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Céline Borelle, EASA conference, “Crisis and imagination”, workshop 123

The crisis of French psychiatry through the case of autism

Field work

This paper is based on a six-month non-participating observation in an evaluation centre specialized in autism diagnosis. The evaluation “team” is composed of several disciplines: two psychiatrists for children, four psychologists, one psychomotricist, two speech therapists and a secretary. The evaluation centre is situated in a French psychiatric hospital. This field work has consisted in observing the different steps in the diagnosis process (first consultation, standardized tests and assessments, synthesis discussion, finale consultation) and the clinical and therapeutic dialogue meetings (collective discussions between psychiatrists on the cases considered as difficult). My presence in the evaluation centre also gave me the possibility to observe informal discussions between health professionals, which were most of the time about narrating and discussing the cases. This field work has been completed by the follow-up of five families who have started a diagnosis process for one of their children in the evaluation centre. The parents, or one of the parents according the families, were met once a month during this year.

Autism

Autism remains uncertain regarding diagnosis, aetiology, treatment and prognosis. First, it triggers chronic conditions. The current consensus on autism is that there is no way out of the autistic condition and that an autistic person can't be cured. Secondly, autism presents biomental aspects and remains causally undetermined. Autism is a clinical diagnosis; a series of symptoms, as far as the origin of autistic troubles is unknown. Third, autism is therapeutically diverse. In France, there is still an unresolved conflict between psychoanalysis and educational methods. Fourth, autism has fuzzy boundaries: the limits of the autism spectrum are uncertain.

The conception of autism in France has evolved over the years as well as the definition of the medical category. After being regarded as a form of psychosis (the term is still mentioned in the French classification of mental disorders for children and teenagers¹), autism has now appeared in medical classifications as part of the larger category of “Persuasive

¹ CFTMEA, last version published in 2000

Developmental Disorders” (PDD) since 1980 in the United States (DSM III²) and since 1993 at a worldwide level (ICD-10³). In June 2005, “recommendations for the professional practice of autism diagnosis” were published by the French Federation of Psychiatry in partnership with the High Authority for Health. This text uses the definition proposed in the ICD-10: “a pervasive developmental disorder defined by the presence of abnormal and/or impaired development that is manifest before the age of three, and by the characteristic type of abnormal functioning in all three areas of social interaction, communication, and restricted, repetitive behaviour”.

The associations of parents with an autistic child created in the 1990s have fought to get autism defined as an organic disorder with a neurobiological origin and claimed the necessity to improve research on the genetic lead. They want to get away from the psychiatric world and reject the psychoanalytic approach, as it makes them feel guilty, mothers in particular. A short insight in the history of autism is necessary to understand why parents’ associations have taken such positions. The first definition of autism was elaborated by Leo Kanner in 1943 from the clinical observations of eleven children. Autism was characterized by three distinct traits: desire for loneliness, aspiration to “sameness”, and language abnormality⁴. Leo Kanner had evoked biological reasons to explain this incapacity to establish affective contact with others. But he also mentioned that he had observed relational problems between the parents and their child, the mother being cold or “refrigerator” and the father being a highly-skilled absorbed intellectual. What remained an empirical observation in Leo Kanner’s view was invested with a principle of causality by Bruno Bettelheim⁵, who proposed a psychoanalytic explanation of autism in 1967. According to him, the parental relationship, notably the mother’s coldness, could partly explain the child’s troubles. The recognition of autism as being a disability in 2005⁶ was considered as a victory by the associations insofar as it was taking autism away from the mental disease and therefore from psychiatry.

Parents’ associations’ demands in terms of care have evolved in the last decades. In the 1970s, the psychoanalytic approach was dominant and it promoted the child’s separation from the parents considered as pathogenic together with placement in psychiatric hospitals. The first parents’ associations were created to ask for the increase of places in psychiatric hospitals and the creation of supplementary institutions in order to avoid the radical separation

² DSM : Diagnostic and Statistical Manual, published by the American association of psychiatry, last and fourth version in 1994

³ ICD : International Classification of Diseases, published by the WHO, in 3 volumes (1993, 1995 and 1996)

⁴ Leo Kanner, « Autistic disturbances of affective contact », *Nervous Child*, vol 2, p 217-250, 1943

⁵ Bruno Bettelheim, *The empty fortress. Infantile autism and the birth of the self*, New York, 1967

⁶ Law for “equal rights and chances , participation and citizenship of the disabled people”, 11th of February 2005

of the child from the family due to the absence of structures. In the 1990s new associations were created which were inspired by the American autism model, in its conception as well as in its care methods. These associations have been working for the importation of American behavioural and educational methods in France and promoting the schooling of their child in ordinary institutions (B. Chamak, 2008). The right to send one's disabled child in an ordinary school was recognized with the 2005 law mentioned before.

Diagnosis: a conflicting process

Autism is still a disease “you have to fight to get” in France using Josphe Dumit's paper title (2006). The psychoanalytic approach is dominant in public health centres and a lot of psychiatrists are reluctant to use that diagnosis to qualify the child's condition due to the labelling effect. They don't want to rigidify a situation that can evolve. Parents' stories about their diagnosis trajectory raise the difficulty of getting a psychiatrist to talk about autism. Nevertheless, the psychiatric world can't be defined as a unified world. Psychiatrists don't consider diagnosis in the same way and then don't have the same diagnosis practices. Psychiatrists who have a psychoanalytic approach of autism are reluctant to give a diagnosis to the parents as it was underlined before. But other psychiatrists, more open to the educational and behavioural methods, favour early diagnosis insofar as, with adapted methods, the symptoms can evolve.

Access to a diagnosis is preceded by a long trajectory made of multiple encounters with health professionals and appeals to associations of parents. The ideal typical trajectory starts with a first appeal to a public health centre when parents consider that there is something wrong with their child. Parents end up taking distance from this centre because they are not given a diagnosis and they are not told what they can do for their child, whose situation doesn't seem to improve. 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 make research on their own and encounter the term on the Internet or a different medium. Once the term has popped up, parents usually contact an association of parents with an autistic child. They are told by other parents to take distance from the public health centres and are redirected towards a specialist in educational and behavioural methods. They are also oriented towards the evaluation centre, either by other parents or by the specialist, to get a diagnosis.

Diagnosis process in the evaluation centre also reveals conflicts within the psychiatric world. First, the psychiatrists of the evaluation centre are theoretically confronted with the

other professionals who intervened into the child's medical trajectory. When parents start the diagnosis process, they are asked to give all the written accounts for past medical assessments or past encounters with health professionals. Those documents are gathered in the child's medical file. Psychiatrists are problematically confronted with the child's past medical trajectory when the child's condition has been qualified with different labels by different psychiatrists and when parents ask the evaluation centre to handle that diagnosis affair. Those situations are difficult to deal with for psychiatrists because they have to face parents who have become suspicious about diagnosis reliability. Those trajectories characterized by successive medical requalifications question the legitimacy of psychiatry to name problems. They reveal the psychiatric world's plurality, which is considered as a lack of coherency threatening the individual credibility of the psychiatrist in the eyes of the parents.

Secondly, conflict also arises during the synthesis discussions between the professionals who have diverging ways to conceive autism and different views on diagnosis utility and reliability. A psychiatrist left the evaluation centre during my observation, saying that he didn't believe in the autism diagnosis enough to label children with it. That is to say he didn't think that autism was a separate pathological entity. He was also questioning the relevance of creating specialized diagnosis centres as these kinds of structures were separating diagnosis and care. According to him, a doctor was supposed to diagnose a condition and follow up the child's trajectory in terms of care. Diagnosis on its own was of no use. This raises the central element that triggers tensions in the psychiatric world: the growing disjunction between medicalization and diagnosis. Associations of parents with an autistic child fight to spread autism diagnosis but it doesn't trigger medicalization as far as they reject psychoanalysis and favour methods that require no psychiatrist and sometimes even no health professionals. The recognition of the necessity to diagnose autism does not imply medicalization of the object, quite the contrary. The associations of parents with an autistic child have rather encouraged a demedicalization of autism. As opposed to Zola's conclusions (1972), diagnosis doesn't always play a role in medicalizing a phenomenon. Diagnosis is progressively disconnected from care. It is considered as being a medical affair by the parents whereas care is becoming non-medical and more educational.

As said before, parents usually have diagnosis expectations before arriving at the evaluation centre. All the more so as following a process of diagnosis in a specialized centre means that there is a precise qualification hypothesis. The diagnosis process doesn't take place in context characterised by an open range of labels possibilities. Psychiatrists pay attention to those expectations and take them into consideration. They try to feel where

parents stand in their diagnosis quest. The psychiatrist adapts the way he announces diagnosis to the parents according to their position towards diagnosis. But the limit to the influence of parental expectations on professional diagnosis is the parental respect of the roles repartition: Parents inform and professionals name. Professionals are not sensitive to parental expectations when they are under the impression that parents want to manipulate them or influence their judgement. In so doing, parents, not always willingly, question the power of psychiatry to name problems. Parents may have expectations about diagnosis but they can't act as if they knew how to label their child, which is interpreted by professionals as an illegitimate claim of diagnosis. Health professionals fear that parental diagnosis claim all the more with the development of the Internet. Indeed, the growing use of that medium favours more precise parental diagnosis expectations and also a more critical view on the psychiatric field (C. Méadel, 2006). Parents' empowerment, through the use of the Internet and the appeal to associations' expertise, questions the logic of the relationship between doctors and patients. Some psychiatrists negotiate with parents new ways to relate to one another whereas some others have difficulties to reframe this relationship.

Creating practical arrangements of care

Parents participating to that research all refused the psychiatric hospital and have created specific arrangements to take care of their child. These arrangements are dynamic: equilibriums changing over time. They may include different health professionals (psychomotricist, speech therapist), specialized educators coming at home, moments of socialization in groups of children, a few hours at an ordinary school... In most of the cases, the arrangement of care is orchestrated by the parents with the help of a person specialized in behavioural and educative methods, whom parents usually see once or twice a month. This specialist studied psychology in France and went to the United States to get trained to behavioural and educational methods. She belongs to an important association of parents with an autistic child in the studied geographical area. The arrangement of care is renegotiated over time with that specialist, according to the child's evolution and the parents' constraints. Parents are the "plan chiefs", as one of the interviewed mothers puts it. They feel they can decide for their child: they choose "their" professionals and the methods. They are in a powerful position as they are the only one to know all the people involved in their child's care. Therefore they can control the way information circulates among those people.

Parents are not only involved in their child's care in terms of choice. They also take a very pragmatic place in it. The specialist in educational and behavioural methods creates a

practical solution for each problem that parents encounter with their child (sleep difficulties, food problems, violence, dirtiness, and difficulties to learn reading or counting...). Parents are supposed to put in practice the specialist's recommendations at home. Parental involvement in the child's care concerns school work but also every moment during which an "inappropriate behaviour" may emerge. Parents are expected to infuse a therapeutic concern in a lot of daily activities, which questions the boundaries between parents and professionals. Parents use a lot of techniques and tools that are created by different health professionals in order to structure the child's environment, control his/her behaviours and reach better communication with him/her. For instance, parents may use different techniques in order to increase the child's capacity to anticipate things: the "timer", which shows the amount of time that the child must wait before a given activity ends or a "vertical calendar", figuring the enchainment of the daily and weekly activities.

Some psychiatrists in public health centres try to discourage parents from using those tools and techniques in saying that the child is raised like a conditioned animal and that those methods don't work on the emergence of the child's subjectivity. Other psychiatrists, such as those working in the evaluation centre, accept this parental involvement in the child's care considering that it is efficient in terms of normalizing his/her behaviours, in other words making them better adapted to social life. Those psychiatrists consider that parental involvement is the key element in the child's development and most of their advices concern "parentality": the way to be parents with an autistic child. The purpose claimed by the evaluation center is to "make parents become parents". Parental practices are expected to take professionals' practices as examples, which blurs the frontier between expertise and "common sense", in the parents' position as well as in the professionals' position. "Parentality" is turned into an educational competence. But the way parents make theirs professionals' practices must respect the difference between the role of curer and the role of parent. Psychiatrists in the diagnosis centre evaluate the parents according to their capacity to "remain parents". The "all therapeutic" is condemned by the psychiatrists and the latter prone an "authentic" relationship between parents and their child, in which therapeutic concern is infused. Parents are expected to initiate activities that are deprived from any educative interest with their child. If psychiatrists are under the impression that parents always refer to the notion of utility in their actions, they consider those parents as being "incompetent".

Due to the uncertainty that characterizes autism, there is a profusion of experimentations. A lot of methods are imagined by both parents and professionals to care for autistic children. Some psychologists get specialized in behavioural and educative methods

and they imagine tips to respond to every single situation encountered by a given family. Some parents create their own association promoting a self-made method of care that has worked for their child. Parents may try a lot of methods in order to find something that “works”. They appeal to a lot of associations, attend training sessions to get familiar with different methods of care, try different methods of communication, antibiotic drugs, paramedical practices...Each couple of parents decides where to put the limits in that pragmatic quest. Psychiatry is confronted with the fact that it is more and more dispossessed from one of its objects. From the canonic object that is psychosis, autism has become a liminal object between mental disease and disability that includes an increasing diversity of actors. The issue for the French psychiatry is to prove that its place is legitimate in the autistic people’s care and that it shouldn’t be reduced to a diagnosis role. What is currently at stake in France is the collective attempt to establish a dialog between the different schools of thought. In order to defend their position in the constellation of actors involved in the autistic field, some psychiatrists try to overcome the conflict between methods and to give a different place to parents in their child’s care.