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# How can the life project of a mentally handicapped person be developed democratically and with respect for the person ?

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**(2020 ID : 118) How can the life project of a mentally handicapped person be developed democratically and with respect for the person?**

Today, to define the rights to compensation of a person with any kind of disability, we rely on his or her life project. However, several questions arise: how is it developed? Are all people who work with the disabled person heard in the same way during consultations? Do families have a say in the medical profession? Is the disabled person himself/herself listened to and, above all, is his/her wishes and desires respected?

The objective of this work is to try to answer these questions and propose possible solutions. This study is part of a doctoral research project still in progress. It is carried out in France with adolescents aged 10 to 18. They all have mental disabilities or dys- troubles. They are educated in so-called ordinary schools or in specialized institutions. They are asked about the feelings they have experienced throughout their schooling and especially when important decisions have been made during their various orientations.

Hochmann (2012) mentions the need to collect emotional information in order to be able to think about appropriate actions. However, to our knowledge, few studies has given a voice to the main stakeholders, students with disabilities. In addition, the latest circulars of the French Ministry of Education, which are in line with international and European regulations, specify the obligation to take into account the life aspirations, choices and desires of these people when making policy decisions (Circular No. 2016-186 of 30 November 2016, n. d. ). Nevertheless, these students have very little say in the various decision-making processes surrounding their schooling. Teachers, health professionals and possibly parents speak out on their behalf. However, Feder Kittay (2015)

thought she knew everything about disability before the birth of her disabled child. Now, living the situation of disability on a daily basis, she says : “ *now she knows*” (Feder Kittay, 2015). This underlines the cleavage and “confinement of position” (Sen, 2009) that is observable between doctors, teachers who rely on real case observations. So “*we encounter a problem of observability, and often obstacles to understanding what is happening from the limited perspective of what we observe*” (Sen (2009, p 200). They enact rules that have the force of norms, and that society posits as omniscient. For the common people, they know. However, we don't know anything until we experience it (Feder Kittay, 2015). Also, how to put an end to these power struggles (Ebersold, 2012; Viné Vallin, 2020)? Would a joint operationalization of the justice theories of Rawls (2008; 2009), Sen (2009) and Nussbaum (2017) be a solution?

In analysing the legislative texts, they invite us to think in terms of capabilities defined by Sen (2009) or Nussbaum (2017), that is to say to leave the concrete, effective possibility for the disabled person to choose between various possibilities, orientations, in accordance with his/her choice of life, his/her personal limitations and to give him/her the capacities to realize his/her choice with the help of compensations defined through the personal compensation plan (Nussbaum, 2017 ; Sen, 2009). And for identities to be forgotten, would placing participants in an original position behind a veil of ignorance, (Rawls, 2008, 2009) be a solution (Viné Vallin, 2020)? Consequently, our research question is as follows : would a joint operationalization of Sen, Nussbaum and Rawls' theories of justice allow for the democratic development of the disabled person's life project?

It is a multi-case study in France, in the form of biographical research (Delory-Momberger, 2014), using a qualitative empirical method. Through it, we want to study in depth the training and orientation path of students with disabilities. It also allows us to take into account many

variables that may affect their sense of justice or injustice. Twenty-five students, aged 10 to 18 years, participated in this study, as well as twenty families and five teachers.

This approach is based on the collection of data from processes specific to this approach. The scientific criteria are based on a verification of the data, ensuring its validity and accuracy. We monitor and question these children's students, parents and teachers about their school careers and the times when orientations were played out, in order to understand the process, what was taken into account, and their feelings. Three semi-structured questionnaires were developed for each group of participants (student, parents, teacher). These questionnaires can be modified and are adapted according to the type of structure, the people met, and the exchanges that have already taken place with this person. To test our hypothesis, we asked questions about the history of their schooling, the history of their choice of orientation and choice of school, what they had taken into account, whether they participated in these decisions, whether they were listened to and whether this decision corresponds to their choice(s), how they felt about their daily schooling, within their field of study, their sense of justice in relation to their overall path. In order to facilitate comparisons between different stories, we used the same coding to arrive at similar categories. We examined the associations between freedom of choice, being and doing and indicators of justice. In order to ensure the validity and accuracy of the data, my interpretations were submitted to the actors who participated in the survey and to a college of researchers.

According to the circular in force in France, these meetings on the guidelines must be “*a projection into the future of these children, of the expression of their aspirations and their life choices*” (2016, §1-1). We can estimate that the participants in these meetings are behind a veil of

ignorance, as imagined by Rawls (2008; 2009). Indeed, who knows what the future will be made of? However, they are not in the original situation imagined by Rawls (2008; 2009). Indeed, the literature highlights the power struggle between the different stakeholders by excluding families (Ebersold, 2012; Ebersold, Detraux, 2003). In addition, according to our data collection, the preferences of the various participants appear to be privileged and satisfied at the expense of what the student is actually able to do and be. We also believe it is important to get closer to the work and capabilities of Nussbaum (2017). Unlike Sen, she does not seek to compare two systems but to propose a person-centred system. It seeks to give her the skills and abilities to answer the following question: what do you want to do and be? The capacities to be defined in the framework of the orientation will belong above all to an individual in all that he/she has unique. Also, we cannot talk about equity since we do not place ourselves in a comparative system. Sen argues that equity precedes justice (2009). Thus, equity between individuals will focus on the respect to grant each one the list of capabilities that we will have predefined during previous consultations. Then the policy decision should lead to a decision corresponding to what he wants to be and do. And a sense of justice should prevail.

Circulaire n° 2016-186 du 30 novembre 2016. , Education Nationale.

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