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Disability in turbulent times: between familiarization and collectivization of care.

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My presentation is based on an ongoing PHD research on the trajectories of the children for whom autism is evoked. These trajectories are analyzed both in terms of care arrangements and problem characterization.

The core hypothesis of that research is that the trajectory of a child for whom autism is evoked depends on the way his or her parents position themselves in different interaction spaces opened in various worlds: school, administrative and medical.

The chosen methodology articulates an ethnographic approach, semi-directive interviews and a family cases analysis. The ethnographic approach allows analyzing the logics of action and judgment in the different worlds mentioned above. These logics are situated in the local institutional context, notably through semi-directive interviews with actors that I progressively identified as having an action concerning autism at a local scale (the French sub regional “département”). Eventually, the follow-up of five families from the moment when they started a diagnostic process in an evaluation centre specialized in autism and during a year permits understanding how individual trajectories are produced, passing through the different worlds mentioned above, in a given local context.

This presentation focuses on an issue that emerged during the research concerning the schooling of disabled children in ordinary schools, which has been recognized as a right in France with the law for “equal rights and chances, participation and citizenship of the disabled people”, passed in February 2005.

The studied “département” is one of the most privileged geographical areas in France as far as the schooling of disabled children is concerned: Between 36 and 48% of the disabled students are individually accompanied in classes by a person recruited by the Ministry of Education under a six-year contract. But this “département” is also affected by the generalized growth of the number of people helping disabled children at school under six-month insertion contracts with no training. In 2009, there were 217 people under these precarious insertion contracts and 169 employees of the Ministry of Education in the “département”.

In October 2010, the local State representative announced that all the funds for 2010 dedicated to the insertion 6-month contracts had been used up and he decided to stop renewing expired contracts. For a lot of children, it meant being sent back home insofar as teachers would not accept them in classes without a person helping them.

The local office for disabled people invited parents to manifest themselves if their child was in a difficult situation at school and spotted 18 problematic situations in December 2010. These situations were described in a report that was sent to the local State representative. The situations were diverse: total removal of the child from school, shortening

of the schooling time, difficult schooling without a person helping the disabled child, schooling breaks...

This paper shows how a given political context characterized by a lack of financial resources has impacted on the different decision-making arenas by questioning or revealing their logics of action and judgement. A pragmatist approach of that crisis situation permits to understand that it becomes the parents' responsibility, individually or collectively, to make sure their children access their right to be schooled in ordinary institutions. This process of parents' being made responsible for their child's future results in paradoxical trends according to the level of analysis.

From a case analysis, we may argue that making parents responsible as individuals is notably conveyed in the medical arena. In the evaluation centre specialized on autism that I observed for 5 months, a couple of parents for instance were told by the chief psychiatrist that they should employ a person to help their son at school whereas the family was living with the support of the active solidarity revenue.

Extract from the last consultation for Galiléo, the 29th of November in 2010

Psychiatrist: We have already wasted some time in organizing the program, there should be a schooling part now....This is a crisis situation in the region...The funds have been used up...but they are going to be renewed in January...

Mother: So this is not going to last forever...

Psychiatry: No, and it would be good to implement a private worker at school. If the school is trusting, it could get on well...

Mother: Can we do that?

Psychiatrist: Yes, we have two or three cases in the region of schools accepting this arrangement, recruiting someone with the parents who employ that person.... I should not tell you that but this is a crisis situation and it is necessary to give ourselves the means that we need to overcome that crisis...We have been waiting for too long, it is time to find a solution for Galiléo...

Father: Someone told me that it was possible to contact the city council...

Psychiatrist: Yes, to recruit a person...But we are going to be demanding, we don't want anybody...

Father: Anyway, the persons usually sent in schools are not trained so...

Psychiatrist: But this is not the beginning of the disabled children' schooling, some persons have an experience with autistic children...It is time to act now! I agree to make a certificate saying that it is necessary to implement a private worker at school...We can propose a convention between the school and the parents so that a person you pay for gets accepted in classes...We have to compensate for the needs that the State can not respond to.

Father: To pay for a person helping Galiléo at school is not a problem, we are ready to eat pasta everyday but where should we go? To whom should we write? Who should we explain that plan to?

This responsabilization of parents raises a major issue: the sharpening of social inequalities between disabled children. Parents don't have the same capacity to claim their rights, the same resources to initiate actions that require entering the register of public justification to get their child back to school or to compensate for the lack of public aid by privatizing the production of care.

Example: Elsa and Thierry, whom I followed up for 1 year and a half from the moment they started a diagnosis process for Martin, 8 year-old, in the evaluation centre that I had observed.

In November 2010, Elsa called me to cancel our appointment telling me that she wanted to get an appointment with the local ombudsman because Martin had been deprived of the person helping him at school.

In January, Elsa and Thierry explained to me during another interview how they had managed to get someone helping Martin at school within a month.

First they had an appointment with the head of the school, who told them he could not do anything. So they met the public administration employing the persons helping disabled children in ordinary schools. They were told that the administration did not have the necessary funds to employ any more people. Thierry also met the local deputy, who said he would question the National Assembly on that matter but could not respond to their individual situation. They wrote to several people: a few ministers, the local education authority, local school inspectors. Eventually, following her step-mother's advice, Elsa decided to ask for an appointment with the local ombudsman who managed to solve the crisis two weeks before Christmas holidays. Elsa and Thierry were eventually ready to call the press and lead a class action as they had managed to gain the support of a lot of parents in the school.

They explain how complicated it was for them to identify the decision-making levels and the responsible people as far as all the persons they met tended to blame each other. Elsa and Thierry exemplify the kind of parents who have the necessary resources to access their right but they are aware that all parents do not have the same resources, which triggers inequalities between disabled children.

Extract from an interview with Elsa and Thierry in January 2010

Elsa: We have rights; we can obtain things but...

Thierry: It is for us to activate those rights...

Elsa: Yes, we have to go for it!

Thierry: Not only to ask for it, but also to follow-up the process, to insist, to come back...

Elsa: We have to fight to obtain our rights! As far as we are concerned, we have the Internet, we know how to write official letters, we have cars... We have possibilities. But for the people who don't have all that, it means that anyway, from the beginning ...

Thierry: they are excluded! In this case, they took and they gave back but only to the people who insisted the most! The poor fellow, isolated, who does not know...for him, it is over! You have to know ...

Elsa: And it also takes some time...

Thierry: Without having a specific knowledge of how the administration works, we see where we can go, who we can turn to... But some people won't know where to enter...

Elsa: and the thing is that administration is a huge machine! So it is very long to find the right way but at the same time, you are in a hurry because you see that your child is not well...

Thierry: There is a right but between everything should be automatic and deliberately let...because I think this is deliberate...I think this a policy, a way to do things...

Elsa: and by comparison some things are automatic...

Thierry : Actually, it depends...There are things for which people are not encouraged to take steps to obtain them ; even if the person does not know anything, it is going to be ok...But on the contrary, for other things, people have to know...

Elsa: And this is a bad calculation because, personally, I think that we make some efforts for Martin, we help him working well at school, he has a person helping him, if everything goes right, he should be autonomous when he is 20 or 22 year-old, he should have a job, earn a salary and bring money to the State...The money that the States spends now is the money that they won't have to spend later; this is much more economical...

Thierry: Yes because a place in a specialized structure costs more money than a person helping Martin at school...

Elsa and Thierry's discourse is tinged with « misérabilisme », expressing pity for the incompetent parents lacking from the necessary resources and it does not consider that parents may not value school in the same way and may not want to access their right. Nevertheless, it permits underlining that the activation of rights, all the more in times of crisis, rely on the possession of different resources, the most important being the capacity to make an « efficient » claim, that is to position one's demand beyond one's particular interest and to bring up the public good as Elsa does at the end on the extract.

So, from the individuals' point of view, that crisis reveals the tendency to privatize a public problem, and the changing equilibrium between State and family in social arrangements of care.

But, if we consider parents as collectively organized in organizations, this crisis has given place to a re-politicization of the schooling problem.

First, it has been an opportunity for the organizations of parents with a disabled child to denounce the persistent problem of lack of means dedicated to the schooling of the disabled children in ordinary schools in comparison with the constant growing of the demands since 2005 ; the fact that teachers do not usually accept disabled children in classes if they are not accompanied; and the growing precariousness of the people helping disabled children in classes, with the progressive replacement of the Ministry of Education employees by people under 6-month insertion contracts with no training. The organizations of parents have claimed the necessity to make of that caring work a real job, with training and stable contracts.

The local organizations of parents were supported by the local authorities and together they organized a press conference. The local authorities also got a meeting with the local State

representative to ask for the renewal of the ending contracts. A demonstration was organized on the 3rd of November in the administrative centre of the « département » gathering hundreds of people according an article published by a local newspaper on the 5th of November. All these actions led to the renewal of a little more than one third of the ending insertion contracts (2100 contracts were renewed among the 3000 ending contracts in the region ; 1400 of the 3000 contracts concerned people helping disabled children at school in the region ; 217 of these 1400 contracts concerned children in the “département” in 2009).

This crisis has permitted an evolution of the relationships between the organizations of parents and the local education authorities: from tensions, with parents' schooling wishes considered as unrealistic by the local education authorities, to more collaborative attitudes, with a collective negotiation about the role of the schooling for disabled children and a consensual redefinition of that role: to respond to every child's desire to learn and need for socialization. (cf. observation of a meeting on the disabled children schooling at the local office for disabled people, the 19th of April in 2011).

But that crisis did not trigger a real unification of the various organizations of parents and did not reduce the competition between different disabilities. It did not favour a unification of the different local organizations of parents with an autistic child. And it did not soften the relationships between the autism organizations and other organizations dealing with different disabilities, such as physical impairments or mental retardation. The vice-president of the local office for disabled people describes the fragility of the union between associations in the disability field:

“Let's say that we gather, we federate...but it is always fragile and eventually, autism is not different from other disabilities...It is always a big challenge to manage to keep organizations together...There is a kind of communitarianism between the disability organizations! Each organization thinks of itself as the only cause, and with autism, this is sticking; this may not be politically correct but...One realizes that the local office for disabled people is fantastic and at the same time very fragile...Each organization tends to say: What about autism? You don't talk about me! What about my cause?”

Extract from an interview the vice-president of the main local organization of parents with an autistic child, in March 2011

Miss L.: A few situations of children removed from school were pointed out in the organization...So we contacted the local office for disabled people to know if they were aware of other similar situations and we realized with terror that it was mostly autism that was concerned...and also a few “dys” (dyslexia, dyspraxia...) So we met the Head of the local education authority and one of the school inspectors. We were with the representative of the local office for disabled people. When we asked if there could have been a discrimination

during the renewing of the contracts, they told us: « No, certainly not ! But it is true that we asked the referee teachers to make choices according the situations because we could not renew all the ending contracts »...Which leads to the conclusion that there maybe was a discrimination ...They told us: It was not done like that...we did not consider the type of disability, it was not a criterion »...Ok but the physical impairments were not concerned and neither were the sensory impairments...

A collective entitled “Schooling Disability X” (Name of the Département) was created on the 6th of November but it was only constituted of organizations of parents with an autistic child so it did not gather organizations dealing with different disabilities. Furthermore, this collective did not gather the whole diversity of autism organizations as it was only formed with 3 of the 5 local organizations of parents with an autistic child, the two main organizations not being members of that collective.

This process of politicization found an echo in the administrative arena, as far as the experts analyzing the cases and deciding how the resources should be allocated started questioning the logic of their judgement: should they take the global context of financial crisis into account? They pointed out the limits of the institutional separation between the decisions they made and the actual allocation of resources. Eventually, they redefined the logic of their action in political terms: to make local authorities conscious of existing needs and to prevent the production of a vicious circle, which would consist in underevaluating needs and hiding the lack of ressources devoted to disability.

Extract from an observation of the evaluation team in the local administration for disabled people:

Administrative officer (addressing the referee teacher): Do you want to tell us about the school auxiliaries?

Referee teacher: I don't talk about anything anymore...I just come from a meeting with complaining parents...There are more and more demands for school auxiliaries, there is a real need but the truth is that we don't go in that direction...

Administrative officer: We have a lot of dyslexia cases coming...

Referee teacher: We will have to define priorities...

Child psychiatrist: We are reaping the fruits of early screening...

Referee Teacher: We are right in the middle of what the 2005 law is about. We use that law but we don't have the means!

Administrative officer: So what about that child?

Referee teacher: If we get out of the current context, if we stick to our goals, there is a need...

Administrative officer: We have to stick to the needs; the context is none of our business!

Referee teacher: In that case, we can give six hours for the first year and then we will see...But despite everything, we have to take reality into account...Means have to be given

according our notifications...The organizations have gathered, the local office for disabled people has taken steps to address the minister, they will have to move! It has to be solved for this coming calendar year!

Administrative officer: So we put nine hours? (laughters) There is a need!

(...)

For another case:

Administrative officer: And what about this child? Do we give him a school auxiliary?

Child Psychiatrist: With the intention of reporting the existing needs, yes.

This regional crisis was eventually an opportunity for some local deputies to tackle the issue of the disabled children schooling in ordinary institutions at the National Assembly; to underline persistent problems (the lack of funds, the lack of professionalization for the accompanying people...) and dangerous trends, such as the growing insecurity characterizing this care work, and the announcement of a 30% staff cut for these insertion contracts in September 2011. The accumulation of local crisis situations, the multiplication of case stories in newspapers, and the fact that several parents have started bringing lawsuits to denounce the 2005 law's trespassing gave a global dimension to the problem of the disabled children schooling. In March 2011, the President Sarkozy asked for a report on the schooling of disabled children and designated the Senator Paul Blanc for that mission. This report comprising 34 measures was published in May 2011. It invites to launch a dynamic of professionalization for the people who accompany disabled children at school; a training on disability at school for teachers and to put the emphasis in ordinary institutions on a collective assistance rather than an individual accompanying in class by school-auxiliaries.

