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**THE HISTORIOGRAPHY
OF AN AUTISM
DIAGNOSIS**

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Abstract: In this article, we will analyze documents and reports about the journey of research and diagnostic evaluations that Daniel and his family went through between the years 2009 and 2012, before receiving the official medical report stating that he was an Autistic Spectrum Disorder (ICD 10, F 84.0), only in 2014. But even before this report, Daniel was already seen and treated as an autistic boy. The analysis of this material will be instrumented by the thinking strategy of Institutional Discourse Analysis (Guirado M 2018; 1995/2018; 1987/2004), sometimes resorting to Michel Foucault's concepts of discourse and production of knowledge/power relations (1971/1996; 1983/1995; 2006; 1976/1985). Through this analysis, it was possible to demonstrate the power relations and games that determine a certain production of knowledge about a boy (Daniel). In this case, the power games that produce Daniel's "diagnosis" are composed of several institutions, not only the Health ones, but also the School and the Family ones. In such a way that an "extra-official" discourse is created, which is not in the medical reports, but which affirms and naturalizes Daniel as a boy who has autism. Finally, these analytical conclusions encourage discussions about the place and effect of the evaluative procedures (reports, reports, tests, among others) of mental health professionals, especially those who work with children and adolescents with developmental syndromes and/or disorders.

Keywords: Diagnosis; Autistic Spectrum Disorder (ASD); Institutional Discourse Analysis; Case study; Power-knowledge relationships.

INTRODUCTION – GENERAL CONTEXT

The base material for the analyzes that will be undertaken in this article were collected or produced (in the case of reports or observations) during the production of the Doctoral Thesis: Daniel: a body in search of senses (Martins-Afonso, 2019). This research was produced at the Department of Psychology of Learning and Human Development, at the Institute of Psychology of "Universidade de São Paulo", under the guidance of Professor Marlene Guirado, we undertook a case study of a boy called Daniel (fictitious name), attended by us in a therapeutic follow-up model, which has a medical diagnosis of ASD¹.

By thinking strategy, Institutional Discourse Analysis (see item on method), it was possible to produce at the time what, according to Guirado (Guirado M., 2018; 2015; 2016), we could call it an analysis of subjectivity. Roughly speaking, the ways in which, very singularly, Daniel produces meanings and affections, and registers them in his memory, carrying them as an expectation in different and new situations in which he finds himself. So singularly Daniel, since he does not speak and, thus, his speech is body and movement. A body and an action that say about themselves, their affections, wills, intentions...

For the present article, we will restrict the scope of our analyzes on the materials and discourses related to what we can call the "diagnosis journey". Since, like most patients, Daniel spent years consulting different specialists, being subjected to different evaluations, "technical" opinions, indications, therapies and treatments. And it was in this set of procedures that truths were produced, in such a way that, long before the medical

1 He was born in 2007, and when he was two years old, the family members began consultations with different professionals, moved by Daniel's delayed motor and speech development. We started seeing Daniel in 2014, when she was already 6 years old and already had an "unofficial" diagnosis of autism, since at the time there was still no report issued by a neurologist or psychiatrist.

report indicating that Daniel had autism, he was already seen and treated as an autistic boy in the different institutional relationships he had. Furthermore, there is a path (which involves discursive control procedures, modes of production of truth, power relations between institutional actors and knowledge disciplines) that leads a child with such or such difficulties to become a case, a case of autism, for example. This way, the case is the final link of a set of procedures and techniques that aim to scrutinize the subject as much as possible, who transforms his actions into symptoms or behaviors, identifying and classifying his movements and his body. Like this:

At a certain point, Daniel's story and medical/psychiatric devices came together and produced a unique discursive domain. This discursive domain is what responds to the name of "case". Daniel became an affair; a case of autism, a case of developmental delay, a case of language delay, a case of neuromotor disorder, etc.(Martins-Afonso, 2019, pp. 53-54)

ABOUT DISCURSIVE CORPORA

The material for the analyzes that follow comes from two sources: 1. From 2009 to 2013, they are mainly documents, medical orders, test results and referrals. They were provided by those responsible to compose the Doctoral research. This material is incomplete and quite inconclusive. There are, for example, requests for tests, but not their results (including genetic tests), giving the impression of an unfinished task in this initial search for answers. 2. Reports from family members and other professionals who assisted Daniel, as well as field observations. All this material is, as far as possible, recorded in the Doctoral Thesis(Martins-Afonso, 2019).

METHOD

This work has the Institutional Discourse

Analysis (AID) thinking strategy as the basis. When we talk about AID as a thought strategy, we point to its character as a way of thinking and doing Psychology and Research; in the specific case of this article, a way of analyzing the discourses that will comprise the body of this research. In epistemological terms, therefore, AID is neither a theory about a certain object nor a methodology, with a certain set of procedures that must be followed to achieve a certain end. So what is this way of thinking, this thinking strategy?

In general terms, AID is based on certain guiding concepts that, as a whole, do not constitute a conceptual scheme about a given object in order to explain it, get to know it, access it, but provide the bases on which the process will be organized. the very act of analyzing and thinking about a certain set of discourses or institutional relationships. Hence the idea of "strategy thinking". For the purposes of this article, we will give greater prominence to the concepts of discourse and institution; because they are fundamental for the analytical exercise of the next item.

We can understand discourse as an act, as an action. That is, if in the classical understanding discourse is taken for its communicational character of "transfer" of information, ideas, etc. (speech representing reality), the AID takes the closest concept to Pragmatic Discourse Analysis by Dominique Maingueneau(1989). This way, discourse is characterized as an act, an event, which assumes position, "position in relation to a target, the position from which it (the discourse) is exercised, that is, it assumes a relationship between positions"(Guirado M., 2000, p. 33).

With this concept of speech instrumenting the thoughts that we can configure the analytical strategy that will guide this historiography, namely: what is the place configured for Daniel in this path that starts from the search for answers by the family

members and reaches the production of an autism diagnosis. And, with this concept of discourse as an act, we will be able to highlight the mode of production of this diagnosis, thus avoiding entering into discussions as to whether it (the diagnosis) is true or false, good or bad, partial or complete.

And also regarding the AID strategy, another concept that instruments the analyzes in this historiography is that of institution. Supported by Guilhon-Albuquerque, Guirado defines this concept as: social relations that are repeated and, in this repetition, legitimize themselves. For the recognition of this practice as the natural and legitimate, and for the lack of knowledge of its instituted character (Guirado M., 2018). This definition of institution takes the concrete scope of practices and social relations. Differing from concepts that think institutions as something above or, at least, part extra part of institutional actors. In such a way that, we can say, institutions are produced from and through the practice, action upon action, of the institutional actors. It is this conceptual perspective that will allow, later on, to delineate and characterize the practices and actions between institutional actors that configure a certain way of producing truths, in this case, diagnoses. This work, in the Doctoral Thesis, we call historiography: "Historiography will be precisely the procedure of recapitulating, resuming and reconstructing the history of the points where the "case" and Daniel are mixed. Not exactly Daniel's story, but the diagnostic story of Case-Daniel." (Martins-Afonso, 2019, p. 54).

MATERIAL ANALYSIS

In this item, we will follow the analyzes that make up this historiography. Let's go!

Documents provided by family members in 2009 contain a CT scan of the skull, when

2 "BERA is an audiometric evaluation. In cases where there is a suspicion of Autistic Spectrum Disorder (ASD) he is asked to rule out the possibility that the child does not respond to the name, the call or sounds in general due to a hearing disorder" (Martins-Afonso, 2019, p. 57).

Daniel was one and a half years old. This examination was carried out on an emergency basis, since the little one, on a family trip, had fallen down a ladder. This examination did not indicate any alteration, only a deviated nasal septum (congenital). So far, no suspicion of any delay or "disorder" in his development has been reported by the family. However, it is noted that, a year later, the documents begin to indicate the beginnings of these suspicions. No more prescriptions for antibiotics or prescriptions for inhalation with saline solution, but referrals and requests for tests signed by neurologists and neuropediatricians. In this regard, it is noteworthy that the first doctors consulted were already highly specialized, neurologists.

In one of these documents, the first in this sequence of "neuro" specialists, at the top of the prescription, "Neurology – Epilepsy" appears. Were requested:

1. ABER²
2. MRI
3. Electroencephalogram
4. Bloodtests
5. Finally, a recommendation that Daniel undergo motor physiotherapy sessions (due to a change in gait).

At that time, Daniel was approximately 2 and a half years old. Of these exams, only the EEG showed any alteration (second report: abnormal, with slight disorganization of the base rhythms). The other alteration indicated, not by a report, but possibly by clinical evaluation, was gait. Thus, through the technical and clinical procedures carried out by this professional (physician – "neurology-epilepsy"), from her position as a specialist, alterations were "detected", and, more importantly, named as such, alterations.

Deviations from what is called typical, “normal”, expected for age.

In the chronological sequence, there are no more documents signed by this doctor. It is another doctor (Pedro), also a neurologist, who starts to see Daniel. As with the previous one, he requests more tests: another MRI and some genetic tests. The “HDs” are spelled in its prescription, as the diagnostic hypotheses are named, X-Fragile and Sotos. Negative result for X-Fragile. Regarding Sotos Syndrome, no specific examination was performed. That is, there is no answer. This movement is curious, because those who accompany and are willing to organize these documents, realize that diagnostic research does not evolve, it does not get anywhere. With each doctor consulted, it seems that the original scene is recreated: a neurologist requesting tests and investigating a possible disorder or syndrome.

All these requests for exams, evaluations, HDs aim to answer an implicit question, namely: “What does Daniel have?”. What names your difficulties? In medical terms, what is your diagnosis? On the other hand, the question of “What to do with Daniel? How can I help you?”, seems to have lost its way. The indication of motor physiotherapy was forgotten; Daniel did not do the sessions.

Still under the sieve of this question – “What does Daniel have?” – Pedro requests a neuropsychological evaluation. On the tab, once again your HD is written, in this case, followed by another acronym: TGD (global developmental disorder, at the time it was another name for “autism”).

We had access to the neuropsychological evaluation report. And here is a technical consideration for the reader to follow the point at which our analyzes will identify the change of record, in which a hypothesis is confirmed as a legitimate and true diagnosis, even if unofficially, about what a three-year-old boy years old “has”.Roughly speaking, the

assessment instruments that we psychologists are authorized to apply are known as tests, and each test is evaluated for some kind of use or purpose; and these validations can be revised and/or extended to other groups. Intelligence tests, assess intelligence (according to your internal criteria and your definition of what “intelligence” is); projective tests assess emotional and personality profiles, basically, and so on. The neuropsychologist who assessed Daniel used the Vineland adaptive behavior scale in her assessment, which assesses/measures how much and whether the evaluated subject corresponds to the number and degree of adaptive ability corresponding to the reference age. However, this “test” is not suitable for the discriminative assessment of autism or another disorder, i.e.,(Carter, et al., 1998). However, this did not prevent the neuropsychologist from writing in her report that Daniel had a condition compatible with autism!

This is how the scene of Daniel’s unofficial diagnosis of autism is set up: a HD by a neurologist, followed by a neuropsychological assessment that ratifies, based on a *scalennonspecific*, a *diagnosisisspecific*. The documents we had access to date up to that period of 2010 (Daniel’s age 3), so there is no definitive report attesting to this or that diagnosis/condition. But, in the family imaginary, although not recorded in documents, Daniel has autism, corroborated by these insidious documents and methods of evaluating and referring HDs.

In the following year, 2011, Daniel is enrolled in a school, *Experience* (fictitious name). According to a report given by her therapeutic companion at the time, the school’s coordination telephoned her, inviting her to follow up with a boy, enrolled for that school year, who was three years old andwith “features of autism”. We highlight this because it seems that in current discourse, from

school to parents, Daniel “has” autism. In conversation with AT, during this follow-up, Daniel’s father would have said that his son has autism, and that the doctor Pedro would have diagnosed it, based on the result of an EEG (sic).

At this point, it is important for the reader to pay attention to the discursive plot that is built around, and sometimes despite, Daniel. The information is inconsistent and little subsidized by real reports and/or real exams. For the father, Daniel has autism because of the EEG; for the neuropsychologist, Daniel has autism because of the Vineland scale; for coordination, Daniel simply has autism. That is, in all of this, it doesn’t matter how this conclusion was reached, the fact is that it seems to be this set of devices and diagnostic exercises that configure the materiality of Daniel’s autism. Here are some highlights to continue this analysis:

- Medical specialties are always “Neuro”;
- Electrons and brain/cranial MRI requested, one with abnormal result and the other “no abnormalities”;
- An indication of motor physiotherapy due to changes in gait (not performed);
- Several HDs, including genetic syndromes;
- Exams (BERA) and HDs (TGD) that do not rebound speak of autism;
- A neuropsychological assessment;
- The school applying for TA for a child with “autistic features”.

There are some repetitions in this material, mainly the medical specialty: they are “neuros”. Neuropediatrician, neuropsychologist, neurologist. In a way, the type of professional already defines a certain place for Daniel in this diagnostic plot: he is the case of a boy

3 Daniel only received a report in 2014, also under curious circumstances, since it was a condition posed by the school he was enrolled in that there be an “official document” that said what “he had”. Thus, the parents pressured the doctor in charge and she issued the document.

who has a problem in the brain, in the “head”, neurological.

And what does he have? Interestingly, it is in answering this question that this whole set of medical-diagnostic-evaluative procedures seems to remain silent. As it is said in common language “they do not close the diagnosis”. HDs, genetic tests, clinical and neuropsychological assessments (insidious as they were, as we saw) remain in this eternal lack of definition. That is, “from the formal point of view of medicine, Daniel does not have, until this moment [2011], any diagnosis” (Martins-Afonso, 2019, p. 63)³.

However, it is in the vacuum of responses from these procedures and health devices that, in the confrontation with other institutions, a certainty is being built about Daniel. That he has some disorder, disorder, difficulty in/in the “head”. This vacuum of “official” medical answers is soon occupied by the “unofficial” certainty that Daniel has autism. Who says so? The school and the family.

Thus, the two main institutions that make up the set of relationships experienced by a 4, 5 or 6 year old boy see him as an autistic boy. Although no doctor, at this point, “signed under” that Daniel has ASD, he lives, is treated and recognized by those who interact with him as “a boy who has autism”. As we said on the occasion of the Doctoral Thesis:

Discursive devices, in different domains of knowledge, aligned and fed each other, without this being orchestrated ‘from outside’, by a head or thinking group. Daniel’s diagnosis of autism was configured in the exercise of forces between the gaps in a diagnostic research history and the family and school discourse about this boy. It is curious, in this sense, that autism appears with overwhelming materiality in the speeches, not in the documents. For this reason, the gaps and suspensions are

not gaps or holes in this story, they are an occasion for the positivization of the discourse on Daniel's autism, as they are appropriated and filled either by the family discourse, or by the school discourse. Since the school fulfilled a double role: it accepted Daniel as the student, but more than that as the student with autism. Thus, it was legitimized at the crossroads of three institutions – family, school and mental health – the brand: 'Daniel, a boy who has autism.' This became his enunciative starting point, wherever he went, wherever he produced history, Daniel would always be accompanied by the discourse of autism. (idem, p. 64).

FINAL DISCUSSION

Is it therefore a question of suspending or denying legitimacy to diagnostic research, or even to the production of diagnoses for children with developmental difficulties, delays or disorders? Not at all! And quite the contrary! In fact, with the present historiographical analysis, our objective was to highlight the tortuous ways of producing truth about a boy and his difficulties, in such a way that, on the one hand, these same devices can be improved for the sake of those who demand, that is, technical means need and can be more precise and careful in their assessments and conclusions. On the other hand, the clinical work with this clientele (be it carried out by psychologists, speech therapists, occupational therapists, or others) would greatly benefit these patients if it were not based solely and exclusively on the diagnosis, official or unofficial, and could thus assess, in the specificity of each patient, their unique demands and needs. In summary, from everything we've said so far, a child is far beyond what an autism "diagnosis" can say about him; therefore, caution must be exercised with generalizations in this field.

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