

THE URGENCY OF EARLY DIAGNOSIS OF DEAFNESS AND ITS EFFECTS ON THE CONCEPTUAL FIELD OF THE EDUCATION FOR THE DEAF¹

A PREMÊNIA DO DIAGNÓSTICO PRECOCE DA SURDEZ E SEUS EFEITOS NO CAMPO CONCEITUAL DA EDUCAÇÃO DE SURDOS

Liane CAMATTI²

Márcia Lise LUNARDI-LAZZARIN³

ABSTRACT: The early diagnosis of deafness has been at the center of policies directed to hearing-impaired children. The aim of this essay is to discuss political issues and contextual aspects of the practice of diagnosis. A bibliographic research was done, addressing the theme from post-structuralist studies, especially for materials that look at childhood, disability and the contemporary political and social context. Historically, deafness, when it does not receive investments, places the deaf in an unfavorable position in the economic and social game. The practice of diagnosis makes sense in a neoliberal rationality, which is concerned with managing the collectivity. Early diagnosis of deafness serves countless interests and objectives due to the multiplicity of interventions that are now possible. With this essay, it was possible to realize that early diagnosis triggers techniques that align the principles of early prevention, identification and intervention. Although Brazilian health networks are precarious to make an early diagnosis, the determination of disability occurs in those networks. The diagnosis ceases to be a set of tests and starts to appear as a policy on life that determines the condition of the disability and places the child in a permanent position of corrigibility.

KEYWORDS: Early diagnosis. Education for the deaf. Neoliberalism.

RESUMO: O diagnóstico precoce da surdez tem figurado na centralidade de políticas voltadas a crianças com deficiência auditiva. O objetivo deste ensaio é discutir questões de ordem política e aspectos contextuais da prática do diagnóstico. Fez-se uma pesquisa bibliográfica, abordando a temática a partir de estudos de vertente pós-estruturalista, sobretudo para materiais que olham para a infância, a deficiência e o contexto político e social contemporâneo. Historicamente, a surdez, quando não recebe investimentos, coloca o surdo em desvantagem no jogo econômico e social. A prática do diagnóstico faz sentido em uma racionalidade neoliberal, que se ocupa da gestão da coletividade. Diagnosticar precocemente a surdez atende a incontáveis interesses e objetivos pela multiplicidade de intervenções que passa a ser possível. Com este ensaio, foi possível perceber que o diagnóstico precoce dispara técnicas que colocam na mesma linha hierárquica os princípios de prevenção, de identificação e de intervenção precoces. Embora as redes de saúde brasileiras sejam frágeis na tarefa de diagnosticar precocemente, a determinação da deficiência ocorre em redes. O diagnóstico deixa de ser um conjunto de exames e passa a figurar como uma política sobre a vida que determina a condição da deficiência e coloca a criança em um espaço permanente de corrigibilidade.

PALAVRAS-CHAVE: Diagnóstico precoce. Educação de Surdos. Neoliberalismo.

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² PhD and Master's in Education. Graduated in Special Education and in Portuguese Language and its Literature/Brazilian Sign Language. Adjunct Professor at the Department of Special Education. Federal University of Santa Maria. Santa Maria/Rio Grande do Sul/Brazil. Member of the Difference, Education and Culture Research Group (DEC/CNPq) and Interinstitutional Research Group on Education for the Deaf (GIPES/CNPq). E-mail: lianecamatti@gmail.com. ORCID: <https://orcid.org/0000-0002-7741-9358>

³ PhD in Education. Federal University of Santa Maria. Associate Professor at the Department of Special Education and the Graduate Program in Education. Federal University of Santa Maria. Santa Maria/Rio Grande do Sul/Brazil. Leader of the Difference, Education and Culture Research Group (DEC/CNPq) and member of the Interinstitutional Research Group on Education for the Deaf (GIPES/CNPq). E-mail: lunazza@gmail.com. ORCID: <https://orcid.org/0000-0003-4831-129X>

FOREWORD

- Tell us a little about your life ...
- *My name is Flora Maria dos Santos⁴, I am 34 years old was raised by my uncles who are my foster parents I owe them everything I am but my mother Mariana Macedo dos Santos also had a great special participation in my life at the time she worked at Colégio Josué Bezerra with a well-known service assistant in the city of Pombal. There I started take my first steps it also started a lot of difficulties in my school life my uncles did not know that I was deaf to my biological mother because she lives far from me from then on she went to the doctor but did not have money to buy the medicine that was very expensive so grew up with the thought that needed to study it is just so I would discover information fighting for a much better life. But my parents were not literate as I was going to be able to do my task to understand the subjects so was trying to want to know everything at home my family wouldn't let me solve anything because I was deaf for them nothing I would learn anyway with a lot of struggle was trying to want to learn I started to work when I was 8 years old when I was 11 years old I was working at home later lived in São Paulo I worked in a furniture store outside and inside today I have a daughter Emilly Suenya and my reason for living, when she was four years old I went back to studying I did the supplementary course in João Pessoa, always taking a course at the Foundation to support to the disabled (FUNAD) meanwhile had me to get by because my daughter father didn't help me. I was unemployed I had to create some things to live on for examples making money, chicken cream, selling sexy shopping, burning spider house in family house, etc. in other words whoever called me to earn some money I went today I'm already working at the João da Mata scholar in my town Pombal, but with this objective of taking the Portuguese Language and Brazilian Sign Language exam, my goal in this course is to improve the deaf. For me it is being a great challenge at UAB because I found some difficulties but I want to overcome obstacles to achieve achievements.*
- At what age did you find out you were deaf? How did you learn to speak?
- *I was born a listener, but I lost hearing eight years old. I was always sick, I had measles and I was deaf. I already knew how to speak Portuguese. Parents can't read, I discovered deafness. I went for voice treatment for six years, six hours of travel. Mom and dad didn't know how to support me because they had no information. I had to study and at school I suffered prejudice. At school did not accept hearing aids and the school was of listener. Had prejudice.*
- And the Brazilian Sign Language?
- *When I discovered FUNAD I was looking for books, people and teachers helped me. I had a deaf friend, worked together, living day-to-day and learning Brazilian Sign Language.*
- How do you do today with the use of both languages?
- *Today I use normal the two languages, Portuguese and Brazilian Sign Language.*

1 INTRODUCTION

The story told in the foreword is real. Just one more statement from so many testimonies, from so many deaf people. It carries with it common points that would appear in as many other testimonies as possible. If not all, in parts. Familiar and common stories and arguments. Narratives crossed by marks of unfamiliarity with deafness, logistical and financial difficulties to pay for treatments, exacerbated paternalism, the search for palliative alternatives related to work or schooling, encounters with sign language only during adolescence or adulthood (usually in an educational institution or in institutions linked to the deaf community), market pressure, the need to put oneself in a condition of production, consumption and competition

⁴This foreword is composed of a life narrative, written in Portuguese, whose translation was maintained according to the original wording. Only the author's name has been modified. Flora is deaf, from Paraíba, Brazil, a former classmate of the Teaching License Course focused on Portuguese Language and Brazilian Sign Language, a user of Brazilian Sign Language and Portuguese Language in oral and written modalities. We thank Flora for complying with the request to bring to this work a little about her story, her relationship with deafness, with languages and with life.

and the search for improvement in an attempt to remain in the social and economic game. The discussion proposed here is designed to attempt to problematize a specific strategy that would subvert the common scenario portrayed by Flora's story: the early diagnosis of deafness⁵.

In Brazil and worldwide, conduct related to children's hearing is dictated by the guidelines of the Joint Committee on Infant Hearing (JCIH). It is an American committee with professionals in the areas of Audiology, Otorhinolaryngology, Pediatrics and Nursing, which issues guidelines related to the early identification of hearing loss and resulting interventions. In 2007, guidelines were launched that guided the formulation of Brazilian health policies. Both in the texts of such policies and in the specialized literature on early identification and intervention of hearing loss, precocity is precisely defined: the identification of the loss should occur until the age of three months and the beginning of the intervention until the age of six months (Lewis, Marone, Mendes, Cruz, & Nóbrega, 2010).

In 2019, these guidelines were updated, suggesting early diagnosis by rule 1-2-3. In other words, the diagnosis must be complete at two months of age and the intervention must be carried out from the third month of life onwards. Despite these clear definitions in the health area, for this essay, more than the observation of the lifetime in which the diagnosis is closed, there are the implications of the notion of "as soon as possible" and of the marks of the classification process of an individual in the hearing impairment record.

The practice of early diagnosis of deafness is nowadays an object of frequent study in the areas of health and, less frequently, of Psychology. However, its effects in the field of education are still rarely discussed. In the Brazilian context, for example, a search in the Brazilian Digital Library of Theses and Dissertations using the keywords "*diagnóstico precoce*" (early diagnosis) and "*surdez*" (deafness) or "*deficiência auditiva*" (hearing impairment) generates 41 results. Of these, only the study from which this essay is derived was produced in the area of Human Sciences. All the others discuss clinical aspects, mainly related to benefits and protocols.

However, it would be unlikely to consider that the entire network of practices involved in the diagnosis has effects only for the health area. The way in which it takes effect has direct implications on the field of education, mainly Special Education. The conduct of families, language and schooling options, development issues are all implicated in the ways in which it is socially invested in preventing, detecting or correcting any deviation from the standard in children's hearing. Here is the most evident contribution of this essay: some clues are presented that help understand the relationship between the current context of the subjects of the education for the deaf and the processes by which they are submitted at birth and in the first years of life.

The articulation established in this study, partly contemplated in this essay, between the early diagnosis of deafness and the schooling practices of deaf children is still untied. We are not denying the permanent presence of clinical interventions in the field of deaf education,

⁵ This essay derives from a PhD research in Education, entitled *Efeitos do diagnóstico precoce da surdez nos processos de escolarização de alunos surdos* (Effects of the early diagnosis of deafness in the schooling processes of deaf students), conducted by Camatti (2017), which aimed to understand how the early diagnosis of deafness has operated in the articulation of regulatory techniques that generate effects on the constitution of the deaf subject and on his/her schooling processes. The focus of the study ended up opening space to also discuss the contemporary political scenario that justifies the urgency of precocity in addition to biological aspects and technological possibilities.

they have always been the determinants in the rehabilitation processes of deaf children, with a strong focus on the ways of conducting pedagogical practices in the context of the school. However, with the advent of research on the importance of sign language for the psychosocial development of deaf children and their articulations in the culture and identity field, the centrality of rehabilitation and clinical practices loses strength in the context of schooling for deaf people, especially in specific school spaces for the education of the deaf.

In this sense, we see a polarization between what is conventionally called clinical and socio-anthropological models of deafness in the field of the education for the deaf. This antagonistic movement, for now positioned as opponents - in the sense of an inability to relate itself - weakened the debate between these two fields: education and health. Therefore, in this work, we intend to displace that binary logic still very present in the field of the education for the deaf and enhance the importance of these two fields in the schooling process of deaf children. With that, we are interested in marking the two-way street that is built between health and education, or rather, the possibilities of a more purposeful than judicative dialogue between the clinical-therapeutic and the educational.

Regarding this updated discussion on the diagnosis, discussing it makes sense as the statistics raised in relation to the lesser activity of the person with disabilities place them at the center of management policies that will reduce the subject's productive limitations and enhance their life. It is in this logic that techniques to improve management of the community and of the body inscribed under the mark of disability are put into operation. This can be done both by forged conducts in the logic of rehabilitation, and in the logic of discourses about identity affirmation - as long as it is just, direct and determined by appropriate behavior. To further enhance the management processes of this part of the population, the search for the feasibility of intervention at the earliest possible age arises.

To outline the methodological options of this essay, we sought to look at the subject in question from the perspective of post-structuralist studies, especially considering the framework of Foucaultian Studies in Education. We opted for a literature review that involved, first of all, studies on the forms of organization of neonatal hearing screening, of hearing health policies in Brazil. At the same time, a comprehensive study was carried out on the political and social context in which early diagnosis becomes almost imperative, seeking in post-structuralist studies those who think about investments in childhood and disability.

Machado (2008), in the introduction to the Brazilian edition of the book *Microphysics of Power*, written by Michel Foucault, states that all knowledge, whether scientific or ideological, can only exist based on political conditions, which are the conditions that both subjects and domains of knowledge are formed (Machado, 2008, p. XXI). Thus, in the epistemological context of the study, there was no attempt to describe the ways in which clinical procedures occur. The questions raised derived from the thought exercise proposed by Foucault's Philosophy of not seeking the truth in oneself, but of seeking the conditions of possibility for the subjects to be in the world in certain ways and not in another.

In the field of Special Education, a large part of the works developed affiliated to post-structuralist studies do so in an attempt to analyze discursive or non-discursive practices

that place the contemporary subject classified in the spectrum of disability to the symbolic place he/she occupies. In the case of deafness, this goes through central discussions about the ways in which childhood and disability are two populational markers that demand continuous care.

From the initial considerations, the text that unfolds aims to discuss issues of a political nature and some reasons and contextual aspects of the centrality attributed to the early diagnosis of deafness. It is a challenge that seeks, to some extent, to create discomfort while thinking, bringing to the debate a theme that socially figures as a solution to a problem.

2 FOR EVERY DIAGNOSED DEAFNESS, AN INTERVENTION IS POSSIBLE ... THEREFORE A PERMANENT CONDITION OF CORRIGIBILITY

The field of Education for the Deaf has, in recent decades, taken important turns around the understanding of the subject of deafness. In this movement, pinpointing some goals was necessary so that other discourses could narrate the deaf, distancing themselves from hegemonic practices regarding the deficit, the incapacity, the non-provision of a skill adjacent to human normality.

In the Brazilian context, since the 1980s, the production of knowledge has increased in an epistemological field that understands the centrality of culture in the constitution and meaning of the subjects. Talking about deafness, in this field, started to relate to investments in (re)inventing deafness based on other references: linguistic and cultural differences. As a movement of resistance, affirming certain truths and refuting others were conditions to demarcate the space of this new field. A great dyad was established there that, for many, needed to be overcome: on the one hand, what was conventionally called the clinical view of deafness; on the other hand, the socio-anthropological view. The Education for the Deaf has taken a turn on itself in an attempt to assume one model at the expense of another. However, looking at this attempt to replace one discursive matrix with another implies, necessarily, understanding that both coexist, are established, and make sense based on a certain rationality. In contemporary times, this discursive shift is implicated in the mechanisms of neoliberal logic.

The lessons of the French philosopher Michel Foucault give rise to looking at neoliberalism from the purpose of understanding how the global exercise of political power is based on a market economy (Foucault, 2008). It is in this sense that we consider it necessary to think about the establishment of practices indexed to an art of governing eminently linked to formal principles of a market economy.

It has been relatively common to treat neoliberal rationality as a game that, in order to be played, imposes rules. Castro (2009) states that neoliberalism implies understanding the rationality of the market, but extrapolating the domains of the economy, encompassing other spheres such as family, birth, delinquency, etc. Thus, conducting oneself rationally in Contemporaneity presupposes gravitation towards these rules from different spheres that place each and every one in a network of knowledge and create the need to not leave the game.

Lopes (2009) systematizes two great rules that are valid for any player: the first is to stay active and the second is to be in conditions of participation, that is, inclusion. For this, there

are three implications: 1) being educated towards getting into the game - through educational mechanisms (not necessarily pedagogical), which mobilize individuals in the direction that each one seeks to guarantee conditions of being and remaining in the productive networks; 2) remain in the game (remain included) - actions that guarantee the leading of conducts and the safety of the population, by means of remaining in groups defined in social, educational, health and work policy records, thus remaining within reach of state actions; 3) to wish to remain in the game - a condition of participation that becomes effective by the alignment of State actions with the logic of the market, making a consumer network spin, which makes everyone want to qualify and take care of themselves.

In 2011, the World Health Organization (WHO) published the World Report on Disability. The document announces two major objectives: to provide governments and civil society with a comprehensive description of disability and to make recommendations for action at technical and international levels. Concerning possible definitions and articulations between human rights and citizenship, the Report opens its doors by clearly defining what is lost. The life of the person with a disability is read in numbers: poor health results, presence of higher rates of risky behavior, lower educational performance and low rates of participation in school life; lower economic participation, high rates of inactivity and disengagement from productive activities; higher rates of poverty, food and housing deprivation, access to basic sanitation and health services; greater dependence on others and assistance programs or services (WHO, 2012).

Together or separately, each of the elements indicated by the Report helps to determine positions and rules of the neoliberal game, insofar as it keeps risks, losses and gains under control. In them, the Report focuses on management practices and, therefore, triggers a mechanism that leads to an efficient governance⁶ of the disabled body (Carvalho, 2015). The demand raised, then, is for more investment, whether in the area of health, education, social assistance, architectural planning, etc.

We emphasize, here, that any possibility of methodological discussion or option for one language or another with a view of the personal development of the deaf seems to be diminished. The rules are clear: participate and do not leave the game. The ideal way to achieve the goals: there is none! Get yours, get everything, no-holds-barred! No-holds-barred! And it is at this point that the opening testimony of this essay is less obvious, less common: being *either* on one side *or* the other is no longer as interesting from the assumption that, at different times and situations, both sides can offer advantages and can make the transit through the game smoother and more fluid.

The discursive recurrences of the testimony show policies of assistance, rehabilitation and education that are inscribed in neoliberal rationality, in addition to a form of market economy, but as a way of life. Functions are assigned to everyone and each one that enables maintenance in market networks. Not being in a situation of exclusion is a common point between the social and the economic.

⁶ We assume, in this writing, the considerations of Veiga-Neto (2005) when he distinguishes between the designs of the word "government". The author defines Government as, in general, spelled with a capital G, as "that institution of the State that centralizes or takes the guarantee of the governing action" (Veiga-Neto, 2005, p. 19). He also suggests that the term "governamento" (governance) is used in texts written in Portuguese whenever it is necessary to refer to Foucault's inspirations on the ways of directing the conduct of groups or individuals.

Several researches have helped in the construction of the understanding of how the rehabilitation policies for deafness and inclusion (not only school) are in the order of investments on the life of the portion of the population comprised by having hearing impairment. This is done either by punctually addressing rehabilitation policies for the deaf, or by addressing the investment of the most diverse orders made in bodies that fall under the mark of abnormality as a way of preventing them from leaving the game (Lunardi, 2003; Pontin, 2014; Rezende, 2010).

Diagnosing deafness early produces large-scale effects that serve countless interests and goals. It is not too much to say that it is celebrated. Not by itself, since, in itself, the diagnosis determines a place of departure for the subject already distant from the center of the norm. It is celebrated for its reverse, for its effect: for the multiplicity of interventions that become possible from it.

The deaf community celebrates that it can invest in an ideal of political and cultural formation based on the reference of sign language. It celebrates the field of medicine that can put into operation a whole apparatus of knowledge and technical resources aimed at rehabilitation⁷ in a critical period. Frightened and hopeful families celebrate the projections of an absolutely normal child. Perhaps, one day, the subject will celebrate, enjoying the good that so much investment in his/her life may have done.

Population governance demands management of biological processes in order to adjust population phenomena to economic issues. In the field of statistics, deafness is a measurable problem. More than 1% of the Brazilian population was registered in the 2010 Census with severe hearing loss. In addition to the numbers, there is a whole field of knowledge that projects corrective measures into the imperfect body: the identification of the disability up to two months of age and the beginning of the intervention up to three months guarantee the child a future - which cannot be better, but at least - more adjusted to normality. From there, techniques are launched that place the principles of early prevention, identification and intervention in the same hierarchical line.

In this game, a complex network is already taking shape in which the diagnosis is no longer a set of tests that will determine the hearing deficit and is now understood by its incidence beyond the field of deafness. It is a policy on life. In the remodeled space of contemporary biopolitics, the exercise of power focuses on managing the vital capacities of everyone and each one. The diagnosis goes beyond the context of the clinic and the abnormal body. It affects life even before the individual exists through calculations, analysis of risk indicators, carrying out tests, establishing comparative relationships, etc. It orbits spheres that allow the optimization of the results of human experience: it guarantees the permanence of the body in a constant condition of correctability, it predicts the best paths, it involves the

⁷ For the sake of preciousness and centrality of the term throughout the text, it is worth justifying the choice to keep the discussion centered on *rehabilitation* processes and not on *habilitation*. Through the dictionary, *habilitation* refers to the process of becoming skilled from an initial situation of disability, while *rehabilitation* refers to the restoration of a lost previous condition (Ferreira, 2009). By this definition, the semantic adequacy in the field of the clinic that aims to develop initial hearing and speech skills in children born deaf requires the use of the term “habilitation”. However, it is necessary to consider that this essay focuses on the study of conditions and policies involved in a field of normal production. What is at stake, much more than the installation of a skill never conquered or the return to a lost skill, is the ability to be in the space of the norm and the reestablishment of a subject’s potency. For this reason, the term “rehabilitation” seemed, for the specific context of this essay, more appropriate

interference of expertise, the set of legal texts, the awareness of families, the collaboration of teachers and the entire social body.

The understanding that removes the absolute domain of the diagnosis from the clinic is possible to the extent that it ceases to be understood as an entity, as an action, and becomes glued to an exercise of power objectified by medical knowledge. This, in turn, is rooted in all social spaces for taking on the task of maintaining or restoring normality. The diagnosis, therefore, appears in an eminently clinical discursive order in which the first installation of the disability implies a conformation in relation to the norm. However, from then on, there is an indefinite demand for the continuity of the examination of the deaf subject; and that happens in any space, especially at school. Examination, evaluation, diagnosis and classification rituals are embedded in everyday pedagogical practices.

For those who live daily with deaf children and family members, especially in rural areas, the weaknesses in hearing health policies that seek to privilege early diagnosis are not new. Often they end up leading neither to diagnosis, nor to related means of intervention, either in the register of clinical rehabilitation or in the register of sign language. Children born deaf continue, even in the face of such large investments, going through the same lengthy processes in which years are lost between the first suspicions of the family, the determination of the disability and the beginning of consistent investments in the order of language development.

Despite that, it would not be possible to say: diagnostic policies do not work. There are two important facets here. On the one hand, there is the effectiveness of public policies and their results in terms of achievements. In this regard, the means that aim to detect deafness until two months of age and initiate corrective intervention until three, are in fact fragile. However, on the other hand, there is the rationality that is installed in a policy for life. The determination of hearing loss occurs in networks and with permanent effects.

If one considers the wide network of medical knowledge interference added to the expansion of State investments in risk assessment and containment, it is possible to say: that the forms of deafness control must affect the very appearance and establishment of the condition of the disability. In this way, the potential for deafness to appear, even before birth, is managed by the State. However, prevention is not always possible. From there, then, a long and permanent process of conforming to the norm led by the lines of diagnosis begins.

At first, it acts by determining the condition of the disability. It gives it a peaceful, calm and therefore accessible and manageable place. In itself, disability is not a problem. Nor could it be, because it is irreversible. There is no more cure, ultimate intervention, medicine or permanent solution to the lack of hearing when a child arrives at school age with the record of the disability. However, the moment it is causing displacements in relation to the normality axis by the installation of linguistic or developmental deficits, then yes, it needs to be managed. It is in this management that the diagnosis continues to intervene when it produces minor diagnosable conditions.

Thus, a constant process of regulation of conduct begins, centrally managed by the school, but also by the family and the clinic. What becomes central to concerns is no longer to diagnose deafness. It is to diagnose any conditions that may, by a comparative relationship,

not keep the child in acceptable conduct in terms of development, learning and language. The deaf child leaves the initial deterministic condition and is inserted into a daily process of small examinations and the establishment of minor abnormal conditions. This is where the power of diagnosis lies: for every condition diagnosed, an intervention is possible. What is being examined are the abnormal patterns of development. They are permanently diagnosed and invested. The lack of hearing, when incorrigible, is now managed by skill compensation systems.

The entire process described acts privileged at the level of the body. However, at the same time, there is a macro-political organization around the leadership of conducts articulated by policies of different orders. The diagnosis, in this case, makes the subject available for the action of public policies of the present. Through all these analyzes, we have stated that the early diagnosis of deafness regulates the constitution of deaf subjects and his/her schooling processes insofar as it functions as a biopolitical practice of interference extended by life, permanently producing abnormal diagnosable conditions under which actions of intervention are applied.

3 CONCLUSION

Diagnostics, from the Greek *diagnostikós*: capable of being discernible. By itself, etymologically, the term presupposes a relationship. Discriminate, separate, distinguish. Between one and the other, between this and those, between anything and the norm. It does not reveal a condition. It determines, in a wide spectrum, parameters for a possible existence. And to put in relation presupposes, in this case, two operations: to discern in order to separate and, soon after, to do everything possible to approximate what was separated.

In this essay, we wanted to look more closely at the dynamics involved in these two operations: in the separation and in the subsequent approach of deaf children when captured by the webs of the diagnosis of deafness. To this end, we start from the notion that the constitution of the deaf person is a historical process, with the possible existence at each time a construction that involves possibilities of being in society, cultural positions, symbolic appreciation of language, methodologies and educational policies, in addition to contemporary governance demands.

When we think of the deaf as subjects of a possible contemporary existence, it makes sense to question the early diagnosis and the regulatory manifestations of deafness that derive from it. Early diagnosis promotes possibilities of capture and investment from the convergence of discourses of different orders that end up producing other ways of being deaf and whose effects lead to his/her schooling processes.

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