

## **When public action relies on parentality – The case of autism.**

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### **Introduction:**

This paper is based on a PHD research concerning the trajectories of autistic children in terms of problems characterization and care arrangements. This research uses qualitative methods (ethnography, interviews and case analysis) and aims at articulating different actors' points of views according their position in different worlds (school, medical, administrative, family), in order to understand the logic of the child's trajectories. It takes place in a French local context.

One aspect of the field work has consisted in a one-year follow-up with five families from the moment when they started a diagnosis process in an evaluation centre that is specialized in autism diagnosis. I observed the different steps of the diagnosis process in the evaluation center and regularly met the parents, or one of them according the cases, for interviews, once a month or so.

Using this case analysis, this paper aims at showing how parents with a child whose condition may be diagnosed as autistic can produce arrangements of care by using the possibilities offered by public action. This paper focuses on the way in which parents position themselves towards public offer. The idea is to look at the people who access their rights or make use of the public offer to understand why other people don't. This paper analyzes trajectories of parents who get their child's disability compensated for and their child schooled in an ordinary institution, in underlining the resources they use and the pragmatic obstacles they overcome. That analysis allows assuming that some parents lack the needed resources or fail the informal tests in intermediary spaces of decision-making.

First, this paper will present a couple of parents' trajectory, which exemplifies the case in which parents confronted with autism have distanced themselves from public psychiatry and produced an alternative arrangement of care. Elsa and Thierry are Martin's parents, who was 8 years-old when they started the diagnosis process in the evaluation centre. Martin has been diagnosed with high-level autism. Then, this paper will underline in that typical trajectory the different steps that can be regarded as moments during which parents' position

toward their child's situation get tested and highlight the types of obstacles that some parents may not succeed to overcome in order to choose for their child.

Most of the times, even though parents encounter difficulties with their child, pediatricians normalizes the situation in underlining that each development is different and the close relatives think that parents are confronted with an authority problem, all the more when the child is the first born, as Martin was for Elsa and Thierry.

Thierry: We saw that there was something...we saw it but...for us, it was part of a development that was more or less normal (...) we thought: it will get into order later...

(...)

Elsa: And the doctors (general practitioner and paediatrician) told us: "It is not serious...You have to wait..."

Thierry: "It will get normal when he grows up, when he develops..."

(...)

Elsa: My father used to say: "you are not strict enough, he moves a lot..."

Thierry: "He watches too much the TV...Everyone tried to find classic reasons to explain his condition..."

Elsa: "You are not strict enough"...We had a major education problem! (laughter)

The possibility that the child may present an abnormality usually emerges when he/she enters the school system. The teacher says to the parents that the child doesn't adapt to school life and that his/her behaviour raises problems in class.

Thierry: Well...And the first year of nursery school (September 2004) ...The teacher well...she had a lot of experience, she was at the end of her career...she knew very well her job, the children...She told us: "There is something deeper; either it is..."

Elsa: After 15 days!

Thierry: physical, like hearing problems or it is...deeper...and more serious."

(...)

Thierry: She said: “There is something that bothers him”...without naming anything...He doesn’t have a “normal” behaviour.

Elsa: What happened was that in class, he didn’t stay in the group; when she told a story, he didn’t listen; he was shouting; he didn’t speak...

At some point, a consultation with the school psychologist may be advised or parents may directly be orientated towards a medico-psychological public centre.

First, Elsa and Thierry went to see an otorhinolaryngologist in November 2004, who found out that Martin had his ears blocked. He got operated in March 2005. Elsa and Thierry thought that once this problem solved, Martin would catch up his language development, and that his behaviour would get normal. But after the operation, the teacher told Elsa and Thierry that there was “something else going on”, “something wrong”. She suggested that Martin meets the school psychologist in September 2005 to get tested. Martin saw this psychologist in October-November 2005 and she told Elsa that he was suffering from a mental retardation. Elsa called Thierry’s aunt, who is a psychologist, to know her point of view on this diagnosis. Thierry’s aunt told her that this diagnosis was “irrelevant”, that “it didn’t mean anything”. The school psychologist had also suggested that Martin should go the nearest medico-psychological center, where he started seeing a psychologist once a week in September 2005.

Parents end up taking distance from these medico-psychological centres because they are not given a diagnosis. The issue of diagnosis is all the more problematic in the case of autism as French psychiatry is characterized by a controversy about medical classifications and autism conceptions, and by a plurality of positions towards diagnosis. From the ethnography of the medical world, we can argue that psychiatrists inspired by the psychoanalytic approach, favour the clinical view, have internalized anti-psychiatry criticisms and are reluctant to label a situation that may evolve; other psychiatrists, more open to educational and behavioural methods, favour early diagnosis based on standardized tests in order to implement adapted methods. Those conceptions of diagnosis rely on different logics of relationships with the parents: on the one hand, the psychiatrist evaluates to what extent parents are ready to accept a diagnosis and consider diagnosis announcement as a possible trauma; on the other, psychiatrists are more open to the fact that parents may claim a right to

get a diagnosis. Public psychiatry, despite its plurality, is largely influenced by the psychoanalytical approach.

Elsa: We were never given any written account from the medico-psychological centre... We were told: "It is progressing, don't worry, time will fix things..." So, we trusted them...

(...)

Elsa: We saw the psychiatrist three times a year... We were taking bearings... But we were the only one talking about what Martin was doing, how he was... We had very little feed-back, we didn't know what they were thinking...

Thierry: what they could perceive... Elsa asked several times but it was completely vague

Me: You asked them?

Thierry: Yes! We wanted a name! We used to tell them: "We want a name on what he has, on what it is!" (fist on the table)

Elsa: We were told: "It is not possible, we can't tell you"

Thierry: We were asking: "What can we do to correct his trajectory?" Apparently it is not the way the medico-psychological centres reason...

Elsa: And, we didn't feel supported... For instance, nobody told us that we should see a speech therapist! (advised by Martin's teacher, during the second year of nursery school)

Thierry: Rather than curing the effects and correcting things, they were searching for the cause... We search for the cause and as long as we haven't found it, we can't do anything... I think they think kind of that way...

Elsa: They didn't propose anything concrete

Thierry: As long as one has not gone back to the roots of the problem... And since the roots are situated...

Elsa: before childbirth!

Thierry: It could have lasted for a long time...

The divergence of views between Martin's parents and the psychiatrist became explicit when Martin's teacher in the first year of primary school (September 2007) told Elsa that he was considering putting Martin out of school. The psychiatrist suggested that Martin

could go to school in the mornings and to the daily psychiatric hospital in the afternoons. During that period of time, Elsa quit her job because her employer didn't agree to reduce her working time and found a place in another company where she can work 30 hours a week. Thierry, who had opened a restaurant, sold his shares to the co-owner and opened a sandwich shop to have more free time.

Elsa: We looked at him (the psychiatrist)!!!

Thierry: It caused so many things, those three words...

Elsa: And I said: "He will never go to the daily psychiatric hospital!"

Thierry: It was out of the question

(...)

Elsa: I told him: "You want to put him in a hospital but you don't even tell us what he has"

Thierry: How can the hospital help him in progressing? What is the aim? What for? And that was the moment when we started wondering...having doubts with the medico-psychological centre...

Elsa: We said to each other: "We are not going in the right direction..."

Thierry: We started questioning their reasoning

Elsa: This is not what we are going to choose

Thierry: What we were expecting was: How are we going to do so that Martin can stay at school?

Elsa: That they tell us: You have to do this, you have to do that!

Thierry: They just wanted to...

Elsa: hide the misery!

At some point, the term of autism is launched. Either a psychiatrist talks about it without relating it to the child's situation (when discussing with the parents another case that seems similar to their child's) or the parents address other specialists, make research on their own and encounter the term on the Internet or a different medium.

Elsa: I remember an appointment at the medico-psychological centre...I had brought an issue of the magazine "Parents" because I had read an article on...

Thierry: on autism!

Elsa: on high-level autism...

Thierry: and we saw Martin

Elsa: I saw my son in that article! (laughter) And I showed it to Dr. T (psychiatrist) and asked: "Couldn't it be that?" And the Dr. T. answered: "What is it? Is it a medical review?" I said: "No, no, it's the magazine "Parents"..." And I realized that he was a little bit upset...

Thierry: And, that moment, it was the first time that...particularly under Elsa's pressure...

Elsa: I hit the ceiling!

Thierry: He told us about "disharmony"...We asked him: "But why don't you tell us it is that?" He answered: "We don't know yet, it is very delicate, we need experts' points of view...But, according to me, it would rather be related to disharmony..."

Me: Did he explain to you what it was?

Thierry: It was really vague...It was very psychological with large notions and concepts...My aunt, who is a shrink, told us anyway that the term "disharmony" brings together...

Elsa: a lot of different things...

Thierry: generally, when one doesn't know how to label a situation, one uses the term "disharmony", which is really useful...

Parents progressively discover an alternative to medico-psychological centres and enter another network of actors made of associations of parents with an autistic child, specialists in educational and behavioural methods and the evaluation centre, which is a recent public structure that is less marked by the psychoanalytical approach than medico-psychological centers.

From the moment when Dr. T. mentioned the daily psychiatric hospital, Elsa and Thierry started considering that the people working in the medico-psychological centre would no longer be "the experts", whose care they would leave their child in. Elsa started talking about Martin's school situation to other professionals, including Martin's speech therapist, who advised her to make an appointment with an office-based psychologist (Nelly C.) "who followed up on children like Martin". Elsa and Thierry got that appointment in early

December 2007. Shortly after that appointment, they stopped going to the medico-psychological centre.

Elsa: It lasted for 3 hours...Nelly asked us a lot of questions and we felt that she was in the concrete! We felt that the questions were...

Thierry: Yes! When she asked a question, it was like bang!

Elsa: really relevant!

Thierry: Her questions sounded correct

(...)

Thierry: She asked: "Does he do things like this? Or things that way?"

Elsa: and each time she was right.

Thierry: We answered yes to every question

Elsa: She was underlining what we did not underline...She brought out things that we didn't systematically see...

Thierry: which were to us...which didn't arouse anything to us whereas she regarded it as being symptomatic of something.

(...)

Elsa: And at the end, she asked us: "Have you ever heard about the autistic syndromes?" And she started defining the Pervasive developmental disorders, the high-level autism, the Asperger syndrome...She told me that I had to call the evaluation centre to get a precise diagnosis. (Elsa made the appointment in December 2007)

Thierry: What we liked about her way of proceeding is that she told us about the diagnosis but she also said right away: "once this is said, you have a lot of things to implement at school, at home..."

Elsa: She gives you everything you need

Thierry: And children like Martin...

Elsa: there are a lot of them!

Thierry: and some of them incredibly strengthen but, she explained to us right away, they reason differently, they learn differently, you have to work a given way... (...)

For the first time, we met someone who told us: you know, high-level autism, Asperger syndrome, some of them are surgeons! There are ways to make them evolve!

Parents are given an active place in the care of their child. They get involved into alternative arrangements of care, regarded as more efficient because they provide pragmatic answers to daily life problems and give children the possibility to stay integrated in ordinary social structures. Parents are not given the same place in the psychoanalytic approach and in the educational methods: on the first hand, parents are part of the problem to cure, or even sometimes guilty of the child's troubles; on the other hand, parents are expected to play a role in their child's care.

Elsa had a second appointment with the therapist specialized in educational methods a week after their first meeting. Nelly C. explained to Elsa a lot of techniques such as the pictograms (alternative method of communication based on pictures), the timer (that allows visualizing time that goes by), the vertical calendar (that permits anticipating events and activities) and the behaviour notebook (to reward or sanction the child's behaviours according their "appropriateness"). Progressively, Nelly C. has trained Elsa to the Montessori method (alternative educational tools) in order to work at home notions that are studied in class. Elsa spends an hour a day with Martin doing that school attending work. She has to negotiate with the different teachers the role that she can play, proving that she is ready to contribute to her child's achievement but in a way that is not too invasive.

Elsa : At the end of last year, I had gone to school to tell the teacher (second-year primary school teacher): "I'd like to know what you are going to do first, at the beginning of the year, to make Martin work on it...Are there books...things that I can start studying with him during the holiday?" And she told me: "You know, Martin is not part of my plans this year, he is still in his first year of primary school, he is not in his second year yet...We will see that next year!" So, it is true that it hurts because I was ready to make some efforts, to prepare everything so that it goes well, and I was told: "No, stop, we are not there yet..."

Thierry: I think that she didn't realize...the whole story, the attending work...It was hard at the beginning of the year...

Elsa; Yes, that's true

Thierry: But now, she has understood the method...she got it...

Elsa: She has seen that we were following up Martin; that we wouldn't give up...

Thierry: and that we wouldn't bother her if everything went right...

Elsa: I told her: "I'm not a teacher"

Thierry: If it goes wrong, we could...She has understood that we could be more involved...It is not a power relationship either but...

Elsa: but sometimes we are forced to...

Thierry: For the teacher, it is like a preserve...

Elsa: But I told her several times that I am not Martin's teacher...That **she** is the teacher and that I am not qualified to do that job...

Thierry: But we can bring...

Elsa: My role is to prepare things and prevent him from being anxious. That's it.

Then, Nelly C. explained to Elsa how to get a person helping Martin in class and how to constitute the administrative file in order to receive financial aids.

Thierry: At the medico-psychological centre, they never told us that we had the right to ask for financial aids, for someone helping your child in class...They never told us about methods helping us in daily life

Elsa: How could I express it? From that moment, we were doing something for our son! The simple fact of knowing that we could do something for him allowed us to feel less helpless. We felt active...

(...)

Elsa: And once, it was during the period when I was angry at him, Dr. T told me: "You know, Madame S., we can settle a taxi system for the consultations' driving in order to relieve you..." I asked: "How is that possible?" He told me: "I can make a certificate that allows him to come to the centre by taxi..." I understood that such a system existed at that moment. So, when I saw Martin's pediatrician, I explained the situation to her, because she was sure that the medico-psychological centre had oriented us towards the evaluation center specialized in autism...

Me: She didn't tell you about that centre herself?

Elsa: No...So I told her: "Martin takes the taxi to go to the medico-psychological centre, is it possible that write a certificate so that he also takes the taxi to go to the speech therapist?" She agreed and did it right away.

Elsa applied to the local administration for disabled people in January 2008.

She feels that the answer given to her demand would depends on her ability to demonstrate her situation, justify her son's needs and prove that what she is asking for

corresponds to those needs. Elsa also feels that her tenacity and persistence can shorten administrative time-limits.

Elsa: What we thought with my husband was that...The administrative file...I mean that we have an education...

Thierry: and you have to do it again every year!

Elsa: No, every two years. What I mean is that we have a correct level...of education let's say, but for people who, I mean, each child doesn't have parents who are capable of constituting files like that, standing up for themselves, for their situation...Because you have to be able to pass your feelings on through writing...And a lot of people are helpless in those kind of moments...

(...)

Elsa: The MDPH<sup>1</sup>, I pressed them! I urged them to process my case! And my technique is the following: I call them regularly so that Martin's file is always on the top of the pile. And it's true that after a while doing that, I would call and say: "I'm Martin's mother" and they would answer: "Yes, Madame S.!" I didn't even need to say my name anymore...(laughter)

Thanks to her "technique", Elsa received an answer in February, only one month after submitting her file. This answer consisted in saying that in the first hand, they had the right to get someone helping their child at school but there was no one available. On the second hand, they were told that they would receive 345 Euros per month to compensate for the cost due to their son's disability. At that point, the therapist told Elsa that there was only one solution: Thierry and she had to hire and pay someone for helping Martin at school, which was possible because he was going to a public school. They hired someone from March 2008 until April 2009, which cost them about 8400 Euros.

Thierry: The thing is that medico-psychological centers are the official channels

Elsa: Yes, and to be honest, as private individuals, it doesn't cost us anything. When we were going to the medico-psychological centre, everything was taken in charge

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<sup>1</sup> MDPH : Regional House for Disabled People, local administrative structure for disabled people where the decisions about disability recognition, aids attributions and persons' orientations are made.

of...We didn't have to bring out one euro...Whereas a consultation with Nelly C. costs us 50 Euros.

Parents progressively develop a critical opinion about psychoanalysis and a suspicious attitude towards public psychiatry in general. They favour educational and behavioural methods that meet their practical needs. From the ethnographic field work, we can oppose two ways of articulating the social meaning of reality and the normalization of behaviours in the care process. In the psychoanalytical approach, sharing a common sense of things leads to behaviours' normalization; so psychiatrists first work on the emergence of a shared meaning of reality. In the educational and behavioural methods, behaviours' normalization gives the possibility to share a common sense of reality, so the psychologist or youth worker tries to correct the child's behaviours in order to make them correspond with what is usually expected by others.

Elsa: I called Dr. T. after the appointment with Nelly C. and I shook him up! I told him that I was really angry, that I didn't understand! He had been following up Martin for two years and a person, whom we had met for three hours, was able to tell us: high-level autism, Asperger syndrome, Pervasive Developmental Disorders!

Thierry: and she is not a doctor

Elsa: and she told us everything that we can do! You are a doctor, you have seen him for two years, and you can't tell us that! I was really mad!

(...)

Thierry: Actually, Nelly explained to us that there was a fight between two schools: The medico-psychological centre, which is...

Elsa: Psychoanalysis!

Thierry: The French official school of psychoanalysis, Freud...As Nelly said: It would go back to the first misunderstood look between the mother and her child...

Elsa: And the behaviourists

Thierry: which is an American school that...

Elsa: that is pragmatic...Nelly says: to each problem, there is a solution.

Thierry: One creates a solution to solve the problem instead of going back to the sources of the problem...The behaviourists don't really consider the sources, at some point they ignore the cause.

Eventually, the therapist (Nelly C.) put Elsa in touch with an association of parents with an autistic child, which confirmed Elsa and Thierry's choice of an alternative arrangement of care.

Elsa: I went to a meeting (...) Other parents told me: "Have you seen Nelly C. ?" Yes. Have you started the consultations?" Yes. "You are saved! Nelly C. gets our children out (of autism)!". When you are told that, you can't help thinking: "Why god weren't I told before?"

The first consultation<sup>2</sup> in the evaluation center took place in January 2009. The evaluation process started in September 2009 and the final consultation, during which a diagnosis and/or care suggestions are given to the parents, was in December 2009. We can notice that before the beginning of the evaluation process, Elsa and Thierry were already well documented about autism and had precise expectations about diagnosis. But, they respected the role repartition between parents and health professionals and didn't reveal their expectations or claim a given diagnosis during the process.

Last consultation, 15<sup>th</sup> of December 2009:

Dr. A (psychiatrist): So, where are you in terms of diagnosis?

Thierry: we are nowhere...

Elsa: we expect a lot from you...We have made research on the Internet...But we can't replace a professional...

Thierry and Elsa were considered as "competent" parents by the health's professionals in the evaluation centre. When they first contacted the center, they were told that they would not be priority because Martin's needs in terms of care were met. Then, after the ADI<sup>3</sup>, I was

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<sup>2</sup> Consultation with a psychiatrist after which the decision is made whether or not the child is going to undergo a diagnosis process.

<sup>3</sup> ADI (Autism Diagnostic Interview) : interview with the parents led by a psychologist, composed of questions on parental observations, on the 4-5 year-old period, in three areas : communication (verbal and non-verbal),

told by the psychologist that Martin's parents were "good informers", that they knew their son very well and didn't spend too much time answering questions or give unnecessary or contradictory details. During the last consultation, Elsa and Thierry were regularly approved of by the psychiatrist:

Dr. A: What do you think about that diagnosis?

Elsa: That is reassuring because it means we are going in the right direction.

Dr. A: Yes, in terms of care, you do exactly what is expected...

(...)

Dr. A: And what about the person who helps Martin in class? Who guides her?

Elsa: She is new but it is going well...

Dr. A: Was she trained?

Elsa: I proposed to see her...Actually, I see her every morning, we have a little talk, she explains to me how it goes, what she does...

Dr. A: It is very good.

(...)

Elsa: We asked for a place in a SESSAD<sup>4</sup>, but we are on the waiting list...

Dr. A: It is very good idea. It can help the person working at school with Martin or relieve the teacher...You have found good answers and the SESSAD can be complementary to what you do. If you get a positive answer, it will not replace what you do but it will be a plus.

Parents learn with time and through meeting other parents in associations how to make a "good" administrative file.

For the second time, Elsa submitted Martin's file, which was registered on the 8th of December by the local administration for disabled people. The last consultation in the diagnosis centre took place on the 15th of December. Elsa and Thierry received the written

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social interactions, behaviours and interests. This interview generally lasts for 3 hours or so. The parents are asked to give precise examples to illustrate each one of their observations. From the parents' answers, the psychologist operates a quotation that indicates whether the researched symptom is present or not and if it's present, the degree to which it manifests itself.

<sup>4</sup> SESSAD : structure that offers the help of a youth worker at home (an hour and a half per week) and at school (an hour and a half per week), consultations with different health professionals, "social skills group" (group in which children are trained to understand and use common social codes)...

diagnosis certificate in mid-January. Elsa called the MDPH to add this certificate to Martin's file, which was possible because it had not been evaluated yet. They received the administration's answer on the 4th of April : Martin was allowed to get assisted in class for 12 hours instead of 9 hours ; and Elsa and Thierry were to receive the same amount of money per month, considering that they didn't have to pay for the person helping Martin at school anymore.

The first step in the process of access to public offer and rights is to get the problem defined. To get one's child diagnosed as autistic opens possibilities of claims, because it includes the child in a public that is identified and targeted by a policy. Nevertheless, as seen before through the case of Elsa and Thierry, access to a diagnosis is preceded by a long trajectory made up of multiple encounters with health professionals, appeals to associations of parents and researches on different media. Elsa and Thierry used familial resources (the aunt who is a psychologist) to question other diagnosis (mental retardation, disharmony); they confronted a psychiatrist with their beliefs based on other sources of information; they appealed to an association to get confirmed and supported by other parents.

It is difficult for the researcher to analyse the cases of children who may be diagnosed as suffering from autistic disorders but aren't because first, the researcher can't use the medical characterization of problems and arbitrary apply it to some children's situations. Secondly, it is difficult for the researcher to deal with a problem that is not identified and named. The issue of diagnosis is twofold: the problem may not be diagnosed by the health professionals and/or the diagnosis upon which health professionals act may not be said to the parents.

We can formulate the hypothesis that some parents can't initiate a possibly conflictual process to access diagnosis or don't realize the value of such a medical label in the administrative area. Furthermore, the ethnography of the evaluation centre allows showing that if parents can be regarded as responsible for their child's troubles, that is to say if health professionals consider that the child's problems may be due to a faulty relationship between the parents and their child; they don't label the child's condition as being autistic but rather characterize the child's situation as marked by an "emotional deprivation" or a "relational problem".

Thus, we can identify several obstacles in the medical world: a lot of psychiatrists in medico-psychological centres don't want to give a diagnosis to the parents; autism diagnosis is controversial; to get one's child diagnosed as autistic signifies that parents have been able to prove that they are not responsible for their child's troubles. It also appears that a lot of health professionals are reluctant to refer to autism, which seems to be taboo: in Martin's case, both the speech therapist and the pediatrician must have suspected that Martin's condition could be diagnosed as autistic but never shared their thoughts with his parents.

The observations of the way the evaluation team functions in the administration for disabled people also allows understanding that the medical judgment is dominant in the final decision about the child's orientation and the aids' attribution : If the psychiatrist considers that he doesn't have enough information, the file is not evaluated and the decision-making postponed. A written diagnosis clearly helps in getting the situation better apprehended; even though officially, diagnosis is not to be taken into consideration to favour the evaluation of the "global situation".

Autism has a liminal place: it stands in between disability and mental health. It has been recognized as implying disability that must be compensated for but at the same time it has a special place within the disability field as long as it is not that fixed and seems to offer possibilities of evolution. Public action towards autism is ambiguous: it stands in between psychiatric and medico-social structures, disability and mental disease, therapy and education. Parents like Elsa and Thierry, who can rely on different resources (social, financial, cultural) have the possibility to avoid specialized structures and access their rights (schooling their child in an ordinary institution, and getting their child's disability compensated for). They can implement alternative arrangements of care that are, at least partially, financed by the public system of disability compensation. But we can assume that some parents don't get a diagnosis for their child's situation and don't have the possibility to consider an alternative to psychiatric or medico-social institutions.

Elsa and Thierry's trajectory shows that psychiatrists in medico-psychological centres don't always inform parents about the possible administrative procedures: taxi system, disability compensation, assisting person at school. We can also assume that all parents don't have Elsa and Thierry's capacity to contest a given proposition of care; to conceive, partially finance, and implement an alternative arrangement of care; to follow-up their child's schooling; to explain their needs and to argue their demand of public aids. Elsa and Thierry have managed to get considered as "competent" parents by different actors in the medical, administrative and school areas. They satisfy those actors' expectations in terms of parenting.

We can assume that some parents don't pass the informal selective moments during which their position as parents is tested.

The ethnography of the evaluation centre shows that parents may not be considered as responsible for their child's condition in some alternative spaces of public psychiatry but that they are made responsible for the child's trajectory. The proclaimed aim of the evaluation centre is to "parentalize the parents", to "set them to work". The recognition of parents as acting in cooperation with health professionals for the child's care is based on two conditions: to share the professionals' view on the child (instead of "denying" the child's disability) and to be able to infuse therapeutic concerns in daily life, to copy professionals' techniques while keeping an "authentic relationship" with the child and avoiding the confusion between the roles of parent and that of professional.

Moreover, the evaluation of administrative files depends on the way parents motivate the plan that they conceived for their child, demonstrate its coherency, and justify its costs. Their argumentation may also be supported by someone who knows them and has access to this decision-making arena. The psychiatrist, who is also the head of the diagnosis centre, takes part in the evaluation of the administrative files. She more strongly supports the demands of parents whom she met for a diagnosis process and whose needs she knows better. Likewise, parents who have good relationships with the referring-teacher for their child may be better supported if that person is also part of the administrative commission that assesses the evaluation team's decisions.

Eventually, even though the possibility to send one's disabled child to school is a right that was recognized by the 2005 French law on disability, parents must satisfy a lot of conditions to make that formal right a reality. They have to negotiate at school the role that they can play. They are expected to show that they are involved in the child's achievements but should not give the impression that they question the teacher's competence and authority. Parents can give some advices but should not tell the teachers what to do; their desire to get their child schooled in a ordinary institution is legitimate as long as this desire seems realistic to the teachers; the educative goals must be agreed by both parents and teachers; parents should be ready to give up some of their demands to get their child accepted to school.

## **Conclusion:**

This research permits understanding the way in which an ambivalent public action ends up in dualizing the child's trajectories, according to the parents' resources. It raises the major following question: as the principle of individual responsibility is becoming predominant in a lot of public health and social issues, to what extent do individuals' uses of a public offer become an implicit regulatory mechanism of a public policy? We may argue that public action towards autism relies on the parents' capacity to make use of the possibilities that it opens. The fact that parents be in charge of what their child becomes triggers social inequalities and opens up a lot of intermediary spaces of selection in different fields (school, administrative and medical), which questions the political delegation of problems' characterization and debunks the myth of the user's choice.