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Article

Multiple meanings of the inclusion of people with intellectual disabilities in the aging process: family narratives[1]

Múltiplos sentidos da inclusão da pessoa com deficiência intelectual em processo de envelhecimento: narrativas familiares

Múltiples sentidos sobre la inclusión de personas con discapacidad intelectual en el proceso de envejecimiento: narrativas familiares

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ABSTRACT

People with intellectual disabilities are living longer and, in some cases, aging with their parents. The study aimed to analyze how these people's trajectories of social insertion, narrated by their parents, contribute to the defense of inclusion processes in their multiple senses. Empirical materialities were generated through narrative interviews with mothers and a father of individuals with intellectual disabilities over 53 years of age, and the analysis was inspired by Foucault's discourse analysis. The study points out that each historical moment articulates different notions of truth to the ways in which people with intellectual disabilities were treated, from exclusion from school, work, affective life and, more recently, the movement for inclusion. The fragility of most of the parents interviewed, in terms of health, protection and security, points to the importance of public policies to support this population, so that these subjects can live and age with greater dignity.

Keywords: Special Education. Intellectual Disability. Aging. Families. Inclusion.

RESUMO

Pessoas com deficiência intelectual estão vivendo mais e, em alguns casos, envelhecendo com os seus pais. O estudo objetivou analisar como as trajetórias de inserção social dos filhos, narradas pelos pais, contribuem para a defesa dos processos de inclusão em seus múltiplos sentidos. Materialidades empíricas foram geradas por meio de entrevistas narrativas com mães e um pai de pessoas com deficiência intelectual com mais de 53 anos, e a analítica foi inspirada na análise do discurso em Foucault. O estudo demonstra que cada momento histórico articula distintas noções de

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verdade às formas como pessoas com deficiência intelectual foram tratadas, desde a exclusão da escola, do trabalho, da vida afetiva e, mais recentemente, o movimento pela inclusão. A fragilidade da maioria dos pais entrevistados, em forma de saúde, de proteção, de segurança, aponta para a importância de políticas públicas de apoio a essa população, para que estes sujeitos possam viver e envelhecer com maior dignidade.

Palavras-chave: Educação Especial. Deficiência Intelectual. Envelhecimento. Famílias. Inclusão.

RESUMEN

Las personas con discapacidad intelectual viven más tiempo y, en algunos casos, envejecen con sus padres. El estudio tuvo como objetivo analizar cómo las trayectorias de inserción social de los niños, narradas por los padres, contribuyen para la defensa de los procesos de inclusión, en sus múltiples sentidos. Se generaron materialidades empíricas a través de entrevistas narrativas a madres y padres de personas con discapacidad intelectual mayores de 53 años, y el análisis se inspiró en el análisis del discurso de Foucault. El estudio apunta que cada momento histórico articula diferentes nociones de verdad a las formas en que las personas con discapacidad intelectual fueron tratadas, desde la exclusión escolar, laboral, afectiva y, más recientemente, el movimiento por la inclusión. La fragilidad de la mayoría de los padres entrevistados, en términos de salud, protección, seguridad, apunta para la importancia de políticas públicas de apoyo a esa población, para que estos sujetos puedan vivir y envejecer con mayor dignidad.

Palabras claves: Educación Especial. Discapacidad Intelectual. Envejecimiento. Familias Inclusión.

INTRODUCTION

Throughout History, many ways of understanding people with disabilities have been reported, from mysticism, abandonment, extermination, segregation, exclusion, integration to, currently, inclusion. However, this movement is not linear, but rather discontinuous. For centuries, those who were “different” remained on the margins of social groups, but when the human right to equality and citizenship became a daily concern, perception about disabled people also began to change.

Dreyfus and Rabinow (2010), based on Foucault, describe the processes of exclusion, such as the confinement of lepers during the Middle Ages, so as to keep in isolation those who were considered dangerous or harmful. After the end of the Middle Ages, the leper colonies were emptied and replaced by an even larger group of people: the mad, imbeciles, fools, drunks, perverted, criminals, and lovers. The process of confinement and exclusion and a new discourse about institutionalization emerged since hospitalization now had to have a moral and social justification.

The authors state that, after the French Revolution, to keep insane and criminal people in the same place led to public outcries. Treatment through hospitalization became a major economic mistake to be abolished or replaced by something more scientific. Traces of these times persisted, gradually gaining new configurations, but clinical and welfare views marked and restricted the lives of disabled people until recently, when, for example, clinical diagnoses presented the life expectancy of disabled people as short. These diagnoses often were correct, because exclusion in different spheres of life, such as health care and well-being, contributed to shortening these people’s lives.

The ageing of people with intellectual disabilities is a recent phenomenon, according to Ferreira (2012). The life expectancy of this group used to be considered lower than that of general population but, nowadays, people with intellectual disabilities are living more due to advances in social sciences and health and improvements in the living conditions of populations worldwide. Although there are still many living in bad conditions, people with intellectual disabilities are living longer and, in some cases, parents and children are getting old side by side. This phenomenon happens not because disability has changed over the years, but because of the way we understand and act towards it, providing these people with experiences much like those of other people.

Therefore, this article intends to show how, throughout history, different ways of understanding disabled people have been naturalized, from extermination and abandonment to, in contemporary times, the gaining of terrain in debates and the recognition of what we call difference. This text brings the conclusions of the Master's Dissertation in Education of the first author, under the supervision of the second. The study sought to answer the following question: how do the schooling and social integration of intellectual disabled adults in the ageing phase, narrated by their parents, contribute to inclusion processes in multiple senses? The following study questions were based on the research problem: How did the historical Brazilian process of schooling and social inclusion of intellectual disabled people take place? What changes do parents see in the way they raise disabled children, comparing the childhood and adulthood of their son/daughter? Which social/educational factors have influenced the intellectual growth of disabled human beings according to the perspective of their parents? What are the biggest challenges for parents in relation to the ageing process of their grown-up children with intellectual disabilities?

When we think about the ageing of people with intellectual disabilities, as well as the practices regarding their schooling, social and school inclusion, we are led to face a non-linear or evolutionary historical path. Rather, we face a history of discontinuity and constructed truths, when families, influenced by the medical truths, believed their disabled children would have a short life span.

However, according to Pieczkowski (2017), the fact that people with disabilities are living longer does not mean that they are living better in a society based on neoliberal principles, because, as they get older, they suffer a double prejudice: as disabled people (often understood as non-productive) and as old ones. According to the author, looking at adults and elderly people with intellectual disabilities is imperative.

Many intellectual disabled adults and elderly people have not experienced the process of schooling and social inclusion, since Special Education was provided apart from regular schooling. The right to include disabled people in regular schools has become a reality over the last four or five decades in Brazil, after the National Policy for Special Education from the Perspective of Inclusive Education (Brasil, 2008).

METHODOLOGY

The research was carried out with parents (mothers and fathers) of intellectual disabled grown-ups over the age of 53. A pre-investigation was carried out with the intention to check if there were enough participants for the study at a Specialized Educational Care Center (CAESP), in the west of the state of Santa Catarina, Brazil. The interviewees were parents of disabled people attending CAESP. The intention was to interview parents of elderly people with intellectual disabilities over 60. But, considering that the number would be limited, the minimum age was decreased to 53.

At CAESP, educational services have been offered daily, in the morning and afternoon shifts, from Monday to Friday, since 1970. Some of the enrolled people whose parents answered this survey have been attending the center since it was founded. In other words, for over 50 years.

Thus, to carry out the research, the institution's manager was first contacted to check if it was possible to select these subjects and also to fill forms with family members information and contact details. Next, we had to establish the criteria for definition of the *locus* and subjects of the research, which were: a. to be a parent of an adult/elderly person aged 53 or over with an intellectual disability; b. the adult/elderly should be attending CAESP; and c. to agree to take part in the study. After that, eight families who met the first and second criteria were identified. Subsequently, family members were called to be informed about the goals and importance of the research. Eight contacts were made with parents, seven of whom were interviewed. One father who was to be interviewed, due to serious health problems, was unable to take part and passed way during the research period.

During the interviews, the mother and father (both) were invited to take part, if they wanted to, because there was no selection based on gender. However, only in one family did both parents take part. In the other families, the mothers were interviewed, because in three of them the fathers were deceased, and, in another three, they had serious health problems and were bedridden, including the one who died during the survey time. The families in which the mothers took part asked the interview to be carried out in their homes, especially because three of them also had to *look after* their husbands. The family in which the father also took part opted to be interviewed at the CAESP. It is important to note that the study took place during a challenging time in human history: the COVID-19 pandemic. For this reason, all the sanitary precautions defined by the World Health Organization (WHO) were taken, such as the use of an individual mask, alcohol gel and social distancing.

As a strategy for collecting empirical material, we opted for narrative interviews. According to Andrade (2014, p. 173), the narrative interview "is a research possibility that has been reframed in the field of post-structuralist research from an ethnographic perspective". The author also states that "narratives are constituted from the connection between discourses that articulate, overlap, add up or even differ or contemporize" (Andrade, 2014, p. 179).

A script was used for the narrative interviews, which were recorded, transcribed in full and then organized into thematic groupings, considering the most relevant and recurring aspects. Analysis took place from the perspective of discourse analysis, inspired by Foucauldian references.

According to Fischer (2001), the researcher needs to consider the discourse, analyzing what is said and how it is said. The author also recalls that Foucault stresses that researchers need to adopt methodological attitudes, and not be guided by subjective issues, or analyze only "[...] 'what is behind' the texts and documents or 'what was meant' by it [...]" (Fischer, 2001, p. 221). In this way, it is necessary to "[...] pay attention that words and things refer to facts and statements, what is strictly 'rare', not obvious. They are beyond the given things [...]". So, it is necessary to pay attention to the conditions in which the discourse is being reproduced (Fischer, 2012, p. 100). Sales (2014), referring to discourse analysis based on Foucault, states that "[...] it is a question of analyzing why it is said, in which way and in which time and context, that means, to question the conditions of discourse".

Furthermore, considering the ethical aspects of the research, the institution and the employees involved had their identities preserved, with the interviewees being identified by the word *interviewee* (I), followed by number 1 (one), 2 (two), 3 (three) and so on. The numbers were added by the order of interviews and the researcher followed the legal aspects set out in the Resolution 466/2012, which guides research involving human beings. This resolution states that research collaborators must be guaranteed confidentiality and anonymity. The analytical material will be stored for five years after the end of the studies.

The Free and Informed Consent Form (FICF), the Consent Form for the Use of Voice (TCUV) and the Institution Statement of Knowledge and Agreement were also adopted. The research project was approved by the Ethics Committee (CEP), under Certificate of Presentation for Ethical Appreciation (CAAE) registration no. 48967121.3.0000.0116. The interviews were carried out only after the project was approved.

The following information is intended to contextualize the collected empirical material. The interviewed mothers and fathers are aged between 77 and 84 years old, and their level of education is mostly primary education. Only one of them has a university degree. We refer to grown-up people with intellectual disabilities as “the child/children”. However, the gender is kept in the interview excerpts. We have chosen to generalize and not differ gender in the interventions, for both reasons: to preserve the anonymity of the interviewees and to simplify the writing (Chart 1).

Chart 1 – Research participants.

Interviewee	Age	Level of education	Age of disabled person	Level of education of the disabled person	Date of interview	Location	Family support
I1	80	Primary school (complete)	53	1st and 2nd years of primary school	August, 09th 2021	Residence	Daughter-in-law who lives next door
I2	84	Primary School (Incomplete)	55	Primary School (up to 13 years old)	August, 08th 2021	Residence	Eldest daughter who lives together
I3	77	Primary School (Incomplete)	54	No schooling	August, 11th 2021	CAESP	Older daughter who lives together
I4	79	Higher Education (Graduated)	58	No schooling	August, 24th 2021	Residence	Permanent caregivers
I5	78	Primary School (Incomplete)	55	No schooling	November, 11th 2021	Residence	Only the elderly mother, without additional support
I6	82	Primary School (Incomplete)	56	Only started 1st year of primary school	December, 2nd 2021	Residence	Son and granddaughter who live together
I7	84	Primary School (Incomplete)	54	She tried to enroll but had it denied	December 03rd 2021	Residence	Son and daughter-in-law who lives next door

Source: prepared by the researchers (2022).

In the context of the interviews, some mothers and the father reported the good feeling of being heard in their concerns, anxieties, and expectations regarding their children. They recalled the pressure of a society that defines normality standards and excludes those who do not match that standard, as well as the burden of being elderly and living with a disabled adult who is about to become elderly too.

The narrative interviews were organized into Thematic Groupings, a term inspired by Andrade (2014), and content of analysis of the selected narratives was done according to relevance and recurrence.

AGING OF PEOPLE WITH INTELLECTUAL DISABILITIES

The ageing of intellectual disabled people is a recent phenomenon. The Elderly Regulation considers elderly people have a priority in the allocation of public policies and resources to guarantee their rights. In addition, the elderly are considered "especially vulnerable" by Act 13.146 of July 6, 2015, which established the Brazilian Law for the Inclusion of Persons with Disability (Brasil, 2015).

> The population's average age is one of the main social achievements worldwide, but it also brings major challenges for nowadays society. These challenges are related to the process of vulnerability resulting from ageing and the unpreparedness of societies to deal with it. (Tonezer, Trzcinski and Dal Magro, 2012, p. 1)

Still according to the authors, it is possible to see the relevance of discussing population aging and its implications for society. When it comes to the disabled elderly, the difficulties of having a social life and community stigmas are accentuated, not only because of prejudice, isolation, and a decrease in social and family bonds, but also due to the lack of public policies.

According to Veras and Caldas (2004, p. 424), there has been a significant increase in the average age of the world population: "The 20th century was characterized by changes, with the increase in the lifespan of population standing out as the most significant fact in the field of global public health. One of the greatest achievements of mankind has been the extension of life spans".

Regarding the schooling of people with disabilities, a few decades ago, those who are now adults and elderly in the western region of Santa Catarina, where this research was done, attended institutions such as the Association of Parents and Friends of the Disabled People (APAE, nowadays called CAESP), or remained only in their homes. Their life expectancy was short, and they rarely became elderly. When they did, the families, which were often large, shared between their members the task of looking after the child. However, even the pattern of families has changed a lot in recent decades. Influenced by a more urbanized society, families have become smaller and there is a new task division in homes. Referring to family care and attention for people with disabilities, Pieczkowski (2017, p. 75) states that:

> In large family contexts, until a few decades ago, a relative was usually prepared in childhood for looking after the child, in case he/she survived the clinical prognosis regarding life expectancy. The prediction of an early death was common because people with disabilities used to live at home, sometimes hidden in isolated places, without any social interaction. Psychical conditions, such as sadness and depression in the face of a life that was not worth living were not viewed as social causes or aggravating factors of disability. Early death was naturalized. A few decades ago, it was common for disabled people to remain in their homes without attending school because families did not believe in the development and ability to learn of their disabled children.

The author reports that these experiences were naturalized by many families of people with disabilities until recent years. However, nowadays, there are new perspectives, contributing, although slowly, to these people being accepted in society and education.

In the state of Santa Catarina, the Special Education Foundation (FCEE) (Santa Catarina, 2017) addresses policies for people with intellectual disabilities who are aging. The foundation is a charitable, educational, and scientific institution, endowed with legal personality under public law, non-profitable, created in May of 1968. It is connected to the State Department of Education, and was the first state public institution in Brazil responsible for defining and coordinating special education policies.

The institution identifies the ageing process of people with disabilities and highlights that:

> People with disabilities are getting older. Due to increased life expectancy, we are experiencing the joint aging of two generations: the disabled person themselves and their main caregiver. In the past, only the disabled person needed care. Now, we face the care need for the caregiver as well. Issues related to death and bereavement need to be discussed within the institution and with families. (Santa Catarina, 2017, p. 39)

Thus, the FCEE produced a booklet entitled *Aging with intellectual disability: basic aspects of care and access to rights*, which brings information about the care and rights of people with intellectual disabilities in the aging process (Santa Catarina, 2017). It was produced by the Center for Education and Experience (CEVI) and the FCEE, with the aim of qualifying the care process in the current panorama of increased life expectancy of people with intellectual disabilities, the private aspects of their aging and the aging of their caregiver and/or family members. The booklet is based on the Natural Functional Syllabus methodology (Santa Catarina, 2017, p. 17), which values:

> [...] the acquisition of knowledge and development of behaviors that are useful in their living space inside and outside the FCEE. This need derives from the age range of the public attended by the center — which requires social inclusion and productivity — and the burden on caregivers and family members, many of whom are of advanced age. The main goal of CFN to develop functional skills in a natural environment, i.e. in contexts that justify users and professionals performing a task.

There are many issues about the ageing of people with disabilities, such as pensions for the death of parents, care for people with disabilities who have been abandoned in old age, lifelong education, special retirement, and many others. According to information contained in the booklet (Santa Catarina, 2017, p. 21):

> The binomial of aging and disability, which has recently emerged in Brazil, has put pressure on society to debate this matter and produce knowledge and proposals that respond satisfactorily to this challenge. We are talking about a field in which understanding of who the person with a disability actually is is still not entirely clear to family members or professionals, especially when we consider that, until the 1980s, intellectually disabled elder went unnoticed by public policies and research centers. However, in the last thirty years, the life expectancy of this population has increased much more significantly than the rates observed in the general population.

Based on these findings about the aging of people with disabilities, concomitantly with the aging of their caregivers/family members, we felt compelled to research the subject and contribute subsidies to the creation of public policies providing care for this population.

NARRATIVES OF MOTHERS AND FATHERS OF INTELLECTUAL DISABLED ADULTS IN THE AGING PROCESS

Many researchers, including Pieczkowski, Lima and Ruhoft (2006), and Gavenda and Pieczkowski (2021), show that when parents know that their child has a disability they get worried and insecure. One of the concerns they express regards who will take care of the disabled child when the parents get old and/or die. In this sense, Pieczkowski (2017, p. 75) writes:

> [...] when the baby differs from the expectations of parents, questions about his/her future, which could be answered over the years, are asked by parents and family members all at once: Will they survive? Will they talk? Will they walk? Will they learn to read and write? Will they have a profession? Will they be independent? Will they have an emotional relationship? Will they have children? And when we die, who will take care of them?

It is worth underlining that intellectual disability is not noticed early and it should also not label a baby who is in full development. However, if the child has organic alterations, these questions may arise faster. Otherwise, they emerge at a later age, when parents realize the disability or are told about it, by professionals or by other people they relate to. Once the parents recover from the shock, families with intellectual disabled children, particularly their parents/caregivers, will have other challenges ahead.

> They are confronted not only with the demands faced by families with children with typical development (TD), but also with the responsibilities and challenges associated with raising and educating a person with ID, who will need medical and therapeutic attention, care, and appropriate stimuli [...]. In addition, activities that are common to most of the population, such as attending school, learning to read/write, dating and finding a job, can be challenges for people with ID and their families. (Rooke, Almeida and Mejía, 2017, p. 93)

Therefore, to supply the research, the narratives collected through the interviews were organized into three thematic groupings, presented below.

SCHOOLING AND SOCIAL INTEGRATION OF INTELLECTUAL DISABLED ADULTS

Analysis of the empirical material (narratives) is an attempt to understand what elderly mothers and fathers think (and must tell us) about the life trajectory of their adult children, how it reverberates in the families. These parents experienced birth, childhood and adolescence in environments filled with different discourses taken as truths. Foucault (1996) refers to the "*acts of saying*", which build discourses according to a certain regime of truth, obeying a set of historical rules, and affirming the truths of a time.

Thus, we highlight Foucault's statement (1996, p. 44) that "every system of education is a political way of maintaining or modifying the appropriation of discourses, with the knowledge and powers they may bring". In the case of discourses in education, conceived as a set of statements capable of modifying knowledge and power, we highlight the narratives of mothers, a father, and the references they make to teachers and doctors.

Otherwise, analysis of these trajectories has not the intention to judge professionals or relatives for what is said about certain actions and their implications in the daily lives of intellectual disabled people. However, there are implications for the school trajectory of these individuals and for the way their relationships are built in all the dimensions of their citizenship: working, living independently, coming and going freely.

When asked about the schooling of his child, Interviewee 1 said:

> [...] She was in third grade and the teacher did not want her in class anymore, because her problem was in her brain [...]. The teacher said there was no point [...]. We went to Santa Maria (town) and the doctor replied there was no reason to send her to school.

These teacher and doctor statements show there was a truth statement at the time that people with cognitive limitations or disabilities should be sent to specialized institutions, which were not a replacement for regular schools, but could offer some protection.

Other statements made by Interviewee 1 show that he wanted his child to have the same opportunities at school as her siblings, and made an attempt to get her enrolled in a regular school. According to the family member, as a child, his daughter attended school until the third year of primary school, with a lot of deficiencies, until the teacher called the family to give her opinion on the child's inability to remain at school, due to a *problem with her brain*, as noticed by the teacher and manifested in the child's inability to keep up with the school activities like her classmates.

At the time, Interviewee 1 accepted the teacher's allegation without questioning. Later, he sought a doctor from a distant reference center in the city of Santa Maria (RS) because there were no specialist physicians in his city. The doctor reaffirmed the teacher speech that school was not a place for his child. Therefore, the family accepted both opinions and took their child out of regular school.

During the interview, the family member said that he and his wife had attended primary school up to the fourth grade and that he considered his child had studied enough, since her parents had the same level of education. He also said that his child's intellectual disability was practically irrelevant or non-existent for the family, as she could carry out many activities at home. At a certain age, the child developed a visual impairment, and this did in fact represent a barrier for the family.

The irrelevance of the child's intellectual disability was reaffirmed when Interviewee 1 was asked about the challenges of living with a disabled child. For this particular family, visual impairment was understood as a limitation, but intellectual disability seemed to be a way of being that was naturalized in a family with a low level of education. Interviewee 1 added:

> [...] Look, it is hard, it is hard! Because some days she gets nervous, she wants to do the job too and sometimes she cannot see, so she attacks herself, she gets nervous as hell! [...].

The idea that there was no intellectual disability was reaffirmed when Interviewee 1 was asked whether he considered only his child's visual impairment as a problem and the absence of a *problem with her head,* as the teacher had said, and he replied:

> [...] No, it is her eyes. She has no problem! She even remembers things more than I do because I have already lived a lot, right? and she remembers [...].

In most of the narratives, the parents deal naturally with the fact of their children not going to regular school nor having work opportunities. Beyond the narratives, our professional experience and many years working with families of disabled people allow us to affirm that, for most parents, in the past, studying until the fourth grade was a privilege even for a few called *normal* people. Thus, for their children, who did not fit in the school standards, a view corroborated by the authority of teachers and doctors, denial of the right to school seemed to be an incontestable truth.

Another report, this time by Interviewee 6, also refers to the narrative of a teacher at a time when there were no debates on inclusion and these discourses reflected the family's agreement with regard to their children not being in the same space as other children:

> [...] In the first year, we put him with the others, but the teacher did not accept it, because he disturbed the class and he did not behave [...], he disturbed the class... so I took him out... Yes, I agreed and took him out because he disturbed the class too much [...].

This narrative reminds us of proverbs that are heard in everyday school life such as "one bad apple spoils the whole barrel", based on an environmentalist/hygienist pedagogical conception.

Most concerns about naturalized exclusion in Brazilian education policy began in the late 1950s and early 1960s, with the foundation of specialized institutions to care for people with intellectual disabilities, such as Pestalozzi Institute and Institutions of Assistance to People with Special Needs (APAEs). These philanthropic and welfare institutions were set up to fill gaps in the public sector and therefore have their value.

Attendance of people with disabilities to regular schools was reinforced by the 1994 World Conference on Education for All, when the Salamanca Declaration was proclaimed (UNESCO, 1994). Discourses and truths until that time and context were that people with disabilities could attend specialized institutions or remain only in their homes.

After some reading and reflection, we realized that Foucault attempts to denaturalize discourses, and allows us to see things through different views, provoking a restlessness. Foucault (2009, p. 49), in his book *The Order of Discourse*, states that "[...] discourse is nothing more than the reverberation of truth being born before your very eyes [...]", and can be enunciated for the purpose of anything, becoming a game. Foucault (1988, p. 96) also points out that "[...] discourse can be, at the same time, an instrument and effect of power, and also an obstacle, a prop, a point of resistance and the starting point of an opposing strategy".

IN/EXCLUSION OF INTELLECTUAL DISABLED PEOPLE: PERCEPTIONS AND TREATMENTS FOR THE DIFFERENT

By analyzing the narratives in the previous thematic grouping, we can see the *inclusion* or lack of it as experienced by people with intellectual disabilities in the 1960s and onwards, through family, medical and pedagogical discourses. When asked about how the treatment of their children was and how it is today, family members reported a sense of change and progress. Interviewee 1 says:

> [...] It is very different now! Everything is different! I cannot even compare it to that time. Good heavens! What are you going to say, say what, since we did not have the education we have now... now there are people who give you advice, who, so to speak, instruct you [...].

This family member points out that things are different nowadays but he cannot say what exactly has changed. He believes that perhaps the little education or lack of advice he had in the past is what resulted in his actions, which triggered him to accept that his daughter should not be included in any other place than a specialized institution, which was common and natural at the time. It is possible to see that the interviewee blames himself and takes responsibility for the child dropping out when he attributes this decision to a lack of individual education and not a lack of public policies regarding the education and social inclusion of people with disabilities.

The naturalization of social processes leads people to often forget that they were invented or that they depended on dated historical contingencies. When we listen to memories through family narratives, we see a time when there was little talking about inclusion at school or at work, where the sexuality of disabled people was considered taboo and segregation in specialized institutions was naturalized.

In recent years, inclusion has become an imperative that few dare to challenge. Any unequal distribution is seen as a dysfunction, as a situation that goes against nature. A natural environment would have everyone occupy the social spaces equally, and, if this is not the case, it is because some, for their own benefit, have operated an atypical distribution against the interests of others and against the world. These others are the excluded ones.

In this way, discourse analysis from a Foucauldian perspective requires us to understand the history of the human beings researched as the production of a discourse oriented towards the starting and spreading of knowledge and writing resulting from complex net events. It is not a question of judgment, but of understanding people with intellectual disabilities and their families in times and contexts that determined how difference was *viewed* and *treated*, when exclusion was naturalized.

Based on a philosophy of difference, attentive to diversity and the notion of truth as a construction that invests in difference and its perception rather than masking it, we can put a strain on exclusion and think of other possibilities for existence.

COHABITATION AND THE AGEING PROCESS OF INTELLECTUALLY DISABLED ADULTS

Although several debates are taking place in contemporary times around intellectual disability and ageing, from the perspective of how the ageing of people with intellectual disabilities and their quality of life is perceived, it is worth thinking about how they take part in cultural processes and how they construct their identities, since, due to their mental capacity, they are disqualified in comparison to the models established by medical, biological, social and educational fields.

When looking for people with intellectual disabilities in adulthood and getting old, we noticed something that had already caught our attention after a few years working in Special Education: a minority are still living with and under the care of mothers and/or fathers. A large part of this population is already being cared for by other relatives.

This shows that the *prediction* some doctors made about the estimated lifespan of people with intellectual disabilities was not a *truth*, but produced effects of truth*,* as Foucault says. A new *truth is* emerging in contemporary times, which brings new challenges. When we spoke to the mothers and fathers of these people, we asked them about the future and the answer showed a unanimous concern about the care of their children, represented by Interviewee 1’s narrative:

> [...] I pray to God that they both die before I do (*referring to the daughter and husband*) because... there is my daughter-in-law who accompanies me, but she also has a family and so at least what I can do I am doing to help, you know what I mean? [...] There is no one to do the looking after... there are the relatives, but they are all married, and they all have families... So, we have... I worry, there are nights when I lie in bed and do not sleep, I start thinking and asking God to have mercy because... what do you think, there is no other way... like my husband, he has to bathe, he has to shave, he has to put on clothes, how is someone else going to do it? Of course, there are four... three daughters, but all three also must work, they have families [...].

This elderly mother takes care of her bedridden husband and her adult and ageing child, and her greatest anxiety and fear is that she will be missing from the lives of those who depend on her.

She is aware that, even if she has other children, this does not guarantee that they will be available to look after their disabled and elderly sibling.

The increase in the longevity of people with intellectual disabilities is related to advances in health care and the development of social programs that help them. Although aging is admittedly a good reason to celebrate, we also recognize its challenging character, a process faced by elderly people with and without disabilities. The loss of functionality coupled with disability-related dependency raises questions, especially for mothers: who will take care of him/her when I am no longer here? Who will be responsible for looking after my child?

Only one of the disabled people surveyed still has a mother and father who are physically and mentally able to tend to his needs. The others either have bedridden or deceased parents, which shows us another reality: the overload experienced by the elderly mother-wife. In Interviewee 6's report, concern about playing the role of *mother* is explicit:

> [...] I think sometimes, my God, what will become of me... what will become of my son the day I die? He loves the granddaughter, my granddaughter... but she is getting married, who knows if he will go with her. My daughter, he loves her very much, but she is not like his mother... so I think about what will become of him, and we do not know about tomorrow… if it will be him or me... but I always hope I go first. I know he will be fine! But not like with me, because I know everything he does, his way. His brothers know too. But they do not have the patience of his mother... a mother is a mother!

In our society, mothers are generally responsible for caring for their children. Pimenta, Rodrigues and Greguol (2010) point out that the greater burden of mothers may also be related to a responsibility attributed by a naturalized view of the work of caregivers. The work of women has historically and culturally been related to the domestic/maternal sphere. This gender division between caregivers seems to be based on the experience of motherhood, thus determining that women must be prepared to deal with care activities in daily life, such as bathing and feeding.

Alves (2012) considers that elderly people with intellectual disabilities are likely to face great challenges in their lives as they and their families get older. According to the author, the death or illness of caregivers, as well as the natural changes brought about by ageing, can imply a significant change in the environment.

Ageing brings significant changes in the lives of disabled people, in a wide variety of aspects (social, emotional, psychological, physical, or neurological), because they are at the mercy of the people they live with. More independence for disabled people helps them greatly when their parents are absent, making it easier for them to care for themselves.

However, how can this independence be built if many people with intellectual disabilities have been infantilized all their lives and deprived of social opportunities? Vygotsky (1989) refers to primary disability as biological and secondary disability as the worsening of primary disability due to social deprivation. In this sense, Pieczkowski (2014, p. 197) states that "[...] children with disabilities are understood from the perspective of lack. Because of this perception, which reflects historical prejudices, they are stigmatized".

This highlights the importance of people with disabilities being seen as full human beings, not as people to be cured. Yet, their differences must be recognized. It is from this perspective that the defense of school inclusion for people with disabilities is based, not in a romanticized way, not in the expectation of *true inclusion,* something yet to come, a process that moves towards an understanding of difference where not every single subject is included into a standard identity.

When we think about the trajectory of the people surveyed, considering that society often does not recognize that they can choose, make decisions, the role of the family in caring for the elderly with disabilities and the overload faced by the family becomes clear.

Additionally, the special school run by APAE, now called CAESP, is valued by those interviewed here as a place where their children were able to make friends, prepare for life with a certain amount of independence and acquire the knowledge they needed for their social interactions. The survey showed that most family members rated the institutionalized environment positively, due to the safety it provides, the activities it offers and the attention of the teachers to the students.

The interviewees said they were afraid that one day these professionals could stop providing educational care for their children. What would the development of these people with intellectual disabilities be like if they had had more opportunities for schooling, work, and emotional relationships in their childhood and throughout their lives? This is not possible to answer, but it is possible to infer.

Even though inclusion can be understood as a neoliberal risk management strategy, the school represents a place for interaction, learning and development. It is important to point out that the people with intellectual disabilities surveyed, despite the social deprivation imposed on them, have a certain degree of independence in their daily activities and could probably have achieved greater autonomy if social opportunities had been more effective.

FINAL CONSIDERATIONS

Through family narratives, we have found out that the way in which the historical process of social inclusion of people with intellectual disabilities took place, in the 1960s and 1970s, excluded them (as well as people with other disabilities) from regular school, work and social life, and this was naturalized.

These family members, at the time, largely understood this type of exclusion as natural. They expressed their perception of the changes in the way disabled children are treated, comparing their childhood with that of children today. They highlighted many social/educational factors, including denial of the right to regular schooling, to work, to wider social inclusion, which had an impact on the constitution of people with intellectual disabilities and the way they are today, most of them being dependent on family members.

However, what emerged very strongly in the research was the challenge for caregivers (family members) of getting old side by side with their disabled and ageing adult child, which brings with it the tribulations, along with the feeling of fear about the future and who will be responsible for looking after their children once these mothers and fathers have passed away.

With concerns about the parents' own death, the narratives show the need for support from family members. In some cases, this happens with family members who live in the same house, plot of land, or even nearby. What we have recorded here is something to think about, because the mothers interviewed feel as if they are disturbing the lives of those other siblings/children who live nearby. They seem to feel that they are the only ones responsible for their disabled children. However, at the same time as these family members offer some support, they also receive it, there is an exchange, so that they do not have some expenses like rent, for example. They are family members who help and are also helped in some way.

The fragility of most of the mothers and fathers interviewed, in terms of health, protection and security, points to the importance of public policies to support them, so that they can live and get old with better quality and dignity. The institutional support that families receive from CAESP is highlighted as essential, as a place to live together, to be welcomed and to be supported.

Perhaps this is the meaning of the term inclusion at this stage of life, since the word has multiple meanings. The meaning transcends the walls of the school and takes on a broader scope:

the political struggle for citizenship, the search for an identity without pejorative stigmas and for the self-esteem of these individuals.

When the mothers interviewed became mothers of children with intellectual disabilities, they lived much more oppressive times than today, especially for the female gender, in which their roles were pre-established by society as supporting the family, with little freedom and a possibility. However, they gained importance and developed their strength in society and in the family by revealing their leading role and indispensable help.

This study does not consider discussions on the topic to be over, but underlines that it is necessary to denaturalize and stress the discourses about norms and understand others in themselves, to assume difference as a fact of the world. The disabled person is not someone to be cured, but to be recognized in his/her particularity. This research, with Foucauldian support, made it possible to think about other paths, to see previously naturalized contexts through different glasses. It was an opportunity to listen and look carefully and understand, through the narratives of mothers and a father, the trajectories of their children with intellectual disabilities, the anxieties, especially of the mothers, in a society that classifies and standardizes. It also allowed us to access family memories, which represent possible ways of in/excluding.

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