

## **Presentation IPA Cardiff – June 2011**

My presentation is entitled: “When public action relies on “parentality” - The case of autism”, parentality being defined as the body of practices linked with the social status of parent.

It is based on an ongoing PHD research concerning the trajectories of children for whom autism is evoked at some point; trajectories being analyzed in terms of both problem characterization and care arrangements.

This research uses qualitative methods at a local scale (French “department”):

- Ethnography of different decision-making spaces concerning the schooling of an autistic child in an ordinary institution, the administrative compensation for the child’s disability, and the medical characterization of the child’s condition.
- Case analysis, that is, one-year follow-up with five families from the moment when they started a diagnostic process in a specialized evaluation centre. I observed the different steps of the diagnostic process in the center and regularly met the parents, or one of them according the cases, for interviews, once a month.
- Interviews with the people I progressively identified as being part of the local regulation system for autism.

The aim of that research is to understand the logic of the children’ trajectories in articulating different actors’ points of views according their position in various worlds (school, medical, administrative, family).

This presentation aims at showing how parents with a child whose condition may be diagnosed as autistic can move away from public psychiatry and produce alternative caring arrangements by using an ambivalent public offer. The attempt to classify mental disorders that went together with the rising of psychiatry during the 18<sup>th</sup> and the 19<sup>th</sup> centuries never ended up in the definition of homogeneous categories and a clear distinction madness and intellectual limitations. Nevertheless, even though the characterization of mental disorders at a micro-level remains vague and fuzzy, the frontiers between the disability field and the mental disease institutions are very strong. Thus, public offer is ambivalent between disability and psychiatry.

The idea is to look at the people who access their rights or make use of that ambivalent public offer to understand why other people may not. The goal is to analyze the 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 obstacles they overcome.

That analysis allows assuming that some parents probably lack the needed resources and/or fail the informal tests in intermediary spaces of problem-characterization and decision-making.

I would like to argue that there is a dualization of the children' trajectories according individual factors (parents' critical competences and resources) and structural factors (litmus tests of parentality in intermediary spaces of problem-characterization and decision-making).

The children' trajectories fork from the moment when parents enter a medico-psychological centre, which is a public structure that is attached to a public hospital and offers mental health care in a given geographical area. French medico-psychological centres are generally under the influence of psychoanalytical approaches to autism. Two ideal-typical trajectories can be drawn from that initial meeting with public psychiatry.

Either the child is followed up by the medico-psychological centre as an outpatient and eventually enters a daily psychiatric hospital.

Or parents end up leaving the medico-psychological centre; obtain a diagnosis of autism in a specialized evaluation centre, which is less marked by psychoanalytical approaches; and organize alternative caring arrangements that are characterized by : the appeal to self-employed health professionals who work with educational and behavioural methods ; the schooling of their child in an ordinary institution with a person helping him or her; the administrative compensation for their child's disability (the financing of the consultations and of the mother's working-time reduction or work withdrawal).

My paper is based on a case analysis that exemplifies the second type of trajectory, in underlining the types of obstacles that some parents may not succeed to overcome in order to choose for their child. But here, I don't have the time to present that case analysis. So I will only draw the main conclusions.

### **When parents distance themselves from public psychiatry, they first use personal resources:**

They mobilize their close relatives and/or appeal to self-help organizations of parents with an autistic child. They also partially finance or at least advance money to implement alternative arrangements of care. They devote time to organizing these arrangements: mothers generally quit their job or reduce their working-time.

### **Parents also display critical competences:**

First, they condemn public psychiatry for offering inappropriate and inefficient care. They criticize the fact that public psychiatry, which is largely influenced by psychoanalytical approaches, consists in searching for the meaning of the child's behaviours rather than trying

to make them better adapted to social life. Thus, it does not provide pragmatic solutions to their daily life problems and fail to favour the child's social integration. Parents progressively redefine care as an issue that is more educative than medical. Finally, they question the position that they are given in the medico-psychological centres. The psychiatrists are reluctant to give a diagnosis to the parents, because the latter are considered as being part of the situation to diagnose and cure. They may no more be held responsible for the child's initial condition but the dynamics of their relationship with the child (reactions to their child's problems and to the diagnosis announcement) is regarded as decisive in the symptomatic expression of the child's condition. Parents ask for clear diagnosis announcements that give them the necessary information to position themselves as decision-makers. They also want to be given an active role in their child's care.

**Parents progressively accumulate competences:**

They learn how to make a "good" administrative file, that is, demonstrate their situation, justify their child's needs and prove that what they are asking for corresponds to those needs. They also develop techniques to shorten administrative time-limits. They get involved into the child's care and become "experts" by infusing therapeutic concerns in daily life and reproducing health professionals' techniques at home. They also develop organizational skills in terms of timetable adjustment, events anticipation, circulation of the information between the different actors. They finally acquire knowledge about autistic disorders.

**Parents are made responsible for their child's development:**

The ethnography of an evaluation centre shows that parents are made responsible for the child's trajectory. The proclaimed aim of the observed 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 problems) and to be able to copy professionals' techniques while keeping an "authentic relationship" with the child and thus, 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 life-plan that they conceived for their child, demonstrate its coherency, and justify its costs.

Finally, parents must satisfy a lot of conditions to make the formal right of sending one's disabled child to an ordinary school 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.

Eventually, we can formulate the hypothesis that some parents cannot initiate a possibly conflictual process to access diagnosis. Some parents may not have the capacity/possibility 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. They may not manage to get considered as "competent" parents by different actors in the medical, administrative and school areas, as they may not 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 gets tested.

This research allows understanding the way in which an ambivalent public action ends up in dualizing the child's trajectories, according 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.

Eventually, the parents who don't get their child's disability compensated for and their child schooled in an ordinary institution, that is the parents whose child is in a specialized stucture, should not be approached only in a way that underlines what they lack from in terms of resources and competences. This analysis shows resources and competences that must be activated by parents so that the social integration that is advocated in the official textes becomes effective. But it also shows how the different institutions (school, administration, medicine) select parents in evaluating their "parentality" redefined as an educative competence. My presentation raises a tricky question : the "obstacle course" described by

parents does trigger social inequalities but that conclusion must be nuanced in two ways: First, the access to rights and the production of alternative arrangements of care is not a better option; the “obstacle course” discourse that is produced by some parents implicitly judges other parents who don’t go through that “obstacle course”, who are both accused and excused; both victims (lacking from the necessary resources and competences) and culprits (resigned and not assertive), and in the end not competent parents. That is why it is crucial to question the institutional construction of that “obstacle course” and the structural conditions under which a choice is possible.