

# HOW AUTISM IS LIVED: ETHNOGRAPHIC NOTES ON THE CARE THAT RECOVERS THE DEVELOPMENT<sup>1</sup>

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**Abstract:** Biomedical professionals say that autism cannot be cured. They say that it will remain within the person until her last days of life. But, on the other side, they say that its damages can be mitigated, they say that proper stimulation and orientation can reduce the impact of autism in a person's body and mind. This way of dealing with this mental pathology is what the biomedical professionals and the therapists would call recovery for the autistics. Taking stimulation and orientation together, it can be said that, for autism, recovery is a way of care that aims to develop the person. To work, this care has to be intensively done in a daily basis throughout the person's life. How this "care that develops" is done in practice? I have been doing ethnography with professionals and families that deal with autism in Brazil, accompanying their practices and efforts to bring more "quality of life" for the autistic. I would like to demonstrate that this "care that develops" only works if it is practiced in a quotidian basis, that is to say, if life becomes a never-ending act of stimulation and orientation. This will only be achieved if a collective of persons, actions, ideas and objects are mobilized. To develop an autistic person, not only the biomedical professionals and the therapists are working, but, also, a whole compound of agents are stimulating and orientating the infant. The family, here, is the main center of this work of collective collaboration.

**Keywords:** Autism, Development, Cognition.

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## 1 – From the psych to the brain

The history of autism can be summarized as a process that begins identifying it as a psychic disturbance to arrive, nowadays, in its conception as a fundamentally cognitive and sensory disorder. This history begins in 1943, when Leo Kanner, an Austrian psychiatrist who emigrated to the United States, publishes *Autistic disturbances of affective contact*, an article which describes the behaviors of eleven children he observed as the head of child psychiatry at John Hopkins hospital in Baltimore. Difficulties in speech, incapacity to make direct visual contact, patterned movements repeated constantly and a certain obsession for the conservation of daily routines, all these behaviors were interpreted by Kanner as symptoms of the “(...) *children’s inability to relate themselves in the ordinary way to people and situations from the beginning of life*” (1943, p. 242). Kanner understood that what is affectively external, strange or extraordinary were taken by these children as an invasion of themselves, as if it were enemies of the control that they have established of their everyday and of their social environments, proved by the constant fits of rage and despair that they demonstrated with any change of routine. Therefore, the key symptom of autism would be an affective disturbance, an “(...) *innate inability to form the usual, biologically provided affective contact with people, just as other children come into the world with innate physical or intellectual handicaps*” (Idem, p. 250). The article is concluded with a statement that parental relationships can be the source of the disturbance. Kanner describes the parents of the children observed as intellectuals, obsessed by the transmission of scientific and artistic knowledge to their sons and daughters and as individuals that are somewhat affectively distant, weaving only formal relationships with other individuals. It is needed, Kanner arguments, investigate how the parents personalities impact on the emergence of autism in these children (Ibid, p. 250).

Like almost all his colleagues of profession in the first half of the 20<sup>th</sup> century, Leo Kanner saw in psychoanalysis not only an useful theory to explain and treat the maladies of the mind, but also a productive tool to constitute the medical and popular recognition that psychiatry missed (SHORTER, 1997, p. 145-189). Therefore, Kanner’s definition of autism is an interpretation of the psychoanalytic theory of the epoch. A difficulty to understand sentiments and to experience affective relationships with the others would be the product of a highly intellectualized and emotionally

empty parental upbringing. Kanner developed this explanatory route in subsequent studies, but its most expressive, compelling and impactful articulation was elaborated by another Austrian who also landed in the United States in the first decades of the twentieth century. In 1967, the psychoanalyst Bruno Bettelheim publishes *The empty fortress*, in which his conception of autism, which had been tailored since 1944 through his reflections and activities as a professor of child psychology at the University of Chicago and as director of the Orthogenic school in the same town, takes the shape that will become world famous. Interpreting autism as a defense mechanism of ego against the world, sort of a thick bubble in which the child would enter in order to lock any reciprocity between her and the others, Bettelheim stated that the trauma that raises this pathology is a consequence of destructive intentions and negative emotions of the parents (1967, p. 72), mainly, the mother. This is not to say that the mother consciously want her child's autism, but to infer that the child perceives and feels rightly that she is not desired, wanted and loved by the mother (Idem, p. 78). Thus, for Bettelheim, the autistic child is the empty fortress, edified by the aversion that the refrigerator mother unconsciously has for her<sup>3</sup>.

As Murray (2008) demonstrates, throughout the first decades of the second half of the twentieth century, the pejorative representation that was made of autism, to some extent, is a product of the Kanner and Bettelheim perspectives. On one hand, the child regarded as a kind of child-wolf, a variation of those stories of boys and girls raised by animals in the forests, refracting language that communicates and socialization based on tender affects. Any attempt to contact these children guard the risk to be answered by attacks, bites, kicks and punches, since it is thought that she wants to be left alone in her own world, oblivious to what her community, her country and even her species share. On the other hand, the parents, especially the mother,

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<sup>3</sup> Charge the mother with the responsibility for the mental illness of the child is a striking aspect in the psychopathologies psychoanalysis history. If Kanner already points to it in autism, Fromm-Reichmann (1948), one more Eastern Europe émigré to the United States, articulates it in schizophrenia, blaming the “schizophrenogenic” mother for the child condition. Anyway, in autism, the thesis of parents as a source of the pathology is still present, even after the whole campaign against Bettelheim and, by extension, against psychoanalysis, that parent organizations have mobilized (NADESAN, 2005; ORTEGA, 2008). However, currently, the argument is of genetic nature. Geneticists believe that a “broad autism phenotype” is spread throughout the family of the diagnosed. In my ethnography, the doctor whom I follow emphasizes the same point in the consultations, stating that genetic mutations that lead to autism are already in the parents, but manifesting themselves in their behaviors in a “more smoothly manner”. In the same way, the idea that more intellectualized parents have more chances to have autistic children is still recurrent. Simon Cushing e Jami Anderson, married, philosophers and parents of an autistic child since 2006, in the introduction to a collection of texts about autism they arranged, tell us that in the first consultation with a neuropediatrician, when he got to know what they did for a living, shouted “well, *no wonder!*” your son is autistic (2012, p. 2).

blamed for not knowing how to adequately love and raise their sons and daughters. The child has an outbreak at the supermarket, screaming and throwing herself against the shelves desperately? Well, according to this imaginary, is lack of education, is the act of a spoiled child whose parents do not set limits. The child does not make friends at school? Well, what a strange family, one that does not show the necessities and pleasures of friendship. It is cold people, it is thought, heartless people whom had kids without really wanting to have kids.

This social perception of autism was severely criticized by the families of the diagnosed. As if the care extremely wearing and complicated was not enough, these families had to live with the image of their children as sort of savage beasts and themselves as the main guilty for such condition. Moreover, in large measure, parents felt that this psychiatric conception of psychoanalytic bias did not consider the particularities of those children and of themselves. While they thought they had, at home, kids that are affectionate and interested in relating emotionally to other children, the doctor said that their child were socially mute and had an affective disorder. As they saw themselves as people who loved their offspring, willing to do anything for the good of them, the expert identified their psychic apparatus as the main factors responsible for the outbreak of autism<sup>4</sup>. It is not surprising to perceive, therefore, that the cognitive turn of the conception of autism was widely supported by the families. Indeed, it is not surprising to know that was one of them that actually triggered this transformation.

Mother of an autistic girl and founder of a parent organization, the English psychiatrist Lorna Wing publishes, in 1981, an article that presents to the anglophone debate the ideas of Hans Asperger, another Austrian interested in autism in the 40s and 50s decades but, unlike Kanner and Bettelheim, wrote in German and did not emigrate to the United States. Lorna coins the term Asperger syndrome to name the condition of children, youth and adults who were seen by their parents and clinicians as interested in what goes on around them but, somehow, unable to live harmoniously with others, who seemed articulate well their opinions and views, but expressed them in a too mannered way to their ages or to the context, people who seemed to have extraordinary intellectual abilities but, in some way, seemed to be unconsciously

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<sup>4</sup> Some accounts of north-american families bear witness to this fact, as Barron & Barron, 2002. Anyway, as indicated in the previous footnote, the rejection of psychoanalysis by the families is very well confirmed by all parent organizations that emerged in the 70s, in United States and Europe, putting them in favor of autism, but against the refrigerator mother theory.

strange, exotic or as the author prefers, *gauche*. Lorna argued that Asperger syndrome was a very similar condition with Kanner's autism: symptoms would be the same, difficulties in communication and social interaction, but the severity of the cases, not (1981, p. 115-130). Thus, the syndrome would be a kind of a light or high-performance autism, terms which became commonplace among researchers who followed the path opened by Lorna Wing, as can be seen in the collection published by the British psychologist Uta Frith, in 1991, which one finds, besides several contemporary contributions, the first English translation of the Asperger's 1944 text.

Reading Asperger's text, one can imagine the reasons that made Lorna Wing prefer open a new file with his name on the archives of autism instead of widen Kanner's category. Lorna is a partisan of a treatment that, in terms of psychiatry, can be considered, let us say, more propositive: orientation to the parents about the cares that must be given to child at home, multidisciplinary therapies and, above all, inserting the child in schools sensible to the autistic particularities, with teachers capable of stimulate her development. Well, Kanner was a chief of an infantile psychiatry hospital which treated the autistic interning them, while Asperger practiced the *Heilpädagogik*, a pedagogic medicine originally architected by nuns and psychiatrists with the aim to provide some treatment to the mentally ill in Austria amidst the rubble of the first world war (FRITH, 1991, p. 7-10). Asperger graduated and worked in the hospital that was the center of this medicine, the University Pediatric Clinic in Vienna (Idem). The purpose of this medicine was to identify the main problems of the patients through psychological tests and, from this, to propose intellectual and bodily exercises that not only filled their time but, also, that stimulate them in a holistic way. The idea was to offer some possibility of social integration, some chance to live just as a normal individual – whatever that is – lived.

From Asperger's text, emanate this enthusiasm with the pedagogic medicine when, for example, he writes that “*we are convinced, then, that autistic people have their place in the organism of the social community. They fulfill their role well, perhaps better than anyone else could (...)*” (1991, p. 89). A medicine of orientation and stimulation could help the autistic “*(...) intellectually intact (...)*” (Idem, p. 85) not only find his place in the organism of the community, but also, gives him conditions to develop abilities that are, in Asperger's view, rarely executed by normal individuals: “*able autistic individuals can rise to imminent positions and perform with such outstanding success that one may even conclude that only such people are*

*capable of certain achievements*” (Ibid, p. 88). While the normal, argues Asperger, would usually be worried by social concerns that drain their concentration and focus capacities, the autistic, self-absorbed, would be heavily mobilized by one and only subject which makes him, since early childhood, explore it in the most constant, focused and arduous way. Asperger exemplifies his argument summarizing the professional life of one of his patients, whom, fond of mathematics since he was three years old, would have indicated, in his doctorate, a mistake in Newton’s calculation (Ibid, p. 88- 89). So, for Asperger, the intellectually intact autistic, when adult, will certainly have difficulties in his affective and familial relationships, but, on the other hand, due to the extraordinary intellectual capacities that the deficiency has given him, can achieve success results and positions in his professional life. The world of labor is the way through which the autistics not only find their place in the community, but the means to them make some good for the social organism. In an epoch that the psychiatric treatment was done by hospitalization or by psychoanalysis, Asperger thought and executed a medicine that proposed to take care by a neurologic reformulation that aims the transformation/suiting of individual behavior.

Nevertheless, the entry of Asperger in the debates about autism is indelibly marked by the etiologic and clinical perspective of the group headed by Lorna Wing. Bringing into the scene another founder for the pathology, Lorna was able to build for her argument a historical backing that disputed with the tradition of Kanner and, most importantly, a backing that made sense for the present. Lorna and her colleagues – basically, a few researchers linked to the Cambridge University Brain Sciences and Cognition Centre – put into motion their work in a time when psychiatry is been transformed by the antimanicomial movement and by the development of the first brain medicines (SHORTER, 1997, p. 239-287). Insert Asperger ideas in this context legitimized and strengthened the view that autism, for more suffering it generates, could not be seen as a kind of madness that demanded the confinement of the patient. It was necessary to leave the kids at home and treat them as individuals potentially capable of executing some kind of harmonic coexistence. The family was seen, furthermore, as an instrument of affective support and of cognitive development, quite differently from the psychoanalytic conception that had the parents as the origin and an aggravating factor of autism. So the presentation of a foundation that even touches Freud's ideas to the English-speaking public retrospectively paved the way for the cognitive approach of autism. With Lorna reading Asperger, autism ceases to be a

affective disturbance and becomes a cognition syndrome and, thus, families meet academic support to get rid of all the guilt that, for them, would have been imposed on them by the psychoanalytic feathers and practices<sup>5</sup>.

This is the autism panorama in the 80s of the last century, one that, in general lines, is still the same nowadays. With the publication of the third version of the DSM<sup>6</sup>, in 1980, which, as Russo and Venancio argue, “(...) aimed to be a non-theory, neutral and generalizable for all times and places and, in practice, globalized the north-american psychiatry” (2006, p. 465), the autonomy of autism was consecrated by its conception as a brain and cognitive disorder. As Lima points out (2010, p. 77), in the text of DSM-III, the physicalist character of this conception was explicitly opposed to an alleged failure of the psychoanalytic perspective in determining the causative factors of autism and, thus, it ceases to be a child psychosis to be designated as a general developmental disorder. References to family, interpersonal relations and psychodynamic as causative agents are replaced by the indication of the characteristic symptoms that must be observed by the clinician in order to set a diagnosis: onset before 30 months of age, lack of response to others, deficiencies in language, peculiar speech patterns – when the child speaks - as echolalia, pronoun reversal and abnormal melody, ritualistic and stereotyped behavior and resistance to change.

Along with the victory of physicalism over psychoanalysis that the publication of DSM-III represents for psychiatry in general and for autism in particular, the indicated treatment becomes the use of medicine to control the most acute symptoms, the stimulation for the global development of the child through multiple therapies, her inclusion in schools capable of educate the autistic and the parents orientation about the cares they have to dedicate to their children at home. A treatment that, for the family, entails considerable financial costs, immense dedication of time and emotional effort, and perhaps the most difficult to be assimilated, the acceptance that their children will always be autistic. If autism ceases to be a disease, it becomes a

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<sup>5</sup> I confess that my reading is strongly influenced by how the cognitive and biomedical perspective views the psychoanalysis of autism. In other words, I reviewed the controversy between psychoanalysis and biomedicine only through the eyes of the second, without carefully exploring what the first, at least currently, is preparing. I intend to fill this gap - which certainly shines in this text - throughout the research.

<sup>6</sup> The *Diagnostic and Statistical Manual of Mental Disorders*, compendium of protocols for the diagnosis of mental disorders of the American Psychiatric Association, is the leading worldwide reference for disorders of the mind. In its first two editions, 1952 and 1958, strongly influenced by psychoanalytic perspective (RUSSO & VENANCIO, 2006; SHORTER 1997, P. 298-305), autism was rated as the manifestation of schizophrenia in childhood. In the third edition, the cognitive logic prevails and remains in the following two versions, the DSM-IV, in 1994, and the DSM-V, in 2013.

foundation of the individual diagnosed. Yes, a deficit condition that may, in some measure, be repaired, a disorder that can, to some extent, be mitigated. However, this type of treatment indicated that, among the guidelines that should be provided to the family, one of the most important was to tell them that autism has no cure. It was as if the doctors were telling the parents that, from now on, if they are not anymore the blamed for the disease of their children, they had to put themselves as fundamental articulators of the development of their kids and, at the same time, painfully and reflexively accept the constant and inexorable presence of autism in their homes.

With the discovery of Asperger in the United States and in England and the publications of the DSM-III and the studies of Lorna Wing and her colleagues, the conception of autism seems to have been detached from that stereotypical notion of madness – huge category in which all mental and behavioral deviation is allocated - but without being completely connected to some form of normality. Autism is inscribed on that classificatory space where float the mental deficits, disorders and syndromes as a spectrum that goes from severe autism to Asperger syndrome, the high-functioning autism. So, in the end, the physicalist formulations, of “non-theory” precision, contributes for the understanding of autism as an enigma, as Frith (1989) have once put it. Repudiating bad parenting as the cause and parental responsibility as the effect, the physicalist turn inscribes autism on the list of brain disorders that flow in cognitive deficits, but, at the same time, recognizing that we know very little about it, assuming that any complete explanation of its causes, courses and effects is empirically weak and clinically partial<sup>7</sup>. How to explain, for example, that children who do not have any brain abnormality in neurological examinations do not speak, do not fulfill the tasks and do not behave as they would normally do in their ages? How to rank in the same category convulsive children who need to wear diapers at the age of nine with those with five years whom can perfectly memorize the map of their cities and can solve complex mathematical equations, but do not make friends and panic when their parents try to hug them? How to conceive that the same drug calms

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<sup>7</sup> About this recognition of the enigma status of autism, it is significant that in DSM-III, among the types of pervasive development disorders (PDD), in addition to autism and other syndromes, is PDD-NOS, or not otherwise specified. As this is a protocol for diagnosis, the DSM allowed – still allows on the DSM-V, published in 2013 – many children were diagnosed with a pervasive developmental disorder not otherwise specified. In short, this diagnosis means that the kid has a unknown problem. Solomon, in his interviews with families of autistic (2013, p. 264-347), noted that this diagnosis was perceived by them or as clinical negligence or as a less compromising way for the doctor to diagnose autism.



some children and helps decrease the occurrence of stereotypies and, on others, triggers nerve outbreaks and acute seizures? Or, how to understand that therapeutic stimuli, educational development methods and extremely sensitive schools virtually eliminate autistic symptoms in some children and, on others, pass completely unnoticed? How to tell parents that, for their children get well, all the efforts and sacrifices are necessary, but even so, may be useless? How to say for families that their children are autistic and autism is an enigma with no known cause and any possible cure? Recognizing the lack of answers to such fundamental questions made autism becomes an enigma, as if he was always beyond words and methods, as if it always escaped the scientific control, as if the words did not give account of autistic reality. An enigma recognized by both experts and parents, if we agree that the use of the puzzle as the image of campaigns that demand social awareness, better conditions, rights and remedies that families organize – sometimes as a mounted set with a piece missing, in others, only a piece with many undocked plugins – is a way of accepting the feeling of being lost that the families say they feel. So the physicalist turn cannot be understood as the moment in which it is articulated a more precise knowledge about autism. It is, rather, a stabilization of the exchange of the psyche by the brain as a nodule and affects by the cognition as a space of manifestation of symptoms, recognizing at the same time, the hardness of the methods, the precariousness of the explanations and the incommensurability of the object when the subject is autism. Or, in another words, it is the recognition that it is needed to clinic, care, educate and live with autism as an enigma<sup>8</sup>.

## **2 – Stimulating the brain, developing people**

So there it is the practical challenge that irrupts with the theoretical concept of autism as an enigma. If, in nosology and scientific research dimensions, the problem is of etiological order – the definition of cause and effect of the disease –, in the clinic, at school and at home, the issue is how to mitigate the suffering, how to take care of the child in a way that her pain is eased and her quality of life is promoted, in

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<sup>8</sup> The history of autism elaborated here, too long for an article of about 20 pages that intends to be ethnographic, is enough to support the general argument of the text. However, to contemplate the relevance of studies on this pathology would be required to visit the work of cognitive psychologist Simon Baron-Cohen, a student of Lorna Wing and Uta Frith, mainly his *Mindblindness* (1997), since his perspective is currently hegemonic in disputes that seek to explain autism.

short, how to make her life good at the same time that it is possible to live good around her knowing that autism is an enigma. For the clinic, the school and the family, this problem is not a theoretical one, but, instead, it is a problem of life.

I am not saying that, in the case of autism, scientific researches and definitions are separated from the clinical therapeutics, educational and familial practices. Quite the contrary. When I started to follow the consultations of the autism ambulatory, at the Clinics Hospital in Curitiba<sup>9</sup>, the neurological and cognitive conception of this mental condition was explicit in the conversations between the responsible neuropsychiatrist and the parents, in the way she, the doctor, explained the problem of the children, in the kinds of therapies she indicated, in the guidelines of care and education she provided, by letter, e-mail or meetings, to the pedagogues and teachers. That was the conception she learned on her graduation in medicine school and at her residencies in pediatrics and in neuropsychiatry and that is the conception she practices in her activities as a professional. However, as a doctor, her problem is not to define the etiological nature of autism, but to help families who seek help because they understood that their children were suffering<sup>10</sup>. For more elucidative and clarifying that it may be, the explanation of what autism is, for the family and for the doctor, does not solve the practical problems. So, what I am saying is that, between the scientific researches and definitions and the clinic, therapies, schools and families, autism must be translated, since it is in those places and with these people that the DSM generic classifications face specific children and nosology meets suffering in

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<sup>9</sup> The autism ambulatory at the Clinics Hospital in Curitiba – a public hospital linked to and managed by the Federal University of Paraná, in southern Brazil – is a volunteer initiative that emerged with the purpose to offer free and periodical medical, therapeutic and pedagogic orientation services to the autistics and their families. The founder and main reference of this ambulatory, one neuropsychiatrist, told me that when she was still residing in the same hospital, she was bothered by the fact that families went there, some doctor would observe the kid, eventually give them a probable diagnosis for their children and then, they would return to their homes with some vague guidelines for care and prescription drugs and that was it, nothing more. In the case of autism, a development disorder that presents different dilemmas throughout the life of the individual and demand, as a way of care, guidance to families and various therapies, establishing the diagnosis – in an ideal of public health system – should be the first step in a long relationship between family and physician. So she believed that it was needed to offer the families a continuous and periodical service capable of observing the pathology course and indicate orientation according to the conditions that the child was presenting in each moment of her development. Besides, considering the material deprivation of the families, she thought that the ambulatory could also offer therapies and pedagogical guidance. It is been four years now that, once in a week, she dedicates one afternoon to this project, having families, children and all sort of professional interested in autism coming over. I have been participating in the consultations and all the actions linked to the ambulatory since may/2013.

<sup>10</sup> This is how I dribble in my research all those discussions about “is autism real or not, only biological or explicitly psychic” or the “medicalization of life” issue. If the families seek a doctor and this doctor say their child has autism, who am I to suspect the veracity of this reality or what authority I have to think this family is being colonized by psychiatry?

flesh and neurons<sup>11</sup>. Well, on these meetings, the enigma is translated as a care that aims the development. Let us see how that happens.

Orientations and stimulations that promote the child development. These are the objectives of the autism clinic when this condition is considered a neurologic syndrome that affects the cognition. Its assumptions works in the following logic: when we are born, the brain – “motherboard” organ of the human being that processes all the information captured by the senses – is a kind of savage and empty territory but, nevertheless, anxious to be inhabited. So, to form neuronal connections the brain has to be stimulated through the relations between individual and environment, both physical and social. As our experiences go along, the brain opens “great avenues” of information processing, that is, regulatory patterns que determine our organisms and our relations with the environment. This dialectics between individual/organism/brain and the environment/physical/social/cultural characterizes, according to the contemporary cognitive neurology, the human way of being in the world. The “great avenues”, or, in the terminology currently privileged by the neurosciences, the modules are axes that sustain the pendulum of this dialectics. Together, this modules form the mind, this big and complex “software” executed by the brain. For example: we would have a mind module that allows us to smell, physiologically predisposing the body to feel odors and, as we live and the world goes into our bodies through the nostrils, organize a mental grammar of olfaction. The forms of these modules are, for the neurosciences, innate and universal, they are part of the normal functioning of any human mind. What varies is the input, the social and physical contents with which each module will be substantiated and molded. That is how it is with all the abilities of the human being. A speech/language module, another one for walking, for alimentation and so on. Now, socialization among humans would be the responsibility of the module that enables us to understand and anticipate the wishes and desires of other human beings. Mental product of genetic changes that would have occurred throughout our evolution, the mind-reading module would makes it possible to perceive – not only through the speech, but through all the manifestations that a body

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<sup>11</sup> This argument, that autism in clinical practice is different, but not separated, from autism in theory, if I understood her, is the same one that Mol (2002) elaborates in the case of arteriosclerosis and, in a certain way, lays on the basis of her whole conception of ontology in medical practice. As Mol, I understand that the disease I'm studying is multiple, quite different depending on where and by whom it is articulated. However, the practice – for Mol, medical, circumscribed to doctors and a hospital, in my case, medical, therapeutic, educational and familial, acting along clinics, schools and homes – ontologically coordinates all these differences, making it possible to refer to a single disease.

is able to offer – from basic emotions, when someone is sad or happy, for example, to subtle refinements of social relations, such as sarcasm and irony. What cognitive neurology understands as a normal individual is therefore one that has all these basic modules of the mind properly processing inputs and outputs, namely, by setting adequately – “as it should be” – the relationship between organism and environment.

In light of this logic, it can be understood why autism is currently classified as a pervasive development disorder. For some reason<sup>12</sup>, in a lot of children<sup>13</sup>, these mind modules are disordered. They would not be adequately regulating the relation between organism and environment and, hence, according to neurosciences, the individual is not developing the way is supposed to be doing it. The consecrated knowledge of pediatrics – inscribed in every textbook studied in graduation and residency – states, for example, that every child should present a speech relatively clear with three years of age, efficient sphincter control until the age of 2 and a perception of the differences between the expressions of happiness and sadness of the mother until the end of the first year of his life. These and many other stages of maturation of the human body are not met by autistic, either because they delay or anticipate too much the paradigmatic chronology of pediatrics. The consequences of this are the symptoms of autism, obviously, the fountain of pain and suffering for the children and their families. As their senses, the captors of all the information the environment offers to organism, would be affected, autistic children are classified either as – there are the words used in clinic – hypo or hypersensitive. In the first case, low sensitivity to external stimuli makes children not easily discern bodily pains. As they do not express any annoyance to parents, a hit in the leg or a slight cold can have serious proportions. The hyposensitive can also hurt themselves deliberately. A boy from the ambulatory – nine years and speechless – has a large burn mark on his left arm, which, according to the mother, is his responsibility. He would have putted fire in his own arm, and when she found it, he was looking at it burning his skin and laughing. One way to stimulate the senses is how the clinical explains events such as

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<sup>12</sup> Among the neuropediatrics, the most accepted reason is genetic mutation. But, on the other hand, lots of doctors understand autism as a product of heavy metal presence in food, of certain kinds of vaccines – such as the one for measles – of pollution and even of a supposedly “individualistic and chaotic” epoch which we would be living in the last decades. In another words, when one speaks about the reasons for the emergence of autism in the individual, in fact, one speaks about a controversy that seems to underpin even more my argument that this pathology is, in theory, an enigma.

<sup>13</sup> Really, a lot. Epidemiologists say that one child out of 10 in the world has autism. They talk about some autism epidemics right now.

this and also all the noisy agitation of some autistic. Jumps, races, and incessant screaming and grunts, toys thrown in walls and bites on the back of the hand would be the methods by which autistic children try to wake up their bodies to the world. Now, the hypersensitive ones would be quiet and calm children who appear to be unrelated to what is happening around them, supposedly absorbed in themselves, but which, in fact, to the clinic guided by cognitive neurology, are so sensitive to the world that any noise or movement is a catharsis that throws them in a maelstrom of sensations very difficult to bear. The whistle in physical education class, the rugged or roughened texture of a new shirt, the light in a sunny day and a walk in the mall are so intense and complex for an hypersensitive autistic child that, as they would not understand such sensations, they react with outbreaks and shakes that can cause serious injuries and traumas, and of course, as it is difficult for parents to know what causes them, their caregivers simply despair. The autistic who spends the days rowing their toys and gazing balls and car wheels spin would be looking for order in the world around him, trying to identify patterns that help him understand his environments. He would be looking for routines that are repeated constantly, both to protect themselves and to try to understand the incomprehensible whirlwind of sensations that the world causes to him.

Hypo and hypersensitive explain the sensory relations between the child and the physical world. Nevertheless, what is understood as communication and socialization deficits is present on both conditions. To neuropsychiatry, in a gradient that goes from mild manifestations to more severe cases, the child will present difficulties to execute a speech, a verbal communication that is built on linguistic signs and phonemes shared by her community. This deficit can be a delay on her language development, its complete inexistence or the maintenance of mistakes in the execution, just as aphasia, dyslexia, pronoun reversal and echolalia, among others. And, still, the child can domain verbal language, but does not know how to use it. That is the case of those children who decorate and faithfully reproduce movie and cartoon lines, but do not use – for the clinicians, do not know how to use – the words of the scripts in normal and banal conversations and communications in their daily lives. The deficit of socialization, in its turn, is understood by the neuropsychiatry as the inability to understand, fulfill and carry out the social and cultural orders and assumptions that are part of the autistic child's environment. This is, on one hand, a difficulty of assimilating basic rules for contemporary living in a large Brazilian city,

for example, observe the boundaries between the house and the street and know that it is dangerous to rush out on avenues. But, on another, it also means having problems to understand classifications that could be defined as basic in the western kinship system, for example, to conceive the differences between relatives – including parents – and the strange, between who has and who has not kinship ties with her, the diagnosed child. For autistic of high performance and for those that developed a good verbal communication, socialization deficits may manifest in difficulties in understanding subtext, figures of speech, metaphors, irony and sarcasm. The neuropsychiatrists say, for example, that in a trivial conversation with friends at school, the autistic student probably will be wondering from where that ace would come out if the person they are talking about is wearing a short sleeve shirt. They also say that, precisely because the difficulty in understanding what the others want from her, an alone autistic can easily suffer in the hands of manipulating adults. Hence the statement that I hear so often in consultations, that autistics are naive because they understand literally the explanations of the others. But, in general, the socialization deficit is explained by the mental blindness, to put it after Baron-Cohen expression (1997). Not look straight in the eyes of the others, not say hi neither bye in the places where he comes and goes, not recognize that the mother is tired or animated and the father is angry or happy would be consequences of an incapacity to comprehend others emotions and desires, that is, read the mind of the others. So, under this logic, for the autistic child, her own emotions and desires would be the only ones in the world, as the doctor whom I follow said: “the socialization deficit is to use the other as a tool for the fulfillment of the child’s own desires and wills”. Considering all the pain and sadness that the socialization deficit generates for the autistics, one understands the metaphor that Temple Grandin – famous north-american Asperger – employed to communicate do the psychiatrist Oliver Sachs how she feels in this world, as an anthropologist in Mars (SACHS, 1995). Their lives would be like a constant ethnography, exploring, locating and interpreting the rules and values of the societies in which they live. However, unlike us, anthropologists who have decided to make a profession out of anthropology, autistics need to be anthropologists to be able to ease their pain. Therefore, autistics were doing a sort of reverse anthropology. The conduits and social realities taken as natural and that we anthropologists of the west try to understand as fabrications, the autistics see them as fabrications and try to naturalize them.

The stimulation and orientation offered by the autism neuropediatrics clinic are forms of helping the child in this work of naturalization or, as the clinicians would prefer, of development. This help comes from, on one hand, the considerable gamut of therapies subscribed the scientific research and performed by qualified professionals, that is, those who made specialization courses in the centers that have elaborated the procedures. Besides the methods of behavioral psychology already enshrined in the history of autism since the 70s of last century<sup>14</sup>, to the families are recommended phonoaudiology, psychomotor exercises in swimming pools, music therapy, equine therapy, and more recently, sensory integration offered by occupational therapists. In the latter, in a hall full of practical and playful materials – trampoline, climbing wall, a ball pool and the like – groups of children play under the guidance of a therapist<sup>15</sup>. The idea is that, besides stimulating socialization, they stimulate their sensations and thus are able to develop the proprioceptive sense, that is, the feeling of your whole body organized upon the sum of the other five senses.

But these professional stimuli will effectively develop the children if their actions are paired up by the amateur disposition and dedication of the family towards the condition of their kids. Here it is all the centrality of the family in the reality of autism. The professional therapies, and this was a statement made by the neuropediatrics whom I follow, are an appendix of the care the families dedicate to their children. The parents are the most responsible for the good development of the autistic, just as they are the most affected by the diagnosis. The diagnosis generates profound and vertiginous transformations in the parents and, sometimes, in other

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<sup>14</sup> As the ABA, that stands for Applied Behavior Analysis. It is a method developed in Californian universities in the 60s, under the guidance of the psychologist Ivar Lovaas, which, in general, consists of proposing practical and supposedly necessary tasks – hold a pen or a cup, walk, talk and tie shoelaces, for example – for the kids, who, in turn, if they can perform satisfactorily, they receive positive reinforcement, and if they can not, are punished with a mild penalty, such as going to the room, and verbal recriminations. These activities must happen in the house of the child and have to be administered by a specialized therapeutic. By far, it is the most utilized therapy in Brazil. For the neuropediatrics whom I follow, ABA has its benefits, but, “it always transforms the kids in little robots”. The critique of ABA is the origin of *floortime*, based on the idea of leaving the child to show the therapist what activities should be implemented, and *teacch*, in which the child is visually stimulated through cards with drawings – like the ones used in memory game – of the bathroom, school, car, letter b, the word street and so on. A mother who uses *teacch*, in her first visit to the ambulatory, took a picture of her child with the doctor to, close to the date of the next consultation, show it several times to the child and, thus it promises the method, he would have less fear that the visit would “break the routine”. These are the major consecrated behavioral and cognitive methods for autism.

<sup>15</sup> Always women. In my research, so far, I have only met a male therapist who works with autistic children in the area of motor skills in swimming pools. I will need to think more about this dominance, but for now, given that 90% of the diagnosed are boys, I affirm that the world of autism I am researching is a world of women who take care of boys.

relatives. There were numerous consultations that I followed that culminated in a kind of wild therapy for families, ones in which parents and relatives talked about their pains and joys with autism, describing “the blessing that this child is, helping us to face life with hope and enthusiasm” or “the despair and fatigue that it is taking care of this boy...he makes me want to drop everything and let life take its course without worrying about the thing this child has”. My field notes are taken by stories of parents breaking up and mothers blaming autism for it, of the “end of social life”, of “nervous crisis” triggered by the child’s autism, of jokes always done in the moment when the doctor is writing the prescriptions for the kids and the parents say “and for our antipsychotics and antidepressants, don’t we get prescriptions too?”, of incursions in the actions of activism on behalf of autism, explained as a product of the condition of the children, and inventions of activities and exercises for caring and educating children at home. If it is not by the voices of the families, it is by the acts and words from the doctor that emanates the centrality of the family in autism. By the way she talks with them and in our conversations, I noted that, for her, the specificity of the families is the fundamental factor for the good development of the child. A specificity that translates itself as love, dedication, care and some practical intuition that adequately answers the everyday dilemmas. Without these elements, she said this to me several times, “my work doesn’t do any good”. A case from the ethnography illustrates the point.

It is a family that had moved to Curitiba in early 2013, the mother heard about the clinic and managed to get an appointment. It was two visits throughout the year. In the first, as the mother had already arrived with the severe autism diagnosis of her only son, ten years old, the doctor did not apply the extensive questionnaire for new patients. At the same time, she observed the kid and talked to the mother, trying to know how his medical history had been unfolded throughout the years. By short and straight answers that built a relatively elusive talk, the mother said that the diagnosis had been given by the pediatrician when the child was four years old. Since then, the boy had rare consultations with a psychiatrist, had done some sparse phonology sessions, continuously ingested various types of antipsychotics, antidepressants and Ritalin and attended only special schools only<sup>16</sup>. When the doctor asked what she expected from the ambulatory (she always asks this to new families), the mother

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<sup>16</sup> In Brazil, a special school is the one for children with mental problems. There are a few that are private, but most of them are public.



answered that she “just wants someone in Curitiba that could see the kid for me, see if everything is all right and telling me what else can I do for him”. With this information, doctor started to talk. Briefly, she confirmed that the kid’s autism was, in fact, severe, considered the possibility that maybe he could have some more serious neurological or genetic problem (he did not articulated any comprehensible word, only what sounded to me as whispered grunts, was still in diapers and throughout the consultation, walked quietly across the room without being interested in toys, the doctor, the mother, me, the mirror [almost all the kids loves to stare at himself during the appointment] and even tried to open the doors of the cabinets [that are kept locked and, also, every kid loves to force the doors to open]) and, aggravating the situation, his age makes it difficult to achieve good results by means of therapies, since “the sooner the stimulation begins, the greater the chances to develop good verbal communication, social interaction and a good learning in general”. Asking the mother to bring the results of the neurological and physiological exams he had already done and booking next appointment, the consultation ends.

After three months, mom and son return. Besides finding that the exams do not show any explicit neurologic dysfunction, the doctor is told that the boy was enrolled in a special school. Mother told, in that same elusive manner from the first time, how his first weeks were going at the school, reporting that the boy was “more agitated and having a lot of difficulty to sleep”. Doctor, again in the same straight and briefly talk, revisited the medication he was taking – proposing alterations in doses to see if the agitation decreased and sleep increased –, recommended to her to try to find some therapies for him, especially phonoaudiology (there were no way of including him on some of the therapies offered by the ambulatory), and confirmed that the special school was the best that could be done at that time. After this, she played a bit with the boy, scheduled next appointment and puts an end in this visit, that did not last more than half an hour. Alone with the doctor and without any family waiting, I ask her why she agreed with special education for the boy, since she constantly criticized this kind of school in almost all the consultations and in other conversations between us. To her, special school was a “deposit of people that no one wants to care for real”, as if it were “a substitute for psychiatric hospitals for children<sup>17</sup>”. “They put them there, together in the same class, children with different problems and of all

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<sup>17</sup> In Brazil, there are no more psychiatric institutions where children with mental diseases can be interned.

ages, and make no effective stimuli, do not exercise intellect and socialization”. So why agree with the presence of that boy in this kind of school? “The mother”, she said to me, in a tone denouncing frustration. “This mother is not really willing to help this boy, if she was, she would be stimulating him since the diagnosis, when he was four years old, and thus he would not be as bad as he is right now”, “that is why, what can I do if she doesn’t want to do anything, if she thinks that special school is the only option for him, she is thinking like that since the beginning of the it, and if no doctor told her this was not the best choice since then, what can we do now, when he is ten”?

After this conversation, I became more attentive to the differences of how the doctor treated the families, on the subjective way she related with them, because she usually tends to be very willing, personal and emotionally engaged in consultations. But, when the families do not seem to her “really” engaged, her behavior changes. Her answers and explanations are more direct and simple, the alternatives of care and treatment become scarcer and her affect for the children tends to be more, let us say, neutral and cold. This seems to be the case with this mother. What explains the protocolized consultation – rare in the context of the ambulatory – is the doctor’s perception that this mother is not effectively engaged to dedication for the child. She would be a fatalist mother, whom accepted her son’s autism as if it could not be changed. For this, she “dumped” the child in a special school where the senses and the intellect are not stimulated and, thus, cannot be used as medical treatment methods for autism. Doctor’s discomfort is with both the fatalism of the mother and the kind of education special schools offer. At it, kids with different problems and ages would be allocated in the same class, precluding the execution of specialized educational activities for their respective mental conditions. This would be the reality of public special schools in Brazil, due to neglect of different state agencies with the specific demands of each mental disorder, which flows, in turn, on teachers and school managers who know nothing about the actions that indeed effectively stimulate schizophrenic, mentally retarded and autistic, for example. In the case of the latter, doctor’s frustration with special schools comes to the understanding that, attending them, “children with such a potential for intellectual developments socialize with others genetically unable to progress and end up learning from them”. In special schools, autistics would be doomed to learn how to be severely impaired in their ability to verbally communicate and normally socialize.

That is why she prefers, as I could note in almost every consultation, that autistics attending regular schools. At it, even understanding that the precarious results from state management is still present and the teachers are not prepared to educate the autistics the way they should be doing, doctor believes that diagnosed children who present minimal intellectual conditions socialize with normal children and, then, can have better conditions to get closer from reality. In another words, *fight fire with fire*, that is, the socialization deficit is fought with normal socialization. For this ideal takes place, it is necessary that families and physicians engaged in the autistic activism fight to make the brazilian precarious conditions of public education are incremented, so that teachers are better trained in the education of autistic and effectively carry out the project of including the “not so normal” in the world of the normal.

But, elaborating the argument inversely, all this effort for inclusion will be in vain if the families are fatalists. Once more, the disposition of the families is the main factor for the development of autistics children. So we identify the dramatic cores that autism opens for families, just like we illustrate a feature of mental health conditions in Brazil after the end of hospitalization. The care implies for the families an effort of time, material and affect resources of such a magnitude that it allows one to affirm that autism is not just a child’s condition, but, instead, the whole family shares it. Autism is spread by the house and trough kinship when it demands that parents live with the dilemma of making a herculean effort that can, in the end, lead to no development, when it requires that the parents deal with the danger of, transforming their everyday in a constant practice os socialization stimulation, have their own socialization and marriage ruined. A father that attends the ambulatory once told me that “before Octavio was born, I was no people, but, after his birth, I forgot about myself”. One can say that all the effort this father dedicated to stimulate his son made not only the child develops, but also himself. He became more humanized, he thinks, more human, more people, with the price of letting all his wants and hobbies go away. Autism sort of healed him, but with the side effect of destroying his individuality. But he is good with that, he is very happy. In a way, for him, autism, for more pathologic it is, built himself, for more antisocial it is, formulated his disposition in sharing and socializing.

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