisor knows the work. He was a social educator before, you know? He's not one of those mindless managers we see everywhere nowadays in the social-medical sector, he understands what we're doing, he's committed to the human and the social... He let us experiment new things new activities and so on. (...) I feel like we were pretty protected from all these cuckoos that govern us... That our work is less corrupted."*

Teacher: *"It's true that there are cases [children] we accept because no one else will. They make a lot of trouble, and we have this style where we try to avoid unnecessary restrictions... It's not always easy... (...) I guess this*

*is very leftist (laugh) but I think it's good thing we do it, all in all."*

But is associated with a caring collective identity:

Social educator: *"For too many children, we're the only people to care... Their school don't want them, their parents don't want them (...) it's far from perfect, but at least here, we care."*

Teacher: *"When one of them succeeds, everything we do for them is worth it. It's not an easy job, but it can be very gratifying emotionally."*

Therapist: *"There are children you attach to more than others, but we couldn't do this work if we weren't at least a bit involved emotionally. Especially us, because we really see them growing, not just passing by for a year or two. (...) I don't think they're so attached to us, I mean to the school, when they become adults. It's like, they don't want to be seen as disabled, and it's okay because it proves we did our job well."*

I distinguish two main sources of professional identity: the health-care and social assistance sector or medico-social sector and its ethics; the organization and its politics. Although I note the use of a collective *we*, that initially seem to designate the whole organization, a more precise examination shows how it actually excludes certain groups. The administrative staff is positioned both within and outside of the groups working at the contact of children, depending on how their decisions are perceived. Moreover this *we* does not encompass the maintenance staff, or the taxi drivers, those whose interventions are described as technical.

On the other hand, identifying to a caring collective is framed as inseparable from belonging to the medico-social sector. An identity that is threatened (*"corrupted"*) by new management practices, replacing an ethos of care by one based on standardized practices<sup>14</sup>. At the contrary, employees posit that emotional care can be a requirement (*"we're the only people to care"*) or a characteristic of their jobs, an emotional labor<sup>15</sup>. The concept of emotional labor refers to the management of emotions and feelings in which one has to engage to meet the workplace rules. It is closely tied to care work, which both involves to helping others manage their emotions, and to closely monitor one's own feelings so as to only show those useful. The intensity of this labor clearly depends on the position within the organization, the time spent with children, and the perceived importance of children's emotional needs. Furthermore, the investment of emotional resources can be turned against employees (*"useful to make us work more without paying"*).

The notion of care ethics emerged from the medical sector (see Chapter 4), it thus is not surprising to find it reclaimed here—hence

<sup>14</sup> I am not emitting a value judgment here. Care ethics also has its limits—see my discussion in Chapter 4 and: Kittay and Feder, *The Subject of Care: Feminist Perspectives on Dependency*.

<sup>15</sup> Hochschild, *The Managed Heart. Commercialization of Human Feeling*.

my choice to call them carers. However it is not caring for others that is fulfilling, but the fact that care-receivers reach certain goals (especially academic ones). It does not imply reciprocity. I would say that it is voluntarily made less visible, because successful care should not be reminded to those who benefited from it, because it would discredit<sup>16</sup> them (“*they don’t want to be seen as disabled*”).

Some emphasize a local expertise distinguishing them from other service providers because of their history and expertise on visual impairments<sup>17</sup>. However analysis rather suggests a continuous negotiation between stability and the introduction of novel practices—constrained by the allocation of material and human resources. A negotiation that is resolved differently by service providers. Moreover, lifelong training and exchanges of expertise on the national level are quite sought after, especially by therapists and teachers. The main asserted difference between this organization and others resisting examination is the engagement to care for anyone, and to do so with a social rather than medical mindset. This is understood as a *political* and *humanistic* decision, yet one that is difficult to make.

The question then is how this identity is mobilized in practice. As I develop in Chapter 10 and 11, it shapes a particular understanding of resources: On the one hand, carers are convinced by the importance of civil rights, a social model of disability and inclusion policies. On the other, they do not believe in the fact these rights will be respected, and that resources will be provided outside of this environment. The goal then is to help children not to depend on services or resources that may not be available. It also contributes to explain the distrust sometimes expressed towards researchers (Chapter 2), as well as at the beginning of my field-study.

### 9.3 *The Researcher’s Roles and their Tensions*

To understand the roles I came to undertake, I propose to examine how I negotiated my place as a long-term participant in the organization, from my introduction forward. I was introduced into the organization by a former employee, now a volunteer. She asked a representative panel of current employees (hereby named carers) if they would agree to let me observe their practices and explain what their work consists in. Some invited me in their classroom or in their sessions (e.g., orientation and mobility session). Others took me to general education schools where they intervened in, presenting me as their intern. That way, they argued, these teachers would happily contribute to my education, and would not feel threatened by my observations. Although I was generally positively received, some carers

<sup>16</sup> Goffman, *Stigma: Notes on the Management of Spoiled Identity*.

<sup>17</sup> On this topic, see also the PhD thesis of Mihout on the professional identity of teachers in French special education schools. Mithout, “*L’inclusion Scolaire à l’heure Des TIC : Perspective Franco-Japonaise*”.

had conditions: a braille teacher agreed to talk to me only if I stayed three hours, learned the basics of braille and listened to the history of French special education. Another stated he was doing me a favor, did not believe that researchers in general could make a meaningful change, and did not have intention to collaborate. As I returned regularly to the field, these relations evolved.

I argue in this section that it is primarily my age and gender that shaped the type of roles I could undertake. Age should be understood in relation with the roles generally attributed to adults. From the point of views of carers, I was younger and a student to inform, but also a professional. For children, and particularly for teenagers, being at school means I am not quite an adult yet. I was thus in-between youth and adulthood. Then there is the intersection with gender: as care work remains a primarily female activity (over 90% of my interviewees were female), being perceived as female posits me more as a potential carer. This is evidenced for instance by a carer saying that it is surprising that a male researcher and colleague remembered the names of the children. However, children had a quite different perception of my gender, oscillating between male and female, because of my gender presentation. This intermediate embodiment (in terms of gender and in terms of age) enabled certain types of interactions with the research participants. As ethnography engages the body of the researcher as a research tool<sup>18</sup>, this should be of particular interest for those interested in methodology.

<sup>18</sup> Hillyard, *Gender Identity and Research Relationships*.

### 9.3.1 *Between the student and the interim colleague with carers...*

In this section, I attempt to show how my age and gender play in outside perception of my potential expertise—and how I managed it to remain in an in-between position enabling for greater freedom. At first, I carried on with the role I was being proposed: carers would talk to me as if I was a student, emphasizing learning by doing while also recommending that I read professional literature. They underlined their appreciation for my curiosity about aspects of their work outside<sup>19</sup> of the IJA. Overall, they put a positive emphasis of being free to negotiate how to work with me, the subjects being addressed, and to have an impact on the research questions asked. Although I developed other kinds of roles, as described below, *being a student* remained a facet of our relations until the end of my PhD, as later comments on my skills reveal (e.g., “*ahah, see, you’ve become a suitable special education teacher*”; or “*This map is not bad, you’ve learned*”).

<sup>19</sup> This included their motivations to do this job (several of them described it a moral conversion after several years working in the private sector), their diverse political engagements or volunteering experiences.

On the other hand, being perceived as a woman, with previous work experiences with children (as a former art teacher in a non-

profit organization, and years of experience as a tutor and nanny), I was rapidly perceived by certain teachers or specialized educators as able to care for the children. I tutored in classrooms, helped out when there was a staff shortage by supervising play times or read stories etc. As my collaboration with a specific teacher intensified, I spent more time with a specific group of five children.

Moreover, being trained as a designer, as an active user of Fablabs<sup>20</sup> and as a researcher for the design of new technologies, I demonstrated that I could help in designing specific instructional material. These capacities were valued, for the perception that I was in touch with their everyday life. I thus accompanied Fablab visits, and spent as much time as possible helping out with a variety of tasks (making interactive maps, producing their designs etc.). This position as a professional with a different expertise is not without echoing the research action approach<sup>21</sup>. As pointed out in follow-up interviews with carers I have not entirely escaped the downfalls of this role, failing sometimes to accompany the development of a local expertise rather than doing things myself—as I was to leave the organization after my PhD.

Being a colleague implies the same type of emotional involvement. It has played against and for me. I discussed in Chapter 2 the importance of emotions in defining a research topic. It is not in itself negative. But there is a lack of resources to help people working in sensitive contexts to deal with the intertwinement of ethical values and emotional difficulties. For instance, one can agree that children's behaviors and modes of communication should be respected, but sometimes have difficulties when this communication means being touched. My approach implies an important personal implication in research work, which might not be adequate for someone else. There is a need to consider the self-care and preservation of the researchers themselves, through psychological support for instance.

<sup>20</sup> Fablabs are collaborative spaces where one can access digital fabrication tools.

<sup>21</sup> McNiff, *Action Research: Principles and Practice*.

### And the other and least-adult with children

As my focus shifted towards children's perspectives, I reflected on the types of interactions I could have with them. Sanders<sup>22</sup> remarks that, when working with children, "no matter how cleverly disguised the method, or socially distant or intensely engaged the researcher, participants will construct what occurs during research encounters in terms of some sort of relationship." Although I would argue this is not a specificity of children<sup>23</sup>, there is a considerable body of work dedicated to developing these relationships<sup>24</sup>. This literature was born from the concern of not doing harm, as well as from practical concern: What are the differences between managing research relationships with children and with adults?

The more time spent in the field, the more children may tailor a specific relationship with an adult (rather than using relations with other adults as a model). Affective ties may then develop, which requires to take particular precautions (see the section on ethics in Chapter 4). This is all in all a specific case of the spectrum between *going native* and the *outsider observer* well-known in ethnography<sup>25</sup>. Indeed there are difficulties and benefits in studying one's own community and a dissimilar one<sup>26</sup>. This is discussed at length by qualitative studies scholars<sup>27</sup>, particularly in feminist scholarship. This is in part motivated by a concern for justice e.g., maybe encouraging minority students to study their own community will to open career possibilities or enable them to become experts and to become part of media representations.<sup>28</sup>). Additionally, there is an ever increasing consciousness that the researcher's own characteristics, e.g. race/ethnicity, gender<sup>29</sup>, play a role in the type of data generated and in the analysis developed, which implied that researchers need to develop a greater reflexivity.

Previous research describes three main stances on the subject, each tied to a specific research need. The first is to take on a usual adult role: researchers as teachers or social social educators are an example of this stance<sup>30</sup>. This may be useful for action and community research. The second stance is rather to become **another kind of adult**, someone who does not exert authority but does not pretend to be a child—thus retaining the idea that children must and should be protected by adults, but also that they are able to discern between adults playing a child and an actual child<sup>31</sup>. The third stance is to become the **least-adult**<sup>32</sup>. It entails to imitate the children as much as possible, to partake in their activities and not to intervene as adults.

Depending on the context, I oscillated between the three stances described above, although **another adult** is probably the stance best

<sup>22</sup> J. Sanders, *Subject Child: The Everyday Experiences of a Group of Small Town Aotearoa/New Zealand Children*, p. 71.

<sup>23</sup> Fournier et al., "Le Sexe et l'âge de l'ethnologue: Éclairants Pour l'enquête, Contraignants Pour l'enquêteur"; Hillyard, *Gender Identity and Research Relationships*, See for instance.

<sup>24</sup> Einarsdóttir, "Research with Children: Methodological and Ethical Challenges"; Graue and Walsh, *Studying Children in Context: Theories, Methods, and Ethics*; A. J. Cocks, "The Ethical Maze: Finding an Inclusive Path towards Gaining Children's Agreement to Research Participation."; W. A. Corsaro, *The Sociology of Childhood*.

<sup>25</sup> Stephen et al., "The 'Insider/Outsider' Dilemma of Ethnography: Working with Young Children and Their Families in Cross-Cultural Contexts".

<sup>26</sup> McCartan, Schubotz, and Murphy, "The Self-Conscious Researcher—Post-Modern Perspectives of Participatory Research with Young People".

<sup>27</sup> E.g., Dwyer and Buckle, "The Space between: On Being an Insider-Outsider in Qualitative Research".

<sup>28</sup> Fals-Borda and Rahman, "Action and Knowledge: Breaking the Monopoly with Participatory Action-Research.[Excerpts]."

<sup>29</sup> Hillyard, *Gender Identity and Research Relationships*.

<sup>30</sup> DeMeulenaere and Cann, "Activist Educational Research".

<sup>31</sup> J. Sanders, *Subject Child: The Everyday Experiences of a Group of Small Town Aotearoa/New Zealand Children*.

<sup>32</sup> Mandell, "The Least-Adult Role in Studying Children".

describing how I interacted with children. It was compatible with my role as a competent caregiver, and with a certain complicity with the children. Still, there were moments of tension, like when children came to me with confidences (e.g. *"I want to tell you, but don't tell the teacher"*), or when I was scolded by a social educator for *"acting silly."*

Artifacts were central to the building of my relationship with children, just as my design abilities were in my relationship with carers. This including coming up with new prototypes or technologies changing the classroom activities (e.g. Ipad, smartphone, probes); producing artifacts they desired (e.g. tactile globe); but also unusual objects. My folding bike in particular was an important subject of interest and initiated shared activities and time. In several occasions, we also made things together: drawings, papercrafts, other artistic endeavors, and probes.

The choice between one and the other depended on the type of activities conducted and the preferences of the people being observed, but also on whether or not it threatened the two roles I had negotiated (a caregiver, and another adult). For instance, I was once asked by a caregiver to partake in the demonstration of a new digital tool to a teenager. The teenager was refusing to try using it. Another researcher present in the room sided with the caregiver, raising his voice and enforcing adult authority. Getting involved in this particular situation would clearly have damaged my role as another adult—I could not however act on behalf of the child either, as this would have probably damaged my role as a competent caregiver. In this particular case, I decided to take a step back and not to get involved. The caregiver renounced some ten minutes later. In a follow-up discussion that day, this child reflected on the episode:

*"There was nothing we could do but wait."* (emphasis mine)

As for the caregiver:

*"I shouldn't have insisted. It was all quite confusing, it's a good thing you stayed out of it."*

Withdrawal from participation often was the most efficient way to react in this type of situation. A retrieval that was physical: I went sitting on a chair in a corner of the room and lowered my head, looking mostly at the floor during the episode. Which introduce well an aspect of my relations in the field that I would like to discuss: the role of my own embodiment, and in particular my gender.

### 9.3.2 *Being other gendered*

There is one aspect of my field experience that I was not represented in the research literature: My gender was perceived as blurry by the children. This is quite usual for me, and not just with children. I do not respect usual gendered conventions regarding clothing, jewelry, hairstyle, voice tone (which itself varies), and according to some, in terms of height and manners. While a few carers commented that I should dress in a more feminine way, children ascribed me to one or the other gender. Their opinions on the matter changing with the situation, or when an adult “corrected” them.

In my experience, the gender ascribed to me follows what they need and associate with a particular gender, e.g. if they want someone to play with outside or to help with a computer matter, I would be addressed as masculine. If they need someone to read them a story or find another caregiver, as feminine. The situation is different with teenagers, who emphasized their need to guess my right or correct gender. However they also often emphasize the difference between me and other people identifying as female: not only I am a different sort of adult, but I am also a different kind of girl.

There are many implications I do not address here—but I want to point out that it affects what children feel like they want or can discuss. It could have been an issue with teenagers, who seemed more insecure around non-conforming gender identities—probably because gender is an important subject at that age<sup>33</sup>. However, it seems to me that it rather diminished barriers that could arise with girls if I was identified as male and vice-versa. Gender assumptions could be projected on me because of that blurriness. On the other hand, it greatly contributed to reveal assumptions about gender (e.g., “so you’re still at schoooooo! I couldn’t, that’s because you’re a girl, girls like school, me I don’t ‘coz I’m a boy”).

Because my gender expression is unusual, I could not avoid reflecting on its impact. Especially given the risk to be barred from research. I was unsure about some parents’ reactions if they were to learn about this. Indeed, there has been a renewed anti-LGBT movement in France during the last few years<sup>34</sup>, which opposed discussing, or even mentioning gender related subjects in schools. Would they all have agreed to their children participating in the research if they had known I was not gender conforming from the start? As pointed out, carers were not likely to identify this in these terms—I was only asked a few times why I was not wearing more feminine outfits. Still, it potentially posed risks, for all involved.

<sup>33</sup> G. A. Fine and Sandstrom, *Knowing Children: Participant Observation with Minors*.

<sup>34</sup> [hrw.org/news/2017/05/17/struggle-lgbt-rights-france](http://hrw.org/news/2017/05/17/struggle-lgbt-rights-france)



#### 9.4 *Summary*

To summarize, I studied an organization that may be distinguished among others by its political stance on the inclusion of visually impaired children considered difficult to care for. On the other hand, it embodies quite well the French history of special needs education. I highlight tensions around the autonomy and material resources: what the law states, the state does not do, which can place carers in unsolvable situations. It also ratify the primacy of standardized practices at the detriment of the flexibility of care ethics, which is not necessarily at the benefit of the children. With insufficient resources, standardized practices require early categorization of children according to their perceived abilities, whereas care ethics seem to provide more flexibility (even if it has its pitfalls).

Given this situation, I undertook a number of different roles, enabled by my in-between status, in terms of age (an adult but still a student), expertise (a carer, a designer, a student) and gender (a female for some, fluidly defined for others). For and with carers, I made myself useful, trying to make up for the time they spent participating in the research. For and with children, I was another kind of adult, one with fun objects. To conclude, I would like to remind that there is no such thing as a neutral embodiment. I pointed out my gender specifically, as it was the most salient aspect influencing interactions with children, but I also am white, sighted, and I hated school—which is arguably ironic.

Why examine age and gender, and not 'race,' social class or disability status, especially given my focus on social class in children's experiences of school. A short answer would be that my age and gender were highlighted during my field work as meaningful characters, either in discussions or in observations. However, I could be blind to how my other characteristics shaped the research relationships. This is something I am careful about, especially in the case of the impact of 'race,' that in this very specific context does not seem significant (see Chapter 12). However my social class did influence the field work, in a more nuanced way: In terms of socio-occupational status, I belong to the highly advantaged group; in terms of perceived social status, it depends. The reason I do not discuss it here is that it would be hard to disentangle from my occupational characteristics. From children's perspectives, it is not an enviable social situation to still be a student: it does not pay, several of them told me, and if you are old and a student, it means you failed to graduate. One commented this is probably because I sometimes use slang words. However from carers' perspectives, I would not be a potential carer if I did not belong

to their social world, on the higher half of the social stratification.

As for the disability status, I propose to briefly consider what it does to children's experiences of school. It generates hostile reactions and discriminations—and inventive reactions to adapt. I discuss it when necessary in the following chapters, but having been bullied for years at school and being considered by school peers as having a 'mental' impairment<sup>35</sup> necessarily shaped my attitude towards children's narratives, i.e., I took it seriously, probably more seriously than if I had not had these experiences. This is something I took into account in my considerations about the roles adults can undertake in research with children. Then there is the need to be attuned to a different sensory experience—which I discuss in Chapter 4 and to a lesser extent in Chapter 14. To summarize, my characteristics enabled certain discussions to take place. It probably barred others. As much as possible, I try in the following chapters to take this into account in the analysis.

<sup>35</sup> For documentation purposes, the slur most often used in the countryside of the North of France was *pleuple*, which means 'simple minded.'



## 10

### *Findings: How one feels at school*

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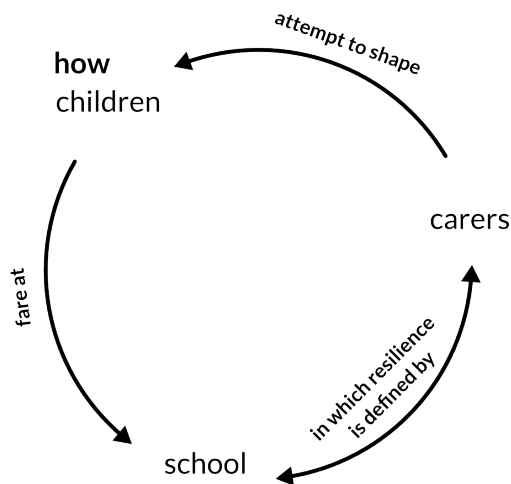
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This chapter presents the first part of my field-work findings. It answers to the research question "How do children visually impaired French feel at school?" by taking two complementary perspectives: children's, and their professional carers. As children primarily describe their experiences of schooling as adversarial, I use the concept of ecological resilience to move the discussion from innate risks towards a more precise account of the formation of personal and relational resources mobilized by carers and children to complete mandatory education, as well as their differentiated distribution and uses.

I use two different terms to refer to children and carers' interview material: narratives for the former, discourses for the latter. Narratives are a form of discourse, which have become advantaged to understand the construction of self and identity, as they reveal how their authors navigate relations and situations<sup>1</sup>. This is adequate for an inquiry focusing on how children understand their past interactions<sup>2</sup>. Moreover, children are used and encouraged to produce narratives<sup>3</sup>. In contrast, carers rather developed their professional rationale, using narrative examples.

### *Visual Overview*



<sup>1</sup> Bamberg, "Narrative Discourse and Identities".

<sup>2</sup> Hohti and Karlsson, "Lollipop Stories: Listening to Children's Voices in the Classroom and Narrative Ethnographical Research".

<sup>3</sup> Miller, Cho, and Bracey, "Working-Class Children's Experience through the Prism of Personal Storytelling".

Figure 10.1: In this Chapter, I present and discuss my findings about how children fare and cope at school, contrasted by how carers understand resilience and its role in schooling.

## 10.1 Study

The motivations for this study is an early interview with the teacher participating in the Accessimap project, P6, as well as and the fact that children had attracted my attention to the question of well-being at school (see Chapter 3). Here is an excerpt from the interview:

*Teacher: "We tend to protect them more, and longer, than other children, except that sometimes it gets really complicated because it really doesn't work out with the other children... For instance, crying at school. Do you imagine a teenager crying at school!? The other kids don't forgive this kind of things, and then obviously it makes our children's lives at school difficult... At some point, they really need to grow up and toughen up, and that's something I remind them of... [...] On the other hand, it's difficult, handling all of that at the same time, we have to be careful about how much we push in order not to break them [...] I used to think that just going to a normal school with normal kids and us around would do that but it isn't truly the case... Plus we invest a lot in these children, and some of the schools do to, but we don't exactly have enough resources to guarantee that long term."*

### 10.1.1 Data Generation

This chapter builds on interviews with carers about their professional roles (see Appendix A.3 and Chapter 4), which are described in Chapter 9; on biographical interviews with children, described below; and observations, including informal discussions with both children and carers.

#### Interviews

The biographical interviews initially aimed at understanding the experiences of disability services more broadly. They were semi-directive and structured as follows:

- Presentation of the researcher;
- Question about their parents' occupation, their age and where they go at school;
- Asking children to remember a day of the week and a day of the weekend that happened several years ago (in primary school for secondary school students, in secondary school for high school students), and describe them to me;
- Asking children to remember a recent day of the week and a day of the weekend, and describe them to me;

- Asking, if it has not come up, who are their favorite people;
- Asking them what they think school is for.

Following the first interviews, I added two questions to better understand schooling experiences and how they relate to their family life: I asked which day of the week they prefer and why, which enabled to elicit how children contrast home and school, or general and special education schools; and if they wanted to tell me a fun story that had happened at school. It aimed at opening new ways of talking about school, since adults often encourage talking about efforts instead, as well as to mitigate the impact my own negative experiences of schooling, which they sometimes asked about, on their discourse.

### 10.1.2 *Data Analysis*

Following the thematic analysis approach introduced in Chapter 4, I coded the material described above using Quirkos. I did not have a preliminary model of resilience. I first probed children's interviews and coded the data relating to barriers, difficulties and feelings (positive or negative) at school. From this I developed the three themes I present here: exhaustion, battle and pain. I then coded interviews of carers, looking at how they talk about children's emotion and well-being at school. Finally, I probed my observational data to identify occurrences denoting children's adversarial experiences of schooling, e.g. body language.

## 10.2 *The Concept of Resilience*

In this section, I discuss the definition of resilience in social sciences. I then focus specifically on the social ecology of resilience proposed by Ungar, which I adopt for my analysis. I move on to outline previous uses in the disability studies community, and conclude by discussing why I did not work with Goffman's concept of stigma to explain how children manage interactions in which they are discredited by their disability.

### 10.2.1 *Defining resilience*

Resilience is a concept used in multiple disciplines, from engineering to psychology. As a psychological concept, it has become lay knowledge, used in everyday language and self-help books to denote a person capacity to resist and adapt to stressful conditions. Resilience

could be defined as follow: "*The capacity of a dynamic system to adapt successfully to disturbances that threaten system function, viability, or development*<sup>4</sup>."

Let's note however that is presented as something that can be cultured in someone in general literature. This precision is important because it explains how carers appropriate and use this notion. However, resilience is a bio-psycho-social-cultural process, between the individual and its environment, rather than an individual trait or characteristic. As such, it rejoins the social relational model of disability<sup>5</sup>, in which experiencing barriers to doing can translate in individual psycho-emotional difficulties, or barriers to being, which further affects future experiences. The capacity for resilience also evolves with time—and it is often used to characterize individual trajectories reaching or missing on normative outcomes<sup>6</sup>. Hence, the definition itself of these outcomes can be criticized (see my discussion of Hutcheon below and Chapter 11).

Resilience is studied through two main means<sup>7</sup>. There are qualitative studies of resilient individuals, to identify what circumstances enabled a different, more positive or negative outcome, in a similar situation. As a complementary perspective, the development of quantitative models of risks can enable to identify which factors tend to protect from, mediate, or prevent a given undesirable outcome.

### 10.2.2 Ungar's Social Ecology of Resilience Theory

In the recent years, there has been a turn to ecological studies of resilience, trying to tie together micro-, meso- and macro- factors affecting resilience. However, Ungar argues that most approaches to resilience in children focus on individual characteristics. In contrast, he proposes to emphasize "*the role social and physical ecologies play in positive developmental outcomes when individuals encounter significant amounts of stress*."<sup>8</sup> He defines resilience as:

1. the capacity of individuals to navigate resources that sustain well-being;
2. the capacity of individuals' physical and social ecologies to provide these resources;
3. the capacity of individuals, their families, and communities to negotiate culturally meaningful ways for resources to be shared<sup>9</sup>.

Ungar further identifies<sup>10</sup> seven protective factors, resources and

<sup>4</sup> Masten, *Ordinary magic: Resilience in development*, p. 10.

<sup>5</sup> C. Thomas, "Developing the Social Relational in the Social Model of Disability: A Theoretical Agenda."

<sup>6</sup> M. O. Wright and Masten, "Pathways to resilience in context".

<sup>7</sup> M. O. Wright and Masten, "Pathways to resilience in context".

<sup>8</sup> Ungar, "The Social Ecology of Resilience: Addressing Contextual and Cultural Ambiguity of a Nascent Construct".

<sup>9</sup> Ungar et al., "Distinguishing differences in pathways to resilience among Canadian youth".

<sup>10</sup> Ungar, "Resilience and culture: The diversity of protective processes and positive adaptation".



characteristics that foster resilience. They could also be classified as individual, relational, or collective:

1. **RELATIONSHIPS:** With a primary caregivers, peers and adult mentors or teachers;
2. **A POWERFUL IDENTITY:** Perceived self-efficacy and recognition of abilities by others;
3. **PERSONAL CONTROL AND EFFICACY:** Being given the opportunity to take decisions for oneself;
4. **SOCIAL JUSTICE:** Having the perception of being treated fairly;
5. **ACCESS TO MATERIAL RESOURCES:** Having access to "*adequate food, clothing, education, and future opportunities for employment*";
6. **SENSE OF COHESION:** Feeling that one belongs and that life is meaningful;
7. **CULTURAL ADHERENCE:** Adhering to a set of shared norms and beliefs.

### 10.2.3 Resilience in disability studies

As described in Chapter 5, disabled children can be considered at higher risks than other children, no matter their protective factors. For instance, good peers relations does not seem to prevent higher rates of bullying<sup>11</sup>. Resilience attracted the interest of a few disability scholars in the recent years, taking a critical or pragmatic lenses on the notion of resilience.

Hutcheon critiques Ungar's take on resilience as remaining too individualistic and as a mean to reach an end: "*For example, what constitutes "adverse conditions" must still be identified and agreed upon, and this has historically been done by an uncritical audience. In this definition, resilience is related to contextual, but largely normative, ideas of health. Not only this, resilience is still an outcome, as opposed to process, to be achieved by individuals, as opposed to groups*<sup>12</sup>."

In contrast, E. J. Hutcheon<sup>13</sup> propose to investigate how post-secondary students understand and criticize resilience. Building upon students' narratives, she contests what counts as a desirable outcome, and what is an efficient resilience strategy. She also argues that criticizing general notions of resilience enables to resist the ever-expanding expectation of performance (at work, in personal development etc.), based on the norm of able-bodiedness. Specifically, she proposes to examine narratives surrounding to rethink five topics:

<sup>11</sup> Hanisch, "Psycho-Emotional Disablism: A Differentiated Process".

<sup>12</sup> Although Ungar does discuss how different groups' hold different concepts of resilience, including the fact that group resilience is sometimes considered more, or as much important than individual resilience E. Hutcheon and Wolbring, "'Crippling" Resilience: Contributions from Disability Studies to Resilience Theory"; Ungar, "Resilience and culture: The diversity of protective processes and positive adaptation".

<sup>13</sup> E. J. Hutcheon, "*Crippling" Resilience: Generating New Vocabularies of Resilience from Narratives of Post-Secondary Students Who Experience Disability*."

1. **COPING, ADAPTATION, SUCCESS AND SURVIVAL.** In contrast with resilience being understood as ability to reach a goal, she proposes to visibilize everyday techniques of coping and survival—but not uncritically, as survival is caused by the lack of resources;
2. **RECOVERY** is often considered desirable (hence rehabilitation). However it is not always achievable, nor is it always desired. She calls for the recognition of multiple forms of adaptations;
3. **(IN)DEPENDENCE.** In contrast with a definition of independence as the ability of one person to conduct activities alone, we should recognize its other forms, such as directing the actions of someone else (see also chapter 4 on care ethics);
4. **VULNERABILITY AND THREAT (RISKS).** Vulnerability is often understood as an individual problem, and a risk associated with disability status, it might be more fruitful to associate it with external threats (see also Chapter 5 on risks of experiencing violence). We can also see it as opening different experiences;
5. **RESISTANCE** to expectations can also be experienced as resilience by those displaying it, although it generally is not considered as such. This is well illustrated by Jessup, Bundy, and Cornell<sup>14</sup>.

With a more pragmatic lens V. Tadić et al.<sup>15</sup> investigated the experiences of visually impaired children between 10 and 17 years-old. They highlight the importance of coping skills, both to handle current emotional difficulties associated with disability and an acute anxiety about future opportunities, as well as the difficult balance to find between independence and safety to foster the desired resilience and independence. Meanwhile, A. Hart et al.<sup>16</sup> and Runswick-Cole and Goodley<sup>17</sup> underline that paradoxically there is little research on interventions to foster disabled children's and their communities' resilience. Goodley<sup>18</sup> and Jessup, Bundy, and Cornell<sup>19</sup> suggest that children engaging in advocacy can be positive both for the individual and the community.

In summary, when studying resilience with disabled people, the way outcomes are defined should be closely examined and criticized or complicated when needed. However, it remains important to do so, because it also support access to adequate resources and to outcomes that may seem out of reach.

<sup>14</sup> Jessup, Bundy, and Cornell, "To Be or to Refuse to Be? Exploring the Concept of Leisure as Resistance for Young People Who Are Visually Impaired".

<sup>15</sup> V. Tadić et al., "Seeing It My Way: Living with Childhood Onset Visual Disability".

<sup>16</sup> A. Hart et al., "Resilience-Building with Disabled Children and Young People: A Review and Critique of the Academic Evidence Base".

<sup>17</sup> Runswick-Cole and Goodley, "Resilience: A Disability Studies and Community Psychology Approach".

<sup>18</sup> Goodley, "Empowerment, Self-Advocacy and Resilience."

<sup>19</sup> Jessup, Bundy, and Cornell, "To Be or to Refuse to Be? Exploring the Concept of Leisure as Resistance for Young People Who Are Visually Impaired".

#### 10.2.4 *A theory of resilience, or a theory of stigma?*

Goffman's concept of stigma<sup>20</sup> is influential in interactionism, and summarized as follows: In a given cultural and historical context, some groups of individuals are considered divergent from the dominant norm (discredited), or as potentially divergent from the norm (discreditable), because of one or several of their characteristics ("*bad personal character*", "*bodily deformities*" and "*tribal characteristics*"). Negative stereotypes are associated with people belonging to these groups. To prevent social disturbances people in the norm stigmatize those who are not (e.g., through blame and shame). Progressively, the stigmatized come to integrate the norm and have to adapt in everyday interactions. They use different strategies to deal with stigma: passing, dissimulating the stigma, or avoiding interactions altogether. Goffman further sheds lights on the creation of spaces where norms are contested, discuss the stigmaphiles (i.e., people comfortable with the stigmatized) which echo the notion of allyship, or the effort made by some to develop a special ability that would hide their stigma. Many of these mechanisms are discussed in this chapter and chapter 11.

The main criticism against Goffman's work in disability studies is that it focuses on the labeled, the stigmatized, rather than the labelers and stigmatizers<sup>21</sup>. To respond to this criticism, Link and Phelan<sup>22</sup> propose to define stigma "*as the co-occurrence of its components – labeling, stereotyping, separation, status loss, and discrimination,*" and link it to oppression<sup>23</sup>. To stigmatize, one must have power. It thus bridges the gap between the two dimensions and enable to study how different individual and groups react to exclusion.

However, there are two main reasons for which I found the concept of resilience better adapted to analyze my findings. The first is that carers fully adopt resilience as an explanatory factor of why children are successful or unsuccessful at school. It also resonates strongly with children narratives of efforts and battles. This does not necessarily mean that this concept is fruitful for academic analysis. Secondly, I found that framing adversarial situations as providing certain resources and not others, as well as the proposed categories of resources, more suitable for both sociology and design work. It offers different lenses to address the same issue, and may thus be re-used by researchers and practitioners using different assumptions as to what is desirable.

<sup>20</sup> Goffman, *Stigma: Notes on the Management of Spoiled Identity*.

<sup>21</sup> Victor Finkelstein, *Attitudes and Disabled People: Issues for Discussion*.

<sup>22</sup> Link and Phelan, "Conceptualizing Stigma", p. 363.

<sup>23</sup> I. M. Young, "Five Faces of Oppression".

### 10.3 *From Exhaustion to Pain: Children's Narratives*

In this section, I argue that children, no matter their perceived level of resilience, face an adversarial context that continuously threaten their well-being. I further highlight and discuss the discursive and relational resources they mobilize. This theme was present in 15 of the 38 biographical interviews.

Children's answers were almost invariably a day without school: either Saturday, most likely to be dedicated to friends (for the teenagers) or extracurricular activities (for the youngest); or Sunday, described as a day of needed rest before going back to school. Following on this, I asked what was different between that day and a day at school, which often prompted long answers or discussion. Narratives about emotions at school enable to pinpoint moments that required adaptations, but also more diffuse feelings of having to be resilient. They offer entry points to discuss barriers at school and resources mobilized to overcome or resist them—and help understanding of psychosocial and emotional experiences of disabled children<sup>24</sup>. Children are designated by their status: gender, impairments, schooling and social origin—all characteristics I found meaningful in analysis<sup>25</sup>.

#### 10.3.1 *Exhaustion*

A first set of narratives that inform us about children well-being at school are about exhaustion. These answers were given by children and teenagers alike, of both genders. In this category, many different narratives co-exist: about impairment effects, about the school environment in general, or about discrimination through neglect.

#### **Impairment effects or adversarial environment?**

Let's begin with what Thomas call impairment effects, in this case the cognitive cost of adaptation strategies:

Ch5; Male blind general/special education secondary school student; advantaged group: *"The others, they don't need to do what I need to do, they don't have to learn to use a cane, and they don't have to remember where things are all the time. I'm sort of a superhero [laugh]. [...] It's really about not seeing well, there's this other boy, he just uses a wheelchair, things are easier for him, the only thing is that he rolls instead of walking."*

In this category of narratives, interaction with the environment are difficult to entangle. There is the issue that classrooms and schools are not specifically designed for visually impaired children—note

<sup>24</sup> Nick Watson, "Theorising the Lives of Disabled Children: How Can Disability Theory Help?"

<sup>25</sup> Why not use anonymized first names and provide a table summarizing participant characteristics? It would have been in line with ethnographic narrative techniques. First, it seemed problematic to describe children by first names given that I designate carers, for anonymization purposes, by their role.

that their own spaces (e.g., desks) are supposed to be adapted. But children also point out the inherent constraints of school

Ch6; Female low-vision general education secondary student; highly advantaged group: *"I like it a lot, and I have my friends there, so it's really good [...] but at the end of the day, it's just so exhausting [...] I like learning and when things are challenging, but at school, there's so many stupid rules you have to follow even if they're not useful, and everything is rigid, and students always have to adapt, and no one cares that I don't see... That's good I suppose but sometimes I feel like I'm going to break. [...] I fell asleep in the middle of the day. Anyway, I shouldn't complain."*

Here, resilience is more defined as an adaptation in front of "life in general"<sup>26</sup>, or more specifically school in general, rather than the barriers associated with disability. She equates her problems with those of her peers, even though she suggests that her impairment makes it worse. She has specific criticisms about school, which she detailed during the interview about weekly planning, unexpected changes of teachers and classrooms, lack of opportunities for self-determination... In contrast, others express feeling that school is an adversarial space, not specifically tied to an event but rather to its ambiance can be found in this discussion:

Ch7; Male low vision general education primary student; advantaged group: *"I don't want to talk about school."*

E: *"Okay. Do you want to tell me why not?"*

*"Because school doesn't like me. It likes normal students better. So I don't like it. But there's nothing much to say. I go to school, I do the school stuff I've got to do."*

E: *"Can you remember the last thing that happened that made you feel like school doesn't like you?"*

*"Not really. It's like, in the air. It sucks energy out of you. But there's nothing much to say, I just feel that way. It's silly, I know."*

E: *"I don't think this is silly."*

(pauses) *"It's like... It's like there are Dementors<sup>27</sup> but you can't see them. See, that's silly. I'm just telling myself stories."*

I find interesting that in both examples, children attempt to minimize their experiences. *"I shouldn't complain"* makes reference to difficulties experienced by other students, either in terms of academic achievement or to get access to pedagogical material (i.e., as discussed later in the interview *"more disabled"*). Whereas the second excerpt shows a first self-dismissal (*"It's silly"*) and closes with another (*"just telling myself stories"*). We could presume that children

<sup>26</sup> Patterson, "Understanding family resilience", p. 237.

<sup>27</sup> Dementors are characters from popular children's books and movies Harry Potter. They are magical creatures absorbing positive emotions in the humans they are around of. Harry Potter was mentioned in several interviews by children of different ages. As Illouz argues about another best-selling book series, it resonates particularly well with the experiences and emotions of these children. Note that Sanders' ethnography with children in 2001 find them interested in Harry Potter, but they do not use it to explain their own experiences. Illouz, *Hard-core romance: "Fifty Shades of Grey," best-sellers, and society*; J. Sanders, *Subject Child: The Everyday Experiences of a Group of Small Town Aotearoa/New Zealand Children*.

exaggerate and then nuance their opinions. However, an alternative explanation would be that at first children assume that narratives about resilience are not welcomed by the researcher / adult or are not legitimate<sup>28</sup>. The fact of preemptively minimizing what they say is also a mean of getting reassurance I will not mock what they say.

<sup>28</sup> See also Chapter 9.

### Neglect and barriers to participation

Exhaustion was also associated to adapt to boredom and lack of stimulation due to barriers to doing, in this case barriers to participation. My observations in primary school general education classrooms suggested that teachers solicit the participation of visibly disabled children<sup>29</sup> less often than the participation of their able-bodied peers. The same issue was repeatedly pointed out by special education teachers. Here is an example of what children have to say about it—and notice the fact that the socio-occupational status of his parents is lower than in the above examples<sup>30</sup>:

<sup>29</sup> In some general education classrooms, I was able to observe interactions with children with other types of impairments.

<sup>30</sup> See Chapter 6 for an overview of how the social class groups are defined.

Ch1; Male blind general education secondary school student; disadvantaged group: *"I sit at the back of the class, the teachers don't give a sh\*\* about me, I wait until it's over. School just pisses me off, and it still makes me feel flat."*

Past field research have suggested that teachers respond more negatively to children coming from disadvantaged families<sup>31</sup>. But the feeling of being neglected by teachers was shared by children from all groups. The difference seems that children use different resources to interpret and react to this issue. In particular, they use different discursive resources: we have seen the use of fiction (Harry Potter), the use of a **language of rights** in Chapter 2, but it may also pass by rejection and verbal devaluation.

<sup>31</sup> More precisely, perceptions vary with the context. Teachers focus on familial and cultural practices in some cases, and on income in others. In the case of my study, there is often, but not always, conflation of familial practices and occupational social status—and perceived income Thompson, McNicholl, and Menter, "Student teachers' perceptions of poverty and educational achievement"; Halvorsen, Lee, and Andrade, "A mixed-method study of teachers' attitudes about teaching in urban and low-income schools".

### Paradox around support and lack of support

Exhaustion can also be attributed to a lack of support (e.g., of a human assistant, who could offset it to enabling focus on school work). However, the relation is probably more complex, as illustrated by this excerpt:

Ch2; Female low-vision general education primary school student; middle class group: *"It's easy for the [sighted] to find things in their bag and on the table, or to eat and so on. Me, I have to be organized, all the time, I have to never forget a thing. On weekends, I can finally relax. So... I'd say that the thing with school is that it's very very very tiring [...] Sometimes I wish there was someone to do all these things for me, but I think I'd hate*

that. Imagine when someone does EVERYTHING for you? I prefer being tired. [...] Also there's often someone to help me anyway, I'm sitting with a friend, she knows when to help.<sup>32</sup>"

Here, needing assistance on normal tasks is devalued, but not giving devalued tasks to others. The same child commented in another occasion on the fact that when she would be an adult, she could have someone cleaning for her because she would not be seeing well enough. Putting some distance with someone assisting, or inscribing assistance as an aspect of friendship makes it acceptable. Resilience here is about asserting competence—although it passes by distinguishing oneself from those doing devalued work, as do children in general<sup>33</sup>. We can suppose here that this is a fear to be excluded by their peers who do not receive assistance, but also the fact that they try to distinguish themselves from unwanted social positions<sup>34</sup>.

Summary One (S1): Children's narratives about their experiences and emotions at school revolving around exhaustion provide interesting examples to (1) discussing resilience from children's points of view and (2) identifying coping strategies that would sometimes not be considered positive (e.g., dismissing someone perceived as having a lower social status) but do have a positive impact on the personal level. The following section identifies and discusses another categories of narratives about resilience. Those that identify school as a battle or a hardship and how to prepare for it.

### 10.3.2 School as a battle

One of the most recurrent metaphor in children's narratives about school was "*the battle*," to be fought, won or lost. This includes narratives about specific "*fight*," but also more generally about "*being tough*" and being tested for resistance. An adversity that does not necessarily result from academic or socialization difficulties, but rather from enduring adversarial attitudes beyond a close circle.

#### The battle for good grades

In the first excerpt below, the participant insists getting good grades is what matters. She also said having friends, although observations suggest she is isolated (playing alone during break time, hardly participating to small groups discussions occurring in the classroom). In the second excerpt, the means to resist bullying is explicitly to have friends, but also to be a better student.

Ch3; Female blind general education primary school student;

<sup>32</sup> The issue of dependence and interdependence is a rich perspective for future design research.

<sup>33</sup> Borgen and R. A. Young, "Career perceptions of children and adolescents".

<sup>34</sup> Note that the expression "*the assisted*" (French: "*les assistés*") serves to designate pejoratively people receiving welfare subsidies.



Figure 10.2: The service dog of the IJA. Sometimes, having a service dog at school helps initiating peer relationships.

highly advantaged group: *"When I go to school, it's like I'm putting a big armor on. [...] But I have good grades, that's the only thing that matters, I think."*

Ch4; Male blind general education high school student; advantaged group: *"My friends defend me against the others, it still hurts, what they say, but it also feels good, that I have friends who defend me. I didn't have friends like that before, it's different since I'm in secondary school, they listened to what was said about visual impairments and stuff. They're like, my private army [laugh]."*

"The others" in that latter excerpt are boys from other classrooms or grades that pick up on him regularly during break time and lunch. I highlight in Chapter 6 that multiple studies suggest disabled children are more likely to be bullied than their non-disabled peers. Here however, the participant complicated the account:

E, reformulation of the two explanations given by the participant in the interview *"So you think those others pick up on you because you're blind, and they don't understand it, because they didn't have the same, erm, disability awareness talks that your class got?"*

Ch4: *"Ah, no, they pick up on me because they're jealous. Well, I think it's because they're jealous. They thought that as I was blind I was dumb, but they're way dumber than I am, you can know that from how they speak! I just have to be better than them"*

The participant here evokes the same hierarchy of disability outlined in the above section (better to be blind than to have learning difficulties); but also the fact he perceives that barriers are erected against him because he does not correspond to the stereotypes associated with disability (not performing well academically). Being resilient at school here entails mobilizing discursive and relational resources to resist stereotypes—while also reproducing them by attributing them to another group. This illustrates well the point of E. J. Hutcheon<sup>35</sup> about the need to think about resilience on a group level. It also supports the importance in disability studies of exploring the intersection of disability experience and larger social factors: the above excerpt hint at complex interactions involving the intersection of class and disability in differentiating children socially<sup>36</sup> through time. As this excerpt reveals, the dynamics can change with the school children attend.

<sup>35</sup> E. J. Hutcheon, *"Crippling" Resilience: Generating New Vocabularies of Resilience from Narratives of Post-Secondary Students Who Experience Disability*.

<sup>36</sup> Jenkins, "Disability and Social Stratification"; Marlies Kustatscher, "Young Children's Social Class Identities in Everyday Life at Primary School: The Importance of Naming and Challenging Complex Inequalities".

### Gendered battles

Another aspect of these narratives I think requires discussion, also related to intersectionality, is the gendered differentiation of expe-



riences. In the narratives and observations related to this themes, girls take a position of defense (as the first excerpt above), including avoidance. Boys on the other hand were a lot more likely to describe a position of attack (which, during observations, for instance translated in showing clenched fists to another child). On the other hand, I have not collected any narratives or observations related to girls that would indicate they find this to be a failure to cope or manage. Whereas boys in that situation often offered statement about not being "strong," "tough" or "winner" enough. For instance:

Ch8; Male low-vision with additional impairments general/special education primary school student; advantaged group *"School doesn't care when I don't hear and when I don't understand. Then I get yelled at [...] it makes me feel so bad [...] I'm not tough enough, you know?"*

This quote offers an interesting counterpoint to narratives about exhaustion. It describes a precise group of events that make school an adversarial space. Then the child hints at the fact that he does not think he manages the situation well, because it makes him feel bad, instead of making him tough. What makes these narratives different from those I classified as being on exhaustion is that children do not attempt to minimize their stories. Having a specific and clear-cut incident to point out as problematic as well as telling a story of resistance may explain these differences. I discuss this further in the section about carers' discourses who frame resilience in a similar way.

### **Fighting with one's friends over perceived abilities**

When they (re-)create a hierarchy following perceived abilities, children oppose judgments or attitudes that may characterize them as underperforming. It is a recurrent topic in most of the excerpts in this chapter.

Ch9; Male low vision with other impairments general/special education primary school student; disadvantaged group: *"School makes me feel like I'm slow, and like I'm stupid. And I'm not."*

E: *"Did something happen that made you feel that way?"*

*"Why do you want to know that?"*

[He walks a little away from me]

E: *"We can stop talking about that if you want. I'm just asking to better understand how you feel at school and how maybe we could change that in the future..."*

[I re-explain the purpose of the research, as well as confidentiality, then propose to go play a game instead of talking.]

*"Nah, okay. I'm always picked on by the others, even my friends, when I have more time for exams. Even the teacher makes fun of me sometimes. So I fight back, I tell them they're stupid too [...] I feel like I never say or do the right thing."*

This excerpt highlights the nuances of what constitutes a successful socialization. This child is not considered to have problems socializing. Yet, he described many occurrences of bullying or difficulties to manage friendships with other children. Other themes were discussed above, but I believe the last sentence merits attention: *"say or do the right thing"* refers to a floating norm about behavior, that I could not get a description of when asking children. But it appears to be shared:

Ch10; Male low vision with other impairments general/special education secondary school student; disadvantaged group: *"Did you like school, when you were my age?"*

E: *"Not really... In fact, I very much disliked going to school."*

*"I can tell you then. You understand<sup>37</sup>. Sometimes, I very much want to break everything. All the things."*

E: *"Why do you want to do that?"*

*"It' like, it's like I'm trapped! I'm never, ever ever, I'll never win."*

E: *"What is there to win?"*

*"At tests, you can always do better at tests they say. And I'll never be cool 'coz I'm too weird."*

In this excerpt, the norm to reach is quite narrow: being *"cool"* refers to achieving a pretty high status at school. Many can have friends, but few can be cool. Similarly, passing tests is not enough. This hints at complex negotiations around expectations about and at school (discussed in Chapter 11. It may also point out the difficulty to achieve more than mere inclusion in general education schools. Note that these two excerpts are consistent with my previous remark about the gendered narratives of battle.

The excerpt below provides an interesting example of how a negative experience of school may be interpreted later in life. It comes from the testimony by a young adult with low vision who received services in this organization as a child:

*"The kids at school, they were really hard on me [...] I didn't have friends, not before going to University. [...] My schedule was so full, sometimes I really had to let off steam, often to the detriment of my teachers. I'd say, I'm sorry to have been such a pain in the \*ss! [...] It's good [the IJA's carers] were there, they opened opportunities for me [...] If one wants to succeed,*

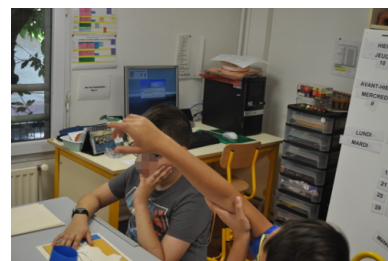


Figure 10.3: Raising hands in a special education classroom.

<sup>37</sup> See my remark in the previous section about narratives and their legitimacy.

*one has to make sacrifices, to suffer."*

I would argue that narratives surround voluntary suffering (sacrifices) is a corollary of school being described and approached as a battleground. It also fuels my above argument about the fact that self-narratives adhering to this framework are more legitimate than those about exhaustion and privileging comfort. It also shows how they can last through time, way after difficulties were dealt with.

S2: a first category of narratives on experiences of school describe it as an overall adversarial space and time, but either for unarticulated reasons or because of difficulties associated primarily with visual impairments. Children perceive they fare well, and minimize their own negative emotions. In contrast, this second category of narratives depicts school as a battleground, where one needs an "armor" or a "private army." The barriers and difficulties were here well defined, and often caused by barriers to being imposed by adversarial attitudes of their carers or peers. These narratives seem more legitimate for children, who do not minimize them.

### **School as pain**

Which leads me to the last theme identified in interviews about school: the feeling of pain. It was much less present than the theme of exhaustion or battle. The pain reported was physical, and associated with negative feelings. Both interviews mentioning it were conducted with boys attending primary school. Both refused to expand on why they felt pain. In both cases, they also declined to talk about their family or friends, but talked at length about their subjects of interests, or adults they liked in the organization.

Ch11; Male blind with other impairments special classroom in a general education school; disadvantaged group: *"I don't want to think about school... It makes me feel sad."*

[We changed the topic for a while. When I was about to end the interview:]

*"About school... it makes my stomach ache you know."*

E: *"Does it ache all the time?"*

*"No, and it's not because I eat too much!! I tell you because [someone] told me that once."*

Ch12; Male low vision general education primary school student; disadvantaged group: *"I don't want to talk about school, it makes my head hurt."*

E: *“Is it school that makes your head hurt?”*

*“Yes, and I don’t want to talk about it”*

E: *“Okay. And how do you feel here?”*

*“Oh, here, it’s quite good. Can we go play?”*

There is a clear difference between these narratives on pain, and those on battle. Here children refuse to talk about it. They had a very clear body language suggested it was distressing: one turned away and grabbed an object to fiddle with; The other became very agitated. I could not observe these children in their general education classrooms, but it seems according to other parts of their interviews that they experienced additional barriers, in this case repeated bullying and negligent families. It plays in a specific way in general education schools, as they had no issues with talking about their time at the organization, a special education school.

S3: In contrast with the two previous themes, some children’s main description of school consists in associating it with physical pain. It was not minimized, but avoided altogether. It appears they faced more significant barriers both at home and school, although getting interested in a specific school subject was a useful strategy to cope. These two children hint at the importance of separated spaces as okay spaces.

### 10.3.3 *A note on special education and separated space / time*

In addition to rehabilitation sessions, many of the children who attend a general education school also have one-on-one tutoring by a specialized teachers, as well as special tutoring in small groups for acquiring or developing their braille skills, learning to read tactile documents etc. This time was contrasted with time in general education school as a relief, or a respite, or even a more qualitative time. This is particularly interesting because it breaks with the dichotomy between general and special education environments and outlines that children might well, knowing both, prefer special education schools. Interestingly, this is a very mixed group, in terms of gender, age and social origin. This is discussed more extensively in Chapter 11, which proposes a reading of these preferences completed with how children would like school to change.

Ch5; Male blind general/special education secondary school student; advantaged group: *“They thought it’s too hard for me to do everything [i.e. school and rehabilitation] at the same time, so I take part of the courses this year, and the other part next year.”*



Figure 10.4: Batuca’braille, the drums and percussions band of the IJA, playing at the ‘Fête de la Musique’.

E: *“And do you think that too? How is it working so far?”*

*“Better! I have more time. I feel like I understand things better too. Well, that the teachers explain better, so I understand things better.”*

Exceptions were made if going to the IJA occurred during a unusual school activity. For instance:

Ch13; Male blind general/special education primary school student; disadvantaged group: *“Last week, I had to be here and work, while the others were going to the movie theater! That was really unfair.”*

It really is on the perceived quality of learning that perceptions differ<sup>38</sup>—and on the affective resources available in separated spaces. Regarding children attending a special education classroom most of the time, within a general education school walls or not, they were overall quite positive about how they felt at school. This group of children preferred a day at school to a weekend day. On the other hand, about half of these children also hinted they were uncomfortable in their familial environment. They were also more likely to say that they did not have many activities or friends outside of the organization. For instance:

Ch13; Male blind with other impairments attending a special classroom in a general education primary school; disadvantaged group: *“I would like, really really like, to have [my specialized teacher] with me all the time at school.”*

E: *“Oh yeah? Why’s that?”*

*“She’s soooo nice. I like her a lot.”*

S4: Children’s narratives about their school experiences often revolve around their difficulties and their ways of coping. This might be because they want to take the discussion as an opportunity to figure problems out, but is most likely fueled by the barriers they keep facing. These narratives can be classified along three themes: exhaustion, battle and pain. The first two are more widespread, and suggest two different ways of talking about adaptation at school. The first is less legitimate than the second, at least when they discuss with me (S1 & S2). The last theme, pain was evoked by children facing multiple barriers at home and at school (S3). All of these narratives point to a variety of resources (discursive, relational etc), which are not always found where the literature suggests they are. Affective and relational resources for instance seem to be sometimes easier to find in separated spaces than in mainstream ones (S3). This is consistent with Goffman’s observation that disabled people may withdraw to protected spaces in which their stigma is accepted<sup>39</sup> but seems to contrast with the lack of friendships, identified by Connors and

<sup>38</sup> Note that in Revillard’s interviews with disabled young adults, a visually impaired interviewee who experienced both general and special education found the later to have lower academic expectations. However, her interviews concerned a different organization. Revillard, “La Réception Des Politiques Du Handicap: Une Approche Par Entretiens Biographiques”.

<sup>39</sup> Goffman, *Stigma: Notes on the Management of Spoiled Identity*.

Stalker<sup>40</sup>, in children attending special education schools or other separated educational organizations.

Within and across these categories, I also identified how class and gender play in children's experiences and coping strategies. Social class, defined by the family referent's occupational status, is especially often mobilized by children to differentiate themselves positively (S2). As a side note, although many of these children have human assistants at school, they barely mentioned them. Given the complex feelings associated with assistance (S1), this would be a topic to explore further.

<sup>40</sup> Connors and Stalker, "Children's Experiences of Disability – Pointers to a Social Model of Childhood Disability".

#### 10.4 *Positing the Children are at Risk: the Carers' Views*

*The children must be molded shaped and taught  
That life's a looming battle to be faced and fought  
Mr Banks, Mary Poppins the movie, 1964*

However, to have a full picture, examining how their carers shape discourses on coping, resistance and achievement.

##### 10.4.1 *Groups of carers*

I distinguish between five groups of carers throughout the dissertation: teachers<sup>41</sup>, teacher assistant (e.g., the librarian, document makers, children's assistants), social educators, therapists (e.g., orientation and mobility, occupational, or low vision therapists) and parents. I hint at this distinction in the first Chapter, and expand this in Chapter 8. To summarize, although they sometimes overlap (the librarian effectively acts as teacher several hours per week, special education teachers may feel more or less close to educators, therapists develop projects with teachers, but some teachers rather work with educators, etc.) they have different points of views, well illustrated by the following extracts:

Educator: *"We say stop when we see that teachers are pushing too much, and that the child feels overwhelmed."*

Teacher: *"There's a safeguard: we're attentive to the child's suffering."*

Assistant teacher: *"We want them to succeed in what they want to do, to be proud of what they do, but our job isn't really to be close to the children."*

Therapist: *"My question is rather: would he feel well there?"*

They all evoke concerns for the well-being of children, but look at the situation from very different angles. Teachers are attentive

<sup>41</sup> As indicated in Chapter 4, I primarily interviewed special education teachers. They serve as relay between general education teachers and the organization, and sometimes intervene in the general education classroom for children experiencing difficulty. They also teach skills such as braille or reading tactile graphics. At the difference from regular teachers, they often follow the same child for several years.

to well-being at school, but it often is educators who insist there is an issue, whereas therapists look at it preventively rather than after the facts. Assistant teachers evoke the moral commitment they have to accompany children's academic trajectories, but a different involvement in children's lives. Although parents are often present in carers' and children's accounts, I have little material about them. They are thus little represented here. This might well be criticized on the basis that for non-disabled children, more attention would have been dedicated to this. I discuss it further in Chapter 16.

#### *10.4.2 Searching for resilience: Well-being and emotional management*

In this section I focus more closely on this topic. How is "well-being" defined? How do carers talk about feelings and emotional management in the classroom? These discourses resonate with children testimonies above, and help to understand the use and distribution of emotional resources (both theirs, and those of the children) during learning activities.

Overall, carers highlight two characteristics enabling a successful inclusion at school: motivation and emotional resilience. These are associated, in their accounts, with children's well-being. Carers identify psychological suffering as: (1) a risk of practices aiming to foster motivation and emotional resilience, (2) a product of their lack thereof, and (3) an obstacle to children's development.

#### **About motivation**

In carers' discourses, motivation is both described as a contextual feeling created by a given activity and as a characteristic: Teacher: *"They were very motivated by this lesson, they engaged a lot with the material, they were attentive, and so on."*

Educator: *"He is always motivated... He always try and learn new things."*

Many carers' discourses point at practices either trying to provide or shape emotional resources and management. Let's consider the following excerpts:

Teacher: *"I know he's afraid to give a wrong answer, and sometimes prefer not to do anything rather than doing something wrong. Then I try to reassure him, because that's pretty much the only thing that works, like 'Don't be afraid. I know you can do it!', because that really motivates him."*

Teacher: *"Him, he needs every activity to be embodied, he needs a hug,*

*or having his hand pressed to be encouraged... I really need to connect with him you see. I also refer to things and people he likes, his mother, his dogs... It grounds abstract activities in his reality, it keeps him motivated and focused, he's less anxious... [ . . . ] Yeah, if he doesn't feel well and relaxed, there's nothing I can do."*

Both evoke the teacher as an affective support for children, that can sustain motivation in learning. This contrasts with other research suggesting that teachers engage very differently with children depending on their (class, among other) characteristics. Note that the teacher quoted in the second excerpt adheres to the learning style theory, hence the "*every activity to be embodied*" in the first sentence. But she also connects it more broadly with a teaching approach careful about children's individual well-being, described as fundamental to learning progress. In contrast with practices of adding or encouraging, some also describe leveraging children's fears to not perform well academically successfully:

Teacher: *"She wouldn't concentrate or do her homework, she didn't make any efforts, and I know she's very worried to fail school and whatnot, so I told her: 'if you don't work more, you'll fail the test, and you won't go to the next grade. You might even go back to the previous one! With the smaller ones!' Well, I'm telling you, it worked! It's just what she was needed, a reason to be motivated."*

Here the teacher identifies a turning point in the schooling of a blind primary school student from the highly advantaged group. To contrast with S1, this child found all assistance legitimate—until being told it would compromise being and achieving normally. However, carers describe crossed effects of well-being and motivation: in their discourses, motivation improves well-being and vice-versa. On the other hand, they also highlighted the need to be careful regarding how to encourage children. The following quotes illustrate this link, as well as further associations with age, gender and perceived children's personality:

Therapist: *"It's more difficult with teenagers obviously, we don't often connect as well as we can with the younger, it's a difficult period regarding their well-being and self-esteem... We have to be very careful not to push them too much, to help them find new sources of motivations, but also keep continuity. [ . . . ] It's different for him, his parents are great, he's a great kid, very smart too, so we keep a really good relationship"*.

Educator: *"I think that there really are differences between boys and girls regarding motivation and schoolwork, like, girls really want to do well, so you can push them forward, they're motivated, and they'll be respectful and so on, even as teenagers, while boys really need more emotional sup-*



port... When things don't go well, they kind of block it inside, while girls manage better... I feel like girls have less difficulties to make friends, but more difficulties with their friends too, like fights and such<sup>42</sup>... [...] Although, don't get me wrong, there are many exceptions to that."

### About emotional resilience

These last excerpts well highlight carers' conceptions of how resilience works and is developed. As is the following which helps to explain children's conceptions of how to thrive at school:

Educator: "Basically, we want them to be more and more resistant to what people do and say, and also handling the frustration, as, hum, as they'll have to, because it's not easy, having an impairment. The tougher they get, the better for them, really..."

Teacher: "I can't seem to repeat enough that he's got to fight to succeed!"

Teacher: "We tend to protect them more, and longer, than other children, except that sometimes it gets really complicated because it really doesn't work out with the other children... For instance, crying at school. Do you imagine a teenager crying at school!? The other kids don't forgive this kind of things, and then obviously it makes our children's lives at school difficult... At some point, they really need to grow up and toughen up, and that's something I remind them of... [...] On the other hand, it's difficult, handling all of that at the same time, we have to be careful about how much we push in order not to break them [...] I used to think that just going to a normal school with normal kids and us around would do that but it isn't truly the case... Plus we invest a lot in these children, and some of the schools do to, but we don't exactly have enough resources to guarantee that long term."

The resources mentioned are material (financial means) but impact relational resources (availability of trained staff). It illustrated their experience and understanding of how to foster resilience in youth: "pushing" refers to the fact of being exigent towards children on the academic level or all strategies that enable to enter the workforce. It describes a community endeavor (that of the organization's staff and specific schools) to support these children, which lacks recognition and thus resources. Hence the focus on developing personal traits ("harden"). On the other hand, it identifies persisting barriers due to stigmatization and oppression (and consequent discriminatory or adversarial attitudes), which also lead them to privilege some coping behaviors and interventions ("not crying at school", providing psychological therapy) over others. Finally, the following excerpts point out the conditions for resilience carers feel are beyond their control:

<sup>42</sup> For a sociological perspective, see: Ringrose, "'Just Be Friends': Exposing the Limits of Educational Bully Discourses for Understanding Teen Girls' Heterosexualized Friendships and Conflicts".

Therapist: *“Sometimes it feels like nothing we do works [...] he’s completely demotivated, he gets upset for the silliest thing... Which doesn’t help him feeling good. Endless circle.”*

Educator: *“We did everything we could. We got her through school, we got her getting more and more autonomous, we gave her the emotional support, we thought she was fine, that we could reverse the fate. We couldn’t...”*

Teacher: *“The children for whom everything else goes well, they’re well. I mean, we intervene, and we intervene early, and that helps a lot in their development and so on, and we follow at every steps but in the end, if the family isn’t participating, it’s rare the children stay motivated. Although I don’t really know why some of them do, and the whole rest don’t.”*

This elicits professional rational and explanatory categories mobilized by carers. However, objectively, it is difficult to assess the extent to which familial and psychological characteristics of children affect their well-being at school, compared to the constraints that are placed on children.

S5: This section provides a counterpoint to children’s narratives reported in the previous section. First I would argue the similarity in the terms used by carers and children do indicate that the former’s conception of resilience is also mobilized by the latter. Yet whereas carers insist solely on children being tougher, their supportive roles, and the responsibility of parents, a lot less is done on the environment. Interventions in school to sensitize children’s peers are made, but most of the responsibility for adaptation is placed on the child, with a consciousness that other factors play in it (e.g., references to the influence of gender<sup>43</sup>), but without addressing the complex power dynamics children’s narratives reveal.

<sup>43</sup> For a discussion about the social construction of gender roles and the roles of fights in that construction, see:

## 10.5 Discussion and Implications

In this section, I first propose to further review the interest of resilience as a concept to examine this material. I then move on to a thematic discussion of these findings, and outline implications for design and sociology research.

### 10.5.1 Resilience and the school ecology

As pointed out at the beginning of this chapter, my interest for Ungar’s theory of resilience stemmed from the data itself. But on a theoretical level<sup>44</sup>, it provides a pretty robust ways to consider the

<sup>44</sup> See Chapter 13 for an extended discussion of using the concept of resilience in a social relational model of disability.

resources provided by different school and out-of-school environments and identify children's different ways to navigate these environments. It also encourages to question norms and beliefs about positive outcomes—without neglected embodied and emotions-filled accounts of experiences. Finally, it is oriented towards interventions (negotiations of resources) as are research participants and my research approach.

Contrasting children's and carers' points of view on resilience at school also enables to identify points of convergence. It is the case of narratives surrounding personal resilience: being strong, toughening up and similar discourses held by carers are either reused by children<sup>45</sup>, or translated figuratively, through evocations of battle, armor and army. But although carers state they are attentive to provide external resources and adapting to the time needed by some children, this temporal dimension rarely appears in children's narratives. They place emphasis on the current time or intrinsic characteristics ("*I'm not tough enough*"; "*I'll never be cool 'coz I'm too weird*"). The fact that adversarial attitudes are taken for granted by carers, and learning to ignore them a skill to develop, might well be a disservice, compared to emphasizing that changes are possible and that resilience has a strong environmental component. However, carers' justified concern about the scarcity of support and resources does not encourage this approach.

<sup>45</sup> Though I am cautious: as I am myself an adult, this is also part of what they think I expect.

### 10.5.2 *Rethinking special education and separated space / time*

I want to begin by emphasizing that I am not suggesting that special education for disabled children is better than inclusion in general education schools. At the risk of repeating myself and others, inclusion is a right and the role of the state to provide the necessary resources for this right to be effective. However, I think it is interesting to further analyze what are the larger factors leading children to sometimes prefer special education, or separated spaces and times. The children were primarily (though not only) coming from lower socioeconomic contexts, so we could hypothesize they are excluded in ways that make them prefer separated spaces. Often framed as less challenging on academic and social levels, thus reinforcing inequalities and not preparing well for adulthood<sup>46</sup>, children also benefit from higher level of resources (very small groups, teacher with whom they have strong relational affinity for several years) that are far from the norm in a general education school, or can hardly become the norm in the near future. Compared to children describing exclusion from general education classroom activities, it can actually

<sup>46</sup> J. Powell, "Constructing Disability and Social Inequality Early in the Life Course: The Case of Special Education in Germany and the United States".

lead to similar outcomes in the present context<sup>47</sup>. Hence, we could also hypothesize that children value their present well-being, or that these are resources they want to have access to, temporarily or not. I discuss the impact on children's outcomes further in Chapter 11. Meanwhile, let's underline that what these children say about schools deeply question inclusion policies as currently implemented.

<sup>47</sup> Lewi-Dumont, "Blind Teen-Age Students' Expectations".

### 10.5.3 *About social class and the hierarchy of disability*

In children's accounts, I have attempted to highlight how class is entangled with experiences of disability, and how children reproduce or contest social stratification. I think the way children associate social status and impairments with academic performance is an interesting insight. Scholars have pointed out their entanglement before: there is a "12-point to 18-point increase in Intelligence Quotient when children are adopted from working-class to middle-class homes"<sup>48</sup>; impairments prevalence and diagnosis vary from a class to another (see also Chapter 6), etc. But finding this idea in children's narratives may shed a new light on how this entanglement between class and disability is reproduced and maintained.

<sup>48</sup> Nisbett et al., "Intelligence: new findings and theoretical developments."

I would also underline that the feeling of being entitled to resources, that seems much more pregnant in more advantaged groups. This might explain differing perceptions of human assistance, and *in fine*, the quality of inclusion in the classroom when human assistance is needed. Finally, the underpinnings of the hierarchy of disability sustained by visually impaired children themselves (devaluing learning disabilities, themselves associated with class, to contrast them with visual impairments) deserve some thoughts. Specifically, it opens *collective ability-based* perspectives for design, where the focus is not on valuing individual abilities, but on developing benevolence towards different or complementary abilities.

### 10.5.4 *Implications for the sociology of disabled childhood*

The main implication for the sociology of disabled childhood is that it demonstrates the importance of class in mediating disabled children's experiences of school. It also highlights often overlooked aspects: even children who are considered to be well-adjusted by their teachers, and who do not identify their impairments as an issue, identify school as a rather adversarial space. Although children having mixed feelings about school<sup>49</sup> is common, but in this case it seems particularly acute<sup>50</sup>. Finally, one aspect might deserve particular attention: in several occasions children probed about my own

<sup>49</sup> J. Sanders, *Subject Child: The Everyday Experiences of a Group of Small Town Aotearoa/New Zealand Children*.

<sup>50</sup> This quantitative study on well-being in French schools for instance suggest that on average, pupils feel well at school. Bacro et al., "Bien-être perçu, performances scolaires et qualité de vie des enfants à l'école et au collège: étude longitudinale".

experiences of school, which I always answered with the fact that I did not like school<sup>51</sup>. Following this, children would tell their own negative stories about school. Did I bias their answers? Yes and no, or more precisely, differently from other ways of asking the same question. Carers' accounts about their own negative experiences of school I witnessed highlighted their own resilience with a motivational goal and minimized their difficulties. The fact that I did not do so might have opened the possibility of expressing this to an adult. However, one could also argue it prompted them to tell their own negative stories as a way of empathizing. To mitigate for this effect, I also asked them about positive stories about school, to little avail.

<sup>51</sup> See also Chapter 9 for a discussion on the impact of age.

### 10.5.5 Implications for design

I see two main implications for design. Conceptually, it enables to reframe assistive learning technologies as **resources**, not only for cognition or access purposes, but to be used to modify classroom dynamics more generally. By reintroducing the group in the process, it shifts from the dichotomy between designing for abilities and designing to address limitations. As it is at the core of the definition of assistive learning technologies, their design should be envisioned from the point of view of the disabled child. But based on which understanding of classroom dynamics? How could it reconfigure the categorizations made by children that impact relations in learning environments? I argue it is an invitation to think about how to articulate it with the Computer Supported Collaborative Learning field, "*centrally concerned with meaning and practices of meaning-making in the context of joint activity and the ways in which these practices are mediated through designed artifacts*<sup>52</sup>." Instead of framing needs at an individual level, the focus would be on intersubjective development of meaning in learning<sup>53</sup> and the relations and stratifications negotiated by children during and between learning activities<sup>54</sup>.

<sup>52</sup> Koschmann, "Dewey's Contribution to the Foundations of CSCL Research".

<sup>53</sup> Suthers, "Technology Affordances for Intersubjective Meaning Making: A Research Agenda for CSCL".

<sup>54</sup> Pollard, *The social world of pupil career: Strategic biographies through primary school*.

### 10.6 Summary

This chapter presents a first set of findings from my fieldwork, primarily in the realm of sociology. Specifically, I argue for using Ungar's concept of resilience to analyze children's experiences of school. I argued that children associate school with feeling exhausted, having to battle or being in pain, and primarily attribute their perceived success of failure to themselves. This seems in part fueled by their carers' understanding of resilience and legitimate fear of lack of resources. Additionally, I have started to highlight how children cate-

gorize themselves and others at school, particularly according to academic achievement. This led me to argue for a **group ability-based** approach to design, and the need to support alternative discourses about abilities.



# 11

## *Findings: Norms to uphold and resources for resilience*

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Ungar's theory of resilience provides a valuable approach to analyze this data, as it links individual embodied experiences (Chapter 10) to norms and beliefs (this chapter) and proposes to focus on the navigation and negotiation of resources. In this chapter, I thus answer the following research question: "What are the perceived goals of schooling and how do they shape the understanding of resilience hence the resources made available?" I want to make two arguments, which extend the discussion of Chapter 10: (1) Far from the hopes put in inclusive education, both children and carers recreate hierarchy of outcomes and abilities. However, I also show it creates dilemmas and attempts to avoid doing so; (2) I want to bring attention to the temporality of education. Current decisions are guided by the envisioned outcomes at adulthood—we need to work with the fact that children's well-being is evaluated against these goals.

From there, I expand more specifically on the technological resources used by children to develop resilience at school. Among other thing, I show how they can be used to challenge perceptions of competence. It provides further ground to discuss resilience and the social relational model of disability, as well as to reflect to what it brings to the literature in the follow-up discussion of this Part of the thesis.

### *Visual Overview*

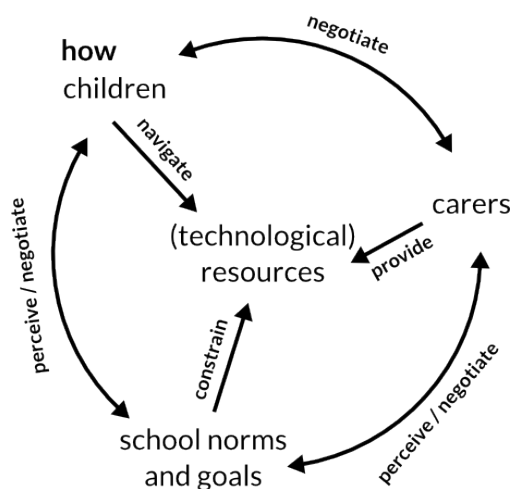


Figure 11.1: Chapter 11 discusses different aspects of children's resilience at school: the perceptions of school goals, which define by contrast who is resilient and who is not; and how children navigate and negotiate material (technological) resources to find different ways of doing—while pointing the limits of these resources.

## 11.1 *Study*

For details regarding the overall interviews methodology and analysis, see Chapter 4.

### 11.1.1 *Data Generation*

This chapter builds on interviews with carers about their professional roles (see Appendix A.3 and Chapter 4), which are described in Chapter 9; on biographical interviews with children, described below; on technological interviews with children; and on observations, including informal discussions with both children and carers. The outline for the interviews are described in Chapter 9 and 10.

#### **Technological interviews**

Technological interviews with children were semi-directive, and followed this overall outline:

- Asking about the technological objects used, if necessary by asking about times and spaces in which they can be used, e.g. classroom, school, home, during family reunions;
- Asking children what they would change in their lives if they had a magician's wand or a genie that could do anything, even things considered impossible.

The first question elicited many stories about uses of technologies. The second was inspired by Connors's and Stalker<sup>1</sup>'s work.

<sup>1</sup> Connors and Stalker, "Children's Experiences of Disability – Pointers to a Social Model of Childhood Disability".

### 11.1.2 *Data Analysis*

Following the thematic analysis approach introduced in Chapter 4, I coded the material described above using Quirkos. I used Ungar's typology of resources for resilience as a starting point for understanding the types of resources used for resilience; and I open-coded the excerpts relating to the goals of schooling. I first probed children's biographical interviews, and then technological interviews. I then coded and compared to carers' interviews. Finally, I probed discussions and observation reports for complementary insights.

## 11.2 Children's Views on Schooling Goals

### 11.2.1 Focus on learning, few words about breaks

A first finding about children's views is that in discussion and semi-structured interviews about schools (e.g., answering the question "so what should I know about school?" or "what do you prefer to do at school?"), their answers focused on learning activities and time in the classroom including the use of Assistive Learning Technologies. This contrasts with research made with non-disabled children, in which narratives tend to focus on interpersonal relationships<sup>2</sup>. This was true of children and teenagers of both genders, within all types of schooling modalities. As exemplified below:

Ch14; Female blind with additional impairments general education high school student; Highly advantaged group: *"My new teacher, she's really nice, and she gave us a book to read. I really like it, I almost finished it already, even though I don't have to. Is that the sort of thing you can tell you about? [...] I like French courses [i.e., grammar, orthography and literature] a lot. I even like it the most... uh, maybe. The poetry. But even the [conjugation] exercises! [laugh]"* [the interviews continue for 20 minutes on the curriculum and her academic interests]

Assistive technologies was another recurrent topic regarding time spent in the classroom. As noted in Chapters 6 and 7, many visually impaired children use some kind assistive learning technologies, most often an electronic braille notetaker or a computer equipped with a magnifier software. When mentioned, it often was in connection with technical failure. For instance:

Ch16; Male blind general/special education primary school student; middle class group: *"Right now my Mobi [electronic braille notetaker] isn't working so well. Once I had everything right, it didn't record, it's just as if I had failed! It's so annoying."*

Ch17; Male low vision general education secondary school student; middle class group: *"I have a computer now! It makes it so much easier. Except when it's not working, and no one knows why, and then it's a nightmare. Sometimes my teachers know this kind of thing, sometimes not. It's usually super silly, like once it just wasn't plugged in right."*

E: *"What do you do when that happens?"*

*"Erh, it's not like I can work without it by clicking the fingers. If I don't have it, I don't have the material, so I just have to wait... Once I asked for taking notes with my smartphone, but we're not allowed smartphones in class. Some people, they're kind of like they don't care I fail for that sorts of*

<sup>2</sup> E.g., J. Sanders, *Subject Child: The Everyday Experiences of a Group of Small Town Aotearoa/New Zealand Children*.



Figure 11.2: Reading a braille page—an electronic braille notetaker can be seen in the top-right corner.

*stupid reasons... I should be working, I want to work, and they don't even let me."*

Learning technologies are strongly entangled with the very possibility of learning in a general education classroom. But they require others' mastery and care. Another aspect to this story is that the material is not renewed often enough for financial reasons. Hence, the Mobi example above, where failure is associated with the device and felt as personal by the child was actually an issue created by insufficient governmental provision—an **invisible** barrier to doing and being from the point of view of children. Another aspect of this last excerpt I would like to point out is the relationship between school and work. Children quickly make judgments about the usefulness of what they like to learn, in relation with perceived impacts on future occupational status<sup>3</sup>. For instance:

Ch18; Male low vision special/general education primary school student; disadvantaged group: *"At school, I prefer history. But we don't have a lot of it, I guess because it's not, like, **real work and more like stories**. I really want to know more about the [French] Revolution, but the lesson is finished. My mom told me I could watch a movie on it, a documentary or something. You, do you know about the Revolution?"* (emphasis mine)

"French" (e.g., grammar, orthography, literacy) and mathematics are highly valued in a way that tend to contradict other works on primary school children's perception of curriculum areas. According to Dutrévis and Toczek<sup>4</sup>, there are strong expressed preferences for artistic activities and sport in that group. In contrast, they were never mentioned as favorite activities in my field work, maybe because those activities tend to be highly visual, but also because they often imply more group interactions. Indeed, break times, the other part of school where group interactions are important were rarely mentioned either.

In my first interviews, break time was almost absent. This was difficult to understand to me, because during observations, either in special or general classrooms, breaktime was expected (for instance by asking or trying to read the hour) and celebrated (e.g., *"Yes! At last!"*). So, when possible, I more specifically asked about break times, which often elicited only short answers.

Ch16; Male blind special/general education primary school student; middle class group: *"Break time? I like break-time. I get to rest."*

E: *"And would you like to tell me what you do during break time?"*

*"Nothing much. I talk with the others. It's better than my old school,*

<sup>3</sup> For a discussion of valued curriculum areas in France, see: Chambon, "La représentation des disciplines scolaires par les parents d'élèves: enjeux de valeurs, enjeux sociaux".

<sup>4</sup> Dutrévis and Toczek, "Perception des disciplines scolaires et sexe des élèves: le cas des enseignants et des élèves de l'école primaire en France".

*they used to insult me and beat me up. Here [at the care center] you can cycle and roll and things. At school I don't have that."*

Children integrated collectively were the most likely to change and avoid the subject. This was explained by observations in different mainstream, general education schools they attended. For instance, with a child attending a Clis<sup>5</sup> most often spends the whole break with the few other children off his class, in a corner of the playground:

*Observation notes: There were ball games happening in the center of the playground and involving mostly boys, and a "Jeu du loup"<sup>6</sup> around the ball games. On the margin, some groups of children engage in more static activities (I heard songs, charades and games based on language, such as having to guess a word based on clues). This is mostly girls. The student of the Clis mostly stay in their corner of the playground, near their classroom. At one point, the six children from the group spent a few minutes throwing and exchanging a ball. Mostly, they watched other children in the recreation area. He had a few verbal exchanges with the other children, about the ball, but he does not.*

The exclusion of children attending special education classrooms in a general education school is a documented phenomenon<sup>7</sup>. But exclusions when a child attends a general education classroom can be more subtle, and vary with their other characteristics (e.g., gender). For instance, ball games generally keep occupying the center of school recreational area, and largely remain a boy activity<sup>8</sup>. Girls were often able to take part in the peripheral activities described above. Meanwhile low vision boys were able to engage in ball games, but blind boys had to find a way around:

Ch20; Male blind general education high school student; highly advantaged group: *"The boys played ball, and I couldn't see it, so I couldn't play. Sometimes I stayed with the girls. One year, there was a boys group against soccer, I stayed with them. It got better when I went to secondary school, then I would just talk [...] They're not my friends friends. They're my school friends. I see my real friends on weekends."*

What emerged from many narratives about class and schoolmates is that they often are not the first socialization circle, which contrasts with empirical investigation with able-bodied children. This was true even of children attending the neighborhood school, but more so of boys. In contrast, friends tend to be formed by pursuing an extracurricular **special interest** (e.g., chess, dance, computer science), which then may ease socialization at school. For instance:

Ch21; Male low vision vocational education student; middle class group: *"I have more friends now that I've taken up hip-hop classes—we're*

<sup>5</sup> Clis is an acronym referring to special education classrooms located within general education schools. They are now named Ulis primaire.

<sup>6</sup> This is a game during which one child is designated as "the wolf". Every person the wolf touches becomes the new wolf. There are many variants to this game: some area may protect children from becoming wolf, it can be called otherwise etc.

<sup>7</sup> E.g., Lansade, "La Vision Des Inclus" Ethnographie d'un Dispositif d'inclusion Scolaire à Destination d'adolescents et Jeunes Adultes Désignés Handicapés Mentaux".

<sup>8</sup> Delalande, "La cour d'école: un lieu commun remarquable".

*not many, but the others admire what we do, they make a circle around us [to watch], it's pretty cool."*

To conclude with what children say about school and how it may inform us of what they find important at school: the fact that narratives focus on individual experiences of learning but avoid breaktime, except when prompted by the researcher, suggests a different pattern in the experiences of school. But it only suggests it. However, when asked, children were sometimes a lot more explicit.

### 11.2.2 *The future-oriented purposes of school*

Ch22; Female low vision general education primary student school; advantaged group: *"Doing great at school is very very important, if you don't, you'll have a bad job and you won't earn money, and you have to keep living with your parents, and you'll have a bad husband."*

This quote perfectly exemplifies the interest and pitfalls of asking direct research questions (in this case: "why, do you think, children have to go to school?"). On the one hand, it elicits unexpected but very evocative answers. On the other, an adult, even an other-adult, asking this questions may lead to answers made from what other adults say about school. Further along in the discussion after this excerpt, the participant commented about the fact she previously had this discussion with her mother. However, discussions about husbands and jobs were far from uncommon in informal discussions between girls. Given the fact that some of them have faced mockery over the fact that no husband would like to have a disabled wife, these kind of discussions to reassure or project themselves in these heteronormative futures. And in general, girls were a lot more likely than boys to emphasize the long terms goals of going to school. They associated going to school with access to independence:

Ch23; Female low vision general secondary school student; middle class group: *"School is that where you have to go to, so you get to a better place."*

E: *"Where is that better place?"*

*"Somewhere you can live alone, and you don't make your parents crazy."*

I could not pursue this discussion as it was time to go to lunch, but I note that the connection made between school and affective or marital life, and how it may itself intersect with class expectations about occupational status would be an interesting area for future research. In their narratives, education is necessary to enter the workforce **even more so with a disability**. Hence, an accrued

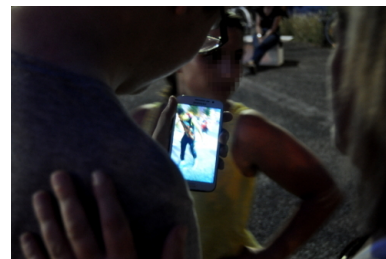


Figure 11.3: A teenager showing a video of him dancing hip-hop to an educator.

commitment<sup>9</sup> to school. In any case, children are pretty clear that these language elements spawn from carers, and more precisely overwhelmingly by their mothers. But they are reinterpreted and reused by children, in different ways:

Ch22; Female low vision general education primary school student; advantaged group: *"I'm not like, really disabled so it's easy for me. I go to a normal school [...] I embody diversity, like my mom says!"*

Ch25; Male blind general education primary school student; disadvantaged group: *"School is important. Do you know they had to pass a law so I can go to school? [...] [My teacher] says that before that, blind children weren't allowed there, can you believe it?!"*

Ch20; Male blind general education high school student; highly advantaged group: *"My mom says I'm lucky to go to school, because many children don't, and if I have good grades, I'll have a good job. But truly, I think it's to learn to act like if I was normal, to move like if I was normal."*

Other opinions were not as positive, and contrasted the activities they like at school with how they perceive school in general. These were almost always expressed by boys. The metaphors used were very vivid:

Ch18; Male low vision general/special education primary school student; middle class group. After a long positive discussion on history courses.

*"I don't really understand what school is about anyway. It's useless, what we learn."*

E: *"Okay. So why do children have to go to school, in your opinion?"*

*"To tame them, like if they were dogs. I've seen a circus dog with my cousin. School is the same thing for humans. Have you seen [the animated picture] Pinocchio? I saw it with my cousin. [We talk about Pinocchio] [The movie] lies. It's when children go to school that they become stupid donkeys."*

To understand the divergences between group of children, we might want to look at gender socialization, but we need to consider intersection with class<sup>10</sup>. Many of the desirable occupations considered accessible with a post-secondary education (e.g., administrative professions) are not familiar to all children. In contrast, piano tuning, chair caning, receptionist work were all taught within this organization and are relatively familiar to the children attending it<sup>11</sup>. These occupations are however not described by children as requiring an education. They do not make mandatory schooling meaningful or useful.

<sup>9</sup> Becker, "Notes on the concept of commitment".

<sup>10</sup> Which is the case for the so-called performance gap between the genders in general. See Chapter 5 as well as: Epstein, *Failing Boys?: Issues in Gender and Achievement*.

<sup>11</sup> This is changing. Some of these activities will soon be outsourced.

Underpinning this, is the in-between or paradoxical position children occupy<sup>12</sup>. They may attend general education classrooms but still feel largely (feeling) excluded. Or pass for sighted but deal with the practical issues of living with an impaired sight. Or they can perform like their sighted peers but their academic achievements are more crucial<sup>13</sup>. Or between current well-being, which is more of a focus in special education and future well-being procured by school. As phrased and quoted in Chapter 10: "*If one wants to succeed, one has to make sacrifices, to suffer.*" Although children do describe some learning activities as self-fulfilling and intrinsically interesting (see above with history), or as school as a mean of socialization and normalization ("*act like if I was normal*") overall their descriptions point towards a shared understanding of school as an entry point in the workforce—and incidentally, of culling and categorizing students to make them fit. Again, this is not a surprising finding, nor something that is specific to visually impaired or disabled youth<sup>14</sup>. But this hints to a specific way of managing the contradictory injunctions of school, by strongly integrating and focusing on academic expectations most often and in fewer cases to reject it altogether.

Finally, I note that this analysis would be very different if I was focusing on youth with late onset of visual impairments and were a lot more likely to develop strong feelings against rehabilitation and vocational education. They sometimes have the same age (18 to 20 years-old), but in this case, as Goffman points out, the loss of social status is a lot more significant. They have to re-socialize with this new identity in a short span of time, and in a less forgiving environment (teenage years) than children with an earlier onset.

### 11.2.3 Resources for resilience

In any case, the data reported here provides an overview of the multiple and complementary strategies that children deploy to navigate school. Let's revisit the examples developed in this section through Ungar<sup>15</sup>'s categorization of protective factors:

1. RELATIONSHIPS: Making friends can also mean making allies<sup>16</sup> and developing specific center of interests enables the formations of peer relationships;
2. A POWERFUL IDENTITY: Discourses about school as a battle contribute to convey and get recognition for one's abilities. Extracurricular activities also play a role by providing new means of identification and different change the perceptions of (dis)ability;

<sup>12</sup> See also: Porcelli et al., "(Micro)mobility, disability and resilience: exploring well-being among youth with physical disabilities".

<sup>13</sup> This anxiety about future occupation is not a specificity of disabled children. However, it does seem to be acute by the fact they anticipate the barriers they will face (rightly so). See also: V. Tadić et al., "Seeing It My Way: Living with Childhood Onset Visual Disability".

<sup>14</sup> Dubet, *Faits d'école*.

<sup>15</sup> Ungar, "The Social Ecology of Resilience: Addressing Contextual and Cultural Ambiguity of a Nascent Construct".

<sup>16</sup> See also Chapter 10, the example of "having a private army"



3. **PERSONAL CONTROL AND EFFICACY:** They seem to be gained through different means: developing interests for certain curriculum areas, getting more independence through the use of digital educational supports (for low-vision students), but also refusing to be "tamed";
4. **SOCIAL JUSTICE:** Hearing and reusing references to disability rights and law or to diversity policies seems to provide a sense of social justice;
5. **ACCESS TO MATERIAL RESOURCES:** Assistive learning technologies are important material resources sustaining the perception of personal efficacy in learning, but are highly fallible;
6. **SENSE OF COHESION:** There does not seem to be a strong sense of cohesion based on belonging to the group of visually impaired or disabled children (in contrast with Deaf culture for instance). Adopting extra-curricular centers of interests seems to support this trait, as well as investing strongly to fit heteronormative norms;
7. **CULTURAL ADHERENCE:** Children seem to share a belief in meritocracy, school as an equalizer—but this also have downsides, when they are confronted to what can be clearly understood as discrimination, or when high academic performance is not attainable. This is probably the least developed characteristics in their narratives.

The above examples highlight how the same resource can reinforce different factors (e.g., extracurricular activities can fuel personal identity and a sense of cohesion), but also the fact that the main shared norm is only attainable by a portion of children. It also suggests that children are indeed able to navigate multiple resources to, as one put it "*survive education*." If extracurricular activities are important resources for resilience, it necessitates to reflect on which activities are available to whom: blind skiing and hip-hop dance may both be physical activities, but correspond to different social positions and associated tastes. Finally, it highlights the personal, but not the relational, impacts of assistive learning technologies—on which I expand in the fourth section of this chapter. Let's now see how it compares to carers' views.

### 11.3 Carers' Views on Schooling Goals

Overall, in this section I argue that carers' views mirror the school functions outlined in the literature<sup>17</sup>: social integration through the

<sup>17</sup> E.g., Dubet and Martuccelli, "Théories de la socialisation et définitions sociologiques de l'école".

development of citizenship and common values and learning to establish peer relationships; preparing access to the workforce, including the early orientation based on perceived children's abilities and potential outcomes; and **in some cases**, intrinsic intellectual development<sup>18</sup>. Overall, I found less focus on curriculum knowledge and more on skills<sup>19</sup>. Yet, they also have a strong commitment to social justice. The necessity to be ambitious for children, to enable them to reach their full potential was a common topic—especially when children are perceived as at risk. I use the same five categories of carers exposed in Chapter 10.

Before moving on, I should remind the reader that so-called *incorporating* teachers<sup>20</sup>'s views are not well represented here, as the organization of my field work led me to spending considerably less time with them than with special education teachers. The differences with special education teachers are numerous: they have a classroom that includes one visually impaired pupil, who they rarely teach for more than a year<sup>21</sup>. This is a different commitment for them<sup>22</sup>.

<sup>18</sup> School also performs care so that parents can reintegrate the workforce and limit unemployment rate by keeping a number of teenagers and young adults out of the job market. It also is a mean of monitoring children's health and development. But this is not the focus here.

<sup>19</sup> This contrasts with earlier sociological research on education. See: Dubet, *Faits d'école*, p. 42.

<sup>20</sup> *Intégrant* in French. The mainstream school teachers who have a disabled child in their classroom

<sup>21</sup> Meanwhile, special education teachers often follow the same pupil for several years, or see them around the organization for a long time.

<sup>22</sup> Views about the purpose of the inclusion and schooling of disabled children are a lot more mixed in this subgroup. My data (observations, discussions, formal testimonies) suggests that: few exhibit openly adversarial attitudes, but may be very opened about trying to avoid "*getting the blind girl*" in their classroom; another group has little expectations for the children in their care, which translates into a lack of attention, or putting passive barriers. E.g., the above example of a teacher refusing the use of a smartphone to take notes; a third does little to adapt pedagogical means but otherwise integrate their pupils; a fourth insists on the moral obligation to collaborate with special education teachers.

A difficulty here is that the relationships I developed with these teachers are a lot more superficial. The interviews and discussions need to reflect well on them. However, practices of exclusion (ridiculing a student for instance) were not changed by my presence. In any case, the social differentiation of teachers in France and how it affects attitudes towards inclusion would be a fruitful topic to explore further<sup>23</sup>.

### 11.3.1 Outcomes: Focus on employment and citizenship

The best outcomes envisioned by carers differ from one child to another, based on comparisons with past similar children (similar in terms of measured abilities at a given age, impairments, and family context). The common component is having the possibility to participate in the community and live independently. The other main goal cited is to gain employment—which is not considered as achievable by all children. This is well illustrated by the following excerpt, but is recurrent throughout this section:

Educator: *"Our goal is that our kids grow up to be happy and feel well, because that would be true equality. And for some it means that they need to be able to choose their job, and having friends and family... and for others, that would probably be having a family and friends and being integrated in a neighborhood and maybe having a civic life? It's getting more difficult to get low-skilled jobs... And disability doesn't help... See that's why I think we need to protect welfare [disability] benefits, so they can do what they want to do even if that's just being with others, caring for others, even if they don't manage to get or keep an actual job."*

These envisioned outcomes are linked to the **perceived** severity of learning difficulties, and a child's attitude towards school i.e., their resilience:

Teacher: *"We never give up, but there are definitely children with whom we hit a limit, and there's no academic progress despite everything we try, and that's okay, not anyone needs to be a math genius, not everyone needs to go to university, but that means that most jobs will be inaccessible, and we have to think about what else they can or need to learn. I mean, there are a lot more accessible skilled jobs than low-skilled jobs when you're visually impaired. [...] We're very lucky, we have the support to try things out, like showing various workplaces and occupations to children. [...] Sometimes this limit is set by the accumulation of frustrations, at school and at home, and they don't want to invest more in learning... So it's about stimulating enough, but not stimulating too much."*

In other words, carers are constantly evaluating "limits" and

<sup>23</sup> There is research on teachers' attitudes and perceptions of the inclusion of disability students, but to my knowledge this is mostly self-reported—hence might miss the dissonance between discourses and practices. In any case, see also: Vaz et al., "Factors associated with primary school teachers' attitudes towards the inclusion of students with disabilities".

whether these limits should be considered physiological and requiring to change the norms and adapt interventions, or social in which case the norm does not have to be amended but alternative interventions may be more adequate. It complicates an analysis of the support of children with learning difficulties on a deficit to capacity spectrum<sup>24</sup>. Developing an alternative understanding of abilities may be equated with discrimination: i.e., not thinking pre-emptively that every child has the potential to achieve equally at school. But focusing on social conditions may obscure specific difficulties. So it turns into continuous re-adjustments and trials.

<sup>24</sup> Goodley, "Learning difficulties', the social model of disability and impairment: challenging epistemologies".

### 11.3.2 Reframing children's potential outcomes

Children's psychological state is understood as an interaction between their learning environment ("*stimulating enough, but not stimulating too much*"), and unexplained external factors generally associated with parental practices associated more or less explicitly with social class. I discussed this in Chapter 10, but with a more generic application. Here the excerpts focus on school and interactions with school:

*After a braille class, two teachers are discussing during lunch hour. I help with tidying the room. They review their pupils' advancement, and talk about a suspicion of familial maltreatment. The discussion turns towards the emotional difficulties of their jobs:*

A: "To be fair, it's not like ALL of our children have difficulties at school. I mean, I was relieved when they said we could have access to therapy at work, but it doesn't seem like something we [the teachers] all care about."

B: "Well, it's not like we all deal with the same children..."

[A nods in agreement]

B: "With this lot, the issue is the family you see... They really don't care about school [...] I don't know why some children manage and others don't. I come from a poor family, but we've always done good at school... Although my parents never fooled around when it was about school! [laugh]"

A: "But you'd think children change when they have teachers who care. And we care. So why doesn't it work?"

The perception of children's current abilities and future possibilities is described as varying between adults regarding the same children. However, there are multiple hints that these perceptions are challenged and renegotiated, both between carers and between carers and children:

Teacher: "Most parents, what they ask, is the kind of job their child is

going to be able to hold later [...] Unfortunately, some of them tend to have a restricted idea about what is accessible to their children, and they don't encourage them as much as their siblings. For instance, they don't care about homework, or think that manual work is automatically the way to go. I try changing that, giving [children] horizons."

Parent: "With us, this organization has gone above and beyond the call of duty, but that doesn't mean we haven't had our fights. [...] I suppose we kind of forced [his general education school teachers] to become flexible and respect how he does things. [...] I don't think they believe as much as we do in his potential. It's insidious really. They're nice and supportive, but they don't care if something isn't going well because, erm, how to put that... Because it's good enough for the blind kid."

Although it would be easy to assume that expectations are constantly lowered for disabled children, it does not well account for the construction of normative expectations and their subjectivity. They do have possibilities to redefine the oppositions made between autonomy and assistance:

Therapist: "She's not confident when it comes to moving independently, but I've come to understand to modulate my expectations: she does great for everything else, sometimes we need to remember things that seem important to us are not that important to [the children], at least at this moment in time. [...] True autonomy consists in knowing our own limits."

This resonates with one of the teenager stating in the previous section that school is for learning: "to act like if I was normal, to move like if I was normal." It shows, all in all, the thin line between lowered expectations, and normative expectations that can become detrimental. Ensuring fairness goes much further than inclusion in mainstream spaces, or even trying to develop and build on perceived child's strengths—given the fact that perceptions of these strengths are themselves biased (as discussed above).

### 11.3.3 Redefining autonomy and normative outcomes

As the last sentence of this quote suggests, carers were cautious with the notion of autonomy. Although autonomy in choices and independence is described as the main goal of education (see above), carers expressed the potential negative outcomes of policies emphasizing autonomy and equality only.

Therapist: "Autonomy here, autonomy there, autonomy everywhere! They're trying to cut the costs, I'm telling you."

Teacher: "One thing is for certain: I can't cover the whole curriculum."



Figure 11.4: A mobility and orientation training.

*So I ask myself: one day they will be adult, what will they need? What tools can I give them? How do I ensure they understand their environment, and that they can have a conversation? [...] It means constant trade-offs, particularly because children can surprise you, and it makes you reconsider what they can and cannot learn. [...] If I don't adapt the [curriculum] program, the problem is that they always feel like they're failing... I can say as much as I want that I believe in them, they're not stupid, they compare. So So I'd rather have them believing in their own ability to learn, and give them the time necessary, than pretending they haven't any specific difficulties."*

*Educator: "We are the ones who say stop. We say stop when we see that teachers are pushing too much, and that the child feels overwhelmed and suffer from this 'everybody can do the same' philosophy. [...] I'm not saying the goal isn't to develop their full academic potential. I'm just saying, sometimes we have a specific idea of what that is, and it can blind us from what the child needs at this point in time. And that's true of all children."*

#### 11.3.4 While defending equal rights

However, they also could be adamant about disability rights and specifically about the right to attend the neighborhood school:

*Teacher: "Integration in mainstream [general education] school is the best practice, but firstly it's their right [...] We can't wait for children to be ready to attend a mainstream classroom, because if we do, we'd never do it. It's not only about what they're going to learn, it's about social participation, and their life project. Inclusion is a right, for God's sake! [...] But there's a safeguard: we're attentive to the child's suffering. It's extremely demanding, and it's not like everything can be adapted for everyone..."*

so far paint a rich picture of the expectations about schooling and the extended core curriculum (e.g., navigating autonomously). It is sharply future-oriented: towards future employment, future socialization abilities, future integration in the community. There is also a prominent "discourses of rights", as I term it, which takes different forms. Some emphasize the right to attend a general education school; outline their concern for equality in other terms and their own understanding of equality ("grow up to be happy and feel well, because that would be true equality"); defend unconditional access to the disability allocation, etc. This goes hand in hand with a larger critical view of schooling and workforce contemporary structure: issues include the celebration of autonomy to withdraw welfare benefits, raised expectations for low-skilled jobs. It is interesting to note that some activities that are not framed as jobs (e.g. "care for others"), could actually be ones. What interests me the most are the (re)framings highlighted by carers. Some are initiated by children themselves, who

reformulate goals by conveying different expectations (the orientation and mobility example); others are made because of the identification of new abilities. However carers keep environmental barriers in mind and sometimes for granted (E.g., "*it's not like everything can be adapted for everyone...*"; "*why doesn't it work?*").

### 11.3.5 *Reshaping general education schooling by rethinking normative outcomes*

Therapist: "*I want to give them tools to think, but also comfort. Well-being. I want them to feel good in their bodies, regardless of their situation [...] sometimes it really is complicated, like, for [this child], his parents want him to go to a mainstream school. And they're right, it's his right, but, he just hates having to be still and he babbles a lot, so my question is rather: would he feel well there? Aren't there other occasions and places in which he can interact and learn with other children that don't require sitting down and listening for hours?*"

As in the excerpts above, carers question the norms they enforce—they also described very different attempts to make inclusive school a reality. It may imply both a reformulation of the aims, approaches and representations used in education. Some are so generic they could apply to all children—and indeed, as special education teachers are aware of social class inequalities in academic achievement:

Teacher: "*Take peer-teaching. It looks really good, but it can also quickly turn ugly: the other children get tired of it, sometimes they're just mean... It's also a weird situation to be in for our teenagers, because they're framed as in need to be helped, because it happens when they join a class. [...] It's not like collaboration is easy for children! We struggle to collaborate, but we're like 'oh, they can naturally do that!'*"

Teacher: "*And inclusion doesn't mean that there shouldn't be time to address specific difficulties, use specific techniques... Work with children's specificities rather than going against them. I'm not just talking about impairments. They're not equal in front of school, it's only normal we compensate for that.*"

I would argue that this is the spirit of the inclusive education law, but it also underlines the many micro difficulties in its execution. This takes us back to the issue, underlined in Chapter 8, that interventions should take into account the group when envisioned and designed. The focus then may be placed on culture.

### 11.3.6 *A non-visual culture?*

This last section highlights a final facet of inclusion and the goals of schooling: transmitting a visual and a non-visual culture.

Teacher: *"I'd say, teaching here is always a tension. On the one hand, we have to acknowledge [the students] need to integrate the common culture, which is made by and for sighted people. [...] But they have to share this world. I don't want to impose sighted people's representations, quite the contrary I think there can be a non-visual culture, and that it shouldn't be optional or a thing for the "high level blind"<sup>25</sup>. I'd rather invite exchanges."*

This is the only excerpt in which the inclusion of visually impaired children is explicitly associated with a clear change of the general education schooling culture. In general, inclusion is represented as something changing disabled children, not schools. However, it hints at the difficulties inclusion can create (see also Part 4).

### 11.3.7 *Resources for resilience*

In any case, the data reported here provides an overview of the multiple and complementary strategies deployed to support the resilience children with different abilities and backgrounds. Those are well in line with the protective factors identified by Ungar (discussed in Chapter 10). Let's revisit them using his categories:

1. **RELATIONSHIPS:** They encourage children to be ambitious, and suggesting potential future occupations requiring efforts<sup>26</sup> at school;
2. **A POWERFUL IDENTITY:** They try to underline children's abilities rather than differences with normative expectations and lead initiatives on disability sensitivity and awareness;
3. **PERSONAL CONTROL AND EFFICACY:** They attempt to adapt to children's preferences and priorities, notably by reformulating normative expectations<sup>27</sup>;
4. **SOCIAL JUSTICE:** They underline children's rights, and sometimes frame special education as a social justice issue, without necessarily focusing on a diagnosis or disability status. This also enables to address both social disadvantages and disability as risks;
5. **ACCESS TO MATERIAL RESOURCES:** They address the barriers placed in general education schools (attitudes and material resources);

<sup>25</sup> The expression "high level blind" refers to blind people who are considered autonomous, have often completed college education or have high academic achievements. High level is a literal translation, high functioning might well be a better translation if we were to compare this with the hierarchy of disability made for other impairments (e.g., "high functioning autistic"). They were also sometimes describe to me as "having overcome disability." The teacher here expresses her reservations about this notion: that there would be an innate difference between the blind and the visually impaired, but also that visually impaired people with additional impairments do not quite belong to this group. As phrased by another teacher: "There is a history of the blind, but it's different from the history of the severely disabled who are blind."

<sup>26</sup> Worth to be fighting for, as highlighted in Chapter 10

<sup>27</sup> Some elements, such as the opposition to discourses about overcoming disability, being quite in line with: E. J. Hutcheon, "Crippling" Resilience: Generating New Vocabularies of Resilience from Narratives of Post-Secondary Students Who Experience Disability.



6. **SENSE OF COHESION:** Developing a sensibility for non-visual culture in sighted people goes towards enabling a sense of belonging to the school community;
7. **CULTURAL ADHERENCE:** There is a shared adherence to meritocracy, while some propose that promoting a non-visual culture could be a step towards a *disability identity*. However, this is probably the factors the least present in carers' accounts.

#### 11.4 *Intersections and Divergences between Children's and Carers' Views*

Children's focus on school as a mean to access valued positions in the workforce echoes the position of carers. School plays a role in shaping citizens ("*civic life*"), but remains oriented towards occupational outcomes. Relationships with peers are welcomed but framed as dispensable, especially for high-achieving students. Interestingly, although many children do describe intrinsic interest in certain curriculum areas this is rarely mentioned by carers.

An aspect on which getting both children's carers' views is important are the barriers perceived in general education schools. Children identify and pinpoint adversarial attitudes (e.g., "*Children have to go to school [...] to [be tamed] like if they were dogs*"), whereas carers may diminish them ("*we work with what we have*" but "*why doesn't it work?*"), in part because they assume their own investment could or should overturn the problem. Furthermore, as we have seen, carers and especially teachers have an ambiguous relationship with the notion of well-being. Mainstream spaces are excluding on many levels and are going to threaten children's well-being. However, navigating these spaces is a right and helping them doing so a moral obligation. They attempt reshaping them through multiple means<sup>28</sup>, but ultimately have a limited impact. To achieve ideals of justice, they focus on what seem the most straightforward: individual dimensions, understood as resistance to ableist exclusion and stereotypes.

It is probably worthwhile to underline that the *community* aspect of Ungar's theory is a lot less developed. The concept of neighborhood life is evoked by one educator and this organization can be understood as a community, with networks of parents, alumni and an adapted neighborhood (see also Chapter 8). But it resonates a lot differently in France<sup>29</sup>, where it is often pejoratively connoted as identity closure or sectarianism, against the national values of universalism. References to a non-visual culture are thus not quite equal to movements surrounding D/deaf culture or the neurodiverse

<sup>28</sup> E.g., changing attitudes, rationalizing educational support as going beyond special education. See the list made in the conclusion of the above section.

<sup>29</sup> Gouëset and Hoffmann, "Communautés, communautarisme. Un concept qui semble poser problème dans la géographie française".

movement, in that it remains aligned with the universalistic agenda of schools.

To conclude, I focus on the uneasy negotiation of expectations, the norms defining resilience, that I find the most interesting. When children perceive school as the way to join the workforce, but refuse (more or less temporarily) to engage in school work and find other interests, are they being resilient? If we were to support children in alternative pathways, would it not amplify inequalities of outcomes? This goes beyond disabled childhood studies, it questions school and ableist expectations of performance and interests. The dichotomies between low and high skills jobs, real school work and stories, serves to fuel larger inequalities<sup>30</sup>. Paradoxically, the fact that it is discussed openly about disabled children is part of the issue: without supporting life-long learning<sup>31</sup> and desired professional and educational changes, or in other words second chances, this only risks to further discriminate disabled people by confining them to lesser paid or more precarious jobs.

### 11.5 *Navigating and Negotiating Technologies at School*

I argue in Chapter 2 that well-being at school is framed as a priority by children, and in Chapter 10 that the conditions for well-being are far from achieved. Indeed, children and teenagers overwhelmingly frame general education schools as an adversarial and exclusionary environment, where social participation remains limited. I have further highlighted the negotiations ("*sacrifices*") made between current and expected future well-being, itself tightly associated with joining the workforce. In this context, I have outlined some of the many resources used and negotiated by children, as well as carers' views on the type of resources useful to create a school environment providing opportunities to develop resilience—but also contest or reshape normative goals of schools.

I now expand at how children navigate technological resources in a school context which ultimately points to design opportunities. Previously, I scratched the surface of this topic: Assistive Learning Technologies play a role in perceived self-efficacy and the fact they are highly fallible due to lack of support or replacement affects self-efficacy negatively; research on this topic rarely consider the classroom environment and dynamics (Chapter 5, 7 and 8); there might be opportunities to think about how they support *group-based abilities* and the recognition of multiple types of abilities (Chapter 8 and 9) without forgetting they are to primarily support disabled

<sup>30</sup> Among which the fact that 'low-skill' workers have a much shorter life span expectancy.

<sup>31</sup> Compared to other Western countries, a much lesser percentage of student complete a higher education diploma late in life. Gaide, "Être Mère et Étudiante En France : Se Confronter à Une Norme de Jeunesse Dans l'enseignement Supérieur."



Figure 11.5: A teenager using his braille note-taker, to charge his MP3 player.

children—and should not avoid taking into account the question of class (Chapter 6 & 10).

The findings presented here stems from my interviews focusing specifically on the use of technologies at school. To my question about what they would change if they had a magician's wand, teenagers often discussed what they would like to change without being prompted to. Most narratives referred to changes that should be made at school—others were about the family economic conditions (e.g. having a nice house, not having to work as much, being able to go on holidays). Only one child reported wishing to be able to see well, although five children also reported they previously thought that, when growing up, they would be able to see, or “*see far away.*” At school, the desired changes were relational and organizational, rather than about technologies. For instance:

*“I would like [my specialized teacher] to always be with me at school because she explains much better, and she’s very gentle with me.”*

*“I guess... I guess that, if there was only one thing I could change, I’d wish that I would have a true friend, and he would come with me at school... Yes, a true friend, someone who doesn’t lie, and helps, and knows to keep a secret.”*

*“Mind you, it’d be great if people didn’t act all weird when they understand I’m, erm, different. I can’t force people to think differently, but maybe there are things that can help, like advertisements or something like that.”*

*“I’d like for more things to be done for us, like I wouldn’t have to wait for book adaptations, and me and my parents wouldn’t have to worry about who will help me later...”*

However, as I argue below, children use new media and assistive technologies to establish relationships in multiple ways—that cannot be simply reduced to the slogan about technologies empowering disabled children. Especially given that access to these technologies depends on the family’s financial resources and that there is a pretty clear gender divide in strategies involving technological resources.

### 11.5.1 *New media and (extra)curricular interests*

The rise of accessible and small media players<sup>32</sup> opened new ways of consuming media at school: (audio) books, videos, music... These devices have a paradoxical status: on the one hand, their use is often taught by professional carers (especially the occupational therapist) because they are considered a necessity for independence and future access to work, thus aligned with normative goals of schooling. On

<sup>32</sup> Most often iPhones or iPods, considered as more accessible and less fallible than other devices, but also mp3 readers.

the other, alarmist discourses around screen time are pervasive. They can also be accused of diverting attention and energy from schooling but also from so-called normal socialization with classmates<sup>33</sup>.

Yet, they also enable to pursue curriculum-compatible interests outside of the classroom; and to develop extracurricular interests, opening new relational resources. This was particularly the case for girls, and for boys considered to **not** be resilient:

*Observation notes: At the documentation center. I'm sitting with a teenager downloading file up to his Mp3 reader. He's downloading an audio version of the fifth Harry Potter. He explained to me he got it for free, but doesn't want to explain how. We talk about upcoming movies, Harry Potter movie adaptations, which movie critics can be trusted and why. The librarian comes up to us and wants to show him a new service, making audio versions of newspapers. He refuses, because he can read what he wants with the screen reader and he doesn't see the point in reading newspapers. She insists it's important for his future life, being able to discuss at work and vote. He starts getting agitated and raises his voice [...] She renounces to get him interested in this new service. He finishes to download his files and leave. The librarian explains to me he's very difficult to interest and that he's doing really badly at school. She thought she could interest him newspapers since "it's not school work" and he reads about movies.*

I perceived his initial activity as developing valuable skills in terms of digital literacy. The librarian contested this interpretation and tried to redirect the interest towards the development of better identified professional and civic skills. This illustrates pretty well the difficulty of trying to provide adequate resources by carers. And the fact this teenager was not well able to connect his interests with long-term goals made his actions illegitimate in a formal education context (the documentation center).

It is the context that defines the legitimacy of using mobile devices. They remain forbidden in the classroom<sup>34</sup> and their uses are monitored albeit not always closely. Break time and the recreation area is one of the context where they are only loosely controlled:

Ch27; Female low-vision general education secondary school; middle class group: *"I'm often alone during breaks and... Well, it's cooler than, I don't know reading a book. It's less heavy too [laugh]. And you're alone when you read a book, but you're not alone on the internet [...] I listen to youtube, sometimes just fun stuff, sometimes history... [...] I feel like, on the internet, I could take my time to talk to people, and they wouldn't mock me."*

Here we have different types of content and a practice developing other forms of socialization. A strategy about which carers are

<sup>33</sup> See also: M. Alper, *Digital youth with disabilities*.

<sup>34</sup> Even if that impairs learning, as exemplified above.

cautious:

Educator: *"I mean... Yeah they're pretty good at meeting people on the internet, but if they're not interesting enough for the people around them, that's going to be a problem... So if they don't manage to join a group at school, yeah, I'm kind of worried, they'll never manage to make true friends... Or to deal with having colleagues and so on."*

Teacher: *"He's so self-centered, with his schoolmates, they have to obey him or he doesn't want to participate... I wouldn't want to encourage that."*

Yet later on, I observed the same girl discussing her favorite youtubers with another child, which points to the importance of these accessible devices to share a common youth culture. As hinted by the previous observations note, a successful socialization at school is also evaluated against its role in a future work environment. Carers orient towards the relational resources they think will be beneficial, whereas children negotiate resources aside—resources that can ultimately benefit school-based socialization. Let's now discuss how resources well accepted within the school can be used in a similar way.

### 11.5.2 Assistive technologies as cool objects

Several children pointed out the prototypes we developed were not so much for learning better, but for impressing their classmates:

Ch26; Male blind with other impairments special education classroom in a primary school; disadvantaged group: *"I hope they'll take it to my school because it's a thing only me, I'm the only student to have it."*

Ch8; Male low-vision with other impairments special/general education primary school student; advantaged group: *"It's a lot more fun than what they have, they're jealous!."*

Some popular devices can be used for accessibility purposes, and because of their unavailability to the majority of other students, mark a positive distinction. Such is the case of the Apple Watch, which several teenagers use for navigation and for feeling safe (from losing one's phone). At the beginning 2016, few teenagers owned an interactive watch, let alone an Apple Watch. But in this case, it is framed as an assistive product to convince their parents to get one from them—and framed as a luxury product with peers:

Ch20; Male blind general education high school student; highly advantaged group: *"I got an Apple Watch, and for once, being blind is not being a loser, it's getting what everybody else can't get. It's just really really cool. I don't have to tell them [his classmates] it's to help not panicking, but the teachers can't forbid it on me because I tell them it's for the disability,*



Figure 11.6: A blind teenager with an Apple Watch, listening to his iPhone.

*independence blah blah."*

Beyond the fact that the wow effect should not simply be disparaged, this is a good example of the negotiations conducted to assert a competence valued by adults (independence) different from the one valued by their peers (being able to trick adults into doing something they do not usually do). All that while retaining the benefits of not having to remember at all time where one's smartphone is, which guarantees to be able to contact someone if needed—a fear this teenager discussed at length during this discussion.

### 11.5.3 Technologies and demonstrating competence

Outside of demonstrating competence in learning activities, being skilled regarding the use of technologies can become a special ability, for which one gets recognition from one's peers. For instance, several teenagers outlined the benefits of using of popular devices in unexpected ways:

Ch32; Male blind general education secondary school; advantaged group: *"my smartphone makes me more-able and cooler than my [sighted] friends, because I can use it with a dark screen as if I was doing magic."*

This occurs outside of the classroom: smartphones are generally forbidden inside. But it can serve to transform the perception of non-visual means of using interactive devices. Non-visual interactions also provide original opportunities for disobedience, for belonging to the group of children through mischief:

Ch13; Male blind male general education primary school student; disadvantaged group: About his braille notetaker. *"I'm not the disabled, but the teacher is! He can't know what I'm doing, and I can play tricks [here, exchanging messages silently with a classmates]. And I am not punished because, you know, I'm blind, so they're nice."*

In both cases, technologies enable to achieve the same actions using different means, and offer different ways to belong in a peer group.

### 11.5.4 Navigating attitudes towards Assistive Learning Technologies

In contrast, adapted means for low-vision children could reveal a lot less attractive. Having to zoom on text was framed as *"baby like"* by a classmate of a secondary school student. They can be used to judge one's academic value—and as developed in Chapter 10, the associated social value. Whereas braille seems difficult, and braille



Figure 11.7: A visually impaired teenager looking closely at his iPhone.

notetakers well accepted, using a computer was often associated with cheating or benefiting from an undue advantage. As I have no example of full classrooms using laptops, it is hard to say whether it modifies this perception. However, there is certainly evidence suggesting so. In one case for example, a teenager mentioned that because he got electronic version of documents, he was able to share them with his classmates and to feel better accepted that way.

Furthermore, adversarial attitudes towards assistive learning technologies seem to occur in two main configurations: when a student performs too well or too badly. The first is illustrated by numerous narratives about classmates accusing one of cheating, or even of pretending to be visually impaired. The second by discourses about not deserving going to school. The reasoning is summed up in this quote: *"If even with a computer I'm stupid, I can't be helped"*. In these conditions committing to the use of Assistive Learning Technologies is necessarily complicated. Here again, it risks reinforcing social class inequalities. However, teenagers also highlighted the advantages of having a personal computer at home at a relatively young age, including for forming social ties.

#### 11.5.5 *Social ties online: belonging and exclusion*

This should not obfuscate situations in which technologies contribute to social exclusion. While social networks are used to develop out-of-school participation, it can also be a tool of harassment. This was particularly the case for blind teenagers. Snapchat<sup>35</sup> is little accessible and does not allow reading aloud the text added to images. Images mocking teenagers can circulate without they knowing their content as long as they do not ask for help. This is far from new: I inadvertently stumbled on Skyrock blog posts from 2004 harassing a former student receiving services from the same organization while researching inclusion before the 2005 law.

Most of the narratives on this subject come from girls. Some declared sharing content (particularly videos) via messaging apps with family and friends from the beginning of primary school. They gave it a peculiar importance, because it was qualitatively better than relations at school. A quote an excerpt discussed above:

*"I feel like, on the internet, I could take my time to talk to people, and they wouldn't mock me."*

In a few narratives, it provided the opportunity to connect with the wider blind community—albeit not without difficulties:

Ch20; Male blind general education high school student; highly

<sup>35</sup> A popular multimedia messaging app among teenagers.

advantaged group: *"I used to follow a blogger who's blind, that was pretty cool, and there was a forum and so on, but there's more and more blind people there, and it became shit. Blind people are mouches à merde<sup>36</sup>. [...] They're jealous, they can't let anything good happen to someone else who's blind. They post super mean sh\*t, I don't want to spend time with them!"*

<sup>36</sup> The literal translation would be sh\*t-eating flies.

I included this last excerpt because it extends my argument about the constantly re-established hierarchy of perceived outcomes in an informal learning context. It also contrasts with previous excerpts about online spaces enabling to equalize users. The conditions for this to happen are a lot more complex.

## 11.6 Summary

In this Chapter, I presented and discussed my findings about children's and carers' views on the goals of schooling. Schooling remains first and foremost a path towards **future** well-being and becoming a productive worker. It explains the choices made about the types of resources to provide or to use. Many examples from my material show the strong hierarchy of outcomes and abilities it requires to establish—but also diverse forms of protesting and reshaping when necessary the universalistic and visual-based approach generally adopted.

The case of technological resources was a productive example of the above mechanisms. Children lead complex negotiations to be able to use technologies as resources for their many purposes. Being able to justify their use by long-term normative benefits, for instance, is one of the strategy used. More largely, they can use technologies to develop relational ties when the school environment in which they spend an important part of their time does not provide them. These findings have empirical, theoretical and design implications, which are discussed in the next chapter.





## *General discussion of Part 3*

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In this chapter, I revisit the findings of Chapter 9 and 10 in light of the research literature and outline implications for design. In the first section, I discuss why I did not use 'race' or place in my analysis of children's resilience at school. I then develop a short theoretical discussion about how my use of the concept of resilience responds to Thomas' social relational research agenda. Finally, I attempt to weave together theoretical and empirical strands from the first three parts of the thesis, which motivates the fourth and final part of this dissertation. Specifically, I discuss how different school could be, and how the social relational model of disability and the concept of resilience can be used to provide *an* answer to this question.

### *12.1 Not Retaining 'Race' nor Place in Analysis*

I discuss in Chapter 5 how larger social factors (social class, gender, 'race' and place) should be taken into account when studying

disabled children's experiences. I have discussed gender and class in these two last Chapters (10 & 11), but not 'race' nor place. This section discusses why.

In my observations and interviews, carers never used 'race' nor immigration status as explanatory categories. There was only one case in which religion or cultural practices were used as an explanatory factor: a catholic family had told their child God punished humans by giving them a disability. In contrast, as discussed in Chapter 10, social class is very often referenced and can be associated with poorer parenting practices. The children never used these categories in describing their experiences of school either. I did make one observation (for instance observations of the differences of treatment between two non-white teenagers in a shop) hinting that being visibly disabled (cane, heavy glasses) may act as a protective factor against discrimination based on 'race' in everyday settings. Effects of feeling like belonging to a discriminated community should thus not be overlooked — but we first should verify if they feel like they belong to a different group, which I have no proof of. Overall, my field work does not support the hypothesis that 'race' is a useful explanatory category to understand experiences of school in this context. By this, I do not imply there are no intertwinement between 'race,' class and disability in France more largely, and between 'race' and class at school. Simply, I have no new elements to offer to support this argument.

One should not overlook the fact that me being white might have prevented this specific topic to emerge in my interviews with children, and that my presence may have prevented observations on this topic. For more perspectives on this issue: there is evidence that children from post-colonial immigrant families are more likely to attend underperforming schools and to come from families with lower socio-occupational status<sup>1</sup>. There is little evidence for systematic discriminations by teachers (e.g., through higher rates of punishment for instance), and differences in educational outcomes vary with gender<sup>2</sup>.

I did identify differences between rural, suburban and urban school settings, but too many differences within each group for risking to include this in the analysis. There are definitely pointers that they afford different opportunities for resilience. For instance, I first identified that children reported more freedom of movement in rural settings. Explanations were multiple: less traffic, and that they were more likely to have extended family networks, including siblings or cousins within the same age range they could visit. However, this does not coincide either with experiences reported by girls, nor with experiences of boys from the more privileged groups. In contrast, this

<sup>1</sup> There are no ethno-racial statistics in France. Only asking one's or one's parent's country of birth is allowed. See: [insee.fr/fr/information/2108548](http://insee.fr/fr/information/2108548)

<sup>2</sup> Lorcerie, "École et ethnicité en France: pour une approche systémique contextualisée".

group emphasized risks of getting lost. Moreover, without frequent public transportations, they were dependent on their parents, except sometimes for going to secondary school and back (using school buses). There also seemed to be differences following the severity of visual impairments: while children with low vision reported outdoor activities, blind children did not, or a lot less. In any case, it was rather difficult to tie with their narratives and my observations in schools. These results can nevertheless open research perspectives. Finally, it introduces the discussion of experiences of rural and urban settings by five children in Chapter 15.

## 12.2 *The Social Relational Model and Resilience*

In Chapter 3, I anchored my research in C. Thomas<sup>3</sup>'s social relational model of model (and research agenda) of disability. Thomas argues for better identifying the socio-emotional effects of disablism and exclusion, understanding the mechanisms of difference and specifying impairments and impairment effects, so as to inform policies and improve the inclusion of disabled people. So far in this thesis, I have mostly attempted to make empirical contributions. In this section I attempt to outline how Ungar's concept of resilience can be used for advancing a social relational research agenda—as well as empirical elements from my field work that echo Thomas' preoccupations.

<sup>3</sup> C. Thomas, "Developing the Social Relational in the Social Model of Disability: A Theoretical Agenda."

### 12.2.1 *Psycho-emotional dimensions of disability*

*"What is of particular interest here are the impacts and effects of the social behaviours that are enacted between the 'impaired' and the 'non-impaired', for example in familial relationships, in interactions in communities, and in encounters with health, welfare and educational services. Who has the power, and how is it wielded? What are the decisions made, the words said, the meanings conveyed, in these networks of relationships? And what are the effects on disabled individuals' sense of self, self-esteem, and existential security? [...] The psycho-emotional dimensions of disability have yet to be theorised; I have merely drawn attention to them. Where can we find the tools and methods for a full theoretical engagement with the social interactions and embodied processes that are involved in this form of disability?"*<sup>4</sup>

Thomas argues for the development of tools and methods to study the psycho-emotional dimensions of disability. I would argue that Ungar's Social Ecology Theory of resilience can be one of these tools. It fits within the social model of disability, in the sense that it shifts

<sup>4</sup> C. Thomas, "Developing the Social Relational in the Social Model of Disability: A Theoretical Agenda."

the focus from individual attributes and towards environmental attributes. Using his definition of resilience as a grid of analysis effectively revealed several of these matters. For instance, I could expand on how school threatens the sense of security—otherwise, there would not be so many narratives about having to protect oneself. In Chapter 10, I have attempted to show the embodied experiences of insecurity, expressed through clenched fists and huddling, recurring physical pain or feeling like if there were Dementors around. Their narratives and my observations also provide rich examples of the *"the decisions made, the words said, the meanings conveyed"* in peers and carers relationships at school and their impacts, on perceived self efficacy, on marital and affective perspectives.

My take is that, while carers see resilience as something that *builds up* at school, children perceive school as a *test* of their resilience. Given that the goals of schools and the skills thus considered valuable are somewhat narrow, the negotiations of resources between children and carers lead to multiple conflicts, especially when the tests seem impossible. Using Ungar's model of resilience, how can schools and policies transform to become spaces where one can become resilient?

### 12.2.2 *Theorizing Difference & Impairment Effects*

*"The unifying category 'disabled people', while of utility as a rallying cry in political struggle, soon came to be seen as problematic under closer analytical scrutiny. Questions were raised, for example: What are the qualifying criteria of being 'disabled', or 'non-disabled' – where are the boundaries drawn? [...] Making links, on our own terms, between the disability studies agenda and health inequality scholarship is an important move that is yet to be made. This would throw important light on the generation and distribution of impairment, and hence of disability, and would underline the connection between socio-economic disadvantage, illness, impairment, and disability, over the life course."<sup>5</sup>*

On these topics, I attempted to make two contributions. (1) Highlighting the strong heterogeneity of the group *visually impaired children* and how these differences shape interactions at school. (2) Shedding light on how impairments and class serve to discriminate children in a school environment.

(1) Children without additional impairments point out a few issues that can quite probably be called impairments effects: the cognitive load of being highly organized, of reading, and the associated fatigue. But most of the narratives that could be considered as show-

<sup>5</sup> C. Thomas, "Developing the Social Relational in the Social Model of Disability: A Theoretical Agenda."

ing impairment effects were rather a product of inadequate support: being tired because one has to manage with technical failures, not receiving adapted documents on time, not daring asking for help to find an object, etc.

Then, we need to consider the differences made between low vision and blind children in the context of school. For instance, their assistive learning technologies are perceived differently, or their needs for a differentiated pedagogy is evaluated based on impairments rather than skills (Chapter 10). It should be understood through the contextual hierarchy of disability I described in Chapter 9. Blindness is the "*core business*" of the organization studied, as phrased by a carer, and is associated with a long cultural history. On the other hand, low vision can be hidden, especially when becoming an adult<sup>6</sup>, but blindness can not.

For *visually impaired children* with additional impairments, who make up a large portion of this population<sup>7</sup>, the situation is again different. In my field work, associated impairments were most often: learning difficulties, auditory impairments and psychological disorders. Each came with their specific effects (e.g., having to rely on an interpret at all time). It is however difficult to have subgroups with the same additional impairments to better pinpoint impairment effects. In the context of school, categorizing children as with and without additional impairments was pretty useful analytically. However, as discussed in Chapter 4, this thesis does not well represent those who do not or very partially attend school.

(2) The relation between social class and the distribution of visual impairments, discussed in Chapter 6 is a lot less likely to be recognized than the one with learning difficulties / disabilities. Academic performance is necessarily a spectrum: for people to have "high" performance, there must be people with "average" and "under" performance. What my material shows over and over again (Chapter 9 and 10) is the association made between current academic performance and future positions by children, the *hidden curriculum*. Not only social class impacts the school experience and academic performance overall (through multiple dynamics—discussed Chapter 5), but associating some impairments with less valued social positions can serve to reinforce adversarial attitudes from their peers.

To summarize, this section points out how my findings may provide empirical or conceptual insights for a social relational research agenda on visually impaired children. In the spirit of disability studies, the question then is:

<sup>6</sup> I am not arguing that hiding one's disability is desirable—but rather that it is a strategy that is known to be used by students to avoid being confronted to disablism. Carrière, "Résilience et Humour Chez Des Étudiants Déficiants Visuels".

<sup>7</sup> See Chapter 6

### 12.3 *How Could School Be Different?*

*“I’d really like to see high school changing. Students should be allowed to be left alone sometimes! I wouldn’t have to always sit all the time, I could choose what to study.”*

This is a quote by a teenager with a realistic idea (according to the teachers) about his future studies and occupation (computer sciences). He also has a strong group of close friend and valued extracurricular interests. He got invested into learning computer sciences aside from school and some of his grades declined. He was thus asked to commit less energy to computer sciences, and more to the normal school curriculum. He speaks from the position of a **resilient** teenager, who could be able to formulate his current needs in terms of resources (e.g., more English courses), justified by well-framed professional goals. Even so, he had difficulties to access the resources he was asking for.

This is a rare situation: very few youth were able to use this regime of discourse<sup>8</sup>, to describe a legitimate enough long term plan. On one hand service providers like the IJA develop programs that widen what counts as resilience; on the other, for those who are perceived as faring well enough in the common school environment, adaptations are not as legitimate. One could say this is a question of justice (allocating resources where they are the most needed). But in this case, it also has detrimental effects (disengagement from school, plummeting grades).

If we re-examine the school adaptations proposed on both sides (children and carers), we quickly stumble on the paradox not just of inclusive schooling, but of democratic schooling: the school needs to be the same **and** different for all. It needs to be the same to support inclusion, but it needs to be different to support the differences in needs and life projects. In practice, claiming schooling to be inclusive tend to obfuscate implicit hierarchies of disability and outcomes (Chapter 10). Furthermore, children’s interactions are affected by their participation in this ranking, a competition they start with very different resources and perceived choices (Part 2, Chapter 5 and 6). The question then is: where do we go from there, if we keep supporting the **collective** well-being of visually impaired children as the main focus?

One of the advantages of the social relational model of disability (Part 1, Chapter 3) is that it connects structural exclusion and its day-to-day perpetuation in interactions. Used in education, it invites focusing on relations in pedagogy and how they may produce *barri-*

<sup>8</sup> Thévenot, “Pragmatic Regimes Governing the Engagement with the World”.

ers to being—while a concept of ecological resilience suggest how relations impact perceived self-efficacy. Many interventions have thus focused on encouraging a growth mindset, with however has little proved effects<sup>9</sup>. What are the opportunities for supporting local environmental changes, building on the categories of resources for resilience we highlighted? Beyond the lack or inadequate repartition of financial resources, we could look into pragmatic ways to develop different ways of demonstrating abilities between children, and between children and teachers. More specifically, I am looking into how design can support the development of a non-visual, or a differently visual, culture at school, and how this may reshape perceptions of abilities.

<sup>9</sup> Sisk et al., “To What Extent and Under Which Circumstances Are Growth Mind-Sets Important to Academic Achievement? Two Meta-Analyses”.

## 12.4 Implications for design

In Chapter 2, I highlight *well-being*, *social justice* and *being heard* as values important to the children participating in the research. In Part 3, I use Ungar’s model of ecological resilience to reframe well-being as a collective issue, which enables to reframe it as a matter of social justice. In this case, social justice is defined as a matter of redistribution of adequate resources within the schooling system (the initial approach) and of recognition as a valued group.

### 12.4.1 ALTs as Resources for Collective Well-Being

Ungar’s typology of resources for resilience offers different ways to conceptualize how technological resources can support well-being. For instance, in the initial research project, well-being stems from self-efficacy, which could be supported by technologies. I focus instead on *community* resources. Ungar’s typology of resources for resilience offers different ways to conceptualize how technological resources can support well-being. For instance, in the initial research project, well-being stems from self-efficacy, which could be supported by technologies. I focus instead on *community* resources, with the aim of a feeling of belonging to a community of experiences and interest based on shared experiences of disability. In practice, this is difficult to implement, as children do not want to identify as disabled, or even as visually impaired, given the negative association of this identity with failing at school and by extension, not having access to a good life. Carers also evoke the ambiguity of the notion: on the one hand community enables to push an agenda, to better negotiate resources; on the other it goes against many representations of inclusion, in which disabled students could blend in the existing educational environment. I propose to explore the design space of ALTs for fostering



a non-visual culture in the classroom, and didactic and pedagogic approaches based on non-visual material. By highlighting and valuing different ways of knowing, it can modify the hierarchy of disability enforced by children in their interactions and discourse, addressing social inequalities at school.

#### 12.4.2 *ALTs for Being Heard*

Visually impaired children participating to the research do highlight that their disability set them apart, that they do not have access to the same resources as others. They however do not see reasons to formulate collective demands. This seems to contrast with previous generations, and might partially be explained by their low and dwindling numbers. In the design of ALTs, I focus on supporting children in finding new means of expression, and of constructing meaning from their experiences. It enables to make learning more explicit, both to pupils and teachers, but also to support pupils in contesting learning activities if needed. I see this as a collaboration not exempt from frictions between teachers and pupils. Equipping pupils in contesting norms, creatively disobeying, can help this collaboration evolve as teachers come to appreciate the creativity and use it to fuel their teaching. Pupils can also raise points or discuss experiences that are helpful for teachers to understand their point-of-view and identify learning opportunities.

### *General Conclusion of Part 3*

I outline the construction of my research topic and aims in the first part and critically reviewed the research literature on disabled childhood and assistive technologies design in Part 2. Part 3 presents my (sociological) findings about visually impaired French children's experiences of school. I argue that children's experiences of schooling may best be analyzed by using Ungar's approach of resilience—Resilience as the ability to navigate and negotiate needed resources.

These resources are of various natures: material, relational... And their allocation depends on their evaluation against normative school goals. I showed how their uses and attributions varied with class and gender, but also when and how norms had to be contested or reformulated. When focusing technologies in general and Assistive Learning technologies in particular, I demonstrated they can be used both to assert and contest abilities and skills—and the worth of their users.

The reader may have found different ways of improving school experiences in these two chapters. As for me, I propose to look into these findings can be embedded through design projects, or how Assistive Learning Technologies could be designed as resources for resilience. This is the subject of the following fourth and last Part.



## **Part IV**

# **The Sensory Turn in the Design of Assistive Learning Technologies**



This fourth and last part of my dissertation presents the design aspects of my PhD research. I describe how I attempted to embed hypothesis drawn from the rest of my research in prototypes used in the field. Concretely, this part is made of three chapters. Chapter 13 outlines my overall approach, drawing from carers' approach of didactic; The literature on the *sensory turn* and non-visual approaches of geography; And how this answers to the three main theories of educational inequalities. From this, I propose an overall design approach, focused on sensory diversity for the geography curriculum. It underpins the two main probes designed and deployed during my PhD.

In each chapter, I first present the findings from the field-study that led me to identify opportunities for design. I introduce the prototypes, which were designed with five pupils attending a special education class part-time. I then move on to present and discuss my findings about their uses in a pedagogical sequence about human habitats, described in Annex A.5. With these two chapters, I have three main aims:

1. Showing how this design intervention modified carers' and children's discourses about what counts as learning, what abilities are valued in the classroom, as well as other measures for the usefulness of Assistive Learning Technologies as tools to reconfigure relations;
2. Proposing concrete examples of the collective meaning-making processes using different non-visual cues in geography;
3. Outlining design recommendations and invite future innovations in this vein. The material for these chapters are based on four main design / pedagogic moments, described in annex A.4.

Hence Chapter 14 focuses on an audio-recording probe. I used it to dive into the use of audio material in geography, between field-trips and the classroom. I argue that it should be considered as part of the development of a non-visual sensory knowledge, and investigate how to support it. Giving children the hand on what they could record highlighted a broad range of useful audio cues and possible uses. Furthermore, my findings suggest it can change the value attributed to hearing and listening skills by pupils and the teacher.

Chapter 15 presents and discusses the multisensory map prototype, called Mapsense. It augments an interactive audio-tactile map (presented in Chapter 7), using tangible interactions and cues to be smelled or tasted. I highlight the ways it reshapes interactions in the

classroom, in three aspects: the ways it supported children in coordinating their diverse sensory abilities in learning activities, and the emergence of different meaning-making processes, seized as a learning opportunity by the teacher; how it makes the classroom more pervasive to children emotional and social lives and to objectives of developing children's sense of citizenship; and the reconfiguration.

With this part, I aim to make three main contributions to the design and HCI literature: the overall design framework I adopted, and the two prototypes described. Moreover, I hope to contribute to the community interested in multisensory learning or multimodal analysis, with my findings on children's meaning-making processes when using a range of non-visual material.

## *A room for design? Of resilience and sensory knowledge*

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In Chapters 9, 10 and 11, I discuss the multiple barriers faced by visually impaired children, notably the lack of financial resources to support them and the adversarial attitudes faced in mainstream schools. Is it not more urgent to offset carers' workload by providing more efficient tools? Why a design intervention if the main problem identified remains the lack of financial resources for what is already in place? Why focusing on Assistive Learning Technologies if they usually contribute primarily to the exclusion from group activities and do not entail a change in the teaching approach<sup>1</sup>? Why not focus on sensitization instead? If the problem is unequal educational outcomes, contributing to the perpetuation of social class differences, how could design address that? Should we not rather focus on parental practices to concertedly cultivate children<sup>2</sup>? Would it not be a better approach, from a pragmatist (Chapter 4) point of view?

<sup>1</sup> Mithout, "L'inclusion Scolaire à l'heure Des TIC : Perspective Franco-Japonaise".

<sup>2</sup> Scott Davies and Jessica Rizk, "The Three Generations of Cultural Capital Research: A Narrative Review".



I already started to discuss this in Chapters 2 & 8 and 12. The aim of this chapter is to outline why I considered it the best possible approach given the context (Chapter 2). To achieve this, my argument relies on theoretical elements and findings from the field.

I argue assistive learning technologies can become resources for resilience in many ways. In this chapter, I propose to design them to support a shared non-visual culture and shift perceptions of competence and abilities. And I want to show how it fits in current research strands on social disadvantages at school<sup>3</sup>.

I first complement the findings about technologies and relationships presented in Chapter 11, which illustrated the various ways in which children used assistive technologies to assert competence. Indeed, it lacks the teachers' (and assistant teachers') views on didactic and pedagogy. Specifically, I show they adopt a logic of *translation* of the visual, rather than a logic of *substitution*, i.e. it is not enough to automatically transform a graphic as a tactile support: sometimes the graphic should become a text; sometimes an entirely different representation is needed. However, this is not well formalized in practice. A body of research that can help formalize this is the literature on the sensory turn and sensory knowledge, about knowledges that are not visual. I outline the implications of this literature in geography scholarship, the curriculum area my interventions focused on. I conclude by discussing how the development of a non-visual approach to the curriculum may address class inequalities in education.

<sup>3</sup> See Chapter 5 and: Scott Davies and Jessica Rizk, "The Three Generations of Cultural Capital Research: A Narrative Review".

### 13.1 *From the Field: Transcription, Adaptation, and Translation*

With this section, I expand on Chapter 8. I build on the interviews described in Chapter 9 and observations during my collaboration with P1. I propose to move away from a conceptualization of assistive learning technologies as merely tools to substitute visual information; and to move towards an understanding of their roles in translating information in a non-visual way. The main difference between substitution and translation is that the latter does not pretend to reproduce perfectly the initial document (a text). Multiple translations co-exist, because there is no perfect equivalence between one language and the other<sup>4</sup>. Translating requires to interpret the text to a certain extent and to reflect on the process itself. This is well articulated in this excerpt:

Teacher assistant: "*All these adaptations, those are things we were taught to do [...] Sometimes, when I see what teachers do, I'm like 'no no no,' sometimes we disagree over whether a tactile graphic would be more*

<sup>4</sup> Malmkjær, "Meaning and translation".

*adequate than a description, but I guess I also see this from a planning perspective [It takes less time to write a description than a tactile graphic]. Tactile graphics take a lot more time than braille. [...] I'd say, it's more **about translating than just transcribing or even adapting. Interpreting the intent of the textbook author or the teacher to represent the material in a new document.***" (emphasis mine)

Here, three main notions are mobilized: transcription, adaptation, and translation. She implies they form a gradual spectrum, and defines them as follows. The minimum is to transcribe, without questioning the content. This would be the case when typing a book in braille for instance. Then comes adaptation which is a more generic practice going beyond the means of presentation of the document (e.g., breaking down the content in a new way). Translating involves more interpretation i.e., taking into account and reflecting on the overall pedagogical and didactic strategies. It results in a new document, in the broad sense of the term: this document can be an artifact, given digital fabrication technologies are increasingly used in this context. In the rest of this section, I focus on how these translations are defined and envisioned by carers. It goes much further than the need to produce adequate documents:

Teacher: *"When I started working as a special education teacher, I knew all the theory, I knew the rules of visual adaptations, how much I should simplify, whether there should be colors, the size and type to use and when I should use a tactile graphic or a text and so on and so on. And then I realized that it just didn't work, especially for the youngest, because we're basically taking the things made for the sighted and put them in the hands of the visually impaired, instead of thinking about how they sense and how they think and everything that must happen before they can use that material, get into the actual learning. [...] They don't tell you about all the ridiculous things you'll have to do [...] like explaining gravity by falling from a chair."*

One can represent gravity by a schema. But this teacher suggests that using her own body to demonstrate the effects of gravity on all bodies is the adequate representation. She also suggests that a lot of representations are developed through non-class-based sensory experiences. The examples she provides later in this interview include going on a boat to understand floating and waves, which enable to later introduce concepts such as tides or differences between bodies of water (e.g., a river, a canal, a sea). For another take on the issue:

Therapist: *"I want to develop a representation that they can use, but I have to be careful that it might be different from ours. There's of course the level of detail, every child uses different [sensory] cues... Of course you learn*

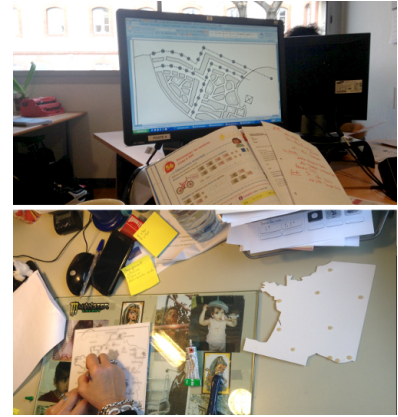


Figure 13.1: Two processes for making maps. Top, the digital file for a raised line map. Bottom, the matrix for a thermoformed map made by gluing small elements to a cardboard background.

*a thing or two and there are similar profiles, but mostly we need to adapt representations all the time, and try different ones, see what works."*

The advantage of using the concept of translation is the multiplicity of potential translations, implicit to the concept. There can be multiple translations in one language and multiple translations in multiple languages. What this last quote shows is that there is not one translation always better than the others. They are evaluated on their usefulness for a specific individual—and for meaning-making in a specific group (Chapter 8. However, a common theme (also present above) is the lack of training regarding the necessary translations and the gap between theory, as conveyed by their hierarchy, and practices:

Teacher: *"We made this history book specifically for our pupils, using bi-graphism [i.e., the document is made for visually impaired and blind children, using tactile and braille schemas, but also colors and enlarged characters], and it worked out really well in the course. Then the school district inspector came, so we were pretty proud to show it to him, and he basically told us we should throw half of it out because it didn't fit the official recommendations. So yeah, you see, we just have to figure things that work by ourselves."*

This results in many local experimentations, shared informally among French service providers working with visually impaired children. Emails, loans of artifacts, videos, local (pdf) catalogs made of written descriptions and photos. Participating in the Accessimap research project is also a way to reflect on practices and highlight the innovations made by teachers. Those were a few of the many ways in which expertise is shared within and across specialists networks (e.g., between special education teachers in different cities, or between document maker specialists and therapists).

Another finding of my field-study better integrated when using the concept of translation is the non-visual culture or world previously evoked (Chapter 11):

Teacher: *"I'd say, teaching here is always a tension. On the one hand, we have to acknowledge [the students] need to integrate the common culture, which is made by and for sighted people. [...] But they have to share this world. I don't want to impose sighted people's representations, quite the contrary I think there can be a non-visual culture, and that it shouldn't be optional or a thing for the "high level blind". I'd rather invite **exchanges**."* (emphasis mine)

Interestingly, it was discussed by several carers<sup>5</sup> but by none of the children. The hierarchy of disability they establish, as well as the difficulties or refusal to define visual impairments as part of their identity (see Chapter 10 & 11), may explain this fact. Additionally,

<sup>5</sup> As well as by visually impaired and blind adults I incidentally met during my PhD.

as exemplified in this excerpt and as I further discuss below and in Chapter 15, carers are ambivalent towards what could constitute a non-visual culture and whether it has benefits for the education of children in their care. I reproduce this excerpt because it highlights that the need for translating meaning goes both ways. Carers describe above how they try to interpret how children make sense of their environments and translate it in another modality, one they can more easily share. These processes of multimodal translation are under-studied<sup>6</sup>. This observation tends to contrast with an analysis of the visual as a distinct sense, one that by essence put the world at a distance—see below, about the sensory turn. There is an intentional co-construction of all senses in which the visual (conveyed tactilely or by enlarging material) has its place and in which in fact it is necessary for developing the other senses. Here the question is how to support translations between differing ways of perceiving the world—one that is primarily visual, the other that is not.

To summarize, this section highlights findings from the field supporting the use of a different metaphor, and ultimately a different model, for assistive learning technologies. They are often described as tools *substituting* visual information (Chapter 7), but the practices they aim at replacing are rather practices of *translation*. Looking at these practices as translation practices, for a non-visual culture, also revealed the ambivalence surrounding a cultural-based approach of education. This can be partly explained by the universalistic approach of French education (see Chapter 12). This ambivalence is also present in disability studies: the appropriateness of defining Deafness as a culture and a difference, rather than as an impairment, has long been debated for instance<sup>7</sup>. The main argument against this view, from my perspective, is that a cultural view is suitable for certain impairments and not others<sup>8</sup> which makes developing a unified theory of disability (e.g., the social model) more difficult. But as I discuss in Chapter 3, I do not believe the two approaches are incompatible.

I argue focusing on non-visual material and approaches benefit teaching in a two-step argument. I first outline the interest for the non-visual in geography scholarship and by extension geography education, to argue that developing non-visual approaches in primary schools is legitimate; then I examine the implications of this non-visual approach, through the lenses of the three main research strands on the reproduction of social capital at school. From this, I argue that assistive learning technologies focused on developing a non-visual culture at school support an agenda that takes into account social class, that can also help tackling social inequalities at school.

<sup>6</sup> O'Sullivan, "Introduction: Multimodality as challenge and resource for translation".

<sup>7</sup> Jones, "Deafness as culture: A psychosocial perspective".

<sup>8</sup> Vehmas and Nick Watson, "Moral Wrongs, Disadvantages, and Disability: A Critique of Critical Disability Studies".

### 13.2 *The Sensory Turn and non-visual Sensory Knowledges*

The Sensory Turn refers to the increasing interest of Social and Human sciences for senses and their uses as cultural phenomena since the 1980s<sup>9</sup>. It is based on the assumption that modern period and knowledge was ocular centric, with vision enabling a distant rationality. This assumption is contested by several scholars<sup>10</sup>, as an inadequate *a posteriori* reconstruction or simplification. Additionally, I would point out that Enlightenment philosophers were already interested in perception beyond the visual, in particular Rousseau's educational philosophy<sup>11</sup> and Diderot's *Letter on the Blind for the Use of those who can see*<sup>12</sup>—but this discussion is beyond the scope of this thesis<sup>13</sup>.

In any case, the sensory turn points to an accrued interest in embodied experiences. This is true beyond Sensory studies, the umbrella term for a cultural approach to researching the senses and vice-versa. We could draw links to cognitive psychology research on embodied cognition<sup>14</sup> for instance. However, Maslen<sup>15</sup> points out that although scholars increasingly describe uses of the senses<sup>16</sup>, or are interested in sensory experiences, they still do not often investigate how specialize sensory practices are transmitted and formed in the first place. This is why she proposes to examine them as a *knowledge*. She proposes that "*the senses can be examined in terms of their contexts, acquisition processes, and applications, like any other knowledge source*". It implies looking at how specific groups acquire skilled use of their senses, and for what purposes. In my context, that means looking at visually impaired children in general, for learning geography in particular.

#### 13.2.1 *The sensory turn in Human Geography*

Geography is a good starting point for this agenda. First, it was the topic of the Accessimap research project (Chapter 2. More broadly, especially in early mandatory schooling, geography is probably the curriculum area the most oriented towards civic and citizenship education<sup>17</sup>. For a design intervention focusing on supporting different dynamics in the classroom, geography (which is intertwined in the curriculum with history and social sciences) seemed like a good choice.

In geography, scholars interested in the sensory turn have long challenged vision as the primary or only way of knowing about space<sup>18</sup>. In fact, we could argue that this concern dates from the end of the XIXth century in anarchist geography and popular educa-

<sup>9</sup> Bull et al., "Introducing Sensory Studies".

<sup>10</sup> E.g., Erlmann, "Reason and resonance: A history of modern aurality".

<sup>11</sup> Rousseau, *Emile, ou de l'éducation*.

<sup>12</sup> Genel, "La Lettre sur les aveugles de Diderot: l'expérience esthétique comme expérience critique".

<sup>13</sup> See this academic blogpost on a to-be-published philosophy essay discussing this subject: *Introduction to The Sonic Episteme (or maybe The Sonic Hypothesis?)*

<sup>14</sup> Wilson, "Six views of embodied cognition".

<sup>15</sup> Maslen, "Researching the Senses as Knowledge".

<sup>16</sup> E.g., Classen, "Worlds of Sense: Exploring the Senses in History and across Cultures".

<sup>17</sup> P. Jackson, "Thinking geographically".

<sup>18</sup> Pocock, "Sound and the Geographer"; Cosgrove, *Social Formation and Symbolic Landscape*; Antrop, "Geography and Landscape Science".

tion initiatives<sup>19</sup>. This is particularly the case in human geography, which refers to the branch of geography concerned with the spatial organization of human activity<sup>20</sup>. Within this general concern for non-visual aspects of geography, different research perspectives co-exist and interact:

1. **PHENOMENOLOGICAL AND POST-PHENOMENOLOGICAL APPROACHES.** Scholars focus on lived and subjective experiences of space or landscapes<sup>21</sup> as well as on spatial practices through which we come to experience space<sup>22</sup>. I would include research focusing on non-representational theory, which also borrows to Actor Network Theory, in this group<sup>23</sup>. It is used for instance to describe blind experiences of landscape<sup>24</sup>;
2. **THE SENSE OF PLACE.** The sense of place refers to how living in a certain area produces attachment—but also how larger social and cultural processes (e.g., one's gender) shape the ways one can inhabit a specific space<sup>25</sup>. The question then can be how to support the development of a sense of place to support engagement in learning<sup>26</sup>;
3. **MINORITIES' KNOWLEDGE OF SPACE.** Being attentive to embodied experiences of space also leads to research trying to identify the spatial knowledge developed by different groups. For instance using a wheelchair and having to physically confront inaccessible spaces enables the development of knowledge on the exclusion of wheelchair users<sup>27</sup>;
4. **NON-VISUAL METHODS.** Available tools, research topics and methods evolve together: With new topics of interests emerging, new adequate methods must be defined<sup>28</sup>; Meanwhile new tools, such as portable audio and video recordings, enabled to reinvestigate known topics differently. For instance, this can mean studying children's interactions and activities through audio recordings rather than observations or visual documents<sup>29</sup>.
5. **IMPLICATIONS FOR MAPPING PRACTICES.** Scholars have reinvestigated maps, an ocular-centric and so-called bird-eye or god-view representation<sup>30</sup>. Indigenous mapping practices for instance have received a great deal of interest<sup>31</sup>. So have community practices and the involvement of youngsters in mapping processes<sup>32</sup>. Finally, given the development of digital and interactive maps enabling the superpositions of layers of data of different types, it

<sup>19</sup> E.g., see the work of Geddes and Reclus on tangible representations of geography. Ferretti, "Situated Knowledge and Visual Education: Patrick Geddes and Reclus's Geography (1886–1932)".

<sup>20</sup> Cloke, Philo, and Sadler, *Approaching human geography an introduction to contemporary theoretical debates*.

<sup>21</sup> E.g., Pocock, "Sound and the Geographer"; Relph, "An Inquiry into the Relations between Phenomenology and Geography"; Schafer, *The soundscape: Our sonic environment and the tuning of the world*.

<sup>22</sup> E.g., Spinney, "A Place of Sense: A Kinaesthetic Ethnography of Cyclists on Mont Ventoux".

<sup>23</sup> Ash and Simpson, "Geography and post-phenomenology".

<sup>24</sup> MacPherson, "Landscapes of Blindness and Visual Impairment: Sight, Touch and Laughter in the English Countryside".

<sup>25</sup> Hunziker, Buchecker, and Hartig, "Space and Place—two Aspects of the Human-Landscape Relationship"; Massey, *Space, Place and Gender*.

<sup>26</sup> S. Price, Carey Jewitt, and Sakr, "Embodied experiences of place: a study of history learning with mobile technologies".

<sup>27</sup> M. Matthews and Vujakovic, "Private Worlds and Public Places: Mapping the Environmental Values of Wheelchair Users".

<sup>28</sup> Gallagher and Prior, "Sonic geographies: Exploring phonographic methods".

<sup>29</sup> S. Mills, "Voice: Sonic Geographies of Childhood".

<sup>30</sup> Kwan, "Feminist Visualization: Re-Envisioning GIS as a Method in Feminist Geographic Research".

<sup>31</sup> D. R. F. Taylor, *Developments in the Theory and Practice of Cybercartography: Applications and Indigenous Mapping*.

<sup>32</sup> K. H. Taylor and R. Hall, "Counter-Mapping the Neighborhood on Bicycles: Mobilizing Youth to Reimagine the City".

opens educational opportunities such as encouraging children to produce their own layers<sup>33</sup>.

Overall, the sensory turn invites scholars to be attentive to individuals' and groups' spatial practices and affects. For an example in this thesis, the reader might want to think about the spatial dimensions of the organization and its neighborhood, which I discuss in Chapter 9. Although this is not a main focus of my research, I attempted to show how it became an extension of the organization itself, that it is defined as a learning and as a safe place<sup>34</sup>. It also shows how the spatial features of the building are imbued with historical and affective significance, and how certain modifications highlighted the enduring religious significance attributed to the building, and contemporary contestations of its pertinence.

### 13.2.2 *Towards Sensory-Attentive experiential learning*

On a *didactic* level, there are two main approaches to teaching geography: spatial (i.e. studying locations, distances, topological features) and ecological (i.e. studying interactions between humans, society and their environments)<sup>35</sup>. Current curriculum and research on didactic principles in geography<sup>36</sup> (p. 26-27) emphasize the second perspective (e.g. ecological) by integrating geography with other disciplines (e.g. history, or social studies).

Focusing on children's experiences in geography education has several implications. Children's everyday environment can provide rich examples of social and spatial phenomena<sup>37</sup>. These local environments exemplify the interaction of factors of various scales (e.g., local, regional, national, international) and types (e.g. topography, history, policy). Furthermore, it provides them with opportunities to develop and exert their citizenship<sup>38</sup>. By learning to assert an expertise on local space, children can contest or debate urban development projects for instance.

The importance of studying local geography as a step towards understanding global dynamics is far from new<sup>39</sup>. Although the geography curriculum differs from country to country<sup>40</sup>, it always at some point focus on local geography either to substantiate a theme (e.g., economic exchanges) or to develop skills (e.g., reading maps). Anchoring geography in children's embodied experiences of space is thus consistent with the didactic of geography. In this perspective, the organization of field-trips provide additional, tailored examples. Field-trips consist in getting to a nearby place (e.g., museum, farm) from which pupils can get firsthand knowledge<sup>41</sup>. Beyond ef-

<sup>33</sup> S. Price, Carey Jewitt, and Sakr, "Embodied experiences of place: a study of history learning with mobile technologies".

<sup>34</sup> See also: Porcelli et al., "(Micro)mobility, disability and resilience: exploring well-being among youth with physical disabilities".

<sup>35</sup> Maria Rellou and Nikos Lambrinos, "The School Geography Curriculum in European Geography Education. Similarities and Differences in the United Europe."

<sup>36</sup> Firth, "Teaching Geography 11–18: A Conceptual Approach".

<sup>37</sup> Bartos, "Children Sensing Place"; Catling, "Children's Personal Geographies and the English Primary School Geography Curriculum".

<sup>38</sup> K. H. Taylor and R. Hall, "Counter-Mapping the Neighborhood on Bicycles: Mobilizing Youth to Reimagine the City"; Di Maio, Gomes, de Oliveira, et al., "Geoinformation: A Social Issue"; K. S. Martin and Hall-Arber, "The Missing Layer: Geo-Technologies, Communities, and Implications for Marine Spatial Planning".

<sup>39</sup> This discussion began at the end of the XIXth century. See: Ferretti, "Géographie, éducation libérale et établissement de l'école publique entre le 19e et le 20e siècle: quelques repères pour une recherche"; Ferretti, "Situated Knowledge and Visual Education: Patrick Geddes and Reclus's Geography (1886–1932)".

<sup>40</sup> M. Rellou and N. Lambrinos, *The School Geography Curriculum in European Geography Education: Similarities and Differences in the United Europe*.

<sup>41</sup> DeWitt and Storksdieck, "A Short Review of School Field Trips: Key Findings from the Past and Implications for the Future".

facts on content learning (which are not as positively pronounced as expected), field-trips are valued because they provide positive emotional and social experiences for pupils, and foster life-long learning and integration in the community.

To my knowledge, developing and integrating non-visual approaches to the teaching of geography is not documented—though Briand<sup>42</sup> led a few experimentations on the topic. In non-visual approaches to the teaching, I do not include adapted maps, as I refer to an approach rooted in non-visual experiences of space to teach geography. What we know however is that children are more attentive to certain sensory aspects of space than others, these variations being tied to where they live and the cultural practices of their carers<sup>43</sup>. Hence one could think it would be fruitful to engage children in discussing their experiences and how they contrast. The differences between them are not merely due to sensory impairments or differences in sensory processing, but also to cultural and personal differences. This can bring different perspectives to say, the study of urban environments. So the question remains: how can children learn geography non-visually?

### 13.2.3 *Space through the Sense of Hearing*

I acknowledge that the senses are never separated and experienced alone<sup>44</sup>, hence my position to discuss them separately could be contested. However, one can choose to set apart a given stimulus, experienced through a given sense, to give it meaning<sup>45</sup>. This is true of the interpretative work required in the primary school geography classroom.

Although I will argue that all senses can be mobilized in geography courses (Chapters 14 & 15), some may be easier to integrate than others. Thibaud for instance argues that "*when you hear a place, you hear a specific social organization of sound as well as the way in which people interact and relate to each other. Sound is both the expression and the medium of various modes of social existence*<sup>46</sup>;" and that "*while vision tends to implement too great a distance between the perceiver and the perceived, and while olfaction tends to produce overly diffuse and volatile phenomena, audition can mix the affective with the cognitive, the universal with the singular in a very balanced way*<sup>47</sup>." In other words, the sense of hearing might be particularly useful for geography teaching and learning.

Augoyard and Torgue brings attention to listening<sup>48</sup> practices. They describe the environment as an *instrumentarium*, in which

<sup>42</sup> Briand, *Geography School Teaching through the Prism of School Outings : For an Approach by Means of Sensitiveness at Primary School*.

<sup>43</sup> Bartos, "Children Sensing Place".

<sup>44</sup> Rodaway, *Sensuous Geographies: Body, Sense and Place*.

<sup>45</sup> Bartos, "Children Sensing Place".

<sup>46</sup> Thibaud, "A sonic paradigm of urban ambiances", p. 10.

<sup>47</sup> Thibaud, "A sonic paradigm of urban ambiances", p. 12.

<sup>48</sup> A difference is often made between hearing and listening, where listening is intentional and hearing is not. Yet, as highlighted above, hearing abilities are not naturally acquired and if the intention to hear is less visible there still needs to be an attention. Moreover as I found both terms used in the literature, I use them interchangeably.



sound "is always shaped subjectively [...]. There is no universal approach to listening: every individual, every group, every culture listens in its own way"<sup>49</sup>. In doing so, they highlight the need to reflect on the cultural shaping of perceptions, on the development of more or less specialized ways of hearing (i.e., *sensory knowledge*<sup>50</sup>). However, there are no clear guidelines about how to teach them to (visually impaired) children for learning geography.

The popular conception of the senses lists five: sight, smell, hearing, taste, and touch. But in my field-study, proprioception<sup>51</sup>, the vestibular sense<sup>52</sup> and echolocation<sup>53</sup> were often cited by carers too. More generally, there is no definitive agreement about the number of senses, as it depends on how one defines a sense. To use smell and taste (the two being interrelated) in geography teaching, we can look at mapping practices of smell<sup>54</sup> or smell experiments in related museums<sup>55</sup>. The tactile sense is already present in the use of small scale models or raised relief maps. But I could not find much indication as to the potential use of echolocation or proprioception for geography teaching. There is literature on bodies in movements in geography, which takes into consideration means of transportation and their social significance or focus on the self-knowledge of athletes, how they are affected by speed and rhythms (see above). On this topic, I think my observations of teaching practices are a contribution (Chapters 14 & 15).

#### 13.2.4 Technologies and non-visual geography

To conclude on this topic, I propose an overview of the previous design propositions for teaching geography non-visually—or more-than-visually, through embodied interactions. I identify three core research themes in HCI: tools to ease everyday navigation<sup>56</sup>, tools for spatial rehabilitation<sup>57</sup>, and accessible maps<sup>58</sup>. The first two adopt the position criticized previously (Chapter 8): they aim at enabling a so-called normal functioning, which is necessary, but not our focus. In contrast, maps have the potential to support a diversity of knowledges and points of view (Chapter 13). However, the research on this topic mostly focuses on how to best translate visual information in another modality, as well as the usability and cognitive gains they provide (Chapter 7).

### Technologies and field-trips

The research literature on educational technologies for field-trip offers a number of insights, though it focuses mostly on the scien-

<sup>49</sup> Augoyard, *Sonic experience: a guide to everyday sounds*, p. 4.

<sup>50</sup> Maslen, "Researching the Senses as Knowledge".

<sup>51</sup> Here defined as the awareness of movement. It was used interchangeably with kinesthesia.

<sup>52</sup> I.e., sense of balance.

<sup>53</sup> I.e., the ability to detect features of the environment through the echo when one makes a sound.

<sup>54</sup> McLean, "Smell map narratives of place-Paris".

<sup>55</sup> J. H. Chu et al., "Sensing History: Contextualizing Artifacts with Sensory Interactions and Narrative Design".

<sup>56</sup> Williams, Hurst, and Shaun K. Kane, "'Pray Before You Step out': Describing Personal and Situational Blind Navigation Behaviors".

<sup>57</sup> Freeman et al., "Audible Beacons and Wearables in Schools: Helping Young Visually Impaired Children Play and Move Independently".

<sup>58</sup> Zeng and Weber, "Accessible Maps for the Visually Impaired".

tific curriculum. It emphasizes the importance of the scaffolding of the experience to ensure reflexivity<sup>59</sup>. This includes the design of introductory, on-site and follow-up activities. Many research projects thus aim at scaffolding activities using technologies, either through an environmental intervention<sup>60</sup> or by equipping children with mobile devices to gather and handle or play localization-specific data or<sup>61</sup>. For instance, Lo and Quintana have investigated the use of hand-held computers by learners during nomadic inquiry for science courses<sup>62</sup>: they enabled children to record photos, videos and audio to answer specific questions, and to tag them to support reflection and exchange. They analyzed their strategies and found, among other things, that **audio recordings are far less used** and only to record discussions and notes. Non-visual learning is not explicitly addressed in this body of work. Closer to my case study, S. Price, Carey Jewitt, and Sakr<sup>63</sup> proposed a mobile application for learning history *in situ*, and documented the development of a sense of place. However, children's engagement with the site visited was primarily visual (e.g., searching for a visual cue of a past construction).

### 13.2.5 Technologies and sensory experiences

My project can be linked to technologies mediating embodied experiences for learning. Full-body interaction for instance exploit sensorimotor processes. These interfaces are based on a constructionism approach, i.e. that learning is most efficient when acquired through doing in a rich environment<sup>64</sup>. Such technologies are often deployed inside facilities<sup>65</sup> (although the recently proposed "World-as-Support" paradigm<sup>66</sup> may change that) and mainly rely on visual stimuli and feedback (e.g., use of pico-projectors). Directing visual attention for learning is a challenge in this area<sup>67</sup>. Therefore, we can expect that this is challenging for audio based technologies as well. There is also an increasing interest for multisensory technologies relying on olfaction and taste, especially for museum experiences<sup>68</sup>. For instance, Hollinworth et al. invited children with disabilities to create sensory boxes to accompany and share their museum experiences. However, that project does not address the challenges arising when it comes to communicate non-verbal sensory experiences from one person to the other to convey a specific meaning.

To summarize, this section discusses the interest for senses other than sight in geography. Its aim, providing pointers in geography scholarship to support my proposition to focus on the development of a non-visual approach of geography education. I highlight the seemingly primary role of audio in acquiring geographic knowledge

<sup>59</sup> Quintana et al., "A Scaffolding Design Framework for Software to Support Science Inquiry"; Collins et al., "Supporting Location-Based Inquiry Learning across School, Field and Home Contexts".

<sup>60</sup> Rogers et al., "Ambient Wood: Designing New Forms of Digital Augmentation for Learning Outdoors".

<sup>61</sup> Milos Kravcik et al., "Mobile Collector for Field Trips"; Lo and Quintana, "Students' Use of Mobile Technology to Collect Data in Guided Inquiry on Field Trips"; Kuhn et al., "Using Tags to Encourage Reflection and Annotation on Data During Nomadic Inquiry"; S. Price, Carey Jewitt, and Sakr, "Embodied experiences of place: a study of history learning with mobile technologies".

<sup>62</sup> Lo and Quintana, "Students' Use of Mobile Technology to Collect Data in Guided Inquiry on Field Trips".

<sup>63</sup> S. Price, Carey Jewitt, and Sakr, "Embodied experiences of place: a study of history learning with mobile technologies".

<sup>64</sup> See also: Klemmer, Hartmann, and Takayama, "How Bodies Matter: Five Themes for Interaction Design".

<sup>65</sup> Malinverni, Ackermann, and Pares, "Experience as an Object to Think with: From Sensing-in-Action to Making-Sense of Action in Full-Body Interaction Learning Environments"; Yoshida et al., "BESIDE: Body Experience and Sense of Immersion in Digital Paleontological Environment"; Norooz et al., "BodyVis: A New Approach to Body Learning Through Wearable Sensing and Visualization".

<sup>66</sup> Malinverni, Maya, et al., "The World-as-Support: Embodied Exploration, Understanding and Meaning-Making of the Augmented World".

<sup>67</sup> Malinverni, Ackermann, and Pares, "Experience as an Object to Think with: From Sensing-in-Action to Making-Sense of Action in Full-Body Interaction Learning Environments".

<sup>68</sup> Hollinworth et al., "Interactive Sensory Objects for and by People with Learning Disabilities"; J. H. Chu et al., "Sensing History: Contextualizing Artifacts with Sensory Interactions and Narrative Design".

from one's surrounding, but also pointers for the use of the other senses. I also attempt to highlight the centrality of sight in most technologies that may be useful in our context. I also outlined challenges to consider: scaffolding the experience (e.g., by directing attention through specific questions), and providing tools to enable a shared understanding of non-visual, non-verbal, experiences. Moreover, I believe design interventions made to support non-visual knowledge is an adequate way to support children's desire for school to better care for their well-being; **and** take into account the need to address class-based educational inequalities that shape children's experiences of school (Chapters 6 & 10).

### 13.3 Sensory Knowledge and Educational Inequalities

As discussed in Chapter 5, the sociological literature on educational inequality often stems from the concept of cultural capital. Class and education is studied through three lenses: (1) how the curriculum and educational organizations are designed and whose interests they support (i.e., socially advantaged groups, who develop educational capital to maintain their own social positions); (2) parental norms differ between class, and parents with higher social status engage in concerted cultivation with schools, proposing activities destined to improve children's performance. Additionally the choices made by parents and children depend on the quality of information they have about schooling (Boudon<sup>69</sup> terms this the primary and secondary effects of class); and (3) at a micro-level, in examining how children acquire traits enabling or preventing them to fit in a given context (e.g., from feeling legitimate at school to displaying the right markers, such as verbal skills, in an interview)<sup>70</sup>. Note that children too are active in this process: as pointed out in Chapters 10 & 11 and in the literature<sup>71</sup>, they develop their own forms of social capital through the establishment of peer relations, which themselves can be underpinned by class-based judgments.

Using the first lens is an invitation to consider what are the values transmitted and enforced in school, i.e. the **hidden curriculum**<sup>72</sup>. Among these values are for instance meritocracy and competition, or the higher value of high-brow culture, e.g. classic literature over popular books. Some scholars further argue that "*the pre-eminence of language over the physical knowledge of the body is among the most definitive expressions of the hidden curriculum.*"<sup>73</sup> This view is consistent with the idea that some abilities, and by extension some people and bodies are considered better than others (Chapter 8). The question then is how to develop a different hidden curriculum: a pitfall is to assume

<sup>69</sup> Boudon, *L'inégalité Des Chances: La Mobilité Sociale Dans Les Sociétés Industrielles*.

<sup>70</sup> Scott Davies and Jessica Rizk, "The Three Generations of Cultural Capital Research: A Narrative Review".

<sup>71</sup> Holland, "Young People and Social Capital"; Marlies Kustatscher, "Young Children's Social Class Identities in Everyday Life at Primary School: The Importance of Naming and Challenging Complex Inequalities".

<sup>72</sup> Anyon, "Social class and the hidden curriculum of work".

<sup>73</sup> McBride and Nolan Jason, "Situating Olfactory Literacies: An Intersensory Pedagogy by Design".

differences in taste and values depending on socio-demographic characteristics and reinforcing them by limiting the type of material or the pedagogical approaches proposed. But even embodied or experiential learning is not naturally easier—motor development differs following environmental factors<sup>74</sup>, as are dispositions to examine an embodied experience as a learning experience<sup>75</sup>. Still, we can ask how other forms of knowledge can be articulated or integrated with the existing curriculum, with the goal of affording equal opportunities in education to those whose bodies are considered not to be in the norm.

Using the second lens, we can look into class differences regarding the importance given to the value given to certain embodied experiences, as well as to how children are encouraged to verbalize them. For example, food practices and perceptions vary with socioeconomic conditions<sup>76</sup> and tasting practices are historically an activity asserting a higher social status<sup>77</sup>. As I show in Chapter 15, teachers expect that children arrive in their classroom with a sensory knowledge, that correspond to parenting practices more often found in advantaged families. Given the specificity of visual impairments, they work with therapists to help children lacking these abilities to develop them, but it remains a form of remediation, rather than a body of knowledge and skills valued in the classroom. Whereas developing it for all children may actually benefit sighted children who do not have the opportunity to develop this knowledge at home.

Using the third lens, we can frame share taste as a sign of social homogeneity<sup>78</sup>. Putting the focus on non-visual experiences, I argue in Chapter 15, enables to make the classroom more pervasive to the diversity children's emotional and social lives. As a result, it enables discussing children's experiences, without labeling one as less worthy than the other. For the children who do not have stories historically deemed interesting in classrooms, e.g. travels, it opens new means of participation and engagement. On the other hand, it gives the teacher more possibilities to assert norms of conduct, which is consistent with the school stated purposes of civic education but is not always considered desirable.

With this section, I aimed to outline the many ways in which the sensory realm is shaped by social structures, with the focus on uses in education in the broad sense of the term. It follows that a turn to the sensory in classrooms is both an opportunity to engage children (disabled or not) and an extension of the aspects of children's lives that school staff may attempt to shape. Before moving on, I should outline that this is not a low-cost intervention that can magically make the inclusion of visually impaired children happen. This can

<sup>74</sup> Dodd, *Factors Influencing Fine and Gross Motor Development among Children 24 Months of Age: Results from the All Our Families Study*.

<sup>75</sup> Malinverni, Ackermann, and Pares, "Experience as an Object to Think with: From Sensing-in-Action to Making-Sense of Action in Full-Body Interaction Learning Environments".

<sup>76</sup> E.g., Cheon et al., "Subjective socioeconomic status modulates perceptual discrimination between beverages with different energy densities".

<sup>77</sup> Charters, *Wine and society: The social and cultural context of a drink*.

<sup>78</sup> Note that there are elements indicating that frontiers between tastes and class have somewhat eroded and that some groups could now be defined as omnivorous i.e., embracing many different forms of cultures and not discriminating against those not doing the same. However, this is a limited evolution. Warde, D. Wright, and Gayo-Cal, "Understanding cultural omnivorousness: Or, the myth of the cultural omnivore".

only become beneficial if the rest of the material conditions for a fair education are met: sufficient and trained staff, accessible schools, etc. Intervening through design could be seen as low-priority. But the material situation was overall satisfying at the time<sup>79</sup>.

<sup>79</sup> Important cuts to the IJA's funding were since made.

#### 13.4 *Discussion: Implications for Design Inquiries*

This section outline the implications for design that guide the rest of this thesis and that could open further research opportunities. I propose to investigate practices focused on fostering a non-visual culture at school and around school, e.g. I focus on field-trips, but this could be the artistic events attended by pupils. This is in line with my focus on the feeling of belonging to a community. This inquiry may reveal domains for fruitful design interventions, carers' endeavors we can support and opening new opportunities for children to assert competency and develop the relationships they desire. I believe that this can be studied through two main perspectives: impacts on the curriculum and the values associated with school and learning; and impacts on relationships, between pupils, between pupils and teachers, and beyond school, e.g. with parents.

A long term design intervention is particularly appropriate here, as it enables to embody both didactic hypothesis and a certain understanding of how relationships in the classroom are, and how they should be. The prototypes developed are **material resources** (Chapter 10 & 11), designed with the goal of fostering belonging, that can incidentally reshape relational and personal resources. Going for long term research also enables to build a detailed and nuanced account of what changes and what does not, beyond the punctual use of a prototype deemed successful for learning. What do carers retain from this intervention in the long run? How do children talk about it? We could also ask: how did it change the researcher? It deeply questions the criteria and means of evaluation too.

More generally, this is one possible answer to the issues in Assistive Learning Technologies I pointed in Chapter 8. In this research agenda, researchers stand to support visually impaired children specifically but try to always consider the group(s) to which they belong. Technologies are tested in the wild, to consider impacts beyond usability. Furthermore, it goes beyond substitution of content to interrogate the didactic scenarios in which they fit and that guide their design. Finally, it brings a focus on how differences of abilities are constructed through what is asked of pupils, rather than on the pre-conception of abilities, hence supporting the negotiations of potential

outlined in Chapter 10.

### 13.5 *Summary*

This chapter details the rationale for design interventions. Given the pragmatist nature of my research, I aim to build a case as to why the design interventions I led were meaningful in this context. This rationale borrows from various aspects of my research: it is inspired by how carers framed document transcriptions and special education techniques as translation practices; by the literature on the sensory turn and on non-visual approaches to geography; but also by critical, cultural and relational disability theory. Finally, it is driven by children's concerns that not enough attention is given to their well-being at school (Chapter 2 & 10) and by a conception of how to provide opportunities for well-being informed by the theory of social ecological theory. The next two chapters will focus on the design interventions themselves and their impacts.



# 14

## *Wearable Recorders and Field-Trips*

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This chapter focuses on the values associated with a non-visual approach of geography. This inquiry was also prompted by the recurring comments of professional carers about their difficulties to understand how children make sense of sounds for learning; and by children's eagerness to make audio recordings in contexts other than field-trips (where it was not allowed initially). I look into a practice based on the interpretation of non-visual cues to build geographic knowledge: field-trips. From my observations and interviews, reported in the first section of this chapter, I argue there is a paradox: though necessary, the listening/hearing practices developed during field-trips is curiously under-valued by both children and teachers. I attempt to show the reasons for this, especially the lack of connection with classroom learning, but also the fact that upon closer examination, field-trips are deemed less useful for children whose parents consciously engage in concerted cultivation (Chapter 13). Based on these insights, I proposed the use of a probe, an audio recorder/player, which design was defined with carers and pupils.

The second half of this chapter reports the main study I made of this probe, during a field-trip part of a pedagogical unit on human habitats (see Appendix A.5). It had multiple goals: providing pointers to special education teachers interested in this approach; better understanding how pupils make sense of an environment and supporting them in developing greater autonomy to do so<sup>1</sup>; and more generally, to understand if and how this design intervention enabled to change their opinions and understanding of hearing practices for geography.

<sup>1</sup> Consistently with supporting the development of the sense of self-efficacy.

### 14.1 *Opportunities for Design: Field Trips Practices*

*Having tea parties on the ceiling  
and highly-questionable outings of every other kind!  
If they must go on outings  
These outings ought to be  
Fraught with purpose yes, and practicality  
Mr Banks, Mary Poppins the movie, 1964*

I first set out to understand pedagogical practices aiming to teach geographical knowledge.

### 14.1.1 Study

#### Data Generation

This chapter builds on the interviews with teachers and therapists described in Chapter 9, as well as on my observations of six geography field-trips lasting from 90 minutes to half-a-day, with a mean ratio of pupils to teacher of 6, involving 7 different carers and 14 children (the same group of five children, the research participants for the probe, was involved in four field-trips).

#### Data Analysis

A first step of the analysis was to identify field-trips as a practice to study. This was done by identifying the importance according to the right "mental representations" which were always associated with "parental practices." The second step consisted in understanding the knowledge teaching and therapy staff have developed about field-trip practices, and more generally, the interpretation of non-visual cues.

### 14.1.2 Results

In many aspects, pedagogical practices do not differ from the recommendation to teach geography to all primary school children<sup>2</sup>. Teachers often adopt an inductive approach, where learning starts with a given place and a given number of traits, towards more general concepts. One way to do so is to compare two places, their similarities and differences. Another is to "zoom out": showing how a neighborhood fits into a city, county, etc<sup>3</sup>.

However, one aspect of this teaching in the organization studied stood out: the importance given to geography field-trips as practices enabling to develop correct abstract representation of one's environment, but also to shape interpretation skills of sensory cues. Yet, as pointed out in my review of geography scholarship (Chapter 13) there are no clear guidelines on how to use non-visual cues to support meaning construction in this discipline<sup>4</sup>. This is what I investigated.

### 14.1.3 Why Organizing Field-Trips.

According to teachers, the primary goal of geography field-trips is to reduce *misconceptions* in mental representations of space and environ-

<sup>2</sup> Firth, "Teaching Geography 11–18: A Conceptual Approach".

<sup>3</sup> Gersmehl, *Teaching geography*.

<sup>4</sup> Though there are many explorations of the use of technologies to support learning during field-trips, mostly focusing on sciences, and primarily making use of the visual modality. See, e.g. Rogers et al., "Ambient Wood: Designing New Forms of Digital Augmentation for Learning Outdoors"; Quintana et al., "A Scaffolding Design Framework for Software to Support Science Inquiry"; S. Price, Carey Jewitt, and Sakr, "Embodied experiences of place: a study of history learning with mobile technologies".

mental features, in order to exemplify and explain curriculum concepts (e.g., discovering different types of roads to explain networks and land use and transport planning). In their words: "*Field-trips [are] about describing things precisely, specifically, with the visual impairment in mind. Especially abstract concepts. Otherwise they can't think about the world [...] they may use the right words, but not know what it means. I need to give them adequate mental representations.*"

Teachers also reported that supporting children in constructing adequate mental representations is a complex art. The difficulty is that children lack means to express what they understood, and teachers lack means to capture what children understood: misconceptions are revealed incidentally (e.g., when a child is asked to describe a plane and mentions it rolls in the air like the aerial transit system). Developing adequate pedagogical practices without this mutual information is thus challenging, especially when considering that "*[the representations useful] for one child might not work for another one*". A secondary goal is to provide an enjoyable experience (which should increase motivation<sup>5</sup>).

**Summary 1 (S1):** Field trips are used to reduce misconceptions that would lead to a misunderstanding of curriculum concepts. However, understanding children's mental representations (teachers) or expressing them (children) remains challenging.

#### 14.1.4 *How teachers point out and describe sensory cues*

There are two essential aspects to using non-visual cues from the environment to construct meaning. They need to be localized and discriminated from others as meaningful, and thus pointed out; and they need to be described in terms of causes (e.g., the noise of the plane is due to its motors, the one of the aerial transit systems to the friction between the wheels and the rails). Indeed field-trips provide many sensory experiences that teachers can exploit. They may refer to all the senses: hearing, such the echo inside a church; kinesthetic and tactile, like a walk along its walls and the texture of its stones, etc (see Annex A.6). However, the sense of hearing was the most used<sup>6</sup>. These sounds come from the built infrastructure (e.g., outside: roads, public transportations; inside: echo, automatic doors), human activity (e.g., discussions, walkers, firemen sirens); and the natural environment (e.g., wind in the leaves). Teachers point out and use sensory cues in a variety of ways. For instance, teachers may point out useful cues and associate them with a description useful to introduce the concept they wish to convey.

<sup>5</sup> DeWitt and Storksdieck, "A Short Review of School Field Trips: Key Findings from the Past and Implications for the Future".

<sup>6</sup> Which is consistent with Thibaud, "A sonic paradigm of urban ambiances".

As an example during a lesson on human habitats (urban, suburban, rural) and their economic features: "*[with echolocation] you can feel it's a large open space [...] you can hear the cars and lots of people because they are talking [...] yes it sounds kinda like a shop but not exactly that [...] It's a restaurant, and a restaurant in a large open space probably means a public square. What do I find on the town square? This is a town square. I find [...]*".

**S2:** Teachers make use of all types of sensory cues to construct meaning, with a clear preference for using audio cues.

#### 14.1.5 How teachers scaffold field-trips.

Prior to the trip, the teacher visits the site(s) to devise a list of stops that can serve as example of the curriculum concepts to introduce. At each of these stops (e.g. during an outdoor field-trips the war memorial; during a museum field-trip, a statue), the teacher provides a short lecture. This is followed by a few questions to assess children's understanding. In a few occasions, she rather provides a problem statement and asks children to make hypothesis. The codesheet provided in Appendix A.6 provides examples for these techniques.

Before the field-trip, teachers may introduce necessary concepts, or a map of the general spatial organization, to which they can refer later. After the field-trip, activities are organized to reinforce children's learning by asking them to reflect on what they experienced. This may consist of working on the same or different map to further generate hypotheses on the phenomena explored (e.g. the differences between cities and villages). It can also consist of reporting the trip in a multimodal fashion, such as texts in black and braille with images. In the teachers' words: "*The field-trips and the artifacts I bring to the classroom are to provide as many information as possible, and many different and complementary representations of a concept [...] You have to vary the approaches, and accompany them in bridging the gap between the experience and the mental representation.*"

My observations also suggest that teachers sometimes struggle to establish ties between the lectures given during the field-trip and follow-up activities. Sometimes, too much time passed during the field-trip and the next class, e.g. because of holidays. According to teachers, tying the two necessitates to learn children's interests and preferences to select the memory that helps developing an explanation. For instance: "*[With this pupil,] you can be sure he's going to remember everything related to food. But [this other pupil] is rather going to remember everything that made him laugh, or that have emotional signif-*

*icance*". However, getting to know children's preferences takes time, and according to the teachers' interviewed, such knowledge is difficult to transmit to future teachers, as it is never really formalized, and was not part of their own training.

**S3:** Teachers attempt to link field-trip sensory experiences with representations such as maps before and after the field trips to provide multiple and complementary perspectives on the same curriculum concept.

#### 14.1.6 Use of technologies

I observed a limited use of technologies during the field-trips: Teachers use cameras to take photos. Sometimes these photos are reused later on in the classroom, or they may be sent to parents. Teachers did not initially identify the absence of technologies as an issue. Indeed, they were not convinced that children could meaningfully use technologies in this context by themselves. Reasons include concerns over safety, and children's perceived lack of reflexivity: "*If I give them a camera, they're just going to record anything and everything, and it'll be impossible to get them to focus.*" However, children sometimes worked with the interactive map described in Chapter 15, once back in the classroom. While, not directly related to the field trip itself, this system uses audio recordings found online, mostly to reinforce engagement through playfulness.

**S4:** Teachers usually do not use technologies except for cameras during field trips.

#### 14.1.7 Children's perspectives

Children mostly describe field trips as an enjoyable experience, the secondary goal of field-trip ("*I like field-trips because I don't have to go to school!*"; "*Field-trips are a reward for the children who obey well*"), but also that they appreciate to be more physically active ("*It's better than being seated*"). One indicated being more autonomous in field-trips to the museum, because, as each tactile object could only be held by one child at a time, and there was not enough time to manipulate each artifact, there is a choice to be made ("*you can decide a bit more what you want to look at, that's cool*"). When asked what they learned during field-trips, the experience was either labeled as similar to classroom activities, or as non-relevant to learning ("*I learn, you know, the usual stuff*"; "*it's not really learning, it's more like stories*"). Finally, I note that their agency remains quite constrained: they do not often

initiate activities (e.g., by asking questions), they can not explore freely outside sites and are often limited to small areas in museums (for safety or accessibility reasons).

**S5:** Children value field-trips as an enjoyable experience, but either do not consider them to be a learning activity, or consider it is not different from the classroom.

#### 14.1.8 *Synthesis and issues*

Organizing geography field-trips is a rich and complex practice which appears useful to reduce misconceptions about objects and environmental features (**O1**): Teachers make use of different sensory cues to help children make sense of their environment (**O2**). The sense of hearing is usually the most used (**O2**), which is not surprising as my review of literature<sup>7</sup> suggests it complements vision well to develop geographic knowledge. Moreover, teachers attempt to link field trips experience with a variety of other representations (e.g., maps, small scale models) before and after the field trips to provide complementary representations of the same concept (**O3**). But capturing children's mental representations (teachers) or expressing them (children) remains challenging (**O1**). From this perspective, teachers value field-trips and non-visual knowledge.

However, further analysis reveals a tension in the way children and teachers describe field trips and the way they perceive the knowledge thus acquired. For instance, children qualify field trips as an "enjoyable experience" but not as a learning activity (**O5**). This may impair children's ability to reflect on how they learn<sup>8</sup>. Furthermore, teachers also described field-trips as simply a playful *introduction to a curriculum topic*. In their words: "It obviously helps, but it's the foundation on which they learn, not what they need to learn. What's important is the concept, the abstract". More surprisingly, they suggested that not all children benefit from field trips: Field trips are for children lacking cultural<sup>9</sup> and familial resources. In contrast with a child needing these field-trips, a teacher stated: "Him, his parents describe everything, all the time. [...] When the parents don't do that, or don't know how to do that, it gives a lot more work to get to the actual learning."

As a result, field-trips are a lot less used with visually impaired children performing well academically, not necessarily because they know how to interpret new sensory experiences well, as it remains implicit for them, but rather because they are able to use graphic representations to answer tests correctly. **Hence field-trips and sensory knowledge remain confined to visually impaired children with**

<sup>7</sup> Thibaud, "A sonic paradigm of urban ambiances"; Augoyard, *Sonic experience: a guide to everyday sounds*.

<sup>8</sup> Fisher, "Thinking About Thinking: Developing Metacognition in Children".

<sup>9</sup> Lareau, *Unequal Childhoods: Class, Race, and Family Life*.

**learning difficulties, instead of an inclusive learning experience for all. I would argue these practices are under-valued. I call this tension the paradox of *using non-visual knowledge in the classroom*.**

Finally, I learned that children rarely use technologies during field trips, and that teachers only use cameras (O4). As discussed in Chapter 7, most ALTs for visually impaired children are designed to be used in the classroom and mainly aim at substituting vision with another modality<sup>10</sup>. Furthermore, teachers did not use the interactive map in their possession to articulate children's sensory experiences with the map representation. This observation is in line with my initial argument, which is that visual-based representations are perceived as more important in learning, hence explaining the choice of designers to target this type of knowledge.

<sup>10</sup> E.g., A. M. Brock et al., "Interactivity Improves Usability of Geographic Maps for Visually Impaired People"; Zeng and Weber, "Accessible Maps for the Visually Impaired".

## 14.2 Design

This section describes the design, and the design process, of the probe: an audio recorder-player. The initial idea consisted of allowing children to record audio cues of their choice during field-trips and to use them in later learning activities.

### 14.2.1 Ideation with carers

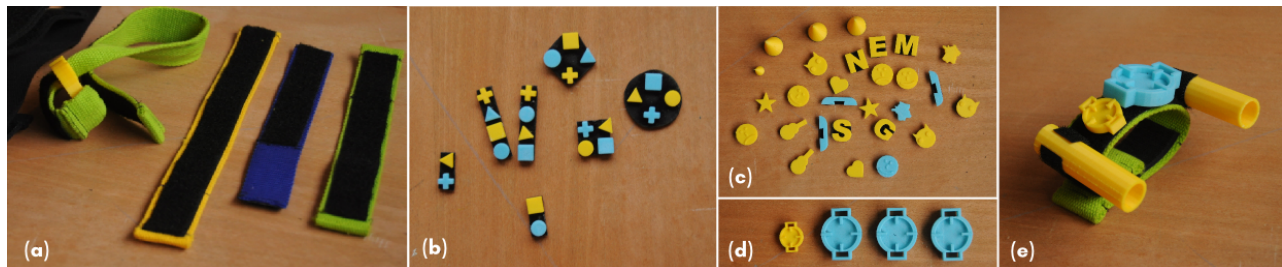


Figure 14.1: The first version of the probe is a Wizard-of-Oz prototype. It consists of (a) straps of various lengths that can be customized by: (b) small 3D printed shapes that can be easily discriminated tactily and used as buttons; (c) various 3D printed modules and geometrical volumes; (d) watch faces. (e) This probe was designed to enable children to build bracelets like those of superheroes / spies, watches or friendship bracelets. This is an example of a "spy bracelet" made by C3.

I defined the design intervention by building on semi-structured interviews with the carers involved. The interviews, with carers who already knew the project, consisted in three main questions about: what they would like pupils to be able to do during the field-trips; the technologies they would allow pupils during field trips; and their safety requirements. Several requirements emerged. When asked about whether they would let children use an interactive device during field-trips, carers were initially quite reluctant. They feared that it would be distracting, and therefore unsafe in an outdoor environment. Some were however eager to give it a try, in order to better understand what children learned. My hypothesis was that this probe could encourage children to devise their own ways of engaging with the material—to some extent, I was curious of whether it could generate a certain disobedience, the same kind of productive opposition I described in Chapter 2 and 11.

The carers wanted the probes to be task focused, robust (both in terms of supporting a potential fall and in being re-usable even after the departure of the researcher) and inexpensive. These requirements led us *not* to give children smartphones or smartwatches. Furthermore, carers forbid us to place a device on the cane or to be hand-held, based on concerns for children's safety during navigation, as they would not receive the training usually required to use a new device in mobility<sup>11</sup>.

<sup>11</sup> This was confirmed by children during a design session. They insisted it should not be hand-held nor placed on a cane.



### 14.2.2 Co-design with children

To engage the pupils<sup>12</sup> in the process, I asked them to co-design a device following these requirements. As a reminder of Chapter 4, probes are devices or tools used to provide design inspiration, better understand people and their uses of technologies, field-test technologies<sup>13</sup>, used as means of engaging users<sup>14</sup>. They are technically simple and flexible: participants are encouraged to invent new ways of using them. In this case, they were also a way for us to embody values, and investigate how participants would adopt, negotiate or challenge them by judging this probe and its uses.

I conducted a brainstorming with the five participating children for the first version of the probe. Once the probe deployed, I collectively decided to take another approach, and devised a second version driven by practical concerns.

*Version 1.* For the first version, I conducted a brainstorming to emphasize the playfulness of the probe. In doing so, I hoped children would see the device as something valuable and fun rather than something made to compensate disability. I focused on the form that children would like, building upon the results of a brainstorming on "a device to make audio memories when going on a school trip". I relied on examples from pop-culture to discuss its appearance: I asked them what kind of characters they like would have such a device. The characters proposed by children were either super-heroes (e.g. Batman) or spies and detectives (e.g. Spy kids). When describing devices, they proposed that it could look like common watches (C1: "So no one notices but it's cool"), that it could look dangerous and impressive (like Batman utility belt), or that it could be playful and distinctive (C2 proposed it could be friendship bracelets for people who like the same football team for instance). C4 also asked for tangible buttons, and the others agreed. In order not to limit design possibilities or have too bulky or unreliable prototypes, functions would be simulated by the field researcher<sup>15</sup>.

Given the variety of ideas proposed by children, I designed a kit (Figure 14.1) to make one's personalized wearable device. It consists of a series of straps, which can be worn anywhere on the body, and of a set of 3D printed modules. Both are covered with velcro to be assembled easily (Figure 14.1). The modules were 3D printed and can be discriminated tactilely. They consist of small buttons (e.g., a cross, square, circle and triangle—Figure 14.1-b), decorative elements (e.g. guitars, tubes or cones—Figure 14.1-c), and watch faces (Figure 14.1-d).

<sup>12</sup> Described in Table 14.1

<sup>13</sup> Hutchinson et al., "Technology Probes".

<sup>14</sup> Boehner et al., "How HCI Interprets the Probes".

<sup>15</sup> I.e., Wizard-of-Oz prototype Dahlbäck, Jönsson, and Ahrenberg, "Wizard of Oz Studies — Why and How".

*Version 2.* However, it was quite difficult to follow each child, which frustrated them—and this approach was unsustainable for the teachers. I therefore consulted the children and carers regarding a variety of commercially available recorder options that I could use for a second version of the probe. This was a collective discussion. Children found that "professional looking" audio recorders were acceptable, and carers agreed to an audio recorder using three simple tangible buttons. I thus bought five Nestling Audio recorder of 83x35x12mm, with velcro stuck in its back to attach it on the wrist. They are pictured in Figure 14.2. The three main functions—Play/Pause, Stop, Record—are accessed by three physical buttons that can easily be discriminated tactily. They are cheap (12\$) and resistant to falls as required by teachers. Five of these devices were made available to the teachers. Note that I chose to use a commercial device rather than assembling them ourselves in order to guarantee that they could be used after I left the field (as required). But this poses usability issues, as there is no audio or tactile confirmation of the device status.



Figure 14.2: The second version of the probe is worn on the wrist. It consists of a strap covered with velcro on which an audio recorder/player. It has three main buttons that are tactily recognizable, one to start recording, the second to stop recording and the third to play the last recording.

### 14.3 Study Design

This chapter presents a study conducted during the overall ethnographic research—they can not be fully separated, but it does focus on a specific subset of questions. Hence the need for presenting its specific design. All methods used were introduced in Chapter 4. The structure of this study follows examples from the literature on multimodality analysis of learning technologies<sup>16</sup>.

<sup>16</sup> E.g. S. Price, Carey Jewitt, and Sakr, "Embodied experiences of place: a study of history learning with mobile technologies".

### 14.3.1 *Research Questions*

This is an exploratory study to investigate the reconfigurations induced by the probe presented above. I wanted to understand if and how it could change the perception of a specialized non-visual knowledge, here hearing. Additionally I wanted to better understand how pupils (could) construct geographic knowledge from field-trips and how this technology could mediate it. To summarize, the key research questions were as follows:

1. How does it affect their interactions and the ways they make sense of the site studied?
2. What would be the guidelines to non-visual (or multisensory) field-trips with sighted children?
3. How do teacher and pupils make use of the ability to record audio content?
4. How does it change the values associated with the field-trip, an activity associated with special education or dissociated from useful learning?

To these ends, I analyzed the recordings produced by the children, conjointly with my observations of the field-trips. This was complemented by semi-structured interviews some time after the activities, to understand if there was indeed a change in the perceptions of field-trips.

### 14.3.2 *Activity*

The activity consisted in a field trip from the urban center in which the organization is situated to the countryside. We stopped at three sites: the center of a village which featured a square, a town hall, a church, and a war memorial; a farm; and the commercial area of a suburban city, which included a consequent post office (see Figure 15.4-a). The teacher asked each pupil to be attentive to particular types of sensory stimuli, according to preferences and abilities she had previously identified (e.g., C<sub>3</sub> and C<sub>4</sub> would describe their visual perceptions, while C<sub>5</sub> was to be attentive to smells). All were invited to be particularly attentive to sound, as we could record them. The reader may have noticed that C<sub>4</sub> has a hearing impairment. He was nonetheless encouraged to be attentive to sonic environmental features and ask questions when needed. This is consistent with his personal educational project, which encourages helping him using his remaining hearing abilities in mobility.

The goal was for children to learn to identify features of rural, sub-urban and urban areas, to be able to recognize these different kinds of habitats in the future and use these analysis skills in other places. The teacher discussed features common to the three in France (e.g., church, town square, town hall, war memorial) and oriented their attention towards phenomena/environmental features she thought representative. For each, she provided additional information, linking it to a theme or to regional geography (e.g., what is a war memorial, why is there one in every village of France; what are commercial areas and economic exchange). She would regularly ask the children to explain the nature and source of their sensory perceptions (e.g., hearing and far away at my left).

The novelty of the device caused some issues, but given the presence of three adults who could help, it did not significantly alter the recordings made. All the children were familiar with the concept of recording and playing audio.

### 14.3.3 Participants

Five pupils, involved from the beginning of my research, participated to this study. Their demographic and other information are reported in the Table below. They attend different mainstream schools part-time (i.e., 3-4/5 days of the week) and the same special education classroom the rest of the week. This study took place in this latter classroom. Their time in this special education classroom is dedicated to develop specific skills (e.g. reading braille) and attend rehabilitation sessions (e.g. mobility and orientation). They are either perceived by their special education teacher as being able to perform better but little resilient, or as unable to follow the same curriculum as their peers. The socio-economic status (SES) reported follows the nomenclature used in French education statistics i.e., the household referent person's occupational status<sup>17</sup>.

<sup>17</sup> See Chapter 5 & 6 about this proxy metric for socio-economic status

<b>Id</b>	<b>Gender</b>	<b>Age</b>	<b>Grade</b>	<b>Impairments</b>	<b>SES</b>
C1	M	10	3rd grade	Blindness with light perceptions, motor, memory difficulties and psychological impairment	Disadvantaged group
C2	M	11	5th grade	Blindness with light perceptions	Disadvantaged group
C3	M	11	5th grade	Severe visual impairment and dyslexia	Middle class group
C4	M	10	4th grade	Severe visual and hearing impairment	Advantaged group
C5	M	11	4th grade	Blindness with light perceptions, multiple learning difficulties	Disadvantaged group

Table 14.1: Information about the children who participated in the design of the probe and the study.

There are two reasons I chose to work with these children specifically. The first was highly pragmatic: they were the students of the special education teacher involved in the research project (see Chapter 2) and would attend the same classroom for a long enough duration. This meant being able to build a relationship with them and to observe changes on the long run. There are relatively few occasions in which five pupils with visual impairments are in the same classroom. The second has to do with my aim to understand the intersection of class and disability at school, how it shapes the available resources (Chapter 10 & 11) and how it shapes opportunities for learning—in part following the values associated with certain courses and ways of learning (see above and Chapter 11).

This group was initially presented to me as a proof of how social inequalities impact impairment rates and educational outcomes: they mostly come from relatively disadvantaged contexts; their parents were described as opposing or refusing professional advices on crucial aspects of care instead of working in *concertation*<sup>18</sup> with them<sup>19</sup>. The gender imbalance being attributed both to the imbalanced prevalence between genders (see Chapter 6) and a difference in attitudes towards school that made them more likely to need support and remedial activities.

An experienced special education teacher was involved in this whole study. She designed the activity led, asking for my inputs as to how to use the probe. She tasked me with sustaining children's engagement by asking questions or answering theirs.

#### 14.3.4 Procedure

Prior to the activity, I demonstrated the use of the audio recorder to each of the children participating. C2 had used the first version of the probe but was absent this day. They were all familiar with the making and use of audio recordings, since we had conducted a similar activity in a museum three months prior. The teacher explained to them the learning goals (understanding the differences between cities, suburbs and the countryside). I invited them to *create memories* and *record sounds interesting for the activity* and told them they would later be used on the interactive map they have in the classroom (see Chapter 15). For each recording, I asked the children why it attracted their attention, why they recorded it. Children could also ask me to take photos or videos: by doing this, I hoped that if necessary they would contradict us on the importance of sounds, and would use something more appropriate to them. I also provided help in technical use. A few days after the field-trip I conducted semi-structured

<sup>18</sup> Scott Davies and Jessica Rizk, "The Three Generations of Cultural Capital Research: A Narrative Review", See Chapter 13 for a discussion of social and concerted cultivation and:

<sup>19</sup> I have to keep this brief, but I would like to note that this is not a general statement I would make on parenting practices and social class. The fact that professional intervention is less welcomed in certain families than others has to do with how disability and care professionals are perceived. Opposition to specialized care happens in all social stratas. However, not all families have access to the same resources and feel they can negotiate the terms of care. On this, families classified as highly advantaged seem to have a clear advantage. This is one aspect that would require further research as those situations are much more complex: for instance, children sometimes contest their parents' opposition to certain care practices.

interviews with each participants, in which we recalled and discussed the field-trip. We also has regular informal discussions over the course of the following three months, during which the field-trip was discussed.

#### 14.3.5 *Analysis*

The analysis borrowed from multimodal analysis: I focused on senses as modalities in learning and on-going participants' interactions to understand their impacts on the construction of meaning. It also borrows from my approach to understand research participants' values: focusing on statements contrasting or opposing two opinions; or in this case two versions of field-trips or children's interactions and learning outcomes (see also Chapter 4 for a discussion of methods).

To these ends, I developed two codesheets. One to describe activities and hearing techniques during field-trips, such as the types of cues recorded, and how they were used. I used it to tag and analyze my written observations and audio recordings of children's comments. It can be found at the end of this thesis, Appendix A.6. The second identifies expressions of values, understood as judgments guiding human conduct, and codify statements made by the participants about learning, the goals of education and the factors affecting success at school<sup>20</sup>.

<sup>20</sup> Note that the themes mirror those developed in Chapter 11.

### 14.4 *Results and Discussion*

According to post-activity interviews (and to the laughter during it), all children enjoyed the activity. Each pupil recorded between 10 (C5) and 28 (C3) minutes of material. Some recordings were initiated by the teacher (3 recordings of about 10 seconds), but the rest of the recordings were made by children. These recordings were of various types (e.g., messages, stories, sound effects) and are documented in Appendix A.6. Finally, they asked for 18 photos in total, and no videos.

#### 14.4.1 *Weaving Sensations In*

To answer the first question, about how this intervention affect social interactions and techniques to construct meaning in situ, I propose to examine changes in the scaffolding made by the teacher and in the ways children participated. The small lectures at meaningful points of the sites visited were instructive. I called this section weaving

sensations in, because the teacher was a lot more attentive to the articulation between perception and curriculum content. For instance, in the example about public squares earlier in this chapter: a cue was given, and a small lecture follows. We can compare it with the following:

At the village square, P6: *"How can I learn about what is around this village square? [...] Yes I could walk around [...] Indeed I can ask people [...] And I know things about village squares. What do I find there usually? [...] Indeed, a church, and sometimes the town hall. How does the Church sound? [...] Very well, indeed it has bells! Let's record them. And why is there a church in the center of villages?"*

It is not so much the probe itself, but the preparations of this activity that included reflecting on the role of the probe that led to this. This points to the importance of mediation when implementing this non-visual approach. Yet, we should not overlook how the presence of the probe reminds to encourage pupils' participation. This excerpt shows that children were also more often invited to elaborate on the kind of cues they could rely on, instead of having these cues pointed out. In turn, children shaped the lectures: They took the initiative of asking the meaning of sounds they were noticing, which I had not observed before.

I highlighted earlier in this chapter that one worry carers had about any kind of mobile tools used during field-trips was the fear children were not able to self-regulate, to use the tool purposefully. I, on the other hand, was interested by how children would use the tool to push the boundaries of the activity, or to legitimize their curiosity for environmental features the teacher did not plan to discuss. One such borderline activity was the recording of more or less class-related messages. Pupils would record messages and pretend sending them to a classmate. This was quickly identified by the teacher as an opportunity to develop their learning techniques, but also as a potential nuisance enabling them to play instead of focusing on the activity. Their diverse attempts to cooperate in order not to record the same thing or making sound effects were perceived similarly. Regarding the recording of sound effects to play during the field-trip (and sometimes re-recorded), they mark an interesting form of engagement, that might be allowing children to imprint their own layer of meaning.

#### 14.4.2 Recordings: Representations of Space and Envisioned Public

I note in my review of technologies for field-trips that the material created from field-trips is generally either visual or audiovisual, with audio being used for taking notes. But S. Price, Carey Jewitt, and Sakr<sup>21</sup> note that the superposition of audio recordings with a specific place (in their case, for a history activity) foster a greater engagement with one's surroundings, whereas visual documents have one focused on their support (in their case, a tablet). In this section, I thus discuss the relation between the audio recordings made and the engagement with the sites visited, which provides pointers as to how to approach this kind of in-situ activity.

If we look at audio recordings (see Appendix A.6 for my typology), we can identify two overarching categories on the basis of their length. Stories, recording of lectures and messages are long (one minute or more). The material was recorded during the field-trip but is easily transferable to another context. Whereas recordings of environmental sounds, or sound effects made by the pupils and played during the field-trip, are much shorter (less than 20 seconds). They are much more grounded in the field-trip, they require this context. The photographs taken were associated with both types of recordings. They were either oriented towards complex objects that have significance for the geography class (e.g., the war memorial). Or provide an additional representation of the element because of their other sensory aspects (e.g., the sound made by the wind in the leaves led to a blurry photograph of leaves).

But then why not ask me to make videos? They combine both aspects. All the pupils involved have previously watched movies, short videos on streaming platforms or family-made movies. C3 also declared having made and shared short videos with a smartphone. He offers an insight:

*"No one needs a video of this, it's not the video that's interesting, you can hear it's trees, lots of trees, and it's all green. [...] We could have made a video when we were in the phone booth, that was fun."*

In this excerpt, C3 identifies different *aims* and audiences for the recordings. Recordings can be used for: (1) *learning*, classmates and eventually non-participants; (2) *playing, expressing playfulness* and non-participants. (1) The video does not bring more or better information about the trees in his opinion. The kind of trees does not matter, because the sound is sufficient to convey the meaning—that it's "all green", the countryside, as does the photo. In contrast, (2) making a video of a moment of play is a way to show their social and

<sup>21</sup> S. Price, Carey Jewitt, and Sakr, "Embodied experiences of place: a study of history learning with mobile technologies".



emotional lives at school outside of school. Video is adequate for this, because it builds on other practices, including family videos.

However, these short recordings questions what constitutes a landscape in this case. They create a discontinuous landscape made of short sequences, rather than a continuous image or movie; as does the collection of photos. A few of the recordings were ambient, but, as C5 put it:

"You don't actually hear anything. It's all [he gesticulates wildly]."

E: "Messy, you mean?"

More specifically, no sonic element is salient. This has to do with the technology used, as the microphone is of relatively low quality. But it also has to do with how geography is taught (e.g., by extracting certain signs as significant for analysis). A different technology, for instance one enabling a high-quality spatialization of sound, might produce a different result. I say might, because a spatialized high-quality recording would also necessitate later on to pinpoint elements of interests as is done when working from the photography of a landscape. The main difference then is the proximity: Something far away can be pointed at in a photograph, but not in an unaltered audio recording. As I expose in Chapter 15, these isolated audio recordings can nevertheless be used to recompose a continuous representation; and as discussed below, they can become representations to be shared with non-participants.

#### 14.4.3 *The Senses as Modes*

Modes, in multimodal analysis, are a shared set of resources to create meaning<sup>22</sup>. Photographs for instance are a mode. But can we quite consider them the same mode for visually impaired people? The reader may have noticed in my description of the activity that children were invited to use all their senses, including vision. C4 for instance was able to recognize the color of a field when looking through the car's window—which, associated with its odor, enabled to identify the type of culture in the area<sup>23</sup>. The field is differently seen and need to be associated with its odor or a verbal description, but the meaning is the same. My intervention focus on sound and the sense of hearing, but it is always solicited in context (as shown in the excerpt above). Hence, in this section I discuss the senses appealed to during the field-trip to construct meaning as modes developed specifically for this group. This provides pointers as to how these modes could be used elsewhere.

*Hearing.* Sounds were the cues most relied on: Sounds can be

<sup>22</sup> Kress, *Multimodality: A Social Semiotic Approach to Contemporary Communication*.

<sup>23</sup> Meaning construction from smell and taste is further discussed in Chapter 15.

heard from a distance, they are incidental and it is generally easy to find their source. It also provides quasi immediate feedback. Using the probe revealed something that I did not understand through observations only: children *produce* the audio cues they need to construct meaning. For instance a child recorded the noise made by his cane on the ground. As we discussed, pavement often indicates older streets, or streets preserved for their historic significance, than does concrete. I should also point out that carers try fostering the development of echolocation i.e., the perception of environmental features through sounds. Or to paraphrase Thibaud<sup>24</sup>, sounds do not just signal events or activities, they are also the medium of activities.

Like visual images, sounds are easy to record and replay: the pupils for instance used non-verbal and verbal content previously recorded to answer a teacher's question<sup>25</sup>. This would not be easily the case for the senses other than vision.

*Smell.* Smell is also incidental, but its source can be more uncertain. Furthermore, nuances can be difficult to grasp as it is not necessarily often used. It is "*diffuse and volatile*"<sup>26</sup>. More interestingly, it often does not change as fast as do the sonic features. As phrased by C1 during the field-trip:

*"It all smells the same since we left the restaurant. I don't know what I must smell."*

There were multiple and distinct smelly events (the field, the road, the trees, the restaurant, the farm), but none between say, the war memorial and the church. Smell however was strongly associated with specific emotions and judgments of value (like/not like).

*Vision.* Vision is particularly useful for acquiring non-proximal incidental information (e.g., C3 noticing the phone booth, which can not be smelled, heard, or otherwise felt). Furthermore, harnessing residual visual perceptions is considered a good thing, both because it supports collaboration with sighted peers and for practicality. But it also causes confusion: Vision is "*treacherous*" to quote the special education teacher:

*"Sometimes, I've got to tell them 'no, don't try looking, try hearing,' because that's just a lot more efficient sometimes. Take roads: it's much easier to know how wide and busy they are by listening than by looking. [...] They'll always try looking, I just try to prevent jumping to conclusions if they don't have confirmation of what they see."*

Hence the example above about looking at and trying to identify the smell of a field. But this also hints that maybe different types of visual material could be developed (and not just enlarged or simpli-

<sup>24</sup> Thibaud, "A sonic paradigm of urban ambiances".

<sup>25</sup> Note that this use of the probe posed difficulties, and that in most cases I had to assist in finding and playing the recording in question. See the section on perspectives below.

<sup>26</sup> Thibaud, "A sonic paradigm of urban ambiances".

fied).

To conclude this section of senses as modes, I want to evoke two last sensory aspects of the field-trip. They can hardly be considered as independent modes, but offer additional insights.

*Movement and texture.* Movements can be used to assess size, as well as to better characterize other cues (e.g., finding the source of a sound or smell). Textures are experienced through cane, feet and hands. The terrain gives useful information at all time. Textures to be explored with the hands were generally from the built environment.

*Emotional state.* Let me define this by an example: the teacher asked the pupils how specific places (e.g., the square) made them feel. As they stated not to know what to answer, she asked how they thought other people in this square felt. She then proceeded to explain emotional states and their social functions: in front of the war memorial, one feels solemnity; on the town square, feeling relaxed or joyful. These emotional states are associated with specific body languages and can be pretended. But she also encouraged them to note and recall their emotional state, as a sort of synthesis of all other sensory cues, positing that appealing to emotions was good for memorization and constructing meaning<sup>27</sup>. So it refers to the overall assessment of one's feelings, as a socially adequate response to the environment.



Figure 14.3: A cane on the pavement.

#### 14.4.4 *Evolving Participants' views*

##### **Teacher**

During post-field-trips discussions, it appeared the teacher uses multiple criteria to approve of a design intervention in learning: impact on learning outcomes, engagement (understood as a proof of a pupil's perception of self-efficacy) and peer-relations. As I demonstrated in the first half of this chapter, these criteria vary from one child to the other. For this group, they are split. For C<sub>1</sub>, C<sub>4</sub> and C<sub>5</sub>, field-trips were framed as affording clear learning gains and technologies as giving the opportunity to assert competency and improve the relationships with their peers. For C<sub>3</sub> and C<sub>2</sub>, the focus was rather placed on keeping them engaged and motivate. These differences are not surprising: they are consistent with my analysis of carers' understanding of resilience and its role in education, outlined in Chapter 10. To be more widely use, non-visual geography field-trips must prove positive impacts on learning and support opportunities

<sup>27</sup> See also: Sakr, Carey Jewitt, and S. Price, "Mobile experiences of historical place: A multimodal analysis of emotional engagement".

for positive peer relationships for all.

The teacher pointed out that the probe made her rethink what would be pertinent audio material for representing curriculum concepts: *"I wouldn't have thought about recording or recording some stuff they recorded, but if I know how it makes sense for them [...] I can use it."* It modified the perceived potential learning gains, as she judged it positively impacted memorization, whereas remembering the details of the field-trip was initially framed as a problem. A new question then being: do these findings hold in mainstream classrooms (see also Chapter 16)?

#### 14.4.5 Children

As for children, several elements contrast with their initial perception of field-trips as a fun activity not related to learning. Two of them (C4 and C5) asked if their recordings would be evaluated, suggesting they did consider it as schoolwork. Related to that finding is C3's expressing that using these recordings afterwards indeed made them legitimate—*"when you record it and you use it in class, it's not silly."* I never heard the previous field-trips discussed, but after this field-trip C1 came up to ask me for the recordings, which he wanted to share it with one of his friend. These findings leans towards confirming carers' discussion of non-visual culture in Chapter 11.

Of interest to me are the particularities in children's responses, which can nuance this finding: C4, who has a hearing impairment, still greatly used the probe. But from my discussions and analysis of his recordings, it emerged that he used it because it was easier for him to record on the moment and review it later, that it helped them discriminating between different audio sources (e.g., the lecture and the environment). As a result, he reported feeling better understood. But children felt a different level of engagement, according to their feedback. C2 and C3, who do not have additional impairments and are in a more advanced grade, were more critical. In C2's words: *"it's more about fun, and helping the others, ain't it? It's good it helps them."* Further in the interview, both of them pointed out that it was different from what sighted children do. If C1 outlines this difference as positive, C2 and C3 see it as negative. Therefore this type of intervention does not directly afford more opportunities for positive peer relationships. Which begs the question: How do we extend the invitation to consider non-visual sensory knowledge to the sighted? How do we conduct and sustain interventions to support long term change?

This intervention questions (1) the implicit dominance of visual material in geography, (2) who have access to this knowledge and is thus considered competent, and (3) how this knowledge is supported materially. On this latter aspect, the introduction of the probe, centering on the sense of hearing, impacted children's and teachers' practices and narratives. It changed their interactions during field-trips, and the type of material used in the classroom. It also altered how and to whom children talk about field-trips, and ultimately the value attributed to this specific way of hearing. The flexibility of the probe was probably a key factor in doing so. Rather than presuming what type of recordings would be useful, or proposing structured activities, my intervention was light, and focused on enabling children to manipulate audio material in geography.

## 14.5 *Implications and Limitations*

### 14.5.1 *The importance of mediation*

Though an increased use of hearing techniques and auditory material in learning activities was well received by this group of children, it does not guarantee the same effect in a different setting. For instance, in a mainstream classroom, the difference with sighted peers can be perceived positively or negatively, which seem to depend on academic achievements. Therefore, I can speculate that the changes discussed above would occur differently in other contexts. Hence, rather than *generalizing* the findings from this exploratory study, which would imply reproducibility, I should focus on how to *transfer* them.

Adopting my approach successfully requires to consider the mediation of those supporting an intervention in practices. I used my theoretical lens to understand, support and extend local practices that pre-existed my intervention. But if I had a different lens, results would be different. A risk I identified, for instance, is to present this kind of artifact as a way to make sighted children empathize with their visually impaired peers (e.g., by blindfolding them). First, many people with disabilities find this offensive<sup>28</sup>. But mimicking disability also misses the point: blindfolding can only be restricted to one moment in time, providing a superficial experience. By reducing auditory knowledge to a way of developing empathy, I obscure the real issue: The need to question which and who's knowledge is considered suitable at school, and to support a diversity of ways of knowing. This implies that instead of presenting to children visual impairments as a lack, I should fully take them into account in

<sup>28</sup> See for instance:  
<http://bit.ly/1d8o49z>;  
 and [disability.illinois.edu/empathic-modelingdisability-simulation](http://disability.illinois.edu/empathic-modelingdisability-simulation)

the design of courses, or present it as enriching school activities. To teachers, it can be presented as beneficial for out-of-school learning. Indeed, learning to be attuned to environmental audio cues in Geography classes afford new occasions for geographic concepts to be used in children's everyday lives. I would argue that this could be done by designing the pupil with visual impairments as the *expert* in hearing techniques, within a larger classroom dynamic encouraging the shared expertise of teachers and children<sup>29</sup>.

#### 14.5.2 *Considering the Senses as a Culture*

More generally, this study is an invitation to consider the senses as a culture when designing novel technologies. Theoreticians of the sensory turn remind us that my ability of using my senses for learning is culturally shaped<sup>30</sup>. It is an invitation to design for supporting marginalized knowledge<sup>31</sup>, in interaction with formal knowledge. Or as expressed by McBride<sup>32</sup>, to "*design from the margins*." Matos' work on a rare whistled language<sup>33</sup> is a good example of this. It also is an invitation to consider how the senses and sensory knowledge are currently, and could be in the future, mediated: Are all sensory knowledges acquired through similar practices (e.g., pointing out and describing)? Are the scaffolding techniques I outlined the same in other contexts?

My findings provide a number of insights **on a hearing, and more generally non-visual knowledge of geography**. Some of my findings echo those made in other domains or with other senses. For instance, the use of metaphors I observed can also be found in<sup>34</sup>. Or in the case of smell, McBride and Nolan Jason<sup>35</sup> advocates to devise ways of producing scents. It could be paralleled with how children learn to produce a number of different sounds to acquire information or express what they mean. And as metaphors are culturally specific (think about how difficult it can be to translate an idiom from one language to the other), how can I support cross-cultural approaches?

Finally, let's outline a few opportunities for design, particularly for technologies for geography. First, a more sophisticated version of my probe would be useful<sup>36</sup>. But my findings on the types of cues that can be used opens new perspectives for auditory representations of space (e.g., maps<sup>37</sup>). Instead of using symbolic cues to represent city areas, it could rather use more complex and realistic sounds, representative of their differences. For instance, touristic areas have a very different sonic ambiance than industrial areas. Furthermore, whereas research on full-body interactions have focused on visual attention to foster learning in a variety of disciplines (including natural

<sup>29</sup> A. L. Brown et al., "Distributed Expertise in the Classroom".

<sup>30</sup> Maslen, "Researching the Senses as Knowledge"; Classen, "Worlds of Sense: Exploring the Senses in History and across Cultures".

<sup>31</sup> Ocholla, "Marginalized knowledge: An agenda for indigenous knowledge development and integration with other forms of knowledge".

<sup>32</sup> McBride and Nolan Jason, "Situating Olfactory Literacies: An Intersensory Pedagogy by Design".

<sup>33</sup> Matos, "The Sound Labyrinth: Computers, Constructionism and Language Learning".

<sup>34</sup> Maslen, "Researching the Senses as Knowledge".

<sup>35</sup> McBride and Nolan Jason, "Situating Olfactory Literacies: An Intersensory Pedagogy by Design".

<sup>36</sup> I began researching accessible tangible interactions on smartwatch but this was not completed during the PhD. See: Brulé, Bailly, et al., "Investigating the Design Space of Smartwatches Combining Physical Rotary Inputs".

<sup>37</sup> Pielot et al., "Tangible User Interface for the Exploration of Auditory City Maps".

sciences—see<sup>38</sup>), the field-trips practices I observed (and the later uses of audio material in the classroom) suggest that auditory attention may be used as well. Because children are not as used to identifying audio stimuli as to identify visual stimuli, they may have to be more attentive to them.

<sup>38</sup> Malinverni, Ackermann, and Pares, “Experience as an Object to Think with: From Sensing-in-Action to Making-Sense of Action in Full-Body Interaction Learning Environments”.

#### 14.6 Summary

This chapter presented what I would term an opportunity for design, in line with the perspectives for design I outlined in Chapter 13. Geographic field-trips are the occasions to observe how children make sense of their environment when the purpose is to develop geographic knowledge. But if they were recognized as activities engaging children and providing a pleasant experience, they are not fully recognized as useful for learning. Learning occurs in a classroom, on a map, in a closed environment—field-trips are messy, engage all the senses, provide multiple distractions and are primarily considered as remedial activities.

I proposed the use of two simple functions, recording and playing sounds, during geography field-trips. From this proposition, I engaged pupils and their teacher in an iterative co-design process leading to the design of a probe. Deployed for a study in a geography field-trip, it enabled to examine more in depth how pupils may construct geographic knowledge, *in situ*, from multisensory cues. It also shows how this design intervention did indeed enable a change of perspective on field-trips.

## *MapSense, a Multisensory Map*

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In continuity on the two previous chapters, I propose to try designing not to substitute visual representations, but to support the development of a non-visual approach to the curriculum. This stems from my focus on social interactions in formal learning environments (Chapter 8) and the fact that technologies provide opportunities for reconfiguring those interactions and relationships (Chapter 11). But also from the will to try supporting the development and the recognition of a non-visual culture at school (Chapter 8 & 13). In Chapter 14 I presented geography field-trips as an opportunity for design and described the uses of an audio-recording probe during a *field-trip*. This chapter focus on a multisensory map, MapSense, used in the *classroom*.

Mapsense is the end result of a long design process and the outcome of my year-long collaboration with a special education teacher and her five primary school students to develop a primarily non-visual geography curriculum. It mediates the use of children's smell and taste using tangible interaction. This chapter takes a case-study approach to deepen some of the insights of Chapter 14 on uses of non-visual material in geography. How do pupils try to make sense of this unusual material, in conjunction with the tactile, audio and tangible material used in this lesson? How does the special education teacher support the development of these interpretations? Multisensory material in the classroom has the potential to support experiential<sup>1</sup> and embodied learning: were these promises achieved?

My findings suggest that this multisensory map have great potential for making the classroom more pervasive to pupils' social, spatial and emotional lives, while the way the material was delivered reconfigured spatial occupation and interaction dynamics between pupils and between pupils and the teacher. In doing so, it afforded opportunities for citizenship education. This chapter provides concrete examples of uses of taste and flavor in learning to support engagement and has implications for pedagogical design beyond special education—the overarching goal remaining to draw opportunities for a more inclusive curriculum and classroom<sup>2</sup>.

<sup>1</sup> Kolb, *Experiential Learning: Experience as the Source of Learning and Development*.

<sup>2</sup> A version of this chapter was published as a journal article. See: Emeline Brulé, Bailly, A. Brock, et al., "An Exploratory Study of the Uses of a Multisensory Map—With Visually Impaired Children".

### 15.1 *Opportunities for Design: Using Pupils' Spatial Experiences in the Classroom*

The motivations for the design of this map are not as clear-cut as were those guiding the development of the probe in Chapter 14. In fact, the approach underlying these two devices (see Chapter 13) was nurtured by each iterations and design interventions preceding their deployment; lucky unforeseen experiments such as giving an audio recording app to a child during an interview and observing him recording the echo of the corridor; ongoing discussions with carers and children; the research literature; and probably a designerly way of seeing discussed in Chapter 2. The timeline in Appendix A.4 gives an overall idea of the continuous re-assemblages and transfers of design properties<sup>3</sup> that resulted in the map presented here.

Nonetheless, I can schematically trace three main motivations that converged in this design:

1. The special education teacher involved in the research project wanted to improve her practices (see Chapter 2). The special education teacher involved in the research project wanted to better understand how some of her hunches about pedagogy worked. One such hunch was to bring traditional food from all continents in a lesson dedicated to learn to recognize continents and their features. She argued this seemed to improve memorization for some of her pupils (especially C5), which she thought could be explained by the theory of learning styles, i.e. that children have a sense or a combination of senses of preference for learning. However, this theory is controversial<sup>4</sup> and lacks empirical basis<sup>5</sup>. Furthermore, smell and taste are not included in this theory. Thus, it seemed useful to look at how food in the classroom may be used for meaning making;
2. A second motivation for this prototype is the will to harness existing technologies aiming to substitute visual material. As discussed in Chapters 13 & 14, proposing a non-visual approach of geography does not necessarily mean rejecting the visual<sup>6</sup>, but rather to approach it differently. I proposed a few pointers about different ways of seeing in Chapter 14, but this chapter and this prototype looked more finely precisely at their articulation;
3. Last but not least, if field-trips are perceived as times/spaces affording greater affective engagement and more opportunities for personally appropriating the material<sup>7</sup>, how to support these two aspects in the classroom? Great attention was given to supporting

<sup>3</sup> Chow and Jonas, "Case transfer: A design approach by artifacts and projection".

<sup>4</sup> See Chapter 8 and: Coffield et al., *A Critical Analysis of Learning Styles and Pedagogy in Post-16 Learning: A Systematic and Critical Review*.

<sup>5</sup> Husmann and O'Loughlin, "Another nail in the coffin for learning styles? Disparities among undergraduate anatomy students' study strategies, class performance, and reported VARK learning styles".

<sup>6</sup> See also: Kwan, "Feminist Visualization: Re-Envisioning GIS as a Method in Feminist Geographic Research".

<sup>7</sup> S. Price, Carey Jewitt, and Sakr, "Embodied experiences of place: a study of history learning with mobile technologies"; DeWitt and Storksdieck, "A Short Review of School Field Trips: Key Findings from the Past and Implications for the Future".

children in the customization of the learning material, particularly the audio data. Defining the material to be used by a group of children is an opportunity to share and discuss cultural references<sup>8</sup>, or in other words to invite a child-defined (childhood) culture (Chapter 3) in the classroom—which in this case takes unexpected forms.

To summarize, in this chapter, I examine the uses of unusual learning material, particularly material to be smelled or tasted, to understand the learning and meaning-making processes including them and the ways it can reshape social interactions in the classroom.

I now discuss two aspects in light of the literature: the conceptual model of education held and existing perspectives on olfaction and taste in learning.

### 15.1.1 *Which model of learning?*

My thesis is punctuated with discussions on the models of education and theories of learning in the literature<sup>9</sup>. As discussed in Chapter 13, the teachers involved conceptualize school as an environment that contributes to shape children's conduct and knowledge in a way that fosters their insertion in the community at large later in life—though as I have attempted to demonstrate, it remains the lowest expected outcome, which only reinforces implicit hierarchy of disability made by children.

This chapter takes an approach to learning different from Chapter 14. Chapter 14 looked primarily at individual engagement with the field-trip and non-visual aspects of space. This chapter looks a lot more into group interactions and collaborative learning<sup>10</sup>, in an attempt to provide actionable insights for inclusion in mainstream and inclusive classrooms. Choosing to use tangible interaction<sup>11</sup> had practical reasons (to enable local diffusion of smell, with an easy to identify provenance), but mostly I was interested in how they could support interactions between children: they can easily be exchanged or manipulated conjointly. Moreover, it needs to be further studied with visually impaired children given that the shared gaze evoked in study of tangible interactions<sup>12</sup> does not manifest the same way.

The assumptions we make about learning provides us with criteria by which we can evaluate the prototype. It does not entirely depart from my objective to understand how values evolved and are negotiated when using devices specifically designed to support a non-visual approach to geography. Indeed, having to work collaboratively also requires sharing and altering one another's values. In other

<sup>8</sup> The brainstorming about super-heroes and gadgets described in Chapter 14 is also a good example of this.

<sup>9</sup> From the discussion of Universal Design for Learning in Chapter 8, findings on the goals of education in Chapter 11 and the will to privilege first-hand experiences in line with Dewey's philosophy of education (discussed Chapter 4) exemplified by the field-trips in Chapter 14

<sup>10</sup> Following Stahl, Suthers argue that small groups are probably the best scale to study this. Suthers, "Technology Affordances for Intersubjective Meaning Making: A Research Agenda for CSCL".

<sup>11</sup> I.e., the use of physical objects to interact with digital information. Ullmer and Ishii, "Emerging Frameworks for Tangible User Interfaces".

<sup>12</sup> S. Price, Sheridan, et al., "Towards a framework for investigating tangible environments for learning"; S. Price and Carey Jewitt, "A Multimodal Approach to Examining 'Embodiment' in Tangible Learning Environments".

words, I want to look at how meanings and values are constructed in interactions between children with multisensory material—including material appealing to olfaction and taste.

### 15.1.2 Perspectives on olfaction and taste in education

*"And suddenly the memory returns. The taste was that of the little crumb of madeleine which on Sunday mornings at Combray (because on those mornings I did not go out before church-time), when I went to say good day to her in her bedroom, my aunt Léonie used to give me, dipping it first in her own cup of real or of lime-flower tea. The sight of the little madeleine had recalled nothing to my mind before I tasted it [...] But when from a long-distant past nothing subsists, after the people are dead, after the things are broken and scattered, still, alone, more fragile, but with more vitality, more unsubstantial, more persistent, more faithful, the smell and taste of things remain poised a long time, like souls, ready to remind us, waiting and hoping for their moment, amid the ruins of all the rest; and bear unfaltering, in the tiny and almost impalpable drop of their essence, the vast structure of recollection."*

Excerpt from "Remembrance of Things Past", by Marcel Proust

The excerpt above is about Proust's famous madeleine. Tasting it leads the narrator to recall long-forgotten memories (which he subsequently narrates over a few thousands pages). This so-called Proust effect has since been investigated<sup>13</sup>: does associating an information with a specific smell enable to better recall it? Although many studies suggest so, others contest this fact<sup>14</sup>. Yet others argue that smell provides a sense of "security, well being, and pleasure"<sup>15</sup>, hence that we should consider how it affects the state of well-being and the focus of the learner.

In other words, smell and taste in education are often considered as useful to process unrelated information rather than meaningful on their own right. Their perception and interpretation are especially subjective, and it is difficult to classify and describe them<sup>16</sup>. But this can also be seen positively. McBride and Nolan Jason<sup>17</sup> argue olfactive components may enable learning experiences "beyond language"<sup>18</sup>, in line with learners-driven and constructivist approaches<sup>19</sup> to learning discussed above.

While, audio and tactile modalities have long been used in technology design, it is not the case for smell and taste. Their use poses a range of technical problem. Odors are difficult to control and delivering them requires to take into account the characteristics of the physical environment. Gustatory interfaces generally require putting a device in one's mouth, devices that most often rely on thermal<sup>20</sup> or electrical<sup>21</sup> stimulation of the tongue. I took a very different approach, relying instead on a Do-It-Yourself approach to the use of olfaction and taste in learning.

<sup>13</sup> E.g., B. J. Lyman and McDaniel, "Memory for Odors and Odor Names: Modalities of Elaboration and Imagery."

<sup>14</sup> For a review, see: Murray et al., "Olfaction-enhanced multimedia: A survey of application domains, displays, and research challenges".

<sup>15</sup> Köster, "The Specific Characteristics of the Sense of Smell".

<sup>16</sup> Quercia et al., "Smelly Maps: The Digital Life of Urban Smellscapes".

<sup>17</sup> McBride and Nolan Jason, "Situating Olfactory Literacies: An Intersensory Pedagogy by Design".

<sup>18</sup> Citing: Carey Jewitt, *The Routledge handbook of multimodal analysis*.

<sup>19</sup> Which focus on social interactions and exchanges as ways to acquire knowledge.

<sup>20</sup> Cruz and Green, "Thermal Stimulation of Taste."

<sup>21</sup> Plattig and Innitzer, "Taste Qualities Elicited by Electric Stimulation of Single Human Tongue Papillae".

## 15.2 Design

MapSense is a multisensory map, that relies tangible interaction to mediate the use of smell and taste (thereby also named smellables and eatables). This section describes the specific instance of Mapsense used in the study below. Given the many steps leading to the final design, the timeline and methods used to design interactions with the prototype are described in Appendix A.4<sup>22</sup>.

### 15.2.1 Process

In the design of Mapsense, children were considered as informers<sup>23</sup>. By this, I mean that the teacher and I took the design decisions, but that these were inspired by multiple previous observations and occasions for the pupils involved to express preferences or devices they would like to build.

### 15.2.2 General setup

MapSense was based on an interactive audio-tactile map illustrated in Figure 15.1, and initially designed by A. M. Brock et al.<sup>24</sup>. Its main components are a raised-line map overlay placed over a 27-Inch touch screen using capacitive projected technology, connected to a computer and speakers. Double tapping on the screen provides audio information about map elements. In addition to the main display and exploration area, the prototype includes a menu to access different types of information (e.g. points of interests, or general directions, see below). It also enables the use of tangibles made of conductive material, some being scented or edible, as illustrated in Figure 15.1.

### 15.2.3 Interaction principles

Interaction was limited to specific interactive elements on the map, which were defined by their coordinates, category (e.g. type of information, such as cities), and content (e.g. audio cues, such as city names or sounds recorded in a given city). To trigger audio cues, users had to double tap on interactive elements, which were indicated by a tactile symbol. Double-taps were used in order to prevent unexpected audio cues during manual exploration. A double tap with a conductive tangible had the same effect than a finger double-tap.

<sup>22</sup> As well as in: Emeline Brulé, Bailly, and Gentes, "Identifier Les Besoins Des Enfants En Situation de Déficience Visuelle : État de l'art et Étude de Terrain"; Emeline Brulé, Bailly, A. M. Brock, et al., "MapSense: Multi-Sensory Interactive Maps for Children Living with Visual Impairments".

<sup>23</sup> Druin, "The Role of Children in the Design of New Technology".

<sup>24</sup> A. M. Brock et al., "Interactivity Improves Usability of Geographic Maps for Visually Impaired People".

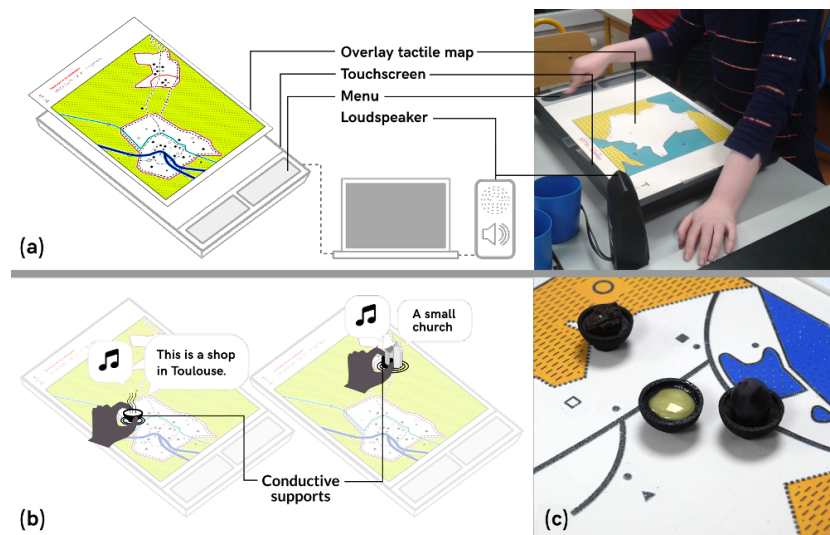


Figure 15.1: (a) The main setup of MapSense consists in a touchscreen, a tactile map overlay and loudspeakers. Double tapping on a map element triggers verbal audio output. (b) MapSense is used with Do-It-Yourself tangibles, placed on conductive supports recognized as touch events. Some tangibles are filled with food and / or scents. (c) On this screen size, 3 tangibles can be used at the same time.

The different types of verbal information delivered by the map were selected via a two-level menu (see Figure 15.2). For the second sequence for instance, pupils were invited to select *points of interest* (e.g. city halls, private services, public services), *general directions* (e.g. roads, rivers, map orientation), and *audio discovery* (e.g. playful cues for each interactive areas). Pupils browsed the categories by swiping, and selected a category by double tapping. Once one type of information was selected (e.g. *points of interests*), all related interactive areas could be triggered by a double tap. The *audio discovery* category provided non-verbal audio cues that had been recorded by the children themselves (e.g. the sound of water, the sound of their white cane on the ground, or noises in schools—see also Chapter 14). Furthermore, users could browse the names of all interactive elements available within each category by using a second menu. A double tap on one of these elements activated verbal indications (left/right/top/bottom) that guided the hand towards the target location.

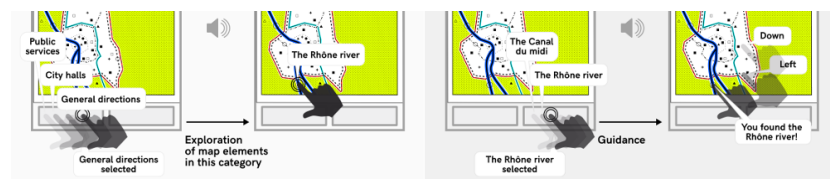


Figure 15.2: A swipe on the bottom left menu followed by a double tap allows the user to define the category of geographical information to display (e.g. cities). Then, the user can choose a specific point of interest within the current category, and is guided towards it with a second menu at the bottom right.

The design of the menu was based on the design of keys or legends for regular tactile maps. Legends were structured around the

different types of geographical information. In general, when discovering a new tactile map, visually impaired people first read the legends<sup>25</sup>. Similarly, in the prototype, students can go through the first menu, and then read the content within each category (second menu). The guiding option to take full advantage of the interactive system: it allows pupils to explore the map by themselves without needing help from the teacher.

#### 15.2.4 Map

I designed a colored raised-line map with the help of the teacher and a tactile document maker. It illustrated the itinerary the pupils followed during a class trip (Chapter 14). It depicts one of France's major cities and the surrounding countryside, a small sized city and a village (see Figure 15.3-a). Audio cues recorded during that trip were associated with interactive elements. Thus, children could associate their subjective experience during the trip with a geographic representation of the trip. The map was produced on swell paper in A3 format, which is a format frequently used. A smaller (A4) non-interactive version of the map with written legend (either in braille or in large characters), could be printed for each child to take home.



Figure 15.3: (a) The map design used during the second sequence. (b) The classroom environment.

#### 15.2.5 Tangibles

Our set of tangible objects illustrates literally<sup>26</sup> various objects that children had encountered during a previous field trip and represents different kinds of urban settings. Their design follows the recommendations and principles derived from previous uses of the same prototype (see<sup>27</sup>). They could be used to trigger audio interaction on the map, or independently. They were designed in collaboration with the teacher, using feedback from the five children involved in the study and represented:

- houses: a farm, a high rise building, two medium and three small

<sup>25</sup> A. M. Brock et al., "Interactivity Improves Usability of Geographic Maps for Visually Impaired People".

<sup>26</sup> Sara Price, Jennifer G Sheridan, et al. "Towards a framework for investigating tangible environments for learning". In: *International Journal of Arts and Technology* 1.3-4 (2008), pp. 351-368

<sup>27</sup> Emeline Brulé, Bailly, A. M. Brock, et al., "MapSense: Multi-Sensory Interactive Maps for Children Living with Visual Impairments".



sized houses;

- shops: a grocery store, a bank, a restaurant and a supermarket;
- services: two post offices and two schools of different sizes;
- infrastructure: an airport, two planes;
- green spaces: fields, parks and trees;
- historical points of interest: churches, tombs, war memorial;

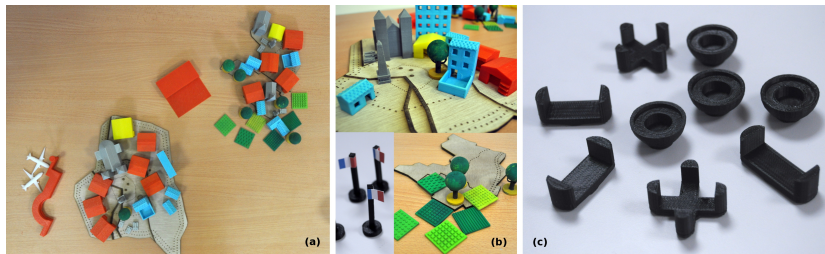


Figure 15.4: (a) All tangibles designed for the study; (b) Examples of tangibles: various buildings, flags and green spaces; (c) Conductive bowls (top right), and conductive supports for the other tangibles.

*Form factor.* I had determined earlier in the PhD<sup>28</sup> that the design of tangibles should:

1. Be larger than three centimeters to be recognizable because small volumes may be difficult to understand;
2. Have bright and contrasted realistic colors, to be consistent with residual visions and not be considered as stigmatizing;
3. Not have sharp relief, as it is uncomfortable or frightening during exploration (i.e. children would avoid some part of the object in order not to fear hurting their fingers);
4. Surfaces should be at least "*two fingers large*" so children can feel the differences between the volumes;
5. Objects that could be compared during the class (i.e. historic sites like the abbey, the cathedral and the castle) should respect the differences of scale.

Furthermore, children expressed a strong preference for tangibles with details (e.g. houses with doors and windows) and textures (e.g. tiles on the house roof) which make them look like actual toys. Pupils also use these details to identify what the tangibles represent.

<sup>28</sup> Emeline Brulé, Bailly, A. M. Brock, et al., "MapSense: Multi-Sensory Interactive Maps for Children Living with Visual Impairments".

*Color.* Color remains an important aspect of design because children with residual color perception can use it in the meaning-making process.

*Easy to make.* The tangibles were designed using Tinkercad, an online sketching tool, and then 3D printed. They can be placed on supports made of conductive materials (see Figure 15.4-c) that are detected as touch events by the capacitive screen, even through the paper overlay. This solution does not allow the touch screen to identify each tangible, but this solution is cheap and does not require too much maintenance in comparison to camera-based vision solutions which might enable differentiation between objects.

*Limitations.* One limitation was that only three tangibles could be used at the same time on MapSense; first because the map was small, and second because children might push tangibles away during exploration. However they have been successfully used to build many different non interactive models (see Figure 15.5). In addition, the tangibles were not automatically recognized by the computer system. It follows that pupils sometimes needed human assistance to identify a tangible..

#### 15.2.6 *Smellables and tastables*

MapSense relies on six different olfactory and flavor cues related to different concepts the teacher wanted the pupils to elaborate on. The teacher first identified several possible associations for each concept. The associations that she proposed were guided by three principles:

1. Similarity to something children had smelled during the field trip (described in Chapter 14);
2. Familiarity i.e., cues that all children are expected to have experienced in their daily lives;
3. Or unknown cues that could introduce new experience and meaning. Some cues were direct associations (e.g. colza oil for colza fields), others were metaphors (e.g. goat cheese for the farm).

The teacher finally chose six cues that were easily available. (1) Pastries were used to illustrate a bakery near the service provider's building, and the tertiary economic sector. (2) A sample of rubber was used to represent the traffic, and thus the transportation infrastructure. (3) Fresh grass was used to illustrate both green spaces in urban settings and on the countryside. (4) Strawberries were used to

illustrate raw products (in contrast with pastries). (5) Colza oil and goat cheese represented the region's farming and livestock. These were direct references to the field-trip presented in Chapter 14. (6) Licking envelopes were used as a representation of the postal infrastructure and services.

The olfactory and flavor cues were contained in small, conductive 3D printed bowls in which children could pick with a small spoon (see Figure 15.4-b), or distributed when the related topic was discussed (e.g., envelop would not fit in the bowls). Using the bowls has several advantages: pupils could easily manipulate them and place them on or around the map; they could contain any kind of Do-It-Yourself scents and tastes (in comparison with scent diffusers, which provide only a limited number of synthetic scents and flavors); finally, pupils associated it with dinnerware.

### 15.3 *Study Design*

#### 15.3.1 *Research questions*

This prototype and study were exploratory, as discussed previously (see Methods in Chapters 4 & 13). The research questions are a synthesis of achieved with the special education teacher involved.

1. How to best support children in making sense of multisensory material and how to integrate them more often? What can we learn about children's meaning-making processes when using smell and taste in the classroom for geography courses?
2. Does multisensory material allow for more connections to be drawn between children's lives, field-trips, and the classroom?
3. How are these activities valued by pupils and teacher? Can this prototype be used to support collaboration in children with diverse sensory perceptions and diverse background?

#### 15.3.2 *Activity design*

The activity was designed with the special education teacher, as part of her progression in the skills base to be acquired by all French pupils (Domain 5: understanding space and time, human organizations and developing citizenship)<sup>29</sup>. The overall design of the pedagogical units and its goals can be found in Appendix A.5. This session focused specifically on geographic skills (e.g., reading and

<sup>29</sup> Ministère de l'Éducation nationale, *Socle commun de connaissances, de compétences et de culture*.

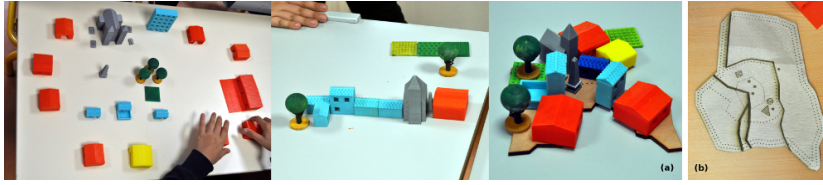


Figure 15.5: (a) Non-interactive models that children reconstructed using tangibles only. From left to right, a major city (C<sub>3</sub>-C<sub>1</sub>), a village (C<sub>4</sub>-C<sub>5</sub>), and a small city (C<sub>1</sub>); (b) Laser cut wood representation of the shape of each city, that can be used with the tangibles.

constructing a map) and revisiting the themes explored in earlier lessons. The goal was to support a pupil-driven synthesis.

The first activity consisted of collaboratively building a physical layout of different types of urban structures (e.g. a major city, a small city, a village) using the tangibles, which they had discovered in a previous lesson. Children worked in pairs (C<sub>4</sub>-C<sub>5</sub>; C<sub>3</sub>-C<sub>1</sub>; C<sub>2</sub> made his alone). Children chose the tangibles they wanted to include, and then organized them on the table (see Figure 15.5). They were to discuss it. The teacher regularly asked the pupils to orally describe what they were doing and why. In the C<sub>3</sub>-C<sub>1</sub> pair, C<sub>3</sub> led the activity. In the C<sub>4</sub>-C<sub>5</sub> pair, the special education teacher assisted at every step, as this pair did not manipulate the tangibles much. Both C<sub>2</sub> and C<sub>3</sub> tried multiple layouts and encompassing or not the wood shape for support. C<sub>1</sub> manipulated the tangibles a great deal, but rather as he was using them to tell stories about the elements represented. I will not examine this part of the lesson as it is beyond the scope of this study, but it contributes to explain existing classroom dynamics and particularly to show the difficulties of collaboration.

The second activity was built around Mapsense. The teacher had a list of themes (described in Appendix A.5 or Table 15.1), that she introduced by a cue to be smelled or tasted. She first asked what they thought it was, and what it represented. Each cue was associated with a step of the field trip undertaken some time earlier (see Chapter 14). The pupils had time to discuss freely or to use the map to find what the cue is associated with. She then asked a question (e.g., why do we build cities?) to which she indicated they could answer using the cue and what they had just discussed. Note that only one child at a time could interact with MapSense (although they disregarded this rule several times), and the others were either helping by providing advices orally, or making hypotheses during this time.

### 15.3.3 Participants

The participants involved were the same than in Chapter 14.

<b>Introduction</b>	Eating a pastry, setting the goal: synthesizing the differences between human habitats and their reasons
<b>Body</b>	<p>Smelling grass and eating strawberries</p> <p>Discovery of the map</p> <p>Associating the three smellables/tastables with different areas of the map</p> <p>Finding different types of roads on the map</p> <p>Discussing the transportation infrastructure (e.g., national/regional roads)</p> <p>Discussing the transportation infrastructure (national/regional roads; canals)</p> <p>Smelling rubber</p> <p>Discussing pollution and its causes</p> <p>Synthesizing differences between farming and industry, countryside and cities</p> <p>Discussing the evolutions of work and how they shape cities</p> <p>Discussing the evolutions of work and how they shape cities</p> <p>Smelling colza and cheese (returning to the village)</p> <p>Synthesizing the similarities of structures between all habitats, starting by the village (e.g., church, town hall)</p> <p>Licking an envelope</p> <p>Discussing communication services (introducing the term infrastructure) through the example of postal services</p>
<b>Conclusion</b>	Synthesis the concepts learned, asking pupils for feedback on the lesson

Table 15.1: Summary of the activity's structure.

#### 15.3.4 Procedure

The children were familiar with the interaction principles. The audio-tactile map had been in use for over a year<sup>30</sup> and we had organized a similar activity 10 months earlier<sup>31</sup>. The teacher reintroduced the map and described its functioning (particularly the menu) before beginning the activity. I assisted children when they encountered issues with the prototype (mostly unrecognized taps) and took over the class discussion when the teacher focused on explaining a concept to one child in particular. Immediately after the lesson and a few days later, I interviewed to get her analysis on how the activity unfolded and on perceived learning outcomes. I also interviewed each participating pupils a few days after the lesson.

<sup>30</sup> Emeline Brulé, Bailly, and Gentes, "Identifier Les Besoins Des Enfants En Situation de Déficience Visuelle : État de l'art et Étude de Terrain".

<sup>31</sup> Emeline Brulé, Bailly, A. M. Brock, et al., "MapSense: Multi-Sensory Interactive Maps for Children Living with Visual Impairments".

#### 15.3.5 Analysis

The data on which the analysis was conducted consisted of:

- 1:41 hours of video from the third lesson of the sequence (see Appendix A.5;
- Four interviews with the teacher: one before the three lessons to define the content, one after the first lesson (described in Chapter 14, two after the lesson presented here. These last three interviews investigated among other things her assessment of learning outcomes;
- Semi-guided interviews with the children, conducted after the third lesson. We discussed the session, what they remembered from it and the goals of learning (this last topic was useful for understanding how they perceived this unit compared to their other school experiences).

To analyze the activity, I relied on multimodal analysis (see Chapter 4 for a description). I transcribed the video data to identify:

1. Broad phases in the lesson: subtasks, moments of switching from a theme to another;
2. Modes of interaction: overall classroom setting including the types of interactions with the map, speaker, utterance, gestures, gaze<sup>32</sup>, olfactory representation, gustatory representation, tangibles.

<sup>32</sup> Indicated by body orientation, which denotes efforts to listen, focus on manipulation etc.

An excerpt from my transcriptions can be found in Appendix A.7.

This type of transcription highlights similar interactions in different events. Given the research questions, my iterative analysis

focused on semiotic chains, i.e. the diverse association of meanings across different representations and modes. I focused on identifying: What kind of associations do the different types of representations elicit? How does it inform us on the potential uses of olfaction and taste in the classroom? I also focused greatly on the spatial occupation of the classroom: the different representations and artifacts may have intrinsic qualities supporting a specific emergence of meaning, but they are also spatially distributed in the classroom, which makes them individual or group resources, enabling certain kinds of social interactions but not others. In the analysis below, I sometimes use observations from my ethnographic study, to contrast or complement the observations made in this lesson.

#### 15.4 Findings and Discussion

All pupils reported having enjoyed the activity. They all engaged with each resources brought to the classroom. I structured the findings around four key themes to understand how Mapsense reshapes learning: smell and taste in geographic reasoning; children's efforts to reclaim the space of the classroom; personal and emotional engagement; and a more general discussion of the implications for citizenship education.

##### 15.4.1 Smell and Taste: (in)congruities

The interpretations of olfactory and gustatory representations are intertwined with the other representations of the same concept (e.g. tangible objects, tactile map). I discuss above of the Proust's effect. I propose here to be attentive to the congruities identified by children across multiple situations when interpreting olfactory and gustatory cues, to how they can be part of "*the re-representation process incorporat(ing) the interaction and context of preceding activities and project(ing) them into subsequent activities*"<sup>33</sup>.

For instance, during the first lesson discussed in Chapter 14, the children visited a farm dedicated to the raising of livestock, which they identified primarily through smell. During the second lesson, they manipulated a tangible representing a farm building. In the third, the farm was represented by the model, the sounds of farm animals played on the map and the goat cheese. During the classroom discussion, which aimed at getting children to formulate that farming was an economic sector that encompassed multiple activities related to the production of food<sup>34</sup>. The teacher asked the group if

<sup>33</sup> Tang, Delgado, and Birr Moje, "An Integrative Framework for the Analysis of Multiple and Multimodal Representations for Meaning-Making in Science Education".

<sup>34</sup> Note that in French, their names are not related: *ferme* for farm, and *agriculture* or *agriculture et élevage* for farming.

they knew other places that smelled like a farm. C1 answered that he knew a similar place that smelled of olives. This was a recall of a class trip that occurred nine months prior, during which they visited an olive farm. The smell of an olive farm is extremely different, so the convergence between the two was not easy to perceive—except for the fact both are *farming* activities. Concept that children were then able to manipulate to apply to another cue (strawberries) and to a different question ("*Why do we build cities?*"). However, the convergence might actually be found elsewhere: This might be an especially strong association because visiting farming spaces often includes a time dedicated to tasting the produces of the farm. I discuss this below, in connection to children's spatial, emotional and social lives.

Yet, eatable and smellable representations seem useful to open a breadth of meanings—or in the words of C3, to encourage "*answers that sound silly*". An example of this type of answers: To the question "*what feels different in the city and the countryside?*," C2 answered "*the lack of space*". But upon the presentation of rubber from a tire, he gave a different answer ("*pollution!*") and went on explaining and discussing with C5 why cities feel more polluted:

C5: "*it smells like cars*"

C2: "*because there are more cars, because there are more humans*"

The argument of C2 is that cities offer less space to individuals. C2's initial answer was a reference to a bodily and personal experience, but it is the smell of rubber that makes it fit into a larger pattern<sup>35</sup>. Here the congruity between the experiences and the representation in the classroom is more visible: C2 discussed the lack of space as affecting the ability to breathe—When manipulating the rubber C5 turned his head away to signify disgust, C1 agitated his hands under his nose as if he was dissipating the odor. This is a particularly evocative representation of pollution. It is also an unpleasant one, which might be a limit of this approach (this is further discussed below).

We had indeed included rubber in the lesson to suggest urban pollution and more specifically to discuss the roles of urban centers in the development of the industrial sector. Its interpretation as a proof of car pollution and population density is interesting, because it connects different aspects of the same issue i.e., the spatial distribution of jobs that affects their family lives. In other words, the potential uses of smell and taste in education go far beyond their use as a memorization technique or as a tool to lessen learner's anxiety. They enable a situated interpretation and learning process, and grounds learning in pupils' everyday lives.

<sup>35</sup> The pollution due to agricultural activities was not discussed. It creates a false dichotomies between cities and countryside, or culture and nature. However, this should be understood as a first step to understand the link between human activities and pollution, which harnesses children's beliefs about the difference between the countryside and cities, enabling appropriation.



These two examples inform us on olfaction and taste as modes too. There can not be a single interpretation of these cues. They are dependent of the learning context in which they are introduced to a higher degree that say, a map. The map has a legend and many indications about what it represents and how it fits with other representations of the same kind (e.g., indications of scale and orientation). Here, this context is provided by the themes of the unit and the other representations available in the classroom.

#### 15.4.2 *Reconfiguring space*

In this section, I turn to the spatial interactions enabled by the apparatus (see Figure 15.3 for a visual depiction of the classroom setting). I address this at the level of the classroom and at the level of the map. MapSense shaped what was allowed in the classroom, especially moving around. And the fact that only one child at a time could interact with the prototype offered new pedagogical opportunities.

First, a few notes on the roles undertaken by C1 in the classroom. This pupil usually is not eager to participate in group activities. However, his known sensitivity to olfactory stimuli became part of a collaborative construction of knowledge. C3 particularly marked his interest to support C1 and C5's participation in the follow-up interview ("*they feel good, they dare to say things*"). Whereas he was usually withdrawn and physically huddled on himself in the classroom, I noted a very different pattern of engagement during this lesson: he turned towards his peers, made tangibles fly to nearby desks...

As Mapsense is currently implemented, it is preferable that only one child at a time can interact directly with the tactile map. When several pupils interact, the audio indications are played at the same time, rendering them inaudible. In this activity, the pupil interacting directly with the map was verbally guided by the others and was in charge of verifying or generating hypothesis by interrogating the map. During this time, the other pupils were free to manipulate the unused tangibles, scattered on their five desks. The tangible were especially used to compare scales and quantities, e.g. comparing the tower's height with the countryside house's, or the number of buildings in the city. But to do so, they had to be exchanged or manipulated, which requires moving around the classroom during discussion. Furthermore, Mapsense not only requires taking turns, but if a pupil thinks he knows how to find the needed information of the map, he is invited to guide the hand of the current user, or bring him the related tangible. Space was thus constantly renegotiated, as a result of Mapsense's integration in the classroom. This is in stark

contrast with the previous lessons observed. Fixed seatings is generally considered an asset because it enables to find needed material (e.g., pens, documents) quickly. Additionally, it opens perspectives from classroom-size geographical representations.

Let's discuss this adaptation process. When it was initially introduced in the classroom, MapSense was used by the teacher as a tool to discover the general content of the map. One student interacted with the prototype, while the teacher described the current interaction, with all other pupils surrounding them. The rest of the lesson relied on individual paper maps distributed to each pupil. Later on, the teacher developed a more collaborative pedagogical scenario: the student exploring the map described his actions and perceptions, while the others reconstructed the exploration on their own paper map. Finally, during this study, MapSense was used as a tool for collaborative inquiry, which the teacher described as a step towards understanding its full pedagogical potential. This changed the way the map was explored.

On a tactile paper map, or on an interactive map without tangible interactions, these pupils are taught to read linearly (e.g. starting from left to right and top to bottom). Carers often argued it enables to develop a survey knowledge of space, providing more precise and generalizable representations. With MapSense, pupils were rather encouraged to focus on finding a point of interest or to discover the map by following routes that interest them i.e., to develop a route-based knowledge. Besides that those are different skills that intersect when it comes to using a map, previous studies have suggested the differences between those two kinds of knowledge were not necessarily true<sup>36</sup>.

What a route-based exploration of the map enables is the grounded of personal stories in a global representation. As planned, the pupils first tried to follow the previous class trip, which started from the special education center on the map. C4 proceeded to find the nearby bakery, from which the pastries they had eaten came from and is a popular place for them. We had made a point of interest for this bakery, as we know their attachment to this place.

<sup>36</sup>Thorndyke and Hayes-Roth, "Differences in spatial knowledge acquired from maps and navigation".

### 15.4.3 *Making the classroom pervasive to children's lives*

As discussed above, Mapsense is inspired by a model of education situated in children's experiences and everyday lives. Hence the decision to use children's audio recordings, and the route-based reading of the map. Additionally, the teacher and I had hypothesized that

using smellable and edible material participates in fostering engagement with the content of the course. It also facilitated the introduction children's narratives about their spatial, emotional and social lives. We can identify three types of experiences to build on. Joint experiences, that the group has had together; shared experiences, such as experiences of similar places, which they compare and talk about; and individual experiences, which they do not necessarily like to share. For instance, C5 did not share his wish of traveling as an adult during the lesson. From here on, we will try to identify implications for socio-constructivist pedagogies, demonstrating that different forms of learning are at work. To do so, we follow the typology outlined by<sup>37</sup>: *"Knowledge construction recognizes that individuals create meaning for themselves rather than just receiving it preformed from others; collaborative knowledge construction more specifically locates this meaning-making in a group context; intersubjective learning further specifies that the process of meaning-making is itself constituted of social interactions; and knowledge building requires that this group-based meaning-making is being done intentionally."*

<sup>37</sup> Suthers, "Technology Affordances for Intersubjective Meaning Making: A Research Agenda for CSCL".

### Children's spatial lives

This case study was on regional geography and we had designed the map to reflect what we knew of pupils' experiences of the neighborhood, so it is not surprising children had related stories. The lesson apparatus afforded a way of grounding their stories in social and spatial structures—but also to reflect on their own lives using geographic tools.

I discussed the interpretation of rubber as a sign for pollution earlier and how it opened a space for discussing familial struggles with spatial mobility. The stories told by children often focus on the spaces they know best: their home and the journey to the service provider's building in which this lesson unfolds; the direct neighborhood of this organization (the park, the bakery, the canal, the post box, the museum and its mummy); the mainstream school they attend; previous field-trips; family members' homes. They can all be situated on the map, or evoked in relation with the tangibles (e.g., C5 *"Me, I live in a building"*) and the smellables and eatables (e.g., C1 *"We get pastries when we pass by the bakery!"*). Those are shared and joint experiences that allow for intersubjective learning and knowledge building.

Intersubjective learning is not restricted to the group of pupils or the classroom. C5, in a follow-up interview: *"Eating, and the sounds, it helps me understand, and think. Maybe it helps me remember. But that I don't know. It helps me think about things I can do when I grow up in*

*a long time.*" We discussed cognitive theories, arguing that smell or taste might foster memorization when associated to a chunk of information. We argue this is different: here, learning is "a process that constructs personal identity, entwining individual learning with group practices that themselves can change"<sup>38</sup>. C5 memorizes what he finds useful for the future, that coincides with what he thinks adults do, what will enable him to participate in society.

<sup>38</sup> Suthers, "Technology Affordances for Intersubjective Meaning Making: A Research Agenda for CSCL", p. 4.

### Children's emotional and social lives

In C5's case, the use of food is especially relevant. He is overweight and often experience negative remarks when eating, from peers and carers. During a previous discussion, he expressed his frustration: "people say it's my fault if I'm fat, but it's not!". This was in contrast with the situation in the classroom where tasting food was a valid way to contribute to the activity—we also had chosen the pastries as eatables to provide an enjoyable lesson experience. C5's bodily, emotional and social lives are here intertwined. Food and health are strong markers of social status (Chapter 6 & 11). It is not only his weight that sparks remarks, but also the fact carers attribute it to faulty parental food practices which need to be corrected for C5's good<sup>39</sup>. Using eatable material necessitates to take stock and engage with these highly social and personal experiences of food—which can become a subject of geography.

<sup>39</sup> Obesity rates reflect social inequalities and that so-called healthy foods are not accessible to all. Devaux and Sassi, "Social inequalities in obesity and overweight in 11 OECD countries"; A. Hilmers, D. C. Hilmers, and Dave, "Neighborhood disparities in access to healthy foods and their effects on environmental justice".

There is ample work on mobile and multimodal technologies to scaffold learning and reflection in the wild. However, less attention is given to bodily experiences and emotions in classroom-based activities. This was the case of my earlier example on rubber, pollution and bodily experiences of the city. In the following-up discussions, the group discussed spatial inequality. C2 talked about feeling betrayed, after being promised that life would be better in the city but having to live in cramped high rise towers: "Cities are for stockpiling people," he said. For those living in the countryside (C3 and C5 especially), the main concern is the lack of potential jobs. This apparatus provided an outlet for vivid social experiences related to the differences of human habitats. I would argue this opens an opportunity for them to understand the impact of policies, but also to transform individual into community issues, i.e., to support knowledge building communities. We note however that this was not an aim of the teacher, hence that it should here be considered as intersubjective learning.

Spatial experiences are imbued with emotions<sup>40</sup>; and emotions are both personal and intra-personal processes<sup>41</sup>. Let me clarify: to identify a given bodily experience as an emotion, one must have

<sup>40</sup> Tuan, "Thought and Landscape: The Eye and the Mind's Eye".

<sup>41</sup> Fischer, Manstead, and Zaalberg, "Social influences on the emotion process".

the ability to name it, borrowing from a set of available cultural resources. E.g., pastries are not only appreciated because of the sugar they contained but also because getting them is a social event; when they find cities suffocating, the pupils refer to familial discourses and academic discourses. Cities are this way because they have "*too much CO<sub>2</sub> [carbon dioxide]*" (C<sub>2</sub>), but also because their parents say so (C<sub>1</sub>). The interest of this activity is that, by asking explicitly to discuss experiences, it lays bare the many associations of meanings, the value judgments, made by children in their everyday lives. It confirms our previous observation about this apparatus as the support and the tool for intersubjective learning.

#### 15.4.4 *Opportunities for citizenship*

MapSense provides many opportunities for an emancipatory curriculum or at least for an education oriented towards the development of citizenship. This includes fostering integration in society by raising societal and cultural questions. Another example for this was related to gender equality... and strawberries. The strawberries and the pastries were there to enable discussing the three economical sectors. However, C<sub>2</sub> refused to eat them, protesting they were for girls only. When asked by the teacher why he thought that, he could not answer. It transformed in an unforeseen opportunity to address gender biases for the teacher. She asked all the other pupils whether they liked strawberries, and the group concluded boys like strawberries too. Previous research has demonstrated that boys are actively discouraged from expressing and reflecting on their emotions, which create behavioral issues<sup>42</sup>. Creating a space where expressing emotional experiences is safe thus can impact different aspects of gender inequalities.

In other words, the multisensory approach facilitated discussions about situated social issues necessary in this context, but go beyond of the geography curriculum. However, it is not without difficulties. It is not necessarily well perceived to address any of these issues in the classroom. For instance, a book made by the French government to address gender inequalities in all classrooms was censored in 2014<sup>43</sup>. Pragmatically, teachers might prefer to prepare and control debates on certain subjects. The breadth of meanings emerging from the use of smellables and eatables is not necessarily considered desirable.

How might this generalize to material pupils have never encountered before? Do these modes depend on previous life experiences? Even the licked envelopes, with the children had never used, were

<sup>42</sup> J. Y. Chu and Gilligan, *When boys become boys: Development, relationships, and masculinity*.

<sup>43</sup> [lexpress.fr/education/abcd-de-legalite-benoit-hamon-n-avait-pas-le-choix\\_1554708.html](http://lexpress.fr/education/abcd-de-legalite-benoit-hamon-n-avait-pas-le-choix_1554708.html)

not completely unknown: they have gone to the post-office or the post-box before. As far as can be known from this study, this type of material for not-yet-experienced geographic topics and spaces opens potential futures as much as it supports engagement with past and present issues.

## 15.5 *Implications and Limitations*

### 15.5.1 *Issues of trust*

Deploying this apparatus or a similar apparatus in another context might be more challenging. As demonstrated, the use of olfaction and taste raises specific issues of trust. Some are practical and can be addressed during the implementation. For instance, if we were to use a device to simulate taste, we would need to prove that the device is perfectly clean before using it or the parts used would need to be disposable (which was the case of MapSense and its spoons). Other issues are more difficult to address. For instance, how do we handle likes and dislikes in terms of flavors? Do we have to only choose eatables that children are likely to appreciate? How do we introduced unknown tastes in the classroom? Hence the issues of trust, and its entanglement pleasantness. The smell of the rubber was highly unpleasant. Yet C2 notes that in this context, trust being acquired, this unpleasantness is acceptable (C2: "*that's at school so it's okay to try*").

### 15.5.2 *The Case for Do-It-Yourself technology design*

To improve the design process of assistive technologies, Hurst and Tobias<sup>44</sup> have proposed to promote Do-It-Yourself (DIY) approaches i.e., to support low-cost, easy to make adaptations of devices and pedagogical material. Digital fabrication techniques, such as 3D printing and laser cutting have the potential to support the making of very small series. There is a growing body of work investigating the use of 3D printing for/by visually impaired people<sup>45</sup>. For instance, Kim and Tom<sup>46</sup> have investigated the use of crowdsourced 3D models to the design of personalized tactile books and the role of the community surrounding carers. MapSense follows this philosophy: during my field-work, carers constantly tinkered and adapted commercialized artifacts and gradually acquired the ability to describe the technologies they would need<sup>47</sup>. MapSense also offers an example of hands-on design of olfactive material and representations<sup>48</sup>.

<sup>44</sup> Hurst and Tobias, "Empowering Individuals with Do-It-Yourself Assistive Technology".

<sup>45</sup> Buehler et al., "Investigating the Implications of 3D Printing in Special Education".

<sup>46</sup> Kim and Yeh, "Toward 3D-Printed Movable Tactile Pictures for Children with Visual Impairments".

<sup>47</sup> Brulé and Bailly, "Designing for inclusion: Examining Do-It-Yourself design activities".

<sup>48</sup> As do for instance: J. H. Chu et al., "Sensing History: Contextualizing Artifacts with Sensory Interactions and Narrative Design".

### 15.5.3 *Transferring the prototype to a mainstream classroom*

How does this all fit in the grand plan of opening opportunities for resilience? Based on these findings, I would argue for a food-based, non-visual, geography curriculum in primary school, grounding geography in eating practices. That concerns for inclusion could lead to fully reconsider the very core approach of geography. More realistically, as an isolated event it can slightly alter perceptions of a pupils' abilities, shifting away from traditionally valued literacy, as I attempted to show in the shifting pattern of C1's participation. But this occurred after a full year of collaboration with the teacher to implement a different approach to the curriculum.

Then we need to think about the reconfigurations it enables. During post-lesson interviews, all of them pointed out the benefits of using MapSense in their mainstream classroom they attend. Reasons range from being active rather than listening (C2: "*you do something instead of being bored*"), being independent (C5: "*I prefer it because I can do things by myself*"), reach their peers (C3: "*it's easier to say hey, I'm there, because they can use it too*") or impress them (C4: "*the other children don't have it, it's special*"). There is more to the use of technologies than the tasks that can be done with it. Interestingly, these takes contrast with previous findings, that showed children being separated from the class when using assistive learning technologies<sup>49</sup>. In those larger groups, collaboration and collective grounding of their social lives in the geography curriculum may not be easy, but it might be worth trying.

<sup>49</sup> Mithout, "L'inclusion Scolaire à l'heure Des TIC : Perspective Franco-Japonaise".

## 15.6 *Summary*

This chapter focused on a multisensory map, Mapsense, which was deployed for a study in a special education classroom. It enabled to study how smell and taste can be used in geography classes, to ground the lesson in children's embodied, spatial and emotional lives. I outlined how it supported a pupil-led re-occupation of the classroom space, as well as pointers of the reconfiguration of relationships between children: Attention to others' learning needs, openings on one's life difficulties, etc. It concludes the part given to empirical findings in my thesis.

### *Conclusion of Part 4*

I present my findings about visually impaired French children's experiences of schooling in Part 3, underlining their many strategies to fit at school, to be resilient in their own ways. This part focuses on prototypes aiming to open opportunities in the classroom to develop for non-visual knowledges of geography.

With these interventions, I attempt to demonstrate how centering these pupils' embodied experiences in learning have more than cognitive impacts. It reshapes the kind of conversations that can occur in the classroom, the interactions with the teacher and between the group, and what is recognized as valued knowledge.

How does it inform us on how to support pupils' well-being at school (Chapter 2)? I attempted to demonstrate that changing the implementation of the curriculum can change, at least for the time of the intervention, the implicit hierarchies of abilities at school. As such, it opens opportunity to develop a sense of personal control and efficacy, as well as sentiment of cohesion and belonging in an heterogeneous group of learners. I show the complex evolution enabled by the cooperation between the teacher and me, and the introduction of artifacts legitimizing new forms of investing the classroom for the pupils.





## *Discussion and Conclusion*

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In this thesis, I reported on an interdisciplinary research project conducted at a service provider for visually impaired children in the south of France. I aimed at understanding how these children fare at school, and exploring how technology designers can, could and should transform classroom experiences. I analyzed their narratives about their time at school, relying on Ungar's theory of social ecology of resilience to do so. Throughout this analysis, I attempted to draw a comprehensive picture of these experiences: how these experiences are shaped by (professional) carers' expectations from school, by children's social class and gender roles. I outlined enduring challenges to ensure the inclusion of visually impaired children, and the need to better support the legitimacy of different ways of doing and learning (in and outside the classroom).

To achieve this, I proposed a long-term design based intervention, implementing a non-visual approach to the geography curriculum with a special education teacher. I hypothesized this could support environmental, relational and personal changes, towards an environment offering more pathways to individual and collective resilience.

In this chapter, I first revisit and contextualize my findings in sociology and design in regards to existing theories and research on experiences of schooling. I then develop the alternative research paths I could have taken. Finally, I outline perspectives for future research.

## 16.1 *Summary of Findings, Implications and Recommendations*

This summary is made of two parts, re-visiting first sociological findings and second contributions to HCI.

### 16.1.1 *Sociology: Are the Kids Alright?*

#### **Initial research question**

How do visually impaired children fare at school, ten years after the law making inclusion in general education classrooms the norm and a right?

#### **Findings**

In chapter 10 and 11, I identify three main themes in children's narratives about school: exhaustion, fighting adversity, and pain. These discourses correspond to different strategies to (mis)fit in. I discuss the resources mobilized by children (and those considered important by carers) to create a more welcoming environment, using Ungar's concept of ecological resilience as a framework. I highlight for instance how they transform friends into allies; how they use the 2005 law on inclusion as to assert their right to participation; the uses of assistive technologies to demonstrate special skills; but also the fact the discrimination they still face often lead them to separate themselves from other disabled children. Overall it highlights that the right to inclusion in a general education classroom remains fragile, but is invested with great hope. Moreover, schooling experiences are tinted with fears of not being able to get employment which they perceived as the main, if not only, vector of integration in society. School performance is thus even more crucial for this group

## Discussion

These findings should not obfuscate that inclusion policies seem to have worked quite well for visually impaired children, overall. They have massively gained access to the their neighborhood school (Chapter 6 & 9). Furthermore, they seem to face less hostile relations than previous generations. This is the argument of other French sociologists<sup>1</sup> and if I contrast the testimonies of young adults about their childhood and those I gathered during my field-study, it also supports this idea. Yet, the closer look I proposed in this thesis points the important shortcomings: school is often unpleasant and if this feeling may be shared by children regardless of their disability status, visually impaired children still describe important discrimination and for a large part see schooling as a battle<sup>2</sup>. Some may argue it has more positive than detrimental effects and encourage efforts—as some carers did<sup>3</sup>. These discourses are also shaped to some extent by what children think is a positive way to talk about school. I hope I have convincingly shown that it actually prevents school from being inclusive: the only result worth fighting for is a good academic performance, which is not guaranteed by pupils' effort.

Yet, I also argue that (most of) *the kids are alright*<sup>4</sup>. In Chapter 10, only a minority of children describe school as painful. Over the course of my field-work, several of the pupils described as non-resilient lost this label and pursued their schooling without troubles. During my discussions with so-called disinvested kids, I discovered passions they were hesitant to bring to light in a school environment, be they about video games or music. Some young adults also described feeling as children and teenagers that their lives would not turn well, but that inclusion as adults was a lot less difficult that they had expected. Their situations may not be ideal, but they manage. Similarly, special education professionals are, overall, highly involved and reflective on their practices. This is less the case of general education teachers working with visually impaired children, both because of a lack of training and support, and of opposition to inclusion in general. Finally, as shown in Chapter 14 and 15, it is entirely possible to improve the situation and to address social inequalities or the hierarchy of disability established by children. However, the cumulative lack of resources some children experience is preoccupying. This might especially be the case of *visually impaired children who do not attend a formal schooling environment*, who as discussed in Chapter 6 are probably more likely to be born in disadvantaged families. Their experiences are not well represented in my research<sup>5</sup>.

<sup>1</sup> Lewi-Dumont, "Blind Teen-Age Students' Expectations"; Revillard, "La Réception Des Politiques Du Handicap: Une Approche Par Entretiens Biographiques".

<sup>2</sup> As a reminder, I proposed to compare this with quantitative studies about well-being in French secondary schools. Furthermore, an epidemiological study on French disabled students in secondary school suggests the same discrepancy I observed. Bacro et al., "Bien-être perçu, performances scolaires et qualité de vie des enfants à l'école et au collège: étude longitudinale"; Sentenac, Pacoricon, and Godeau, "How Do Disabled Students Perceive High School?"

<sup>3</sup> For a short discussion of the uses of the metaphor of war in education, see: T. Price, "War! Metaphors Are Damaging Our Schools".

<sup>4</sup> This is a reference to a song by the Who: [en.wikipedia.org/wiki/The\\_Kids\\_Are\\_Alright\\_\(song\)](http://en.wikipedia.org/wiki/The_Kids_Are_Alright_(song))

<sup>5</sup> This is discussed more extensively below.

### Implications and open questions

These findings shed an interesting light on matters of inequalities in educational outcomes, and points out the specificity of a disabled youth. They imply visually impaired children are given less autonomy, are a lot more monitored than their non-disabled peers. Or in other words, they are treated like children, like if they were younger. However, they also feel from a very young age the expectation to take responsibility for themselves and perform well at school (and by extension in the workforce). Which can be explained by the current structure of general and special education: they can be deemed unable to attend a general education classroom earlier than their non-disabled peers (during or at the end of primary school, whereas non-disabled pupils are oriented towards vocational or remedial education during secondary school). These findings are consistent with the literature on progressive (self-)selection and social inequalities at school<sup>6</sup>: they show that children from disadvantaged contexts are more likely, with the same performance, to be re-oriented or relegated to vocational education. In other words, experiences of school as a disabled pupil can not be understood without taking into account social inequalities, but can not be reduced to them either. Furthermore, my findings offer interesting insights regarding school as an agent of socialization. Dubet<sup>7</sup>, for instance, argues that school has *lost* the primary role in the socialization of children, that it increasingly competes with other mechanisms (such as the peer group). In contrast, I argue my findings imply that school remains the primary agent of socialization for visually impaired children. This is especially true for primary school, given the number of additional skills they need to master (e.g., orientation and mobility). But it remains largely true in secondary and high school. As for the other means of socialization (neighborhood peer group, family, extracurricular and leisure activities), they are largely shaped by children social background. This is probably more the case than for their non-disabled peers, because physical access to these activities need to be negotiated (and not all families have the means to do so<sup>8</sup>).

<sup>6</sup> Mollo-Bouvier, "Review: Diversité et Handicap à l'école. Quelles Pratiques Éducatives Pour Tous ?"; Boudon, *L'inégalité Des Chances: La Mobilité Sociale Dans Les Sociétés Industrielles*.

<sup>7</sup> Dubet, *Faits d'école*.

<sup>8</sup> Lantz, "Les personnes handicapées ont-elles droit au loisir? L'exemple du cirque contemporain français".

### Recommendations

I have four recommendations from these findings:

1. The topic of well-being appears qui needs to become more central in school pedagogical projects and policies more largely;
2. The disability sensitization, as well as didactic and pedagogical training of general education teachers should be a priority to give

disabled pupils a legitimacy in the classroom;

3. Improving inclusion in general education settings should go hand in hand with improving access to leisure activities and spaces;
4. As social inequalities impact impairments and care, they should be a focus of disability prevention policies.

#### 16.1.2 HCI: How to design assistive learning technologies?

##### **Initial research question**

How do we design assistive learning technologies to foster their adoption? Which evolved into: How could they be designed to support children's well-being at school?

##### **Findings**

I demonstrate the classification of visually impaired users in technology design (e.g., blind, visually impaired, visually impaired or blind with additional impairments) might seem natural but is not always adequate (Chapter 7 & 8). Furthermore, technologies designed for visually impaired users is most often described as substituting visual information, using other modalities (e.g., tactile, audio). The term substitution can actually be misleading or limit design opportunities, as teachers and document makers insist that the notion of adaptation or translation better describe their craft (Chapter 13). Finally, I build the argument for designing to support a disability culture in the classroom, understood as a way to create a sense of cohesion, a sense of the collective between children labeled as disabled. In line with socio-constructivist pedagogies rooted in experiences, I propose a non-visual approach to the teaching of, and designing for, geography. I show how this enables to propose alternative ways of participating in learning activities, in and outside the classroom, and the opportunities it offers for developing an emancipatory curriculum.

##### **Discussion**

If I described my stance as building a *non-visual* approach, I attempted in Chapters 14 and 15 to nuance this expression. It is easier and more memorable, but it does not describe well nor what I did, nor geography learning practices, nor low vision children, nor

does it account for differences in hearing in the group of the pupils involved in my studies, and it overlooks that tactile and visual representations share many characteristics. The most adequate term, I suggested, would be *differently-visual*. In other words, I am not arguing for throwing the baby out with the bathwater, for stopping researching for more efficient interaction techniques and tools to support the production of adapted contents; but rather for also taking into account the implications of the sensory turn and recognizing what it can bring to the classroom. In other words, rather than assuming a common sensory culture, practices and vocabulary, there is potential in working out ways to make sensory knowledges explicit, to encourage reflection on sensory experiences<sup>9</sup>.

### Implications and open questions

Beyond the pragmatic implications of using a *non-visual approach* to geography in the design of new technologies (e.g., developing opportunities for visually impaired children in field-trips, going beyond initial preferences for the visual modalities), this thesis boils down to what is considered the roles of school—and by extension, what is learning. The way I approached the design and the evaluation of my prototypes is probably more as a way to support interactions between learners than learning as content retention. Chapter 14 and 15 both discuss implications for design, but I want to detail three key points: How exactly this approach relates to research on well-being at school; How it relates to discussions about the aims and priorities of school in France; And how it relates to discussions on the competency-based curriculum.

Multiple conceptual models on well-being at school are available<sup>10</sup>. These models generally include the ability for children to have social relationships, not being bullied, access to adequate material and pedagogical resources, ability to participate in school decisions, or in other words if they adjust well; measures of individual health including mental health; and they may include a measure of the school overall academic performance (to evaluate inequalities in outcomes and to control for differences in expectations). Interventions to foster well-being may thus target individual health (e.g., mindfulness exercises), pedagogy (e.g., including talking about health) and school culture (e.g., establishing ways for pupils to express their opinions or mediation for interpersonal conflicts). The approach I deployed embedded several of these aspects (Chapter 13 and 15)—but was not evaluated using this model. Why? This is a problem of scale: The group was too small; the time too short and

<sup>9</sup> Let's note this echoes recent Deaf culture scholarship. For instance Baynton writes that: "*Recent research has shown that Deaf people process visual information differently than hearing people, and in some ways more efficiently. This has complemented a growing emphasis in recent years on the centrality of vision to Deaf experiences, with some Deaf people suggested that they instead be referred to as 'Seeing people' or 'Visual people.'*" Baynton, "Beyond culture: Deaf studies and the deaf body".

<sup>10</sup> E.g., Konu and Rimpelä, "Well-being in schools: a conceptual model".

included changes in schooling modalities (passing from primary to secondary school); and emphasizing sensory diversity is to displace the focus, from schools or individual students, towards improving the well-being of visually impaired (disabled) children as a group. My aim was to argue this type of intervention was possible and theoretically sound. Evaluating it broadly is a different research endeavour. . . <sup>11</sup> Furthermore, the point on which it may differ from other interventions is my attempt to support forms of disobedience enabling to reconfigure relationships in the classroom<sup>12</sup>. This quite clearly goes against calls for the return of authority at school, a major topic in French education politics and their commentators in the last decade<sup>13</sup>. But also against measures of adjustment at school: if we were to consider school is not an adequate environment for the pupils who attend it, adjustment is not desirable. Of course, this is not a black and white situation, since, as discussed in Chapter 14 especially, it needs to be a collective movement enabling to prove both content retention, acquisition of skills, and improvement in social relations in the classroom. Finally, the corollary of discourses about authority at school is the traditional curriculum. It emphasizes teacher-centered activities and the retention of content over pupils' appropriation of the material. The approach I developed however is much more compatible with a competency-based curriculum, where skills (oral, written etc) are evaluated across disciplines<sup>14</sup>. The advantage of this curriculum is its flexibility, for the pupils to learn at different rhythms and to accommodate the evolution of knowledge. The primary school curriculum in France is currently competency-based, but if this changes, my approach loses its relevance. By discussing this three points, I hope I have contextualized my research in current debates surrounding education, and provided pointers to explore collective and emancipatory approaches to well-being at school.

### 16.1.3 Recommendations

From these findings, I have four recommendations, more directed towards designers (and carers):

1. Participatory design processes often value convergence and collaboration—but supporting the expression of divergences and their material negotiation is just as important. More generally, this thesis shows that users' values are not sufficient to decide what should be designed, and that an ethical theory and viewpoint is useful to examine them;
2. Given the national contexts in which assistive learning technolo-

<sup>11</sup> Let's note that the topic of evaluation beyond the situated deployment is not absent from my research preoccupations, as this is key to the pragmatist approach. I have thought of using citations, identifying research projects using the same approach, uses by teachers or design practitioners, i.e., trying to identify at an early stage if this is an approach that can indeed help shape a future considered desirable. But these metrics also reflect citation practices in research communities, one's position in the academic field or abilities to mediate the research. One's position certainly contributes to making certain interventions more desirable than others. However, it limits any ambition to evaluate the merits of an intervention in themselves.

<sup>12</sup> For a reminder, observing disobedience and misuses of technologies offer interesting insights on children's strategies to draw pathways to resilience—see Chapter 11.

<sup>13</sup> Foessel, "L'autorité: faiblesses dans la transmission".

<sup>14</sup> For instance, Metatla and Cullen used a multisensory approach for developing storytelling and social skills Metatla and Cullen, "Bursting the Assistance Bubble": Designing Inclusive Technology with Children with Mixed Visual Abilities".



gies are deployed, including the modalities of schooling, the official curriculum and its implementations, and corresponding teachers' beliefs, there is a need to take into account local specificity in the design and the mediation of assistive technologies;

3. The necessity to make the curriculum accessible could be framed as an invitation for innovations in didactics for a mixed-group of pupils—taking into account other social factors than disability;
4. Consequently, this thesis supports research on assistive technologies looking into supporting carers and children in making and sharing resources and material.

## 16.2 *Alternatives and Limitations*

In this section, I propose to reflect on alternative courses of research. My aim is to point out the limitations of the research related, and the argument developed, in this thesis, as well as to revisit the framing of disabled childhoods and assistive technology design as research topics. I begin by outlining other possible research approaches and reflecting the implications of my theoretical framework. I then discuss the ethics of a design-based research with children to address educational inequalities. I conclude by pointing out whose voices are missing in this research and how it shaped my point of view.

### 16.2.1 *Why not adopt one specific theoretical approach from the start?*

The main difficulty encountered in writing this thesis was to articulate different research approaches and assumptions, from multiple bodies of research. The way I built my theoretical framework was an argument in itself, an argument for research integrating critical, social and relational approaches to disability and design. Which means I do not argue for studying disabled children without taking into account the risks and inequalities they face. But I do not argue either for a fatalistic view. Those are both sides of the same coin. This is because my empirical work leads me to conclude that visually impaired children are conscious of the inequalities they face. Opening a space for discussing the aspects of their lives that put them at so-called risks can enable a collective reconsideration of these stories. By this, I refer to the transformation of individual experiences in political and actionable knowledge, one that opens perspectives of emancipation<sup>15</sup>.

<sup>15</sup> Phipps, "Whose Personal Is More Political? Experience in Contemporary Feminist Politics", *On the politics of experience*, see:

### 16.2.2 *Aren't there more important things to do than designing?*

I encountered two main objections to the use of design in research, from disability activists, parents or teachers. First, that this type of local and individual-focused interventions fosters individualistic rather than collective emancipation. Second, that the most vulnerable visually impaired children were not included. These two aspects are highly intertwined, but I try to discuss them one successively.

Interventions against social inequalities often focus on the macro-level (e.g., reducing the number of retentions in grade, extending the common curriculum, improving social diversity in schools, providing specific funding to school in disadvantaged areas, inscribing integration in neighborhood schools into law). All these measures are crucial to reduce educational inequalities. Micro-level interventions against disability-based discriminations often consist on empathy-building toolkits and activities, such as simulating disability. My field-work includes examples of the successful impacts of such interventions from children's points of view (this is discussed in Chapter 10). However, these kits are criticized. Some argue they sustain attitudes of commiseration instead of supporting access to civil rights<sup>16</sup>. In other words, they may foster changes at the individual level, without envisioning how exactly it leads to structural change (nor the kind of structural change it could create). To paraphrase Mingus<sup>17</sup>, the actual need is to move from discourses about empathy and being alike and towards discourses recognizing the full diversity of human abilities and interdependencies. Design is merely a tool that happened to appear useful, that enabled to move forward with all participants in this context. However, taking into account this alternative pushed towards eliciting the theoretical, didactic and pedagogical underpinning it.

<sup>16</sup> E.g., Straumshein, *Disability Awareness Draws Scrutiny*.

<sup>17</sup> Mingus, *Changing the Framework*.

### 16.2.3 *Whose voices are missing?*

For a research wanting to understand visually impaired children's experiences of schools, many voices are missing or downplayed: those of parents, those of mainstream school teachers, those of younger children<sup>18</sup>, those of children of all ages who do not receive a formal education<sup>19</sup>. I have discussed the reasons behind these lacks in the thesis (Chapter 4 & 8 especially). They are due to the framing of the research, the conditions of the field-work and various ethical considerations. I hope however I have demonstrated their values and views about what is to be done often **do not converge** (hence the use of design as a mediation and proof-of-concept tool).

<sup>18</sup> I conducted observations only with 3 to 6 years old and have not used them in this thesis.

<sup>19</sup> On this topic, let's note the children I designed with were in-between special and mainstream education, susceptible to be oriented towards either—or even to be institutionalized. The question of who's considered educable and why thus remains central.

Deciding whose voices should be heard is making a classification.

I chose to limit my research to visually impaired children because this category has a history in France that shapes current care. I however show that this category is not used by the children it designates (in Introduction and when outlining hierarchies of disability made by children). So basing an intervention on sensory diversity, focused on visual impairments, is not something children would ask. So why would that be an acceptable course of action? It touches to the contradictions of child-led research and participatory design processes, which articulate a concern for emancipation on the individual, group and population level. Children may not want to get more involved (Chapter 2); they may also actively participate in the exclusion of some of their peers to assert by contrast their right to education (Chapter 11). More generally, it is an equilibrium to be found between the present and the future, and individual and group interests. We can not expect all children to have equal resources to commit to group changes. Nor should they be sided for that reason. It also follows that though I have argue for placing children's points of view and values at the center of the research, I have not adopted a purely relativistic approach of values, in which all value systems are equal. Is this still participatory and child-centered then, or is that just a different way to control their conduct in the classroom?

The exploratory nature of my research is a consequence of this concern. It does not resolve the tensions and conflicts. If anything, it makes them central, moving away from absolute notions of empowerment and agency towards more detailed accounts of the trade-offs and limits of any intervention motivated by educational justice. There are concrete ways through which I could have widened participation however. There were opportunities for establishing a research protocol to involve children who do not attend formal learning environments that I did not perceive at the time, specifically proposing craft activities or small-scale interventions<sup>20</sup>. It would have been a different thesis, one mapping notions of well-being and learning from multiple perspectives, probably more focused on design as a research tool.

<sup>20</sup> Both Mapsense and the audio probes represent at least 2 weeks of work, when accounting for the fabrication process.

### 16.3 *Future Work and Research Perspectives*

In this section, I provide pointers for future work on the topics discussed in the thesis, as well as my own research perspectives. On the experiences of schooling of visually impaired children, two directions can be taken: broadening the focus (to different spaces, and different groups of disabled children) and clarifying aspects of their experiences. As for my own research perspectives, they focus on

developing interdisciplinary research framework and methods.

### 16.3.1 *Future work: Broadening the focus*

#### **Complementary quantitative data on schooling modalities**

Given the inductive and exploratory nature of my PhD research, as well as the time constraints placed on it, I could not further develop a complementary and quantitative study. I think it would have been useful to get a clearer idea of children's schooling modalities over time and how these decisions were made. From my field work (and the DEPP data, discussed Chapter 6), it seems that this selection is done at the entrance of each new school (e.g., from primary to secondary school). But my observations also show numerous exceptions, such as pupils who ask or are proposed to spend one more year in secondary school to have more time to develop independent living skills. Why are some pupils maintained in general education, and others reoriented towards adapted professional education or special education? Moreover I highlight in Chapter 11 the difference made by carers between non-resilient children and children unable to follow the curriculum, as well as the adjustments made in terms of schooling modalities. I further outline how special education can be seen by some children as a more inclusive space. It would be interesting to verify if the correlations between social class and schooling modalities and experiences hold, as well as the influence of other factors (parents' education, perceptions of schooling modalities, views on disability, etc).

#### **Similar Intervention in different Contexts**

A very concrete research perspective to follow-up on this thesis is to try out a similar intervention in larger classrooms in mainstream schools. There are practical problems to be addressed: for instance, field-trips are difficult to organize for larger groups which limit their use in a mainstream context. Some researchers propose virtual-reality field-trips<sup>21</sup>—current commercialized solutions (e.g., Google Expeditions) being primarily visual experiences.

There are many elements motivating this research perspective. The audio-tactile map at the basis of Mapsense has previously been used in primary schools, the involved teacher noting impacts on personal and relational resources, but this material has not been fully analyzed. Furthermore, impact on carers' practices should be studied.

<sup>21</sup> Tuthill and Klemm, "Virtual field trips: Alternatives to actual field trips"; Stainfield et al., "International virtual field trips: a new direction?"

In Chapter 10, I show models of disability and beliefs about inclusion greatly vary depending of the training or support received<sup>22</sup>—but I also show there is a great diversity in teachers who hold a positive opinion of inclusion. How do teachers come to commit to inclusive schooling in France? For instance, I designed a scaled model of a bee, as a game to be assembled for the pupils to prepare a field-trip to an apiculture learning center (see Annex for full description and photos). Though designed to address the specific problems the special education teacher ran into when trying to explain the specificities of insects, it turned out the learning center staff found the model useful to improve the understanding of their sighted visitors. What began as a so-called assistive product actually opened pedagogical opportunities—blurring the frontier between adapted and normal learning material and learners.

<sup>22</sup> E.g., see: Bruce, “Teachers’ perceptions of the inclusion of students with disabilities in the general education classroom”.

### **Language, socialization and emotional lives**

Trying to understand conjointly socialization and children’s emotional lives seems like a very promising avenue for research. First, there is a linguistic aspect to my research that I have not fully developed: the use of metaphors to express emotions in different groups of children. Chapter 10 focuses on metaphors of battle and their uses, and evokes the use of the Harry Potter franchise to express emotional state. Metaphors and narratives are interesting in themselves, but also for the perspectives they open for participatory research methods. Can studying them enable to develop child or group material to talk about their current and envisioned emotional lives? Second, I give the example in Chapter 11 of a girl who states that without performing well at school, one can not find a good job or a good husband. It instantiates in the discussion the gendered and class-based expectations from schooling, acquired primarily in her family. But it also hints at how early disabled girls are told the value of their companionship is compromised. Studying these discourses and their effects may offer new insights on gendered experiences of disability and victimization.

#### *16.3.2 Research perspectives*

As to my research perspectives in a near and not-so-near future, they focus on developing the implications of my PhD on methodological and theoretical aspects:

DEVELOPING NEW DESIGN APPROACHES ON THE TOPIC OF ACCES-

SIBILITY. Researchers on assistive technologies have only recently begun to use more participatory design methods. But there are under-developed approaches, such as the possible contributions of participatory critical design, i.e. the introduction of unusual artifacts to reflect on assumptions made about users or technologies. This follows and expands on one of the red lines of this thesis: how are ‘users’ categorized and represented and why?

FURTHER THEORIZING HOW TO TAKE INTO ACCOUNT SOCIAL CLASS IN HCI. Many applied research focuses on a problem specific to an underprivileged community and how to solve it. But as exemplified by my PhD research, sometimes its roles are revealed by the use of a new device or is hidden by a different issue. Furthermore, there is always a tension between building universal but adaptable systems, that may marginalize some; and developing specific and local projects, which may have only limited effects and may hide the need for structural changes. This is consistent with my ongoing work<sup>23</sup>, and would probably benefit for further empirical work in other contexts.

<sup>23</sup> Brulé and Bailly, “Taking into Account Sensory Knowledge: The Case of Geo-technologies for Children with Visual Impairments”.

ARTICULATING NEW METHODOLOGICAL AND TEACHING RECOMMENDATIONS. One remark often made by my students is that either someone is made for doing participatory design or is not. On the contrary, I believe that designers and engineers would benefit from developing the ability to innovate while involving various groups and communities. Still, it raises many challenges to be prepared to face, be they ethical<sup>24</sup>, methodological and practical. I believe there is still much work to do on transparency in this area, building on teaching experiences on disability and design during the PhD, that I did not represent in the thesis.

<sup>24</sup> Spiel et al., “Micro-Ethics for Participatory Design with Marginalised Children”.



# A

## Appendices

### A.1 Résumé français

#### A.1.1 Introduction

Entre 1945 à 1975, l'Organisation des Nations Unies (ONU) pose les fondations des politiques publiques internationales favorisant l'inclusion des personnes en situation de handicap. L'accent a d'abord été placé sur la réadaptation et la prévention, et le handicap conçu comme relevant de l'assistance publique<sup>1</sup>. Sous l'impulsion des mouvements pour les droits sociaux des années 1960 et des actions, l'ONU a graduellement favorisé un modèle d'égalité dans l'accès aux droits et pris pleinement en compte le rôle des barrières sociales et environnementales dans la production même du handicap : d'un attribut personnel, le handicap est devenu un décalage entre les individus et les ressources à leur disposition. Cette situation de décalage entrave leur pleine participation à la vie sociale. Dès lors, il est nécessaire de mettre en place l'assistance humaine et matérielle nécessaire pour leur garantir l'accès aux mêmes possibilités et aux mêmes droits. La Déclaration des droits des personnes handicapées, adoptée par les Nations Unies en 1975, reflète ces efforts. Il a fallu 30 ans de plus pour qu'elle devienne juridiquement contraignante : la Convention internationale relative aux droits des personnes handicapées a été adoptée en 2006 et est désormais ratifiée par une majorité de pays.

Les lois françaises relatives aux droits des personnes handicapées de 2002<sup>2</sup> et de 2005<sup>3</sup> incorporent cette définition du handicap. Pour les enfants en situation de handicap, ces politiques publiques semblent avoir amélioré l'accès à l'enseignement formel et aux classes dites ordinaires : avant la loi de 2005, la fréquentation d'une classe ordinaire dépendait de la bonne volonté des autorités locales et sco-

<sup>1</sup> Brégain, *Pour une histoire du handicap au XXe siècle: approches transnationales (Europe et Amériques)*.

<sup>2</sup> Loi n° 2002-2 du 2 Janvier 2002 rénovant l'action sociale et médico-sociale.

<sup>3</sup> Loi n° 2005-102 du 11 Février 2005 pour l'égalité des droits et des chances, la participation et la citoyenneté des personnes handicapées, Page 2353, JO n° 36 du 12 Février 2005.



lares. Cela restait majoritairement l'affaire des familles. La loi en a fait une exigence, inversant la responsabilité de l'adaptation : auparavant, les élèves pouvaient fréquenter une école ordinaire s'ils étaient capables de s'adapter ; depuis lors, les écoles doivent implicitement s'adapter aux élèves, ce qui a été renforcé par la loi de refondation de l'École de 2013<sup>4</sup>.

En effet, cette réforme consacre le principe d'une école permettant l'inclusion de tous les enfants. L'inclusion va au-delà du droit à fréquenter une école ordinaire. Elle affirme que tous les enfants sont différents et que les enseignants et enseignements doivent s'adapter à leurs besoins. En pratique cependant, l'adaptation des écoles ordinaires pour l'accueil des élèves handicapés n'est pas encore la norme. Si le nombre d'enfants handicapés en enseignement ordinaire a doublé depuis 2006, cette statistique cache que le nombre d'enfants fréquentant les établissements spécialisés ou médico-sociaux d'enseignement est resté stable<sup>5</sup>. En outre, il existe de nombreux chevauchements entre les modalités de l'enseignement spécialisé et celles de l'enseignement ordinaires. Les élèves peuvent ainsi fréquenter : une classe adaptée, proche de l'éducation spécialisée, dans une école ordinaire (Unités Localisées pour l'Inclusion Scolaire *Ullis*) ; un établissement spécialisé et une Ullis, etc. Les modalités d'enseignement sont également différenciées du fait de l'attribution personnalisée à une aide humaine individualisée ou aux technologies d'assistance.

Les résultats de ces évolutions légales sont mitigés. Les parents d'enfants handicapés allant à l'école ordinaire (toutes modalités confondues) sont globalement satisfaits de l'établissement fréquenté et de l'enseignement reçu, mais moins que les parents d'enfants non handicapés<sup>6</sup>. De nombreux indices laissent cependant à penser que les familles luttent encore pour que l'Etat respecte les droits de leurs enfants en situation de handicap, qu'il s'agisse des articles à chaque rentrée scolaire sur l'absence d'AVS/AESH rendant la scolarisation impossible ou des travaux académiques sur l'accès aux droits sur le terrain<sup>7</sup>. En somme, il semble réaliste que comme l'avance Ebersold, les pratiques d'enseignement actuelles excluent toujours les enfants considérés comme trop différents des normes scolaires<sup>8</sup>.

<sup>4</sup> Loi n°2013-595 du 8 Juillet 2013 d'orientation et de programmation pour la refondation de l'école de la République.

<sup>5</sup> Makdessi, "L'accueil des enfants handicapés dans les établissements et services médico-sociaux en 2010".

<sup>6</sup> Le Laidier and Prouchandy, "Pour la première fois, un regard sur les parcours à l'école primaire des élèves en situation de handicap".

<sup>7</sup> Ceci est discuté en ainsi que par : Lansade, "'La Vision Des Inclus' Ethnographie d'un Dispositif d'inclusion Scolaire à Destination d'adolescents et Jeunes Adultes Désignés Handicapés Mentaux"; Revillard, "La Réception Des Politiques Du Handicap: Une Approche Par Entretiens Biographiques".

<sup>8</sup> Ebersold, "Idéologie de La Réussite, Réinvention Des Institutions et Reconfiguration Du Handicap".

### A.1.2 Questions de recherche et enquête

#### Première question de recherche

En revanche, cela ne nous renseigne pas sur le vécu et les expériences scolaires des enfants en situation de handicap. Qu'ont-ils à dire sur l'impact qu'ont eu ces politiques publiques ? C'est la première question de recherche de la thèse. C'est une approche trop rarement adoptée, particulièrement en France<sup>9</sup>. Alors que les enfants sont les principaux acteurs du système scolaire, leurs points de vue et ressentis reçoivent une attention moindre, ce qui a également pour effet de restreindre leur participation aux décisions les concernant<sup>10</sup>.

Ce manque d'études limite par ailleurs le recul que nous pouvons prendre sur la manière de délimiter ce genre d'enquête. On peut par exemple se demander si les catégories diagnostiques sont pertinentes pour l'étude des expériences scolaires. En s'intéressant spécifiquement aux enfants dits déficients visuels, dont la prise en charge se distingue clairement de par son histoire et ses modalités contemporaines (Chapitre 6) de celles des autres groupes d'enfants en situation de handicap, cette thèse questionne aussi les modalités d'identification à un groupe — durant la scolarité ou en dehors.

#### Enquête

Cette thèse se base sur une enquête principalement ethnographique, conduite de 2014 à 2017 dans le sud de la France au Centre d'Éducation Spécialisé pour Déficients Visuels ; Institut des Jeunes Aveugles (CESDV-IJA). Cette enquête a été conduite dans le cadre du projet ANR Accessimap, visant à développer de nouvelles technologies d'assistance dans le domaine de la cognition spatiale et de la mobilité. Il s'agissait à la fois de développer des outils pour les enseignants et des dispositifs permettant d'encourager la collaboration entre élèves<sup>11</sup>. En particulier, l'équipe développe un dispositif de carte interactive grand format, sur une table tactile.

Le financement public accordé à Accessimap s'ancre dans le développement des usages des technologies de l'information et de la communication (TIC) à l'école, sujet majeur des politiques éducatives depuis les années 1970<sup>12</sup>. Les TICs sont depuis longtemps la focale de discours promettant une pédagogie différenciée pour une éducation personnalisée dans un système scolaire inclusif<sup>13,14</sup>. Dans cette perspective, les TICs auraient le potentiel de renforcer l'autonomie et l'indépendance des élèves handicapés en leur permettant d'accéder

<sup>9</sup> Lewi-Dumont, "Blind Teen-Age Students' Expectations"; Coudronnière and Mellier, "Qualité de Vie à l'école Des Enfants En Situation de Handicap. Revue de Questions."

<sup>10</sup> UNICEF, "The State of the World's Children. Children with Disabilities".

<sup>11</sup> Christophe Jouffrais, *Innovation Biomédicale (DS0404) 2014. Projet AccessiMap. Les Cartographies (Open Data) Interactives, Collaboratives et Accessibles Pour Les Déficients Visuels*.

<sup>12</sup> Bernard and Ailincăi, "De l'introduction des TIC à l'École aux pratiques actuelles des jeunes."

<sup>13</sup> McMillan Culp, Honey, and Mandinach, *A Retrospective on Twenty Years of Education Technology Policy*; Isaacs, *Transforming education: The power of ICT policies*.

<sup>14</sup> Ces discours ont récemment suscité des critiques publiques fortes. Par ailleurs, réaliser ces promesses soulève de nombreuses questions conceptuelles et pratiques.

aux mêmes opportunités que leurs pairs. Cependant, les études en contexte montrent que l'utilisation de technologies d'assistance sont loin de garantir le développement d'une pédagogie différenciée ou la possibilité de participer pleinement aux activités en classe<sup>15</sup>.

De plus, cet objectif d'autonomie par l'utilisation des technologies doit être pris avec prudence. D'une part, parce qu'être aidé par quelqu'un (plutôt que par des technologies) ne signifie pas nécessairement perdre son autonomie. D'autre part, parce que l'assistance personnelle étant coûteuse, les technologies peuvent servir d'alibi pour la réduire, parfois sans mesurer l'impact réel sur les résultats<sup>16</sup>. Par exemple, lorsque les technologies d'assistance sont évaluées, ce n'est généralement en comparaison avec la réalisation de la tâche en question avec son assistant, mais avec le fait de faire la même tâche seul<sup>17</sup>. Enfin, parce que leur mise en place, maintenance et intégration aux activités nécessite en réalité une forte médiation pédagogique et technique, ce qui est rarement pris en compte que ce soit pour les technologies d'assistance ou les technologies éducatives.

## Deuxième question de recherche

Réaliser le potentiel des technologies d'assistance et des technologies éducatives requiert alors de remettre en question certaines des hypothèses guidant leur conception à l'heure actuelle. C'est la deuxième question de recherche explorée dans la thèse, qui propose de changer de focale dans la conception des technologies d'assistance pour le contexte scolaire. Il est possible de concevoir des technologies qui n'aient pas pour objectif de réaliser des tâches précises qu'il faut aider les élèves à accomplir seuls. Il est possible de porter plus d'attention aux technologies en contexte et à la manière dont elles permettent et soutiennent certaines relations dans les espaces scolaires.

### A.1.3 Définir "enfants déficients visuels" et leurs besoins en termes de technologies

#### Du diagnostic à une catégorie pour l'accès au soin

Une première difficulté de cette recherche est de s'accorder sur une définition des enfants déficients visuels. Les critères en terme de capacité visuelle sont bien établis, bien qu'ils aient des variantes nationales : est malvoyante toute personne avec une acuité visuelle après correction inférieure à 0.3 dans le meilleur oeil ou un champ

<sup>15</sup> Mithout, "L'inclusion Scolaire à l'heure Des TIC : Perspective Franco-Japonaise"; Metatla, Serrano, et al., "Inclusive Education Technologies: Emerging Opportunities for People with Visual Impairments".

<sup>16</sup> Par exemple, dans une enquête en France, Mithout montre que doter les élèves malvoyants de technologies d'assistance s'inscrit dans un processus d'inclusion partielle, où il n'est pas nécessaire d'adapter la pédagogie à l'élève. Mithout, "L'inclusion Scolaire à l'heure Des TIC : Perspective Franco-Japonaise".

<sup>17</sup> Agree et al., "Reconsidering substitution in long-term care: when does assistive technology take the place of personal care?"

visuel inférieur à 20°. C'est un handicap assez rare, touchant moins d'un enfant sur mille. Cependant, ces critères sont contestés et contestables car ils excluent certaines personnes nécessitant assistance ou réhabilitation. C'est le cas de certains troubles neurovisuels qui ne remplissent pas nécessairement ces critères, ou d'enfants avec des acuités visuelles supérieures à ce seuil mais qui rencontrent des difficultés dans leurs activités. Par ailleurs, environ la moitié des enfants malvoyants présentent un handicap associé, et sont généralement accompagnés par les mêmes structures. Les catégories de diagnostic ne recouvrent donc ni les évaluations fonctionnelles, ni parfaitement les catégories utilisées pour organiser les services de soutien, qui font l'objet de nombreuses négociations entre administrations et professionnelles du handicap (Chapitre 9). De même, est un enfant toute personne n'ayant pas atteint l'âge de la majorité légale, 18 ans. Cependant, les organisations accompagnant les enfants en situation de handicap le font généralement jusqu'à leur vingt ans, voire plus tard. La définition légale de l'enfance ne recouvre donc pas parfaitement qui, dans le groupe des personnes malvoyantes et aveugles, est un enfant aux yeux de l'état et des diverses institutions avec lesquelles ils interagissent.

### **Ce que les sciences sociales ont à dire des expériences des enfants déficients visuels**

L'étude, tant du handicap que des enfants et *a fortiori* des enfants en situation de handicap, est souvent le domaine de la recherche médicale ou psychologique. Sous l'impulsion d'organisations militantes pour les droits civiques, des courants de recherche insistant sur l'aspect social des expériences de ces deux groupes se sont développés depuis les années 1980, notamment autour du modèle social du handicap et de la nouvelle sociologie de l'enfance. À leur intersection se trouvent les études sur les enfances handicapées (*disabled childhood studies*), qui se sont particulièrement développées en Angleterre et dans les pays scandinaves.

Ces travaux, principalement empiriques, accordent une grande attention aux recherches permettant d'améliorer les services destinés aux enfants en situation de handicap<sup>18</sup>. Dans le cas de l'école, ils ont notamment cherché à comparer la qualité des relations sociales ainsi que les compétences scolaires acquises dans les écoles ordinaires et spécialisées. D'autres se sont penchés sur la difficile définition de l'égalité dans le cadre scolaire, puisque les normes définissant les capacités à acquérir peuvent en elles-mêmes exclure les enfants en situation de handicap<sup>19</sup>. Enfin, ces études ont montré que les carac-

<sup>18</sup> Carpenter and McConkey, "Disabled Children's Voices: The Nature and Role of Future Empirical Enquiry."

<sup>19</sup> Berg and Schneider, "Equality Dichotomies in Inclusive Education: Comparing Canada and France".

téristiques socio-démographiques des enfants affectent leurs expériences du handicap au quotidien. Dans le cas des enfants déficients visuels, les données disponibles suggèrent par exemple que le groupe dans son ensemble a des performances scolaires plus faibles. En revanche, à contexte socio-économique égal, leurs performances scolaires seraient similaires (avec l'accompagnement et les adaptations actuelles) à celles de leurs pairs non handicapés<sup>20</sup>.

Cependant, on constate un manque d'études sur les aspects émotionnels des expériences scolaires, en particulier avec les enfants les plus jeunes. Ainsi, il n'y a eu à ma connaissance que deux études qualitatives en France sur les expériences des jeunes déficients visuels, toutes deux menées avec un nombre réduit d'adolescents aveugles. Ce manque est problématique, puisque l'étude de cohorte sur les enfants handicapés en France suggèrent une exposition plus importante aux violences (scolaires et intrafamiliales)<sup>21</sup>. À celles-ci s'ajoutent quelques travaux quantitatifs sur l'expérience du collège. Sentenac *et al.*<sup>22</sup>, par exemple, suggèrent une augmentation relative du risque de ne pas aimer l'école pour les enfants en situation de handicap, particulièrement pour ceux percevant par ailleurs les exigences scolaires comme élevées, mais l'étude ne distingue pas les différents types de handicaps.

Enfin, les travaux sur les modalités didactiques et pédagogiques améliorant l'acquisition des savoirs scolaires par ces enfants restent, aujourd'hui encore, limités<sup>23</sup>. Il s'agit avant tout d'une littérature professionnelle, variant d'un pays à l'autre. L'évaluation de leur efficacité est complexe, vue la diversité de situations de handicaps et de scolarisation dans ce groupe. Il en est de même de l'enseignement de la prise en main des technologies d'assistance.

### La recherche sur le design des technologies d'assistance

Alors que 40.2% des enfants déficients visuels à l'école primaire et 66.4% au collège utilisent des aides technologiques, les technologies utilisées par les enfants déficients visuels à l'école sont rarement étudiées en situation par les sciences sociales<sup>24</sup> ou par les chercheurs en Interaction Humain-Machine (IHM) (voir Chapitre 7). L'IHM a pourtant proposé de nombreuses approches et prototypes pour améliorer l'accès aux représentations visuelles, via l'utilisation des modalités auditives et haptiques (tactile et proprioceptive) et leurs combinaisons<sup>25</sup>. On peut cependant constater que rares sont les technologies qui ont été évaluées en contexte, ou sur des périodes longues, ce qui limite les possibilités d'étudier et de prendre en compte comment ces technologies peuvent remodeler les activ-

<sup>20</sup> Chanfreau and Cebulla, "Educational Attainment of Blind and Partially Sighted Pupils".

<sup>21</sup> Le Laidier and Prouchandy, "Pour la première fois, un regard sur les parcours à l'école primaire des élèves en situation de handicap".

<sup>22</sup> Sentenac, Pacoricona, and Godeau, "How Do Disabled Students Perceive High School?"

<sup>23</sup> D. D. Hatton, "Advancing the Education of Students with Visual Impairments Through Evidence-Based Practices".

<sup>24</sup> Mithout, "L'inclusion Scolaire à l'heure Des TIC : Perspective Franco-Japonaise".

<sup>25</sup> E.g., A. M. Brock et al., "Interactivity Improves Usability of Geographic Maps for Visually Impaired People"; Lenay and Declerck, "Technologies to Access Space Without Vision. Some Empirical Facts and Guiding Theoretical Principles".

ités et les relations dans la classe. De même, elles sont avant tout conçues comme des moyens de remplacer et substituer les représentations visuelles, questionnant rarement l'utilité ou la justesse de cette représentation pour l'apprentissage, ou leur insertion dans des démarches didactiques et pédagogiques différentes (Chapitre ??).

Par ailleurs, ces travaux reportent certaines caractéristiques socio-démographiques (en particulier l'âge et le genre) des personnes évaluant leurs prototypes, mais en prennent peu en compte l'impact au delà de la tâche à effectuer. Les nuances apportées par les sciences sociales à l'hypothèse de performances scolaires inférieures des enfants déficients visuels du fait de leur handicap, le risque accru de faire face à des violences à l'école, ou encore les nécessités d'adapter l'approche pédagogique pour une école inclusive, sont peu visibles dans cette littérature. Cette thèse se propose donc d'étudier les expériences scolaires des enfants déficients visuels en France, et leur médiation par les technologies éducatives et d'assistance, en se concentrant sur les points de vue des enfants.

#### A.1.4 Approche de recherche

### Méthodes

Ainsi qu'indiqué dans l'introduction, ma thèse s'appuie principalement sur une enquête ethnographique. J'utilise pour la décrire la typologie proposée par Creswell<sup>26</sup>: épistémologie<sup>27</sup>, design et méthodes. Il s'agit d'une enquête pragmatiste. D'une part car elle vise à étudier et **reformuler** un problème de manière à améliorer les circonstances de vie de ses participants. D'autre part car je m'appuie sur une littérature principalement interactionniste ou héritant de l'interactionnisme, courants ancrés dans le pragmatisme. Ils s'intéressent à la construction des normes et des processus sociaux via l'observations des interactions. Ce qui n'empêche pas de décider de prendre un point de vue, dans la conception de l'objet de recherche, informé par des approches structuralistes. L'enquête a un protocole dit de 'méthodes mixtes', qui mobilise des données quantitatives pour appuyer certains résultats obtenus qualitativement. Enfin, j'utilise des méthodes d'enquête issues de l'ethnographie et de la sociologie (observations, collection de documents notamment de littérature professionnelle ou d'archive, entretiens, tenue d'un carnet auto-ethnographique, analyse secondaire d'une enquête quantitative) et de l'IHM et du design (probes et prototypes) ; pour l'analyse, si je me suis d'abord tournée vers les outils de la théorie ancrée, j'ai choisi l'analyse thématique descriptive pour analyser les récits faits à propos de l'école et l'analyse multimodale pour analyser les cours

<sup>26</sup> Creswell, *Research Design: Qualitative, Quantitative, and Mixed Methods Approaches*.

<sup>27</sup> La traduction littérale de 'worldview,' terme utilisé par Creswell, est plutôt 'vision du monde.' Il s'agit là d'un concept plus large que l'épistémologie, car il vise plutôt à décrire les valeurs et la perspective des chercheurs.

de géographie observés ainsi que l'utilisation des prototypes développés.

L'enquête a impliqué environ 50 enfants et 40 professionnels de l'accompagnement éducatif et thérapeutique. J'ai également recueilli les témoignages de plusieurs parents. L'implication des enfants et adultes varie. J'ai par exemple travaillé tout au long de mon terrain avec un petit groupe d'enfants de 8 à 11 ans et une enseignante spécialisée, que j'ai pu observer en classe et en rééducation, et avec qui j'ai conduit la plupart des activités de design participatif. Dans d'autres cas, observations et entretiens étaient occasionnels. Des informations détaillées sur les participants peuvent être trouvées dans l'appendice A.3. Enfin un plus grand nombre de personnes (notamment les personnels administratifs, l'équipe de direction et les personnels supports, mais aussi des enfants accueillis par l'organisation) ont de fait été impliquées ponctuellement dans les observations.

### Des disciplines multiples

La thèse emprunte à de nombreuses disciplines : sciences sociales et en particulier sociologie et anthropologie ; 'cultural studies', ces champs interdisciplinaires qui se sont constitués autour d'objets de recherche tels que le genre ou le handicap ; design et Interaction Homme-Machine (IHM). Les méthodes mobilisées sont issues des approches ethnographiques et de l'IHM, un choix qui à la fois découle de et a constitué mon objet de thèse. Les méthodes ethnographiques se sont rapidement imposées du fait du peu de recherches sur les expériences des enfants déficients visuels, rendant l'approche qualitative et inductive appropriée. Quant aux méthodes de design, celles-ci viennent principalement de mon parcours professionnel en design, dans les années précédant la thèse. Le design est ici défini comme un regard expert<sup>28</sup> de la chercheuse plutôt que comme une discipline. Cependant travailler à la croisée des champs permet de redéfinir le "problème" de l'inclusion scolaire dans les deux champs : si les sciences sociales ont formulé des politiques publiques permettant de diminuer les inégalités scolaires (dans les expériences et les résultats scolaires), elles s'intéressent peu aux technologies dans ce cadre. Les chercheurs en IHM s'intéressent eux aux technologies pour réduire les inégalités scolaires, mais ces travaux restent principalement empiriques et contribuent peu à la littérature de sciences sociales. La thèse a été rédigée de manière pluri-disciplinaire (c'est à dire en superposant les apports de différentes disciplines), du fait de son objectif premier de produire des ressources pour les différents acteurs concernés : enfants, enseignants, organisations. L'ambition est cependant d'ouvrir la perspective d'un objet interdisciplinaire à la

<sup>28</sup> Grasseni, *Skilled Visions: Between Apprenticeship and Standards*.

sociologie, à l'IHM et au design.

### Étudier les valeurs

Dans cette perspective, je soutiens dans la première partie que la question des valeurs dans la recherche et les artefacts proposés est centrale. D'une part, l'objet de recherche et son financement ont un fort aspect normatif et une visée transformatrice d'une organisation éducative. D'autre part, le fait d'avoir par ailleurs une formation de designer et un engagement bénévole en faveur des droits des enfants favorise une approche interventionnelle, inspirée par la recherche-action. Enfin, mon investissement au delà de la recherche a largement conditionné la possibilité même de faire de la recherche sur ce terrain : les participants ont très tôt exprimé leur préférence pour une implication forte et sur la nécessité de voir des actions et résultats concrets vu le temps investi dans mon accueil et mon initiation à leurs métiers. Il s'agissait pour eux de distinguer leurs valeurs de celles qu'ils peuvent percevoir chez les chercheurs, que ce soit en entretiens ou durant les discussions informelles.

Par valeurs, j'entends ici les jugements guidant l'action, face à un problème — celui de l'inclusion scolaire, et donc celui de l'exclusion. Dans le Chapitre 2, je reviens sur le début de mon travail de terrain et les conflits entre chacune des parties prenantes du travail de recherche. Le problème initial, comme souligné dans l'introduction, est le manque de technologies éducatives accessibles pour enseigner la géographie, et avait été défini avec des représentants de l'IJA. Cependant, une fois le projet de recherche Accessimap financé, ma présence sur le terrain actée, les participants ont tenté de modifier le cadre et les buts de la recherche.

Ces conflits se concentrent autour de deux sujets : l'impact concret du projet de recherche sur le quotidien et les pratiques ; la définition des usages (notamment de la caractérisation des "enfants déficients visuels" et du rôle des technologies dans la classe) utilisée dans la conception de technologies. Ainsi les membres du personnel s'inquiétaient du fait de s'investir sans voir de résultats concrets de la recherche, ou encore de devoir adapter leurs discours durant les rencontres avec les chercheurs afin de maximiser les résultats concrets, les objets qu'ils pourront utiliser à l'issue du projet de recherche. De son côté, l'équipe de recherche met plutôt en exergue l'importance d'une recherche sur les technologies ne pouvant pas être immédiatement concrétisées et distribuées. Le désir de trouver un compromis, de s'engager à améliorer le quotidien est très présent dans la formulation du projet, mais le transfert de technologies s'avère complexe et



les exigences académiques limitent nécessairement l'engagement sur le terrain.

Cela influe la définition des usages : les participants expriment leur sentiment d'être mal représentés dans les dispositifs conçus par les chercheurs, mais aussi que les conditions dans lesquelles les recherches sont menées ne leur laissent pas la possibilité de rectifier cette représentation. Par exemple, pour une enseignante spécialisée : *"ils posent les questions qui les intéressent, donc je ne peux pas dire 'ce n'est pas de ça dont il faudrait parler.'"* Au niveau de la définition de la catégorie 'enfants déficients visuels,' le personnel de l'IJA souligne la dimension contextuelle du handicap, ainsi que le rôle des interactions sociales sur la réussite scolaire, mettant en exergue une visée de justice sociale, par l'adaptation non seulement des tâches mais aussi des contenus. Du point de vue des chercheurs, cela est au delà des questions d'ingénierie et de design des technologies, et celles-ci visent plutôt à réparer le handicap. Il y a aussi une visée de justice sociale, mais par un chemin différent, de normalisation. Quant aux enfants, ils s'identifient rarement à cette catégorie, pour des raisons discutées ci-après. Ce que les technologies peuvent apporter de leur point de vue est avant tout une forme de bien-être immédiat : la satisfaction de posséder l'objet, la simplification de l'accès aux contenus pédagogiques s'ils ont connu des difficultés par le passé, etc.

### **Positionnement personnel, valeurs et éthique**

Aucun de ces systèmes de valeur n'est immédiatement préférable. Tous visent à une meilleure qualité de vie présente et future. En revanche ils posent des problèmes différents, qui vont avantager certains plutôt que d'autres. Ainsi, une visée réparatrice du handicap exclut nécessairement les personnes trop éloignées de la norme scolaire. De fait, les évaluations de ces dispositifs sont réalisées principalement avec des élèves ayant de bonnes performances scolaires. Dans ce contexte, je me suis trouvée face à la nécessité d'arbitrer les valeurs que je souhaitais soutenir — au risque sinon de ne pouvoir agir. Du fait notamment de mon positionnement dans le champ académique et d'une assez longue expérience de bénévole et d'activiste dans le champ des droits des enfants à l'éducation, j'ai adopté un cadre éthique développé dans les études féministes, une éthique de la sollicitude (*care ethics*). Par contraste avec des approches éthiques basées soit sur les conséquences de nos actions, soit sur la déontologie, l'éthique de la sollicitude est basée sur l'attention aux besoins en situation, la prise de responsabilités des chercheurs quand il s'agit de répondre à ces besoins, le développement de compétences de '*care*'

(de sollicitude, de soin dans l'interaction), tout en créant un contexte favorable à l'expression d'avis divergents sur les manières dont cette sollicitude s'exprime<sup>29</sup>, car elle peut notamment épuiser, dans le cas de relations asymétriques, ou priver d'autonomie. Elle est plus adaptée à mon objet et approche de recherche, parce qu'elle s'adapte au contexte et vise avant tout à prendre soin des relations entre les personnes — sans perdre de vue les enjeux éthiques plus larges, c'est à dire dans ce cas particulier les enjeux de justice sociale qui sont l'objet de tensions entre les différents acteurs impliqués.

<sup>29</sup> Tronto, *Moral Boundaries: A Political Argument for an Ethic of Care*, pp. 126–136.

#### A.1.5 *Quand les enfants racontent l'école : la question centrale du bien-être*

##### **Dispositif d'enquête**

La troisième partie de la thèse s'intéresse à ce que les élèves déficients visuels impliqués dans l'étude disent de l'école, à la fois en entretien et dans les conversations informelles. Être élève dans cette étude implique le fait de recevoir une instruction formelle, dans un contexte spécialisé et ordinaire, à temps plein ou partiel. Cela exclut les enfants déficients visuels et dits polyhandicapés, accompagnés par l'IJA au quotidien, principalement en internat, et dont les modalités d'instruction diffèrent (peu ou pas de cours formels, nombreuses activités ludiques, accent placé sur l'autonomie au quotidien). Ce choix est à la fois dû à la nécessité de limiter l'étude de terrain vu le temps disponible pendant le doctorat et au cadre que j'ai donné à ma recherche : les lois sur la scolarisation en milieu ordinaire ne s'appliquent pas directement à ce groupe, bien qu'elle ait très probablement d'autres effets, qu'il reste à explorer.

Dans cette partie, je m'appuie sur mes observations en classe ordinaire et à l'intérieur de l'organisation, ainsi que sur les X entretiens menés avec les enfants (de 6 à 18 ans). Ces entretiens menés avec les enfants sont semi-directifs : la grille d'entretien comportait, après des questions socio-démographiques sur leur âge ou le métier de leurs parents (données parfois complétées par le personnel de l'IJA), une question ouverte sur ce qu'ils faisaient durant une journée d'école et une journée de weekend, ancienne d'abord, récente ensuite. Puis une question sur quel était leur jour préféré dans la semaine (ce qui suscite des discussions comparant l'école à d'autres milieux). Enfin, elle comportait trois questions supplémentaires, si ces sujets n'avaient pas été abordés durant l'entretien. (1) Pourquoi aller à l'école : la question visait volontairement à recueillir en entretien du matériel

sur leur rapport aux discours sur la scolarisation, observés également dans d'autres situations. (2) Qui sont leurs personnes préférées à l'école, qui visait à mieux comprendre leur perception des relations avec leurs pairs et leurs enseignants (notons que cette question suscitait des anecdotes positives comme négatives). (3) Leur demander de me raconter un souvenir d'école "chouette," "cool," "joyeux" ou encore "rigolo," choisissant un mot appartenant à ce lexique et précédemment utilisé par l'enfant dans l'entretien.

Cette dernière question visait à contrebalancer deux difficultés de l'enquête. Premièrement le fait que plusieurs enfants m'ont demandé si j'avais personnellement aimé aller à l'école — question à laquelle j'ai toujours répondu par la négative. Deuxièmement le fait que les enfants ont été interrogés dans un contexte que je leur ai proposé de modifier : je me suis toujours présentée comme une étudiante, ayant besoin d'apprendre des choses sur l'école et comment bien faire l'école pour eux. On peut dès lors supposer que leurs récits et anecdotes sont également des argumentaires, qu'ils mobilisent des formes de discours susceptibles de me convaincre, en recourant par exemple à des discours à forte charge émotionnelle. Il est donc peu surprenant de constater des différences avec une enquête<sup>30</sup> par questionnaire auto-administré sur leur bien-être à l'école. Cela ne diminue en rien l'intérêt de recueillir et examiner ces discours pour comprendre les expériences scolaires, mais il faut souligner qu'il ne s'agit pas ici d'établir un constat clinique. Il est plutôt question d'examiner la construction de sens par les élèves, ses aspects sociaux et relationnels, ainsi que comment elle s'inscrit dans le contexte scolaire actuel. Pour cela, j'analyse en contrepoint mes entretiens avec le personnel de l'IJA ainsi que les discours de parents et d'enseignants ordinaires recoltés tout au long de l'enquête de terrain. Ces entretiens sont semi-directifs et consistent principalement à recueillir leurs descriptions de leurs pratiques et comprendre leur carrière professionnelle, au sens interactionniste du terme. Cela me permet notamment de comprendre comment les enfants ré-interprètent la multitude de discours tenus sur leur éducation ainsi que les conditions menant le personnel éducatif à former des définitions du bien-être à l'école.

<sup>30</sup> Sentenac, Pacoricona, and Godeau, "How Do Disabled Students Perceive High School?"

### Ce que les élèves disent de l'école

#### ENCODAGE

La première étape de l'analyse thématique, l'encodage, suggère des spécificités quantitatives aux discours des enfants étudiés sur l'école. Ainsi, la cour de récréation, largement plébiscitée dans les

études sur l'école primaire<sup>31</sup>, n'est quasiment jamais évoquée par les enfants participant à mon étude. Les contenus scolaires en revanche sont abondamment discutés, y compris par des élèves considérés comme peu intéressés ou en difficulté scolaire par leurs enseignantes. Les adaptations de documents et les technologies sont un thème important, ainsi que les relations avec les enseignantes spécialisées. Je constate en revanche relativement peu d'évocation des "aides humaines", AVS ou AESH. Cela alors que les observations en classe suggèrent qu'il peut y avoir une forte complicité entre les élèves et leurs assistantes (démontrée par leurs échanges hors activités pédagogiques par exemple). Ce contraste pouvant s'expliquer par le fait que les assistantes ont une relation moins durable : elles sont beaucoup plus susceptibles d'être remplacées d'une année à l'autre. Enfin, les relations avec les autres élèves sont évoquées dans des récits sur les activités pédagogiques et les technologies et documents adaptés.

<sup>31</sup> Delalande, "La cour d'école: un lieu commun remarquable"; Sanders, "Subject Child: The Everyday Experiences of a Group of Small Town Aotearoa/New Zealand Children."

**THÈMES DÉVELOPPÉS** Je propose dans la thèse d'analyser les récits sur les dimensions émotionnelles des expériences scolaires à travers trois thèmes : la fatigue, la bataille et la souffrance. Quelques éléments descriptifs : la souffrance n'est évoquée directement que par peu d'élèves (5 entretiens), et en majorité des élèves provenant de familles éloignées de l'univers scolaire, rencontrant souvent d'autres difficultés (par exemple violences intra-familiales), et suivant une scolarisation (totale ou partielle) à l'IJA, l'organisation étudiée. La description de la scolarisation comme une bataille ou comme source de fatigue sont en revanche beaucoup plus partagées, et se recouvrent partiellement (21 et 18 entretiens respectivement). Notons que l'analyse de ces récits peut être complexe : comment classifier, par exemple, un récit suggérant la présence de Détraqueurs, des créatures magiques absorbent la joie de vivre et engourdissant l'esprit dans la saga Harry Potter, à l'école ? En contexte (voir Chapitre 10), cela ne semble pas évoquer une souffrance mais plutôt une impression générale que l'expérience scolaire n'est pas satisfaisante mais sans savoir précisément décrire ce qui devrait être différent.

J'explore également dans la présentation de ces thèmes l'intersection du handicap avec les autres caractéristiques socio-démographiques et d'identification, ou autrement dit, les variabilités dans les socialisations des enfants. Par exemple, l'identité de genre modifie le rapport à la déficience visuelle : la cécité en particulier fait obstacle les activités considérées, dans les cours de récréation observées, comme masculines (par exemple jouer au foot) plus que celles considérées comme féminines (par exemple les discussions et jeux de rôles). Cela

se manifeste aussi dans les manières de décrire l'expérience scolaire : dans le thème de l'école comme une bataille, les filles évoquent avant tout des attitudes de défense et les garçons d'agression.

#### TENSIONS AUTOUR DE L'IDENTIFICATION AU HANDICAP

Sur le sujet de l'identification, la thèse met en avant un résultat particulièrement intéressant au regard de la littérature existante. Les précédentes recherches sur ce sujet, généralement réalisées par entretiens, les enfants handicapés soulignent se sentir comme les autres<sup>32</sup>. Les entretiens, ainsi que le vocabulaire utilisé par les enfants sur mon terrain, semblent au premier abord confirmer ce phénomène : le handicap, le sien et celui des autres, est décrit au travers des aides techniques utilisées, extérieures aux personnes. Mais croiser les entretiens aux observations de terrain suggèrent que cette non-différence revendiquée s'effectue également par l'établissement d'une hiérarchie des handicaps. Individuellement, les enfants indiquent être comme les autres mais attribuent le handicap à d'autres — sur mon terrain, aux enfants à la réussite scolaire moindre, ou à ceux nécessitant des aides humaines et techniques importantes. En d'autres termes, le handicap est associé à l'éloignement de la norme scolaire.

<sup>32</sup> E.g., Connors and Stalker, "Children's Experiences of Disability – Pointers to a Social Model of Childhood Disability".

#### DU BIEN-ÊTRE À LA NORME SCOLAIRE

En mettant la focale sur les expériences scolaires, ma recherche s'inscrivait dans une littérature valorisant la diversité des expériences de l'enfance, plutôt que dans un objectif de mesure clinique du bien-être pour la réussite scolaire<sup>33</sup>. Ceci s'inscrit dans une sociologie de l'enfance qui défend des cultures et des processus de construction du sens chez les enfants distincts de chez les adultes. Cependant, dès les premiers entretiens et observations, il m'est apparu nécessaire d'inclure dans l'analyse la perception que les enfants ont des buts de l'école, et comment celle-ci informe leurs expériences — telles qu'accessibles au travers de leurs récits et des discours entre pairs. Les discours sur l'école incluent de nombreuses références aux droits accordés par la loi de 2005 et sur l'école en tant que seule voie d'accès à l'autonomie par le travail de la vie adulte. Les difficultés scolaires sont donc, dès l'école primaire, associées à une vie adulte indésirable, chez ses parents, sans compagnonnage, etc. Il leur faut se conformer aux attentes scolaires et à une entreprise de normalisation : les enfants utilisent couramment une comparaison avec le dressage des animaux, y compris des animaux de cirque. On comprend alors mieux les discours sur la fatigue ou la bataille, qui outre leur ancrage dans des rythmes scolaires et de rééducation très intenses, permettent

<sup>33</sup> Comme le font par exemple les études sur le climat et la victimisation dans le cadre scolaire. Sentenac, Pacoricon, and Godeau, "How Do Disabled Students Perceive High School?"

à la fois de montrer la volonté de se conformer à la norme scolaire et la nécessité de l'adaptation.

### Le point de vue du personnel enseignant et médico-social

Étudier les récits enfantins est une manière d'étudier l'impact des discours parentaux et des discours du personnel enseignant et médico-social. Dans les discours des professionnels de l'éducation impliqués dans l'accompagnement des enfants déficients visuels, les conduites désirables à l'école ordinaire sont l'effort et la résistance à un environnement scolaire considéré excluant. Il faut alors être attentif au bien-être (formule utilisée par les éducateurs) ou à la résilience (formule plutôt utilisée par les enseignantes spécialisées) des élèves, qui sont présentés comme une condition de ces conduites — donc de la réussite scolaire. En pratique, il s'agit d'encourager verbalement les enfants à être "forts," à ne "pas se laisser abattre," leur rappeler l'importance de la réussite scolaire pour avoir "un bon travail et une bonne vie" à l'âge adulte.

La réussite scolaire précoce et son impact sur la vie adulte revêt ici une signification particulière : il est possible très tôt dans la scolarité, c'est à dire dès l'école primaire, d'orienter un enfant vers l'éducation spécialisée ou professionnelle. Cela est conceptualisé comme une bifurcation vers un nombre limité de possibilités à l'âge adulte : professions adaptées telles qu'accordage de piano, cannage-paillage ou réception, parfois en milieu de travail protégé ; une vie sans travail avec des subventions publiques (AAH et PCH) mais une intégration à la communauté perçue comme limitée ; et dans certains cas une vie en institutions fermées qu'il s'agit de chercher à éviter. En d'autres termes, la scolarisation est considérée comme particulièrement cruciale pour ce groupe d'enfants, et il n'est pas rare d'entendre ces vies futures utilisées comme repoussoir, un argument pour illustrer dès l'école primaire l'importance de l'école.

Je souligne dans la thèse que ces bifurcations en dehors ou en marge de l'école ordinaire sont justifiées soit par un handicap considéré comme trop important pour que l'enfant bénéficie de la scolarisation sur le plan académique, soit par un manque de **résilience**. Ce dernier est souvent attribué au manque de suivi par la famille des recommandations éducatives (ou le manque de cultivation concertée, pour reprendre le terme de Lareau<sup>34</sup>), qui est lui-même souvent associé à un contexte socio-économique défavorable. Ainsi dans le dispositif de classe de primaire spécialisée à temps partiel dans laquelle j'ai mené une importante partie de mon travail de design, les élèves viennent depuis plusieurs années majoritairement de familles des classes populaires (ouvriers, employés de service à la personne). En d'autres termes, il est difficile de séparer la recherche sur l'expérience du handicap à l'école de celle sur les inégalités sociales, car les deux sont souvent saisis par l'intersection de leurs effets. Dans les discours

<sup>34</sup> Lareau, *Unequal Childhoods: Class, Race, and Family Life*.

des enfants, désigner des élèves en situation d'échec scolaire ou issus de milieux plus populaires comme étant des enfants en situation de handicap est une des manières de se distinguer de la situation de handicap.

### **Au delà de la psychologisation : un modèle écologique pour la résilience**

Le bien-être et la résilience sont toujours, dans les discours du personnel éducatif spécialisé, une caractéristique personnelle, qui peut être améliorée par des discours d'encouragements, le rappel des gains futurs de l'investissement dans la scolarité ou une prise en charge par la psychologue travaillant à l'IJA. La thèse montre en revanche des différences notables dans les discours des différents groupes professionnels sur ce sujet. S'il s'agit d'une préoccupation des enseignantes, elles estiment que cela ne doit pas conduire à des adaptations de la quantité de travail scolaire. Les éducatrices en revanche décrivent en revanche parfois devoir alerter les enseignantes, insister pour que la quantité de travail scolaire soit relâchée temporairement, être des "garde-fous." Les deux groupes développent des approches différentes du bien-être et du développement de la résilience, présentées dans les entretiens comme complémentaires mais aussi en tension.

Au delà des discours tenus aux enfants, de la prise en charge psychologique et de la modulation de la quantité de travail scolaire, on trouve toute une panoplie d'autres actions plus ou moins explicitement associées au bien-être et au développement de la résilience des enfants. Cela inclut la psychomotricité, les sorties organisées ou encore les activités artistiques organisées au centre. Ces deux approches sont en tension : si la première vise à une justice sociale par l'égalité d'opportunités professionnelles (et, dans les discours, économiques), la seconde requiert la reconnaissance sociale de la différence, un sujet beaucoup plus difficile car il viendrait s'opposer à la stricte égalité républicaine. Cela s'exprime de différentes manières, et ce dans tous les groupes professionnels étudiés : certaines parlent de l'équilibre à trouver entre "la culture des voyants et celle des non-voyants", d'autres évoquent le fait de permettre aux enfants d'être fiers de leur handicap tout en pouvant recevoir de l'aide face aux obstacles qu'il crée, d'autres encore évoquent leurs doutes face aux évaluations existantes des capacités scolaires des enfants. Paradoxalement, ces interrogations sont au coeur des préoccupations sur l'école inclusive, mais semblent avant tout être débattues dans les structures d'éducation spécialisée (des Ulis aux instituts sensoriels donc), ou dans les établissements scolaires publics disposant d'un lieu ressource spécifique.



Dans la thèse (chapitres 10 et 11), je propose d'examiner ces actions en utilisant le modèle écologique de la résilience d'Ungar<sup>35</sup>, que je situe dans les théories interactionnistes du handicap (notamment celle du stigma) et les approches critiques de la résilience dans les études sur le handicap. Ungar propose de déplacer la focale, de la résilience comme une caractéristique de l'individu qu'il s'agit de développer, vers la résilience comme capacité de l'individu et de son entourage à négocier les ressources nécessaires à son bien-être et à une situation désirable dans un contexte donné. Favoriser le bien-être peut alors consister à modifier la définition des situations désirables en fonction des besoins des individus : par exemple, si l'accès à l'emploi est présenté comme très désirable par les enfants, il s'agit de proposer des formes adaptées de travail à rémunération juste. Il peut également s'agir d'adapter les ressources proposées pour atteindre la situation désirée : l'inclusion scolaire étant au centre des politiques éducatives, ce modèle articule les interventions centrées sur les capacités de l'individu à celles menées à une échelle plus large, qui pourrait par exemple être le développement de la culture non-visuelle à l'école.

L'adoption de ce modèle comme grille d'analyse des entretiens et observations a un double avantage. D'une part, il permet plus facilement la comparaison avec d'autres travaux de ce champ, menés dans d'autres contextes. D'autre part, il offre une série d'entrées possibles aux designers s'intéressant à la question de la résilience et du bien-être scolaire.

<sup>35</sup> Ungar, "The Social Ecology of Resilience: Addressing Contextual and Cultural Ambiguity of a Nascent Construct".

## Implications pour le design

Pour ma part, suivant d'une part l'analyse des valeurs résumée précédemment et mon intérêt pour les discours sur la culture non-visuelle, je propose dans la thèse d'explorer les possibilités d'intervention **par le design de technologies éducatives**. Suivant le modèle proposé par Ungar, je m'intéresse aux ressources matérielles mises à disposition, les technologies éducatives, mais comme des outils pour favoriser le développement d'une autre ressource, l'attachement à une culture et une communauté non-visuelle. En effet, je note que si l'une des valeurs mises en avant par les enfants est celle de l'importance d'être écoutés, ils l'expriment principalement au niveau individuel, là où la plupart des avancées pour les droits des aveugles ont été réalisées par les associations d'aveugles, précurseurs dans les associations de personnes handicapées en France<sup>36</sup>. Comment, dès lors, s'attacher à permettre des formes d'identifications positives au fait d'être malvoyant ou aveugle et aux expériences notamment phénoménologiques que cela recouvre<sup>37</sup> ?

### A.1.6 *Approche par le design : des technologies pour une approche non-visuelle de la géographie ?*

Dans la quatrième partie de la thèse, je développe deux perspectives de réponse à cette question. D'une part je m'attache à démontrer l'existence d'une norme visuelle du travail scolaire, et ce y compris celles utilisées dans l'éducation des enfants malvoyants. Je montre également que l'intérêt des modalités non-visuelles dans l'apprentissage est largement invisibilisé, et ce notamment car les parents les plus favorisés sont largement plus susceptibles d'avoir incorporé les techniques des spécialistes au quotidien, et donc de favoriser la manipulation d'images mentales ou d'images tactiles, elles-mêmes largement favorisées à l'école. D'autre part, j'explore comment utiliser les modalités non-visuelles dans le contexte scolaire, dans le cadre de la géographie, et propose deux prototypes conçus avec une enseignante et ses élèves, pour étayer et encourager cette approche. La norme visuelle du travail scolaire Une première étape dans cette argumentation est de démontrer l'existence d'une norme visuelle du travail scolaire. Pour cela je m'appuie sur trois approches complémentaires : une enquête sur les modalités de transcription des contenus scolaires, dans un contexte d'apparition de nouveaux outils élargissant les possibilités et compétences demandées aux transcriptrices spécialisées ; une discussion de la littérature sur le tournant sensoriel et corporel, dans les sciences humaines et sociales et dans l'IHM ; et finalement, une enquête sur les modalités non-visuelles

<sup>36</sup> Elles se sont notamment développées autour de l'Institut National des Jeunes Aveugles, et se sont renforcées au début du XXe siècle, pendant et après la seconde guerre mondiale. Ainsi, l'Union des Aveugles de Guerre utilisait la devise 'Pour les aveugles par les aveugles' dès 1919, tandis que l'Union des Aveugles Civils l'a adoptée au début des années 1930. Celle-ci est très proche de la devise de l'UPIAS depuis les années 1970, "nothing about us without us."

<sup>37</sup> Kleege, aveugle légale donc avec des perceptions visuelles restreintes, parle ainsi du processus d'écriture réflexive qui 'l'a rendue aveugle.' Celui-ci lui a permis de s'approprier une identité, être aveugle, plutôt que de référer à sa 'déficience visuelle.' Dans son cas, s'approprier cette identité a nécessité d'une part l'examen critique des représentations des aveugles et le processus d'appropriation de nouvelles manières de faire (comme le braille) plutôt que des techniques de compensation basées sur la vision (comme l'agrandissement de caractères). Kleege, *Sight unseen*.

déjà utilisées dans l'enseignement de la géographie, et leurs perceptions par élèves et enseignantes. Ces trois approches mettent en relief les nombreux obstacles au développement d'une didactique et d'une pédagogie non-ancrée dans les représentations visuelles, même dans les disciplines utilisant des méthodes non-visuelles pour la production de connaissances.

### **Transcription-traduction des contenus scolaires**

Étudier les enseignements prodigués aux enfants déficients visuels rend visible, par contraste, la prégnance des supports visuels à l'école. Je constate par exemple lors d'observations en classe 'normales,' 'inclusives,' qu'une double-page de manuel scolaire de primaire comporte rien moins que huit images différentes, d'importance variable pour la compréhension. Les illustrations servent à illustrer le contenu, mais aussi à rythmer la page. Transcrire ce matériel pour un enfant malvoyant ou aveugle relève alors plus de la **traduction** que de la transposition. Il faut déterminer ce que les contenus visuels apportent à l'objectif d'apprentissage, lequel doit être transformé en image tactile, lequel devrait au contraire devenir une description textuelle et quels sont les éléments saillants, et cohérents pour une personne malvoyante ou aveugle, à conserver. La dimension ludique des illustrations des manuels est donc souvent minimisée, dans le cas des agrandissements de textes, voire disparaît complètement, lors du passage en braille. Notons cependant qu'avec le passage aux manuels électroniques permettant désormais aux élèves du secondaire d'agrandir le contenu à leur convenance, ce travail de transcription-traduction s'efface au moins partiellement au niveau de la production de document.

Il reste cependant présent au niveau des techniques enseignées pour l'approche des documents visuels, à la fois pour les élèves malvoyants et aveugles. La découverte d'une image est plus méthodique, prend plus de temps que la lecture d'un texte. Ce que j'ai constaté dans les entretiens avec les personnels supports, l'équipe de transcription et les enseignants spécialisés pendant la thèse, c'est que réduire le nombre de transcriptions à réaliser manuellement a deux effets parfois contradictoires. D'une part, cela leur donne plus de temps pour explorer comment utiliser les modalités non-visuelles dans l'apprentissage. De l'autre, elles se heurtent à plus de difficultés à justifier leurs avantages, puisque cette possibilité d'agrandissement peut être considérée comme suffisante pour beaucoup d'élèves dans un contexte de restriction des ressources financières de l'organisation et d'austérité de l'état.

Un autre obstacle au développement d'approches didactiques et pédagogiques non-visuelles est le manque de formation et de ressources dans ce domaine. Une enseignante spécialisée note ainsi qu'on lui a appris à faire des images tactiles, mais pas à adapter l'enseignement pour les élèves qui ne sont pas encore à même de comprendre un concept sur la base d'un schéma tactile. Une difficulté que les thérapeutes (ergothérapeutes, psychomotriciennes, instructrices de locomotion. . .) disent également rencontrer, bien que le degré auquel elles ressentent ce manque varie, et pour certaines sont activement impliquées dans le développement de ressources professionnelles basées sur leurs observations.

La norme visuelle dans l'enseignement et dans les sciences Ces éléments empiriques viennent appuyer les recherches menées sur ce que l'on peut nommer le tournant sensoriel, ou tournant corporel. Le tournant sensoriel fait référence à l'attention renouvelée pour les expériences sensorielles et phénoménologiques dans divers champs des sciences humaines et sociales, notamment dans l'éducation<sup>38</sup>. Mais à l'intersection des sciences de l'éducation et de la recherche en IHM, c'est le mot incorporé (*'embodied'*) qui est largement utilisé<sup>39</sup>. Un tournant largement ancré dans les théories constructivistes<sup>40</sup>, qui semblent pouvoir être plus facilement utilisées en classe notamment du fait des innovations dans les interactions tangibles<sup>41</sup>.

Les recherches se réclamant de ces courants sont néanmoins très variées. Ainsi, McBride et Nolan<sup>42</sup> contestent la "*prééminence du langage sur les savoirs incorporés*" qui leur semblent être "*l'un des traits déterminants du curriculum caché*"<sup>43</sup>. La notion de **curriculum caché** renvoie à plusieurs explications de la reproduction des inégalités sociales dans les établissements scolaires : l'école ne transmet pas seulement des contenus, mais également des valeurs et des conduites, des modèles des traits qu'arborent les bons et les mauvais élèves. Selon leur origine sociale, les élèves sont plus ou moins susceptibles d'avoir acquis ces valeurs et conduites dans leurs familles. Non d'ailleurs que les approches basées sur les expériences corporelles échappent à ces problématiques : Malinverni *et al.* démontrent ainsi que les élèves sont loin d'être égaux dans leur démarche pour comprendre ce type de dispositif — on y reviendra<sup>44</sup>. Didactique et pédagogie non-visuelles en géographie La géographie, et notamment en géographie humaine<sup>45</sup>, se révèle un domaine particulièrement fructueux pour explorer pleinement les implications du tournant sensoriel et corporel. S'il s'agit d'une discipline très visuelle, où cartes, schémas et représentations de données ont la part belle, on trouve aussi un intérêt ancien pour l'expérience corporelle dans l'apprentissage de la géographie<sup>46</sup>, ainsi qu'un intérêt contemporain pour la production

<sup>38</sup> Classen, "Worlds of Sense: Exploring the Senses in History and across Cultures".

<sup>39</sup> E.g., Malinverni, Maya, et al., "The World-as-Support: Embodied Exploration, Understanding and Meaning-Making of the Augmented World"; S. Price, Carey Jewitt, and Sakr, "Embodied experiences of place: a study of history learning with mobile technologies".

<sup>40</sup> Suthers, "Technology Affordances for Intersubjective Meaning Making: A Research Agenda for CSCL".

<sup>41</sup> S. Price, Sheridan, et al., "Towards a framework for investigating tangible environments for learning".

<sup>42</sup> McBride and Nolan Jason, "Situating Olfactory Literacies: An Intersensory Pedagogy by Design".

<sup>43</sup> La traduction est mienne. Citation originale: "*the pre-eminence of language over the physical knowledge of the body is among the most definitive expressions of the hidden curriculum.*"

<sup>44</sup> Malinverni and Pares, "Learning from Failures in Designing and Evaluating Full-Body Interaction Learning Environments".

<sup>45</sup> Qui, schématiquement, s'intéresse à l'aspect spatial des activités humaines, plutôt qu'à la géographie physique comme la topographie.

<sup>46</sup> Par exemple dans la conception de maquettes et de musées par les géographes anarchistes à la fin du XIXe siècle. Ferretti, "Situating Knowledge and Visual Education: Patrick Geddes and Reclus's Geography (1886–1932)".

de savoirs géographiques par d'autres sens que la vision<sup>47</sup>. Enfin, au moins dans l'enseignement supérieur du moins, la sortie scolaire comme travail de terrain est une méthode éprouvée<sup>48</sup>.

Dans les cycles primaires des pays européens (avec des spécificités nationales), les programmes encouragent l'enseignement de la géographie à des échelles emboîtées. Il peut s'agir par exemple de d'abord étudier la classe, puis le quartier, puis la place du quartier dans la ville et celle de la ville dans la région et dans le pays, ou au contraire de commencer par le globe, et d'y situer le pays, les régions, les principales villes et la relation des enfants à cet environnement. Ils encouragent également de faire comprendre les phénomènes spatiaux par la comparaison de types de lieux différents. Dans ce contexte, s'appuyer sur les représentations spatiales existantes des enfants ainsi que sur les sorties scolaires peut s'avérer très fructueux<sup>49</sup>. L'usage de la réalité virtuelle ayant d'ailleurs été proposé pour multiplier les sorties possibles à bas coût (au détriment cependant... des sens non-visuels).

Mon intérêt pour les approches non-visuelles de la géographie discutées ci-dessus trouve son origine dans, et m'a mené à développer, les observations de l'enseignement de la géographie en classe spécialisée (à effectifs réduits). Cette partie de mon enquête de terrain s'est concentrée sur les voyages de classe et des sorties scolaires en géographie, mais aussi sur d'autres pratiques, dans la classe, basées sur l'expérience kinétique, le goût, l'odeur et le toucher (Chapitre 13). Je suggère dans la thèse que le développement de ces approches multi-sensorielles se heurte à plusieurs obstacles : le manque de ressources sur le sujet et le manque de ressources pour déployer ces approches évoqué plus haut ; mais également le fait que ce travail multi-sensoriel est décrit comme nécessaire pour les élèves en difficulté ou en fragilité scolaire, assimilés aux élèves dont les parents ne font pas ce travail d'association entre l'expérience phénoménologique et les concepts spatiaux au quotidien ou aux élèves vus comme peu **résilients**. Des élèves qui s'avèrent principalement venir de milieux socio-économiques défavorisés. Si je pointe quelques explications possibles pour ce constat, notamment la distance des familles aux services médico-sociaux et à l'école, je n'ai pas enquêté sur cet aspect.

Le fait d'associer ce travail multi-sensoriel aux élèves en difficulté à l'école vient renforcer en revanche l'argument que l'école contemporaine est basée sur une norme visuelle. Je montre à travers l'analyse d'entretiens avec thérapeutes et enseignantes que l'apprentissage des sens, par les sens, est décrit comme une **base** relevant du domaine de la famille, ou dans le cas de handicaps sensoriels, des thérapeutes et des éducatrices. Il est utilisé dans le cadre scolaire

<sup>47</sup> E.g., Thibaud, "A sonic paradigm of urban ambiances".

<sup>48</sup> Krahenbuhl, "Collaborative Field Trips: An Opportunity to Connect Practice With Pedagogy".

<sup>49</sup> T. Price, "War! Metaphors Are Damaging Our Schools".

avant tout parce que cette base est considérée manquante, entravant l'acquisition des savoirs scolaires, plutôt que comme une opportunité pédagogique inclusive<sup>50</sup>.

Ne voulant pas présumer de l'impact de cette norme sur les élèves, je me suis intéressée à leurs discours sur, et à leurs conduites durant, ces activités. Je fais le constat dans la thèse non pas d'une opposition famille/école mais d'une opposition jeu/apprentissage-travail. En particulier, les élèves les plus proches des normes de performance scolaire insistent sur le fait que les sorties ne sont pas un travail scolaire, que ce n'est pas là qu'on apprend, et ce alors qu'elles en revêtent les apparences (elles sont structurées autour de pauses et de courtes présentations orales par l'enseignante). Les élèves qui en sont plus éloignés reprennent plus facilement les discours des enseignantes ("*On a appris sur les olives !*"), mais recherchent et évoquent surtout les relations interpersonnelles créées pendant les sorties. De fait, la littérature sur les sorties scolaires en général prouvent rarement un impact direct sur les apprentissages scolaires, mais pointent leur rôle dans la motivation à apprendre ou sur le climat scolaire, c'est à dire les relations interpersonnelles à l'école<sup>51</sup>.

Ceci converge avec l'approche écologique de la résilience<sup>52</sup>, proposée plus haut comme manière de dépasser les approches individualisées contre les discriminations rencontrées à l'école. Plutôt que l'angle individuel du projet de recherche initial, j'ai adopté l'angle du développement d'une communauté et culture non-visuelle à l'école, puis enquêté sur les différents obstacles à cette approche, notamment le fait que la difficulté à s'adapter à la norme visuelle à l'école peut facilement être assimilée aux familles plus défavorisées au niveau socio-professionnel. À travers cette discussion, j'espère avoir montré qu'elle pouvait avoir des impacts beaucoup plus larges sur les relations entre élèves et leurs perceptions du travail scolaire.

### Prototypes et scénarios pédagogiques proposés

Les deux derniers chapitres, Chapitres 14 et 15, décrivent chacun un prototype développé durant la thèse, tous deux testant cette hypothèse qu'encourager le développement d'une culture non-visuelle à l'école la rendrait plus inclusive. Elle ouvre de nouvelles questions de recherche : comment enseigner la géographie de manière non-visuelle ? Comment l'utilisation de matériels non-visuels impacte la compréhension ou l'approche des concepts géographiques par les élèves de primaire<sup>53</sup> ?

<sup>50</sup> Notons qu'une recherche doctorale a été conduite sur les sorties scolaires multi-sensorielles en géographie. Briand, *Theses.Fr – Médéric Briand, La Géographie Scolaire Au Prisme Des Sorties : Pour Une Approche Sensible à l'école Élémentaire.*

<sup>51</sup> Behrendt and T. Franklin, "A Review of Research on School Field Trips and Their Value in Education."

<sup>52</sup> Ungar, "Resilience and culture: The diversity of protective processes and positive adaptation".

<sup>53</sup> Les élèves avec qui ces expérimentations ont été menés sont dans un groupe à niveaux mixtes. Ils sont considérés en cycle élémentaire ou moyen.

## UN BRACELET POUR LA GÉOGRAPHIE PAR LES SORTIES

Le premier prototype présenté est un bracelet permettant de faire des enregistrements audios durant les sorties scolaires. Cette attention au son vient de trois hypothèses de travail. Il s'agit d'une modalité déjà largement utilisée par les élèves, soit dans le cadre thérapeutique, soit dans le cadre des loisirs. L'usage de l'ouïe semble particulièrement judicieux pour l'étude de phénomènes spatiaux<sup>54</sup>. Enfin c'est une modalité facile à utiliser sur une carte interactive (présentée ci-dessous) qui, hypothétiquement, permettrait d'établir des liens entre la sortie et les ressources utilisées en classe.

<sup>54</sup> Thibaud, "A sonic paradigm of urban ambiances".

Dans la thèse je m'attache à vérifier ces hypothèses empiriquement. J'ai enquêté sur les types de sons utiles à enregistrer pendant les sorties avec ces prototypes. Je propose un tableau récapitulatif des types de sons enregistrés en sortie et de leurs utilisations par les élèves. Cela permet de mettre en relief les manières dont les élèves créent des indices sonores par leur interaction avec l'environnement avec leur canne, ou encore pour les élèves de montrer un intérêt pour un sujet particulier, permettant à l'enseignante de l'identifier et le développer. J'ai également enquêté sur les discours tenus par les élèves sur les sorties, et montré que leur association renforcée avec les cours en classe permettent de rendre les sorties plus légitimes, en tant qu'activité scolaire, à leurs yeux. Cette expérimentation est un premier pas vers la possibilité d'une littératie auditive à l'école.

## UNE CARTE MULTISENSORIELLE

En partant du prototype de carte audio-tactile développé par l'équipe de recherche de l'IRIT pour le projet Accessimap<sup>55</sup>, nous avons exploré avec une enseignante spécialisée des scénarios pédagogiques dans lesquels elle pourrait être utilisée avec du matériel olfactif et gustatif. L'utilisation de ce type de matériel n'avait pas encore été observé ou testé de manière systématique. Dans les deux sessions d'évaluation, nous avons utilisé deux approches. La première s'est intéressée à l'étude de la carte, avec le placement d'éléments olfactifs sur la carte elle-même, dans des objets permettant de déclencher les descriptions sonores des points d'intérêts. Durant la seconde session, nous nous sommes plutôt concentrées sur la discussion de concepts géographiques appuyés par la carte. Les éléments à sentir et à goûter circulaient dans la classe pendant l'exploration et la discussion de la carte interactive.

<sup>55</sup> Décrite dans: Emeline Brulé, Bailly, and Gentes, "Identifier Les Besoins Des Enfants En Situation de Déficience Visuelle : État de l'art et Étude de Terrain".

Dans la thèse, je discute des modalités pratiques pour ce type de design dans une classe, comme l'utilisation de produits du quotidien, plutôt que d'un diffuseur d'odeurs, ce pour élargir la gamme des

odeurs possibles. J'explore également comment ce type de matériel peut devenir une ressource en géographie, dont il est **interprété en conjonction avec d'autres représentations**. En effet, si à première vue cette approche favorise l'engagement<sup>56</sup>, une deuxième expérimentation a permis d'étudier comment les enfants se servent de ce matériel pour discuter de leurs expériences (sensorielles) quotidiennes en rapport avec les concepts de géographie, comme l'urbanisme, là où ces concepts restent habituellement abstraits. Cela peut s'expliquer par le fait que les goûts et expériences sensorielles restent largement socialement et spatialement déterminés<sup>57</sup> et sont donc une manière d'évoquer des situations sociales et de les discuter en classe dans la perspective de justice sociale et de résilience des enseignantes interrogées (voir Chapitres 2 et 11).

<sup>56</sup> Emeline Brulé, Bailly, A. M. Brock, et al., "MapSense: Multi-Sensory Interactive Maps for Children Living with Visual Impairments".

<sup>57</sup> Bartos, "Children Sensing Place".

### A.1.7 Discussion et conclusion

Enfin, dans la discussion et conclusion de la thèse, je rappelle d'abord l'intérêt d'interpréter le rapport à l'institution scolaire des enfants handicapés avec la littérature sur la reproduction des inégalités sociales. De Boudon<sup>58</sup>, je retiens les difficultés causées par la sortie précoce du système scolaire, un risque plus important pour les enfants en situation de handicap. De Dubet<sup>59</sup>, je retiens le fait que là où l'importance de l'école pour la socialisation a décliné pour les enfants en général, elle est toujours le principal mécanisme de socialisation des enfants en situation de handicap. Comme leur place à l'école est peu légitime et précaire, mais que l'école tient un rôle prépondérant dans leurs vies, il est peu surprenant que les expériences scolaires soient principalement décrites comme douloureuses.

<sup>58</sup> Boudon, *L'inégalité Des Chances: La Mobilité Sociale Dans Les Sociétés Industrielles*.

<sup>59</sup> Dubet, *Faits d'école*.

Au regard de mon travail sur les technologies éducatives inclusives, j'utilise la discussion pour souligner à nouveau la possibilité, et la désirabilité, de ne pas se contenter d'une approche individualiste des technologies à l'école, qu'il s'agisse de technologies d'assistance ou non. Je continue à plaider, au contraire, pour la prise en compte du contexte de la classe et du groupe. J'attire également l'intérêt d'une approche du design émancipatrice et attentive aux conflits de valeurs, permettant aux élèves et aux enseignantes de formuler les problèmes créés certaines normes scolaires et d'y désobéir, d'abord à l'échelle de leur classe, et potentiellement à un niveau plus large par la production de ressources pédagogiques partageables commencée durant la thèse.



## A.2 Detail of the Bibliographic Research

The bibliographic research on the sociology of disabled childhoods in France was conducted on two French research portals: the CNRS's (biblioshs.inist.fr) and cairn (cairn.info), with various keywords ("special education (éducation spécialisée);" "disability (handicap)" and "education (éducation)" or "school (école);" "inclusive schooling (école inclusive);" "assistive technologies (technologies d'assistance)"; "children (enfants)"; "teenagers (adolescents)"; "France;" and their combinations. It highlighted the following publications as sources for French-written social sciences on disability:

1. *Alter*, a French or English written European research journal on disability.  
<https://www.journals.elsevier.com/alter-european-journal-of-disability-research-journal-europeen-de-recherche-sur-le-handicap>;
2. *La nouvelle revue de l'adaptation et de la scolarisation*, a French journal on special education.  
<http://www.inshea.fr/fr/content/la-nouvelle-revue>;
3. *Contraste - Enfance et handicap*, a French journal on disabled childhood.  
<https://www.editions-eres.com/collection/202/contraste-enfance-et-handicap>;
4. *Handicap : revue de Sciences humaines et sociales*, a French journal on disability, published from 1998 to 2005;
5. *Reliance : Revue des situations de handicap, de l'éducation et des sociétés*, published from 2005 to 2008.  
[www.cairn.info/revue-reliance.htm](http://www.cairn.info/revue-reliance.htm).

I then searched these journals for articles adopting an experience-near approach to the study of disable children. As discussed in Chapter 3, this research yielded few results.

### A.3 Table of All Participants

Note: There are many incidental participants, pupils or carers, I have observed that I do not report on this table. For instance, observations in school playgrounds necessarily involved many additional participants, for a short amount of time, who could not be individually identified.

ID	Role	Type of involvement
P1	Document maker specialist	Repeated interviews, longitudinal observations
P2	Document maker specialist	Early interview, longitudinal observations
P3	Document maker specialist	Longitudinal observations
P4	Orientation and mobility instructor	Early interview, early observations
P5	Orientation and mobility instructor	Early interview, involved in design probes
P6	Special education teacher	Repeated interviews, longitudinal observations, involved in design activities
P7	Special education teacher	Early observations
P8	Special education teacher	Early interview and observations
P9	Special education teacher	Longitudinal observations, involved in design probes
P10	Special education teacher (arts)	Repeated interviews, involved in design probes
P11	Special education teacher	Repeated interviews, longitudinal observations
P12	Special education teacher	Repeated interviews, longitudinal observations
P13	Occupational therapist	Longitudinal observations, involved in design probes
P14	Occupational therapist	Repeated interviews, longitudinal observations, involved in design probes
P15	Low vision therapist	Early interview
P16	Psychomotor therapist	Repeated interviews, longitudinal observations, involved in design probes
P17	Speech therapist	Early interview
P18	Psychiatrist	Mid-field-study interview
P19	AVS/AESH	Repeated interviews, longitudinal Observations
P20	Librarian	Repeated interviews, longitudinal observations, involved in design probes

Table A.1: Research participants: Part 1 of the carers interviewed or most involved in observations and the design process

ID	Role	Type of involvement
P21	Educator	Mid-field-study interview
P22	Educator	Repeated interviews, longitudinal observations
P23	Educator	Late interview, longitudinal observations
P24	Educator	Early interview
P25	Manager	Longitudinal observations
P26	Parent	Early interview
P27	Parent	Mid-field-study interview
P28	Parent	Late interview
P29	Special education teacher (National School for the Blind)	Mid-field-study
P30	General education teacher	Early observations
P31	General education teacher	Early observations
P32	General education teacher	Mid-field-study observations
P33	General education teacher	Late interview
P34	AVS/AESH	Mid-field-study interview
P35	AVS/AESH	Early observations
P36	AVS/AESH	Late observations
P37	IT team	Late interviews, longitudinal observations

Table A.2: Research participants: Part 2 of the carers interviewed or most involved in observations and the design process

ID	Gender	Disability	Schooling	SES group	Type of involvement
Ch1	Male	Blind	General education secondary school	Disadvantaged	Early interview, technology interview, longitudinal observations
Ch2	Female	Low-vision	General education primary school	Middle class	Early interview, technology interview and observations
Ch3	Female	Blind	General education primary school	Highly advantaged	Late interview, technology interview, late observations
Ch4	Male	Blind	General education high school	Advantaged	Late interview
Ch5	Male	Blind	General/special education secondary school	Advantaged	Longitudinal observations, technology interview, mid-field-study interview
Ch6	Female	Low-vision	General education secondary school	Highly advantaged	Technology interview, mid-field-study interview
Ch7	Male	Low vision	General education primary school	Advantaged	Mid-field-study interview
Ch8	Male	Low vision with additional impairments	General/special education primary school	Advantaged	Early interview, longitudinal observations, technology interview, involvement in both probe studies as C4
Ch9	Male	Low vision with additional impairments	General/special education primary school	Disadvantaged	Longitudinal observations, repeated interviews, technology interview
Ch10	Male	Low vision with additional impairments	General/special education secondary school	Disadvantaged	Longitudinal observations, mid-field-study interview, technology interview
Ch11	Male	Blind with additional impairments	Special classroom in a general education school	Disadvantaged	Repeated interviews, technology interview, longitudinal observations, involvement in both probe studies as C1
Ch12	Male	Low vision	General education primary school	Disadvantaged	Mid-field-study interview, technology interview
Ch13	Male	Blind	Special/General education primary school	Disadvantaged	Repeated interviews, technology interview, longitudinal observations, involvement in both probe studies as C2
Ch14	Male	Blind with other impairments	Special classroom in a general education school	Disadvantaged	Early interview, early observations, technology interview
Ch15	Female	Blind with additional impairments	General education high school	Highly advantaged	Early interview, technology interview
Ch16	Male	Blind	Special/General education primary school	Middle class	Mid-field-study interview, technology interview and observations
Ch17	Male	Low vision	General education secondary school	Middle class	Repeated interviews, technology interview
Ch18	Male	Low vision	Special/general education primary school	Middle class	Early interview, longitudinal observations, technology interview, involvement in both probe studies as C3
Ch20	Male	Blind	General education high school	Highly advantaged	Technology interview, repeated interviews, late observations

Table A.3: Research participants: part 1 of the children interviewed and most involved in observations

Ch21	Male	Low vision	Vocational education	Middle class	Late interview, technology interview
Ch22	Female	Low vision	General education primary school	Advantaged	Mid-field-study interview, technology interview
Ch23	Female	Low vision	General education secondary school	Middle class	Mid-field-study interview, technology interview
Ch24	Female	Low vision	General education primary school	Advantaged	Mid-field-study interview
Ch25	Male	Blind	General education primary school	Disadvantaged	Technology interview
Ch26	Male	Blind with additional impairments	Special classroom in a general education primary school	Disadvantaged	Repeated interviews, longitudinal observations, involvement in both probe studies as C5
Ch27	Female	Low vision	General education secondary school	Middle class	Mid-field-study interview, technology interview
Ch28	Female	Blind	General education primary school	Advantaged	Late observations, late interview
Ch29	Female	Low vision	General education high school	Advantaged	Technology interview, mid-field-study interview.
Ch30	Female	Low vision	General education secondary school	Middle-class	Technology interview, mid-field-study interview.
Ch31	Female	Blind with additional impairments	Special education secondary school	Middle class	Technology interview, mid-field-study interview.
Ch32	Male	Low vision	General education secondary school	Advantaged	Technology interview, late interview.
Ch33	Male	Blind	Pre-school	-	Late observations
Ch34	Male	Low vision	Pre-school	-	Late observations
Ch35	Female	Low vision	Pre-school	-	Late observations
Ch36	Male	Blind with additional impairments	Pre-school	-	Early observations
Ch37	Male	Blind with additional impairments	Special classroom in general education school	-	Early observations
Ch38	Female	Blind with additional impairments	Special classroom in general education school	-	Mid-field-study observations
Ch39	Male	Blind with additional impairments	Special classroom in general education school	-	Mid-field-study observations
Ch40	Male	Blind with additional impairments	Special classroom in general education school	-	Mid-field-study observations
Ch41'	Female	Blind with additional impairments	Special education primary school	-	Late observations

Table A.4: Research participants: part 2 of the children interviewed and most involved in observations

#### A.4 Timeline of Design Iterations

OCTOBER 2014. This was the beginning of my field-study. Caregivers demonstrated great interest in digital fabrication techniques. I accompanied them to the local Fablab and provided information on tools. During observations at the school, I observed the use of toys or scale models to help children manipulate spatial representations. It was often used in mobility and orientation therapy, to explain three dimensional spatial concepts, such as altitude or being on top/under something. A special education teacher described her pedagogy as inspired by theories on learning styles. She demonstrated it, taking the example of a kinesthetic approach i.e., she uses the feel of movement to explain a concept: to teach numbers, she used a different object, doing a different movement, a number of times (e.g. ten was represented by a toy car jumping ten times).

I also observed several activities related to the use of smell and taste in special education. For a lesson on world geography, the teacher offered pupils to try food typical of certain places. We also observed that many children refused to play to the Fragrance Loto game. This game consists in matching a scent enclosed in a box with its image. The reasons all the students gave to refuse to play it regarded its perceived low quality: "*fake*," "*artificial*," "*cheap*"... This is why I used actual food instead with MapSense.

JANUARY 2015. I designed and 3D printed a tactile globe to gather insights on the relevance of this technology and the potential uses of Do-It-Yourself 3D representations in the classroom. Its affordances triggered interesting behaviors: children would use it as a ball to play, they would share it, or throw it to one another, etc. They seemed to allow for ludic storytelling in the classroom. The teacher outlined it had a positive impact: It successfully triggered children's interest and contributed to their representations of space.

FEBRUARY 2015. An interactive map using a raised-line overlay<sup>60</sup>, was implemented in the special education center. It was subsequently adopted by several teachers and therapists<sup>61</sup>.

JUNE 2015. Brainstorming with carers and children on the interactive map's benefits and limitations enabled to identify a major additional need: providing a wider variety of cues and representations to support the pedagogy used with children living with multiple impair-

<sup>60</sup> Based on: A. M. Brock et al., "Interactivity Improves Usability of Geographic Maps for Visually Impaired People".

<sup>61</sup> Emeline Brulé, Bailly, and Gentes, "Identifier Les Besoins Des Enfants En Situation de Déficience Visuelle : État de l'art et Étude de Terrain".



Figure A.1: Probes designed in January 2015. Top left: a 3D printed tactile globe. Bottom left: a tablet with a laser cut overlay, creating an interactive map. Right: an audio-recorder app.

ments (e.g., deafblind, learning difficulties). It was not sufficient to bridge the gap between children's experiential knowledge (e.g. class trip) and a two-dimensional representations (e.g. map). During the discussion on the potential means to bridge that gap, carers insisted on the fact that the chosen technologies should be as cheap and easily customizable as the audio-tactile map. First occurrences in my notes of the notion of translation (Chapter 13).

AUGUST 2015. During pupils' summer holidays, I worked with the teacher for a week to identify the best way to answer these needs. Following the design insights gained during the field-study (e.g. on the use of figurative objects and of food), I started researching the literature in cognitive and learning sciences on multi-sensory cues. It suggests that using olfactory cues helps memory retrieval and triggers autobiographical memories, thus being consistent with the socio-constructivist approach to the geography curriculum deployed by the teacher. This is how they decided to use tangibles and olfactory and gustatory cues. They designed the lessons described in Emeline Brulé, Bailly, A. M. Brock, et al.<sup>62</sup> at this occasion. These design sessions also aimed at finding the rightful way to present tastable and smellable cues. To do so, I consulted a food designer, who suggested that some kind of tableware was appropriate for this. That way, food and liquid can easily be contained, and their consumption is similar to everyday practices.

<sup>62</sup> Emeline Brulé, Bailly, A. M. Brock, et al., "MapSense: Multi-Sensory Interactive Maps for Children Living with Visual Impairments".



Figure A.2: Tangibles as literal representations of the course content, designed in August 2015 and deployed in September 2015.



Figure A.3: The conductive supports designed for the interactive map.



SEPTEMBER 2015. MapSense was deployed for two lessons. This is described in Emeline Brulé, Bailly, A. M. Brock, et al.<sup>63</sup>. Following this study, the teacher expressed the need to refine the prototype, and to come up with a reproducible pedagogical scenario involving an outdoor session, tangibles and multi-sensory inputs. Furthermore, we needed to better understand what, and why, this type of interactive system lead to a better learning outcome. For this, we needed another analysis methodology.

<sup>63</sup> Emeline Brulé, Bailly, A. M. Brock, et al., "MapSense: Multi-Sensory Interactive Maps for Children Living with Visual Impairments".

OCTOBER 2015. The teacher gave two lessons on the same subject (e.g. types of human habitats): one was a "hands-on" lesson, a class trip for the discovery of the regional capital, the second was the group discovery of the interactive map of Toulouse. This did not uncover design insights, but familiarized the children with this type of pedagogical scenario.

FEBRUARY 2016. I produced new tangibles for geography and observed more closely their manipulation by pupils. This clarified our understanding of children's meaning-making processes. We identified that tangibles could either be: 1) a simplified, smaller representation of something not graspable without sight (e.g. a post-office); 2) a signifier, using a detail as a cue to be recognized (e.g. a post-box); 3) a symbol (e.g. a postcard). This guided the design choices made with the teacher in regard to the tangibles.

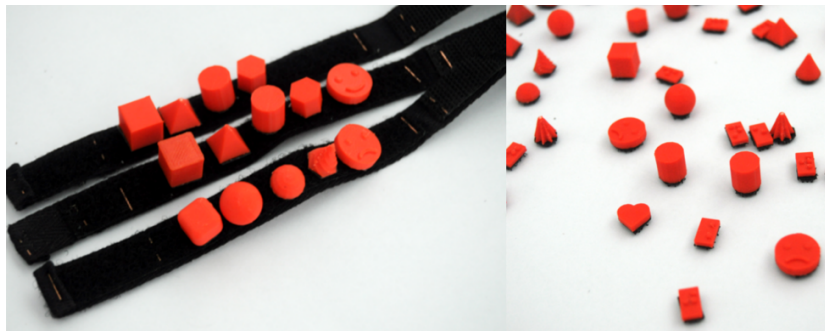


Figure A.4: Black and red wristbands for teaching mathematics. They were made at the demand of a pre-school teacher who saw the probes described in Chapter 14. The colors were chosen by her pupils. The wristband is covered with velcro, as are the red blocks. These red blocks can be attached easily to the bracelets. This enables to work on sequences of elements, fine motor skills, recognition of volumes and their similarities...

APRIL 2016. Design of the tangibles used for the study described in Chapter 15 with the teacher.

MAY 2016. Two first lessons described in this paper (an outdoor session and a lesson on the discovery of tangibles, see Appendix A.5). Design of wristbands for teaching mathematics at a pre-school level.

JUNE 2016. Lesson using the full prototype (e.g. interactive map, tangibles, smellable and tastable cues), described in Chapter 15.

OCTOBER 2016. Official end of the field-study.

2017. Punctual observations, interventions and feedback interviews. It included for instance the design of a bee for a course, the fabrication of the refined bi-color tactile globe...

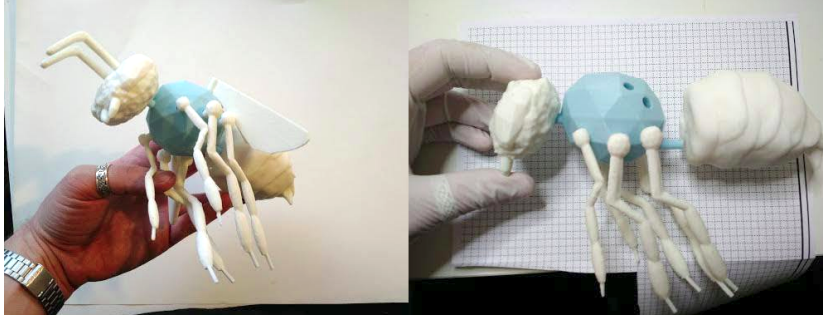


Figure A.5: Probe designed in April 2017. 3D puzzle of a bee. The various body parts (e.g. head, thorax, legs) can be separated and reassembled. The bee was to be customized, by adding fur to the thorax, as well as colors.



Figure A.6: A bi-color and textures tactile globe designed for classroom used. The steps to replicate it are outlined on Instructables: <http://www.instructables.com/id/Simplified-Bi-colour-Tactile-Earth-Globe-for-Visua/>

## A.5 Pedagogical Unit

### *Learning objectives*

The teacher outlined the following objectives for the trimester which are based on the curriculum:

1. THEMES. Describe, schematize and compare different types of human environments (e.g. urban, suburban or rural), and their organization (e.g. in terms of population, economical activities, or infrastructures); understand the different kinds of transportation infrastructures (local, regional, national);
2. SKILLS. Developing the understanding of environmental cues; Map reading; following an itinerary; constructing the itinerary followed during a class trip; work collaboratively by formulating hypotheses and discuss them; Discover new technologies (the prototypes);
3. CONTENT. Learning about regional geography, especially the regional capital;
4. More generally, developing general culture and vocabulary, and fostering engagement with geography.

### *Organization*

The unit spanned over 3 lessons. Five children participated in these lessons. Other participants included the specialized teacher, me during lesson 1 and 3, a mobility and orientation trainer in lesson 3, and a carer in lesson 2 (who assisted with manipulation). The 2nd and the 3rd ones were video recorded.

*First lesson.* The first lesson was a field-trip, described in Chapter 14. It focused primarily on developing the understanding of environmental cues and covered all the themes cited above.

*Second lesson.* This lesson took place in the special education center. The children freely explored the tangibles designed for the pedagogical unit (see Chapter 15). The teacher reminded the children about the field trip. Pupils were then instructed to elaborate hypotheses about what each tangible represented, before discussing these hypotheses with the rest of the class. The teacher provided cues when needed. These cues were of different types: associations

with previously explored tangibles (e.g., "*it is related to the one you've guessed before*"), with previous class trips, or with everyday scenarios (e.g., "*this is where you go when you have to send a letter*"). This lesson was a preparation to the third lesson and an occasion to re-discuss the themes.

*Third lesson.* The third lesson was conducted in the classroom and is described in Chapter 15. It focused on synthesizing the elements to be acquired in the pedagogical unit.

A.6 *Meaning Construction during Field-Trips*


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SCAFFOLDING FIELD-TRIPS	
<b>Sensory cues used</b>	
Visual cue	"What color do you see on the left?" "Yellow"
Audio cue	"What do you hear?" "The trees!" "How do you hear the trees?" "Because the wind moves their leaves."
Tactile cue	Exploring a statue tactilely, or the type of material used
Echolocation cue	"How do you feel here?" "It's very open, like there's no building"; "It feels like it's a big building"
Kinesthetic cue	Walking around a building to evaluate its shape and size.
Olfactory cue	And what does it smell? Can you guess what it is? It's a smell my dad likes. It's a flower. It's a field of colza!
<b>Teachers' techniques</b>	
Pointing out a cue	"Do you hear this? No, not there, on the other side, over your heads"
Imitation	"It does a sound like that [imitates]"
Metaphor	"the doors that open and close, like a slap"
Spatial description	"There's the main road, on our right. It goes from south west to north east. You can hear the cars pass. There are trees alongside. Hear the wind in the leaves?"
Hypothesis on cues	see the examples questions in "sensory cues used"
Motivating audio recordings	"Why do you think I'm asking you to record this?"; or to a child "Why did you want to record this?"
Problem statement	"We want to understand the difference between cities and villages. So, what feels different?"
Lesson	Describing World War I, in relation with the war memorial behind her.
Storytelling	"Greece, which is a country of the EU, used to have many gods and heroes. One of them was Heracles. He was strong. Let's play strong with your bodies! Grrrr! [flex the arms muscles]"
Hypothesis on the curriculum	"That's right, the cars are louder. It's because they go faster [...] Why are faster roads useful?"
Assessment question	"So, why did we build this war memorial?"

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Table A.5: This table summarizes the types of cues used during the field-trip and, the teacher's techniques to introduce them.

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USES OF THE PROBE

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<b>Types of recordings</b>	
Sound effects	Imitating a dog, recordings a track with another recording in the background.
Recording of the lectures	Recording an explanation about a war memorial, or a story.
Environmental	Sounds of different streets, sounds of cars on different roads.
Generated environmental	Sounds of the cane on different grounds.
Messages	"You should come over here, I have something to show you."
Stories	"I was told that in a little village like this one, there were witches."
<b>Uses of recordings</b>	
Augmenting the field trip	Using the dog sound while exploring tactily the statue of a dog.
Answering a question	Searching in the audio recording of a teacher to find an explanation.
Using it as an argument	"There are less people in villages, because we hear less cars and less voices [than in the city]. Hear that!"
Sharing with others	"I want to send a message to tell the others to come and see!"
Playing	"I could play magic tricks during field-trips to my other [sighted] classmates."
Make souvenirs	"We usually make a photo album, we could make an audio album;" "[sighted children] take pictures, I take sounds."
Reviewing a part of the trip	"I don't remember what we did after that. Let me check."
Augmenting storytelling	"I figure we can make some kind of multisensory book from this."
Augmenting a map	Back in the classroom, overlaying a point of interest with audio.

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Table A.6: This table summarizes the uses of the probe described in Chapter 14.

## A.7 Example of Fine Grain Multimodal Analysis

Time	01'18"31	01'18"50	01'18"54	01'19"07	01'19"28
<b>Classroom setting</b>	C2 interacts with the interactive map, assisted by teacher, C3 observes C2, others are seated, first author stands up	Idem	Idem	Idem, researcher introducing rubber as an olfactory resource to C1	Idem, researcher presents the rubber to C3, which leads C1 and C3 to engage in a discussion
<b>Speaker</b>	C1	First author	C1	C1	C1
<b>Utterance</b>	"in Toulouse, there are services, a hospital and so on. In the countryside, there are no hospitals."	"so what feels different in the city and the countryside?"	"space is reduced"	"What is that? Oooh it's rubber"	"the pollution!"
<b>Comment</b>	He repeats a remark made earlier by the teacher	emphasis on "feels" (which in French is a synonym for smell)	-	-	-
<b>Gestures</b>	hands below the table	move around the classroom	-	-	points upward
<b>Gaze</b>	either turns towards its classmates, or, when hesitating, away from them	nothing in particular	-	-	follows the olfactory representation, turns towards C3
<b>Olfactory representation</b>	-	-	-	-	rubber
<b>Gustatory representation</b>	-	-	-	-	-
<b>Tangible</b>	-	-	-	-	-

Table A.7: Excerpt from the second phase of the multimodal analysis. It consisted in the analysis of sub-units of interactions, identifying the resources used by the children during their meaning-making processes.

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## Understanding Visually Impaired Children's Experiences of Schooling

Emeline Brulé

**ABSTRACT:** In 2005, France passed a law on equal rights and opportunities, participation and citizenship of people with disabilities. It consecrated the right of all children to attend their neighbourhood school and re-organized the provision of services to this population, including the provision of assistive technologies. This research conducted a decade later between 2014 and 2017, investigates visually impaired children's experiences of schooling and the roles of technologies in supporting their well-being at school.

I developed a mixed-methods interdisciplinary approach, blending qualitative sociological research with Human-Computer Interaction experiments. Specifically, I conducted a two-years-long ethnographic study at a service provider for visually impaired children in the South of France, during which I made several design interventions. This field-work is contextualized by a critical review of the statistics on the schooling of visually impaired children provided by the Ministry of Education.

I use an ecological understanding of resilience to examine children's narratives about school, across different schooling modalities (e.g., mainstream and special education school) and sociodemographic characteristics. I discuss the resources and strategies children and their carers use to open opportunities for well-being at school, including uses of technologies. I contextualize these by investigating desirable schooling outcomes that define who is resilient and what resilience is for.

From there I propose to develop a non-visual approach to the (geography) curriculum inspired by the sensory turn. By changing what is considered as a valued way of learning, this thesis aims at providing opportunities to develop the sense of belonging and the perception of self-efficacy in the classroom. It informs us on the uses of hearing, smell, taste, and kinesthesia in geography; it supports pupils in re-shaping of the learning activities and spaces; Finally, it opens opportunities for collective geographical knowledge rooted in experiences of social inequalities. More broadly, it opens a discussion on building collective well-being and resilience in schools.

**KEY-WORDS:** Meaning-making; Resilience; Geography; Geography Curriculum; Multisensory; Sensory turn; Sensory Knowledge; Disability; Education; School; Human-Computer Interaction; Design; Pupils; Children; Probes; Classroom.

**RESUME :** Depuis 2005, la France reconnaît le droit des enfants handicapés à être scolarisés dans leur école de quartier. Cette recherche, conduite de 2014 à 2017, s'intéresse aux expériences scolaires des enfants malvoyants et aveugles en France, permettant de comprendre les impacts de ces changements législatifs. Plus spécifiquement, elle s'attache à comprendre comment le bien-être des élèves est défini dans ce cadre, tant par les élèves que par les acteurs médico-sociaux et les enseignantes ; les ressources négociées et mobilisées par les élèves pour améliorer leurs conditions scolaires ; ainsi qu'à proposer des manières dont les technologies éducatives d'assistance peuvent être conçues et utilisées dans cette optique. Pour ce faire, il est proposé d'explorer comment le tournant sensoriel peut permettre de concevoir des dispositifs techniques et didactiques inclusifs.

**MOTS-CLEFS:** Bien-être ; Résilience ; Ecole inclusive ; Géographie ; Curriculum ; Multisensoriel ; Tournant sensoriel ; Handicap ; Design ; Probes ; Métier d'élève ; Interaction-Human Machine ; Construction du sens.