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Version auteurs

## *Agency or disempowerment: Children with learning disorders in France*

### **Abstract:**

The paper deals with the agency of children with learning disorders, living in France. Conducted by qualitative methodology with children, parents and professionals, the research opens up the debate on how adults speak for the children and create diagnostics and care trajectories for them. It also questions the silences of the children, the ways they interpret and make sense of their world (Corsaro, 2018). Finally, we question how children are able to act by following Hirschman's (1970) three options: *exit*, *voice* and *loyalty*. As in the sociology of minorities, questioning the agency of children comes down to highlighting not only the processes and systems to which they are subjected, but also the diversion tactics, secondary adjustments, avoidance strategies and resistance techniques that enable them to take hold of issues.

### **Key words:**

Children, learning disorders (LDs), agency, silences, secondary adjustments, care trajectories

## **Introduction**

Children's health questions the *agency* of the actors involved from a dual perspective. Firstly, for a long time, within society and within sociological and anthropological research, the voices of children remained inaudible. In effect, "children are marginalized in sociology because of their subordinate position in societies and in theoretical conceptualizations of childhood and socialization" (Corsaro, 2018, p. 6). It was not until deterministic theories of socialisation, perceiving it as a unilateral process, were exceeded by constructivist theories that the agency of children was taken into consideration. Indeed, these theories "argue that children and adults alike are active participants in the social construction of childhood and in the interpretive reproduction of their shared culture" (Corsaro, 2018, p. 7). Secondly, in the field of health care, patients were, for a long time, perceived solely as objects of care (Armstrong, 2014). Questioning the agency of children with learning disorders therefore opens up the debate on the role of dominated actors in an area in which adults, carers and educators, speak for the child (Mayall, 1994) and create a diagnostic and care trajectory for them.

Learning disorders (dyslexia, dysorthographia, dyscalculia, etc.) (LDs) are intrinsically related to the current schools' focusing on reading and writing (Garcia, 2013). Due to several reforms in France, schooling is now mandatory till the age of 16 and the general secondary school has become virtually the sole pathway (Maurin, 2007). Children are thus encouraged to go as far as possible with their studies in order to ensure their professional future. Those diagnosed with LDs (around the age of 8 or 9) are considered to have a problem with one of the skills crucial to their education. On the one hand, they are entitled to personalised support. On the other hand, this

support imposes constraints on them, such as several sessions per week of speech and language therapy, occupational therapy, psychology, psychomotor education, orthoptics, etc.

This research was conducted using a qualitative methodology: comprehensive and semi-structured interviews with children (7 people), with parents (13), mostly middle-class<sup>1</sup>, and with professionals (45). The interviews were supplemented by focus groups with professionals and members of parents associations.

Questioning the agency of children involves, first, looking into the concept. It cannot be reduced to a capacity for choice or intentional action because individual action does not exist outside of the social and, conversely, the social does not exist without individuals (Elias, 2001). Agency can be defined as the capacities conferred by social structures on individuals who are, as such, able to reflect and act on the social world around them (Giddens, 1979). As for the children, James and Prout maintained in the 1990s that they “are not just the passive subjects of social structures and processes.” (James 2011: 40, quoted James, Prout, 1990, p. 8). We will try to find out, following on from Corsaro, how children “interpret and make sense of their world and participate in it” (Corsaro, 2018), what their experiences of the situation of a “dyslexic” or “dysphasic” are. The concept of agency applied to children also prompts analysis of whether they “do things oneself, rather than being done to” (Mayall, 1994, p. 2). Are they actually “active in the construction of their lives” (James, 2011, p. 41)? Thus, two questions guide our reflection: to what extent do children actually interpret and make their own sense of their disorders? And to what extent and by what means can they influence diagnosis and care trajectories?

To this end, we will start by exploring the field resistances and the children's speech; next, we will focus on the ways the diagnostic and care trajectories are interpreted by parents and children; and, finally, we will analyse the impact that the children can have on these trajectories.

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<sup>1</sup> Some of them work in the medical, social and educational sectors; others have jobs in the army or the commercial or technical sectors.

## 1. Discourse of disorders: the silence and speech of children

We should start by highlighting the difficulty of accessing children's speech. In the families we met, 3 children refused to be interviewed and another child (a seven-year-old diagnosed with dysphasia) was present but delivered his opinion exclusively through nods of the head. How should we interpret these silences? Do they mean that the children have nothing to say about their disorders? That they are not capable of talking about them? Asserting this would mean, firstly, that children lack subjectivity or understanding of their own lives, whereas most of researches highlight their extensive capacity to make sense of their own day-to-day world, such as school (Delalande, 2015), health (Favretto, Zaltron 2013), their body and self-care (Diasio, Vinel, 2017). Secondly, it would render us unable to explain why some children did want to speak to us. These refusals may also reveal that the research tool was not quite suitable for children, being conducted over a short time-scale and using an interview technique. Vignettes or scenarios, body maps and group brainstorming are better ways of obtaining speech from the youngest age groups (Favretto, Fucci and Zaltron, 2018)<sup>2</sup>.

This difficulty in accessing children's speech may, conversely, be considered crucial data for our field. As Anteby writes, "forms of field resistance teach us as much about a given field's tensions as other more traditional data sources (such as archives, interviews, observations, and surveys)" (2016, p. 198). Therefore, we will analyse why the children prefer to talk about subjects other than their disorders or to focus on their achievements rather than their failures.

Namely, the children do not spontaneously mention their difficulties, but

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<sup>2</sup> Given the rarity of the children's speech, parents' telling what their children said and crosscutting narratives of parents and children sheds light on the tensions, potential contradictions and convergences of adult and child perspectives. 4

rather activities with which they feel at ease, those they want to show off:

Léo, aged 10: *[in poetry] I am the best in my class. Because I... always get an A and loads of people get "fails" or... "could do better". Last time, for my mum's birthday, I learnt a Year 8 poem.*

As well as describing a scenario with the aim of maintaining "face", as in any social interaction (Goffman, 1967), he is also escaping a "stigma" (Goffman 1963, p. 2-3): "an attribute that makes him [a stranger] different from others in the category of persons available for him to be, and of a less desirable kind". Hence they need to highlight their capabilities and their progress:

Lucas, aged 13: *It takes less and less time. I know that in Year 7 we spent over 2 hours doing homework, nearly every night. Now, it takes us around 30 minutes to do homework.*

They also tend to diminish their failures. Léo recounts an altercation with a substitute teacher:

*He said: "You must look carefully at the word, remember it and write it out in one go, instead of doing one letter at a time". But I told him: "Sir, I don't do it one letter at a time, I do it three letters at a time".*

The child wants to prove to the interacting adults – the teacher and the interviewer – that his difficulties are not as pronounced as they think. Likewise, in class, children can always identify a pupil who is more stressed or less able than themselves:

Fleur, aged 8: *No but there are some too, when we do maths, like Bastien and Chloé, they don't understand anything.*

Léo: *They don't JUST make fun of me, but my friends too. Of Thibaud. Because he really does have difficulties. Really really really. More than me, you see?*

Fleur talks throughout the interview of the scholastic abilities she has supported by the educational assistant (EA), who accompanies her, writes for her and corrects her calculations. The children we met therefore<sub>5</sub>

interpret the school situation more positively than the adults, both parents and teachers. They recognise that they do not write quickly or that writing and reading are tiring for them, but their difficulties are not a problem *per se*. It is the perception of adults and their projection of an uncertain future that makes them problematic. Mayall (1994) describes how the children and adults face different challenges. Children love to play, go out with friends, do sport... They are not particularly interested in their success at school; they live more in the present (Diasio, 2014) than in a hypothetical projection produced by adult institutions.

We might also assume that, like those seriously ill children who do not express their feelings and awareness of their situation, not by ignorance but to protect their parents (Bluebond-Langner, 1980), children with LDs protect themselves and their family against the interviewer by downplaying their difficulties.

In the children's speech, we can also hear the words of adults. Léo admits that he moves a lot, and repeats his mother's words, when describing his behaviour and that of his friend: "*He is like me, he does not stay put*". Lucas and his mother both emphasise how helpful the IT tools and teaching arrangements are, and the effectiveness of the therapy sessions. Their discourse echoed each other's on several occasions. Lucas seems particularly observant and his mother uses the personal pronoun "we", to describe the schoolwork and therapy appointments. Nonetheless, it would be highly reductive to treat the children, in these cases, solely as transmitters of the adults' vision. It is likely to be more of an "interpretative reproduction" (Corsaro, 2018) and therefore a selective one, as much as their parents' reception of the specialist's discourse. Moreover, medical anthropology highlighted that when communities maintain dense links, disease narratives are more collective than individual (Skultans, 2007).

This consistency between children and parents is not universal, and divergent interpretations between children and parents enable us to extract some features of the agency of children.

## **2. Cross-referenced interpretations of the diagnosis and care trajectories**

At the various stages of the search for a diagnosis, which takes between 6 to 18 months or even longer, the opinion of the young patient is never sought, whereas parents describe the trajectory as an “obstacle course”. Yet, multiple assessments are used to diagnose LDs because it is a diagnosis of exclusion: after several month or even years of uncertainty, buffeted between general practitioner and psychologist(s), the process starts by excluding sensory disorders (sight and hearing), then eliminates intellectual disability, moves on to tests specifically targeting neurological disorders, and finally LDs. Thus, the children are taken to see a large number of professionals, multiplying the number of consultations, tests, repeat sessions with the same professional to validate the results, etc. Having finally obtained a diagnosis, parents face the proposal of various therapies, prompting them to commit themselves and their child for several months, often several years, without anyone promising them a cure. The child is compelled to attend weekly or even twice-weekly sessions with different specialist. As observed by Mayall (1994), when it comes to health, adults expect the child to accept, without discussion, the solutions proposed. Contravening a recommendation made by a health professional or parent is perceived as deviance or a lack of maturity.

Sometimes the interpretations of the parents overlap with those of the children, and at other times they are totally disjunctive. Discrepancies between the perceptions of children and parents are particularly prominent in relation to the diagnosis. While the parents we met mostly agreed with the diagnosis, the children did not seem to identify themselves with the “dys” words, or with the medical interpretation of their difficulties, particularly the youngest ones. Fleur (aged 8) knows that she has dyslexia and dyspraxia, but says she does not know exactly what it means: “*I don’t know how to explain, in fact, I don’t even know what it is,*” she states.

It is difficult, from a limited sample, to determine what distinguishes the children who accept the diagnosis and the school support and those who resist them. But we can argue that identifying oneself with a class group<sup>7</sup>



or with similar children among their entourage (friends, cousins, etc.) is recurrent among the children who accepted an interview.

Lancelot, aged 12: *Last year there was a “dys” Year 7, we were all together. And so yes, we were together and the number of pupils was less than in the other classes...*

This small community produces a positive “dys” identity even in an ordinary class. And, the children who accept the “dys” identity bring tools to class and seem to like using them, and even to present them as signs of distinction.

Lucas, aged 13: *Well, it’s difficult, reading, writing, spelling... <...> I have a pocket scanner. It’s a small scanner that you move over the pages and in the evening we print it out and stick it in the notebook.*

Mother of Noé, aged 10: *This year, with his computer, he explained to the others how the computer works, what he uses it for, and in the end the others were all envious of it.*

School support is heavily dependent on the teaching team and on negotiations in which parents engage to very varying degrees, depending on their resources (knowledge of the medical-social world, proximity to the school world, etc.). Children rarely have a role in negotiating this support; it is the parents who face the institution. Actions taken by children are limited and mainly consist of transmitting information to parents (for example, if a teacher is punishing a dyslexic pupil for poor handwriting). Furthermore, some families describe punishments for children who have “voice” (Hirschman, 1970):

Mother of Nathan, aged 14: *He (the teacher) had written a very, very, very harsh comment and when he gave Nathan his copy, [he said] “You’ve done nothing, as usual!” Nathan got annoyed and explained that he was dyslexic. And he was excluded from the lesson for talking back. <...> So I reacted straight away. <...> We laid our cards on the table and the year in French went really well.*

Parents, provided they agree with the diagnosis and with the idea of support (which is not the case with all those we interviewed), find themselves negotiating with the school... and also with their children.

Several mothers told us how their child resisted support, which they perceived as a stigma, because their difference was rendered visible through the presence of an adult in the classroom other than the teacher, or through a particular object. Léo in particular did not want an EA because a friend's experience had shown what a stigma it could be: "*the first time that... that Robin had an EA, pupils made fun of him and all that, and I don't want that to happen to me*".

Despite potentially accepting the diagnosis, only rarely do children enjoy the multitude of therapy sessions proposed. The children would prefer to have more free time.

*Léo: If I could choose, I would prefer not to go there, firstly because how... firstly I would have more time for fun and... secondly, well... I could stay longer with my granny and grandpa.*

Parents recognise that the large number of assessment and therapy sessions are tiring for the children. They are torn between two contradictory injunctions – ensuring their child's success at school and their thriving (De Singly 1996), the future and the present.

### **3. The child agency: exit, voice and loyalty**

So how much margin do children have to act? Hirschman (1970) states that in a situation of dissatisfaction, actors have 3 options: *exit*, *voice* and *loyalty*.

The first option is rarely available to children because the middle-class parents we met are driven by school pressure meaning social success. The prominent exception here is the question of acknowledgement of disability: if a child refuses, he or she is generally listened to. It must be said that this decision causes some uncertainty among parents, who are afraid of stigmatising their child. As for follow-up care, parents are expected to

bring their children to appointments in accordance with the trajectory defined by the professionals (Mougel, 2009). However, parents are more likely to respect their child's resistance if they are not themselves convinced of the necessity of a particular therapy. Léo's mother, for example, explained to us that he did not want to go and see an ophthalmologist offering a treatment for dyslexia; she implied that she accepted her son's decision, adding that neither she did "*believe*" in these techniques. So it is difficult to assert that the child's position has the upper hand. The mother of Noé (aged 10) is the only parent who cancelled her son's follow-up care:

*Noé had huge difficulties with the speech and language therapy, because it highlighted his problem, and he wants to be like the others. So, quite quickly, we stopped. <...> We tried to restart the speech and language therapy, but he didn't want to go, so it was complicated. He did everything he could think of at the therapist's to avoid doing anything. And now, "speech and language therapist" is a dirty word, he doesn't want to hear it.*

She presents her son as an actor and says she appreciates the teachers who also see him as "*an actor in his own school career*". As a professional of the disability sector, she has rather an exceptional place in our field, attributable to her specialism and therefore to her knowledge and ability to resist school pressure.

Other children do not like going to speech and language therapy sessions, but go anyway. Mothers admit being exhausted ("*I feel like I run everywhere*"). They are also worried about the potential overload on the children. That does not mean that they would stop the follow-up therapies or stop seeking a diagnosis. Léo's mother owns up that, given her son's lassitude, she no longer tells him in advance before taking him to see a new specialist; she just takes him straight there. Léo does not object, "*because he is obedient, and he's a good boy*".

The voices of the children are not often heard because the parents and

professionals are immersed in developmental theory and the vision of a linear trajectory (Corsaro, 2018). The children, on the other hand, want to live in the present.

Léo: *Well, my mum talks to me about it all the time, she talks to me about it all the time, but... with all that talking, I would prefer to forget... forget about it and then... and then, what? And then... (pause) And then, get on with my life, basically.*

Resisting, for Léo, is therefore forgetting the definition of the situation that his mother frequently reminds him of. The refusal of an interview with the researcher may form part of this avoidance, as does talking about friends rather than themselves during interviews.

To deflect from the constraints of the therapy programme, children will interpret interactions with professionals in terms of affects, a recurrent event in their narratives. Several children state that they really like certain professionals (French teacher, speech and language therapist, psychologist), and they like the sessions because of the games they play; they especially like the professionals when they are “*nice*”, and, as such, they comply with the trajectory imposed upon them. On the contrary, to other professionals children attribute negative characteristics or attitude. Thays (aged 6), for example, says that his speech and language therapist is silly.

Léo: *Wednesdays and Mondays are the worst days of... of the week. <...> Because there is a teacher who hates me. And so, this teacher doesn't like you or all the boys? All the boys. Especially me and Thibaud, one of my best, my almost best friends. <...> (pause) Because Thibaud is like me, he doesn't stay put.*

Interpreting the situation in terms of affective relationships may be seen as the *agency* of the children because they are making their own sense of the situation (Bluebond-Langner, 1980).

It's also the interpersonal argument that the parents can understand. Léo's mother, who is very critical of her son's school, wanted to change

schools but gave up on the plan because Léo did not want to be separated from his friends.

Lastly, Hirschman remarks that loyalty, the only model of behaviour in highly restrictive contexts, does not signify acceptance of the rules imposed. While a child is often obliged by the parents to attend therapy sessions or have specific tools at school, he or she can always undertake “secondary adjustments”, “getting around the organization’s assumptions as to what he should do and get and hence what he should be” (Goffman, 1961, p. 189). Corsaro (2018) points out that often, for children placed in a highly regulated context, secondary adjustments are the only way of acting. Noé’s mother clearly explains that her son was able to make it impossible for the speech and language therapists to do their job. The grandfather of Baptiste (aged 14), who had been to speech and language therapy since the age of 4, 20 km from home, explains that after several years, Baptiste “*was fed up*”. To continue the therapy, his mother booked an appointment with another therapist, a stone’s throw from the school, to which Baptiste could go on his own during the day. After several missed sessions, the speech and language therapist refused to see him anymore. As for tools, resistance may be open, such as refusal to bring a digital schoolbag to school, or, as is most often the case, tacit – objects left at home, lost, broken, too complicated to use, etc. These secondary adjustments enable the children to resist the rule imposed without actually breaking it. These same children who resist most of the therapy and support refused to speak to the researchers. Thus we see their twofold resistance – to the naming of their difficulties and the resulting support systems offered – as well as to research on the subject.

### **Discussion - Conclusion**

The children with LDs we met have their own interpretations of the situation, which can be considered as part of their agency. They tend to interpret their own trajectory by erasing the difference from other pupils. The youngest children admit that they do not understand or accept the medical terms imposed upon them. They are not focused on their school career in the way that the parents and professionals are. Our research<sup>12</sup>

therefore confirms the conclusion reached by Corsaro (2018) that children interpret their situations and make their own sense of their life.

But they are not the principal actors of their care trajectory, or of their school pathway. Some make positive sense of school support or tools (e.g. computer or scanner) and like the therapy sessions. But their opinion is often overlooked. We can therefore partially confirm the observation made by James and Prout (1990) that children are not just the passive subjects of social structures and processes, but we can also confirm that children are often marginalised. “Rarely are they viewed in a way that appreciates what they are – children with ongoing lives, needs and desires” (Corsaro, 2018, p. 6). As in the sociology of minorities, therefore, questioning the agency of children comes down to highlighting not only the processes and systems to which they are subjected to, *but also* the diversion tactics, secondary adjustments, avoidance strategies and resistance techniques that enable them to take the position of subjects (Foucault, 2001).

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