

Autism in question: diagnostic historicity, clinical practice and parents' narratives

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Abstract: We will present some challenges faced in institutional psychoanalytic work with children diagnosed with autism. The parents' recurrent accounts of the medical diagnosis and the relationship established with their children will illustrate our discussions. We will emphasize the importance of a critical position on the professional's part in relation to the directions of a totalitarian and timeless diagnosis, focusing on the understanding of human suffering and psychopathologies in our time. The discontent facing individuals at society's margins results in the search for remedies, such as functional rehabilitation and behavioral adequacy. The National Policy for the Protection of the Rights of Autistics, which has been demanded due to the discontent and the struggle of family members, suffers from the incidence of contemporary scientific discourse in the direction of its alleged universality. Such a policy guarantees not only legitimate achievements in the condition of the citizenship of autistics, but also promotes their legal and anonymous protection, through codification.

Keywords: autism, family, diagnosis, psychopathology, psychoanalysis.

Introduction

Over the years, the experience in the institutional psychoanalytic care of children who currently receive the medical diagnosis of ASD (Autism Spectrum Disorders) has brought us some lessons, as well as doubts and theoretical and interventional impasses. First, we learned that the psychoanalytic clinic itself, having made great strides in the studies of psychosis, would still have much to do in the clinic with subjects in early autistic states, especially in early childhood, while constantly being confronted with ethics, psychoanalysis techniques and necessary tactical inventions to welcome and treat the suffering condition of human beings in a given context and in their time. The second lesson concerns the test this professional is subjected to by the clinic, his desire in its radicality, as the subject in an autistic state does not attribute to him a place of supposed knowledge, and does not subjectively demand his help.

This “non-place” puts at stake all necessary transference construction in a therapeutic relationship, making a twist in the direction of treatment necessary. Menès (2013) will point out that “The autistic, in the Discourse of the Analyst, would be in the historical place of the hysteric, not as a barred subject of an unconscious knowledge to be deciphered, but as object a, which causes the analyst's desire and his work of elaboration” (p. 84).

The third lesson refers to the specificity of the transference management with parents of autistic children. In this management, the analyst sustains the construction or restitution of a desire, of a bet and of a subjectivating parental reinvestment on a subject that moves away from the other, welcoming from the beginning the suffering of

the parents themselves. Providing his or her narcissistic recovery becomes necessary for the beginning of the child's actual treatment – caring for those who they will continue caring for and educating those individuals who stand on the threshold of the social bond.

Diagnosis in the Diagnostic and Statistical Manual of Mental Disorders and the diagnosis of social discourses

Technoscientific discourse, coupled with contemporary ideas about childhood, tends to take the child as a describable, predictable, adaptable and controllable object, disregarding what would make each child unique – a history originally woven into the wishes of its parents. We refer, at this moment, to a phenomenon that we call *child objectification* as the effect of this current social discourse. Childhood experts, in turn, tend to adhere to these social mandates about the child by classifying and normalizing them. The child is thus placed in a position of pure object, which makes us think of the approximation of a particular place referred to Soler (2003) in relation to autistic and psychotic children, denominating them *object-children*. In this position, the function of the subject and his/her bonds others are hindered.

Thus, we can assume that ideals and contemporary discourse on childhood possess the power and the risk of a similar incidence on children in general, hindering their singularization in the desire of the other, setting them in certain discursive places and hindering their subjective work, either in the relationship with their parents, school or in the early stages of mental health development. The professional who attends to children cannot, therefore, be unaware of this social discursiveness that imprisons the child in certain places and that also entangles him. To assume a position in the presence of parents that does

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not embody and shutter knowledge, with the weight of a single "truth" about childhood, is a laborious task, for often the first request addressed to us is to teach and guide them on how to best care, treat and educate "*The Child*"; disregarding what would represent "*One child*" for each father and each mother, in particular. The same logic concerns the diagnosis and treatment of the Autism Spectrum Disorders (ASD) in the Diagnostic and Statistical Manual of Mental Disorders (DSM) (American Psychiatric Association, 2013), insofar as what is produced is the creation of "*Autism*", distinguished only by its degree of symptomatic severity in "mild, moderate and severe". Thus, we lose sight of what we could singularly find as the suffering of *one* subject, of each one's history, way of being in the world, and whether or not to let oneself be entangled by the other.

Dunker (2011) emphasizes the notions of formation, constitution and construction to think that there are hegemonic forms of subjectification and recognition of symptoms – "it is not any form of discontent (*Unbehagen*) that can be elevated to the condition of socially relevant suffering. And it is not any form of suffering that needs to or can be framed as a symptom" (p. 135). In the case of diagnosing ASD, there is a growing use of this nomenclature (as well as the disappearance of the term psychosis) and what is described in this picture not only in the medical and clinical fields, but also in school discourse, as well as in the families' daily narratives. We share, in this sense, Dunker's statement that, in addition to a diagnosis of structure, one of fantasy and one of sexuation, a "diagnosis of discourses (as a paradigm of the social bond) is necessary". We will then point out how the appointment of *Autistic* gives the subject a status of social recognition with their due rights in favor of inclusion, as well as causes harmful effects due to their subjectification.

Symbolic knowledge and the educational function of the parents

The act of educating would represent one of the primordial functions of parents with children. Let us remember, however, that the educational function, in Freud's aphorism (1937/1976) – according to which education is impossible –, comprises everything that escapes or what exceeds the content of what one wishes to "teach", composing its subjective and unconscious dimension. This conception of the educational function of parents over the *infans* is totally different from what is often attributed to them in our current social context – the mandate of cognitive and behavioral reeducation, which is essentially anonymous. The educational function to which we refer, on the other hand, operates as a transmitter of symbolic marks of humanization of the child, sustained by a desire, by the affiliation and by belonging to a given culture.

Readdressing to parents the place of knowledge on the child implies, thus, in transference managements that sustain the castration and the lack of knowledge in

the professional themselves, so that they do not prevent the uncertainties and the puzzling formulations that parents can elaborate in relation to children. This task, we know, is not easy, for anguish inevitably emerges. In this sense, the psychoanalytic work with the autistic child and family will demand from professionals an even greater challenge in the direction of their subjectification to the detriment of the tendency towards their objectification, insofar as the autistic state itself implies, in its radicality, the direct demand from the child towards the other, as well as a puzzle that presents itself to many parents as indecipherable or inaccessible and therefore paralyzing and destructive. Therefore, in psychoanalytic work with children, especially those that demonstrate a particularly radical way of bonding with the other – children called autistic –, the welcoming and *narcissistic restitution* of their parents are elements fundamental to the treatment. The support of this position in the preliminary interviews and in the group arrangements of parents' care in the institution set up as starting points for welcoming them and for supporting their narratives, stories and where their fears and desires about the child lay.

The construction of the case in psychoanalysis: ethics, theory and praxis

In regard to the approach and ethics of psychoanalysis, let us remember that theory never develops without or is independent of a praxis. Kupfer problematizes the fact that many autistic children in treatment show development, to the detriment of the onset of a subject. She states that the autistic child has a will, but it is a will that is not exercised in the field of the Other, marked by the desire of the Other: its logic is linked to a certain conservation of the self.

Then, from this operation, one can state that it allows an appropriation of the objects of the world, it allows to develop functions, allows the apprehension of a code that is, however, pure code. It can account for the so-called laws of language functioning and this allows for a certain intellectual development, a certain apprehension of knowledge. (Kupfer, 2002, p. 225)

She will, however, point out from this observation in her clinical practice that in the cases of autism the development and learning of codes may progress so well that it can mislead pediatricians and other professionals, since these types of development are not a guarantee that the child's subjective constitution is operating. Thus, when thinking about the possibility of schooling for autistic children, part of the humanizing and promoting function of social bonds offered by the school, go far beyond its function of transmitting knowledge and formal content.

All methods that go in this direction - of pure intelligence, working with a pure code in which

there is no message or it is almost autonomous - will only further exclude the autistic. It is not a matter of making them develop these possibilities of knowledge, it would only reinforce their alienation. The idea is to continue in the direction of tying knots, to install this child in the field of the Other. (Kupfer, 2002, p. 226)

Soler (2003) proposes an epistemological analysis of Lacanian theory and clinic from the borromean scheme, articulating the propositions about the structures of language and discourse with the categories of the imagination, the symbolic and the real. He emphasizes that these three dimensions may be tied, but not necessarily, and the forms of entanglement may have different modalities. Another aspect presented is that each record (Real-Symbolic-Imaginary) could operate with autonomy, without dominance of one over the other. Soler quotes Lacan in a definition about the real: “the field of the real cannot be colonized except by the sciences of life . . . the real is death” (p. 42), which points to a reality of a living being, to an impossibility to think about, an impossibility to represent. The subjects in autistic states confront us with the radicality of a living human being, in which life and death always appear hand in hand. Attending to autistic subjects places us in the pursuit of possible entanglements between the real body, the imaginary of alterity and the symbolic at play in language.

How the diagnosis of autism affects parents

In our clinical practice with autistic and psychotic children, parents should be part of the treatment. We do not seek to focus on their unconscious fantasy, but on the discourse they develop about their children. Kupfer and Lajonquière (2015) point out that at the beginning of care it is necessary to seek the narcissistic recovery of the parents, who, faced with the problem of their child, are initially overloaded with extreme anguish and helplessness. The author states that by legitimizing and recovering the parents’ knowledge about the child, the professional welcomes their discontent while parents, seeking to support them in their educational roles, as the manifestations of autism greatly compromise the transitional dialogue between them and the child.

A mother’s report following the recent news of her three-year-old son’s medical diagnosis of autism illustrates its effects on the relationship with the child as well as the suffering of countless mothers we have witnessed in our clinical practice:

I realized that something was not right with my son since he was a baby, because he was very restless, he cried non-stop and did not calm down on my lap, it caused me a lot of anguish and despair. At that time, however, the pediatrician said that he was well, he

was gaining weight within the growth curve, and he did not have any recurrent diseases. He suggested that I could be very stressed and anxious because it was my first child, that I was overprotective and was overly concerned with him. At two and a half years, P. had improved, but the pediatrician referred him for a consultation with a neurologist. When I asked why, he told me: “It’s still early to talk about autism, but you should start a neurological investigation and do these tests (neuropsychological, auditory, tomography and brain magnetic resonance), then come back in six months”. Although all the exams requested by the neurologist had normal results, when I returned to the pediatrician for a maximum of 30 minutes, he supported the diagnosis of the neurologist, stating that my son, who was three years old at the time, had ASD, but fortunately it was a mild degree and that we should still carry out a genetic examination. From this day on, I felt as if I had lost my son, a life of three years in 30 minutes! I remembered hearing that autism was genetic and had no cure on a TV program. From that moment on, I became an autism specialist. I started researching all about ASD on the internet. I think I forgot how P., my son, was before I knew the diagnosis of autism. I no longer know P., my son, I do not remember the things he did before, how he played, his maneirisms, but I know very well what autism is and its characteristics...

Autistic rights and their effects on families and schools

Before the Inclusion Law came into force in Brazil in 1994, we followed a case in which the child’s medical report indicated not only the ICD (International Classification of Diseases) in relation to the GDD (Global Developmental Disorders) associated with epilepsy, but also a medicamentous and educational prescription drug: “child without conditions of regular school attendance”. This mother said she did not know what else to do, because on one hand she suffered pressure from the social worker to immediately enroll the child in public school and, on the other hand, the denial of the public schools themselves, citing the medical report and suggesting that the mother should pursue a special school.

Currently, after the implementation of the Law of Inclusion and the National Policy of Protection of the Rights of the Person with Autism Spectrum Disorders (Brazil, 2012), considered as “Person with Disability” (Art. 1) for all legal purposes, the medical report started to have another role in schools and care areas. Any child who has been medically diagnosed with autism has the right to attend school (Art. 7) by law (Law no. 12,764/2012), as well as the other requirements contained in his Statute of Rights. Several parents use this medical report not only to guarantee educational rights, but also to pay for treatment

and obtain benefits for the family (exemption from various taxes, such as sales tax on buying a car, reduction of working hours, etc.). Although many of these benefits are legitimate and necessary for many families, as pointed out by Merletti and Leão (2014), we find that obtaining the medical report for this cause also has harmful and perverse effects, either for the parents who receive their child's autism diagnosis, either to the disabling role assigned to the child, as well as to the expectation of the educators who will receive the student, already clinically diagnosed, in their classroom.

Schools and educators have failed to reflect on teaching strategies for the student with difficulties and have been requesting other methods, such as medication, functional rehabilitation and systematic behavioral training, as ways of minimizing their unwanted behavior in the classroom, believing this to be the only way of dealing with autistic children. Since the medical community generally supports the incurable and genetic causality of autism, many educators believe that there is nothing much they can do for these students, and that including them in the classroom, by virtue of their rights and with a medical report attesting to it, is an obligation imposed by the State. Also, under pressure from families, they feel powerless and helpless without the educational contributions that sustain and legitimize their practice and their teaching knowledge.

Most families, however, show a certain relief, and even a preference, to think that their children's autism falls into the area of disabilities, with cognitive deficits and deficits in neurocerebral functioning, rather than as a psychic disorder or mental illness. According to Martins (2008), the terms *bioidentity* and *biopsychiatry* point to the relationship between the discourses and practices of biological psychiatry, supported by the DSM, and its effects on the process of subjectivity production in the social area. The author refers to the Foucaultian thesis in which medicine is a biopolitical strategy, trying to show the process of body management and the medicalization of health as forms of control that embody biopower in the contemporary world.

Narrating, historicizing, subjectivating... the autistic child finds a place in the desire of their parents. Considering the discourses of the families of children diagnosed with ASD enabled us to place institutional professionals in a fundamental position, be it in schools or in health centers, social promotion and children's rights. It is an initial position of listening and ethics that enables the acceptance of the child and the family from their suffering, legitimized by their own speeches and stories, and not only by their public legality, conventionally instituted from classificatory or with the pretension of a universal and unequivocal right. We seek, in this measure, partnership and social co-responsibility of the family in the construction of care, in the symbolic transmission and in support of a critical position on the child's possible places and destinations in the contemporary world (Merletti, 2012). The production of so-called "bioidentities" – I'm

autistic, I'm hyperactive, I'm dyslexic, and so on. – may thus be questioned.

We will give the final word to one autistic child's mother, here's her narrative:

My son cannot speak, but at times he looks furtively and smiles. I try to play and share what might have been funny to him, but his smile is soon gone. Sometimes he cries but cannot point or show where it hurts. I'm desperate, I wonder if it's the head, belly or ear. I try to help, but he cannot show me and it's so difficult for me to find out because sometimes it seems he does not know his own body and what ails him! Sometimes the people on the street ask anxiously why he is crying or screaming, I am desperate too and what I say to them is that I do not really know! It must seem strange to others that a mother does not know how to respond to what the child has, but that is what really occurs to me. I get very distressed, not knowing if he's doing well at school and what he's able to do there. So I felt the need to call an assistant (therapeutic companion) and the school accepted it, albeit with reservations. She accompanies him for a part of the school day, keeps a journal of his activities, about what he's been interested in or approached at school, and gives it to me every day at the end of classes. When I go to pick him up, I run anxiously behind the helper to talk to her, to hear from my son, to read the diary. Over time I realized that when I went to pick him up at school, I was more anxious to see the helper and diary than to find and see my own son! I have been criticized for including this professional in school and to have invented this scheme of the journal, as if I were intrusive or controlling, for being too invasive on my son's school life and other school professionals. But what no one knows is the pain I felt, the emptiness I found when I was going to hug him and asked him how his day had been at school. I did not get hugged back nor did I receive a look! Do you know what it is like for a mother that feels the emptiness of a hug and the emptiness of the look of her own child? Or see your child crying, screaming or hurting, with a pain that you cannot understand and know where it is, unable to do anything to heal it? This pain is in us, too, I do not have enough words to explain it. The journal was just a way I found to fill some of this void and somehow try to communicate with him and get close to him. I think the companion and the journal worked more for me than for my son, to help me keep trying to communicate with him. The availability and commitment of the professional and the school to my son, as well as the respect and acceptance of my suffering by you, in this institution, in this group of parents, gave me the strength not to give up, to continue speaking and wishing to communicate with him.

Autismo em causa: historicidade diagnóstica, prática clínica e narrativas dos pais

Resumo: Apresentaremos alguns desafios enfrentados no trabalho psicanalítico institucional com crianças diagnosticadas autistas. As narrativas recorrentes dos pais sobre o diagnóstico médico e sobre a relação estabelecida com seus filhos ilustrarão nossas discussões. Ressaltaremos a importância de uma posição crítica dos profissionais diante dos rumos de uma diagnóstica totalitária e atemporal incidindo na compreensão do sofrimento humano e das psicopatologias em nossa época. O mal-estar gerado diante de indivíduos à margem do laço social produzem, como efeito, a busca de sua reabilitação funcional e de sua adequação comportamental. A Política Nacional de Proteção dos Direitos da Pessoa com Autismo, reivindicada a partir do mal-estar e da luta de seus familiares, sofre a incidência do discurso cientificista contemporâneo na direção de sua pretensa universalidade. Tal política garante não somente conquistas legítimas na condição da cidadania da pessoa com autismo, mas fomenta, por outro lado, sua tutela jurídica e anônima, objetalizando-a.

Palavras-chave: autismo, família, diagnóstico, psicopatologia, psicanálise.

Autisme en question : historicité diagnostique, pratique clinique et récits des parents

Résumé : Nous présentons certains défis du travail psychanalytique institutionnel avec des enfants porteurs du diagnostic d'autisme. Les récits des parents concernant le diagnostic médical et sur le rapport établi avec leurs enfants illustrent nos discussions. Nous soulignons l'importance d'une position critique et atemporelle pour la compréhension de la souffrance humaine et des psychopathologies de notre époque. Le malaise provoqué face à des individus éloignés du lien social produit la quête de leur réhabilitation fonctionnelle et de leur adéquation comportementale. La Politique Nationale de Protection des Droits de la Personne Porteuse d'Autisme, revendiquée à partir du malaise et de la lutte de leurs familles, s'allie au discours scientifique contemporain dans la direction de son universalité prétendue, tout en étant sous son influence. Telle politique assure non seulement les conquêtes légitimes vers la citoyenneté de l'autiste, mais favorise, d'autre part, sa tutelle juridique et anonyme, l'objétalisant.

Mots-clés : autisme, famille, diagnostic, psychopathologie, psychanalyse.

Autismo en causa: historial diagnóstico, práctica clínica y narrativas de los padres

Resumen: Presentaremos algunos desafíos enfrentados en el trabajo psicoanalítico institucional con niños diagnosticados autistas. Las narrativas recurrentes de los padres sobre el diagnóstico médico y sobre la relación establecida con sus hijos ilustrarán nuestras discusiones. Resaltaremos la importancia de una posición crítica de los profesionales frente a los rumbos de un diagnóstico totalitario y atemporal que incide en la comprensión del sufrimiento humano y de las psicopatologías en nuestra época. El malestar generado frente a individuos al margen del lazo social produce, como efecto, la búsqueda de su rehabilitación funcional y de su adecuación comportamental. La Política Nacional de Protección de los Derechos de la Persona con Autismo, reivindicada a partir del malestar y de la lucha de sus familiares, sufre la incidencia del discurso cientificista contemporáneo en la dirección de su pretensa universalidad. Tal política garantiza, no solo logros legítimos en la condición de la ciudadanía de la persona con autismo, sino que fomenta, por otro lado, su tutela jurídica y anónima, convirtiéndola en objeto.

Palabras clave: autismo, familia, diagnóstico, psicopatología, psicoanálisis.

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