

Making adult: *capacidade* and the ambiguities of maternal care in intellectual disability

Helena Moura Fietz¹  0000-0002-6568-4760

¹Louisiana State University, Baton Rouge, LA, USA. 70802 – levans10@lsu.edu



Abstract: Capacity/ability is a central category for discussions on disability in Brazil. It also leads to a reflection on how ableism orders society regarding the abled-body/disabled-body divide. In the present paper, I draw on the care practices for adults with intellectual disabilities to examine how the adulthood/childhood binary mirrors the ableist logic. Based on research conducted between 2017 and 2018 with mothers of adults with intellectual disabilities in the city of Porto Alegre, Brazil, I analyze the paradoxes of being at the same time responsible for promoting “autonomy and independence” and guaranteeing the well-being of their children. I argue that for people with intellectual disabilities, “adult” and “child” are categories commonly used to classify behaviors. Thus, rigid notions of what it means “to be an adult” produce the tension between protection and autonomy that mediate care. Finally, I contend that adulthood, as much as capacity, acts as a hierarchizing category that classifies persons and assesses what good care is for adults with intellectual disabilities.

Keywords: Motherhood. Intellectual Disability. Adulthood. Ableism.

Fazer adulto: capacidade e ambigüidades do cuidado materno na deficiência intelectual

Resumo: A noção de capacidade é central para o tema da deficiência e suscita reflexões sobre como a lógica capacitista organiza a sociedade a partir do binômio corpos capazes e corpos não capazes. No presente artigo, parto das práticas de cuidado de adultos com deficiência intelectual para examinar como o binômio infância e adultez espelha tal lógica capacitista. A partir de pesquisa realizada junto às mães de adultos com deficiência intelectual na cidade de Porto Alegre entre os anos de 2017 e 2018, analiso os paradoxos de uma maternidade que é, ao mesmo tempo, responsável pela promoção da “autonomia e independência” de seus filhos e pelo seu bem-estar físico. Argumento que as noções de adulto e criança são constantemente acionadas para classificar comportamentos de pessoas com deficiência intelectual, fazendo com que a tensão entre tutela e autonomia que medeia o cuidado seja produzida a partir de noções rígidas do que é “ser um adulto”. Proponho, por fim, que a categoria de adultez, tal qual a de capacidade, se aplica de forma hierárquica na categorização de pessoas e na avaliação do bom cuidado para adultos com deficiência intelectual.

Palavras-chave: Maternidade; Deficiência Intelectual; Adultez; Capacitismo.

Hacer adulto: capacidades y ambigüidades del cuidado materno en discapacidad intelectual

Resumen: La noción de capacidad es central en el tema de la discapacidad en Brasil y plantea reflexiones sobre cómo la lógica capacitista organiza la sociedad a partir del binomio cuerpos capaces y cuerpos no capaces. En este artículo, me aparto de las prácticas de cuidado de adultos con discapacidad intelectual para examinar cómo el binomio infancia y edad adulta refleja esa lógica capacitista. A partir de una investigación realizada con madres de adultos con discapacidad intelectual en la ciudad de Porto Alegre entre 2017 y 2018, analizo las paradojas de una maternidad que es, al mismo tiempo, responsable de promover la “autonomía e independencia” de sus hijos y para tu bienestar físico. Sostengo que las nociones de adulto y niño se utilizan constantemente para clasificar los comportamientos de las personas con discapacidad intelectual, provocando que la tensión entre tutela y autonomía que media el cuidado se produzca a partir de nociones rígidas de lo que significa “ser adulto”. Propongo, finalmente, que la categoría de edad adulta, al igual que la de capacidad, se aplique de forma jerárquica en la categorización de las personas y en la valoración de la buena atención a los adultos con discapacidad intelectual.

Palavras-Clave: Maternidad. Discapacidad intelectual. Edad adulta. Capacitismo.

Introduction

The Association where I did my weekly fieldwork¹ between 2017 and 2018 suspends its activities during the summer. Trying to make up for lost time, I and six of the mothers with whom I used to play volleyball while their grown-up children were doing sporting activities got together for a barbecue. After lunch, the kids went to watch TV and we stayed at the table to chat. One of the mothers, Dione, shared a story that illustrates the central dilemma of this article.

I met Dione in 2017, while carrying out research into the relationship between care practices for adults with intellectual disabilities and family expectations for the future. That was the year I arrived at the Association. Founded almost 20 years earlier, the Association offers sports, artistic and leisure activities to people with disabilities in the city of Porto Alegre every day of the week. As it is a non-profit and philanthropic institution, the fees paid by members are considerably lower than those of other institutions, so families from different socio-economic backgrounds attend. On Thursdays, I used to go to the main office and talk to the mothers who sat in the waiting room while their children took music therapy and judo classes. On Fridays, I would go to a space provided by the Brazilian army, where students practiced sports activities in the afternoon. There, I played volleyball with some mothers while they waited for their adult children. The weekly game brought us closer together, leading us to want to meet up during the summer. Dione is the mother of Raul, a man with an intellectual disability who, at the time, was thirty years old. Like many of the people I met during my research, when Raul turned 21 and left the special education school where he had studied for most of his life, he found himself with almost no alternative activities, whether work, education or leisure. Faced with this reality, Dione got together with other parents to set up a cooperative for people with disabilities. Their aim was to create a space where their children could be productive, socialize and develop their skills.

That afternoon, Dione shared with us a memorable moment that happened during a film workshop she was in charge of. The choice of film caused some disagreement among the parents, since many thought the chosen animation was too “adult” for their children. Dione, however, insisted that she would not show them a “*Turma da Mônica* (Monica’s Gang)” cartoon but something more appropriate for their age group. After all, they were all over twenty-one. The film chosen was *Jack and the Cuckoo-Clock Heart* (Mathias MALZIEU; Stéphane BERLA, 2013). According to her, the film tells the story of a boy who, when born on a cold winter night, is abandoned by his biological mother. The woman who finds and adopts him realizes that his heart has frozen and puts a clock in its place. The prosthesis works and Jack survives, but in order to continue living, he must avoid emotions, such as feeling fear or falling in love. This results in young Jack having a childhood controlled by his mother. He is only able to leave the house alone and go to school when he turns ten years old. His mother, having swapped his heart for a clock so that he would survive, finds it difficult to accept Jack putting himself at risk since she had given up so many things to ensure his survival. Throughout his life, Jack gradually gets to know the world, takes risks and falls madly in love with a young woman, contrary to his mother’s advice. In the story told by Dione, there was a constant tension between protecting himself from the risk of death that emotions could bring and the chance of experiencing life to the fullest. In the end, Jack chooses the latter and his mother has to accept his decision. Beyond the film’s plot, Dione was moved by the conversation she had with the young people at the end of the session. She began with a very simple question: what was the protagonist’s name? To her surprise, everyone answered by giving their own names. Thinking there was some kind of mix-up, Dione corrected them but one of the participants promptly told her that she knew the boy’s name was Jack, but “it was Isabela that she saw there”. Dione then realized that this was how they felt: imprisoned by their mother’s constant supervision.

Dione’s story reflects the tension between protection and overprotection that is evident when we talk about maternal care for people with intellectual disabilities. It is a dilemma that takes different forms as these children reach adulthood. In this article, I address this tension based on its relationship with the assumption that people with intellectual disabilities are “eternal children” and I focus my analysis on the ways in which ableism operates in care practices based on judgments regarding what is or is not appropriate for an adult to do. I then propose that centering ableism requires a reflection on the different manners of experiencing and performing adulthood.

Despite their many differences, my interlocutors share the experience of having been the main caregivers for their children throughout their lives. Now adults, they have lived since childhood under different diagnoses that have placed them in the broad category of “person with intellectual disabilities”. I draw on their experiences to analyze the ways in which maternal care practices for adults with intellectual disabilities are traversed by the construction of the

¹ This article is the result of my PhD thesis (2020), “*Construindo Futuros, Provocando o Presente: cuidado familiar, moradias assistidas e temporalidades na gestão da deficiência intelectual no Brasil*”, published as a book by Editora Hucitec (2023). The research was carried out as a doctoral student in the Postgraduate Program in Social Anthropology at the Federal University of Rio Grande do Sul (UFRGS) and funded by CAPES, to whom I am grateful. I would like to thank my colleagues Cíntia Engel and Lucas Besen for reading previous versions of this article, as well as the anonymous referees and the editors of this thematic dossier for their valuable contributions to the text.

adulthood-childhood binary based on the ableist logic that orders society in terms of bodies that are more *capazes* or less *capazes* (Alison KAFER, 2013; CAMPBELL, 2009). I will not provide a definition of what disability is, since I am more interested in what it produces (Logan SMILGES, 2023; AYDOS, 2021). I also recognize that such definitions and classifications of what counts as disability are always contingent, localized, relational, and dependent on continuous negotiations and, therefore, encompass very diverse bodies and minds (KAFER, 2013; LOPES, 2015; 2019). Nevertheless, the specificities of intellectual disability, traditionally less studied by both disability studies and anthropology (Faye GINSBURG; Rayna RAPP, 2018; 2020; KAFER, 2013; Eva KITTAY, Licia CARLSON, 2010; LOPES, 2019; 2022; Patrick MCKEARNEY; Tyler ZOANNI, 2018), are central to the analysis proposed here. After all, as a diagnostic category, intellectual disability is commonly used to refer to a “cognitive delay” perceived in childhood and which impacts the subject’s “adaptive functions.” Therefore, one of the specificities of its diagnosis is that it is accompanied by the presumption of a **disharmony** between chronological age and “mental age,” a term widely used by health and education professionals to refer to expectations of what a person should do at a certain life stage. For this reason, I propose that understanding the effects of this diagnosis and these assumptions in the care practices of my interlocutors involves examining the way in which ableism informs and reflects notions of adulthood and childhood.

Disability is always experienced in relation to and produced from its constitutive binary: the able body (KAFER, 2013). It is no coincidence that many of the mothers I have worked with report having noticed in early childhood a “difference” between their children and other children of the same age, a difference related to the so-called “developmental milestones” such as crawling, walking, talking, etc. Although not always made explicit, the able body is the norm, and disability operates by “infusing individuals and populations with varying degrees and qualities of humanness based on their proximity to normativity” (SMILGES, 2023, p. 9). Mindful of the ableist logic that orders the world in terms of abled and non-abled or disabled bodies [*corpos capazes e não capazes ou deficientes*], conferring on the latter a diminished state of human being, I will look at the experience of intellectual disability and its relationship with the notion of adulthood (CAMPBELL, 2009; Anahí MELLO, 2016). The childhood/adulthood binary mirrors the ableist logic and informs the care practices of my interlocutors since, in the case of intellectual disability, the assumption of *incapacidade* is directly related to expectations about what an adult should do, can do and how they do it. It is in this sense that ableism also acts in the production of more capable or less capable mothers, with the *capacidade*² to mother being marked by the tension between the demand to preserve the adult status of their sons and daughters to guarantee non-ableist care and the need for protection in a world poorly prepared to deal with their differences and specificities. Thus, I argue that the category of adulthood, similarly to that of *capacidade*, is applied hierarchically for both classifying individuals and for evaluating what counts as good care for adults with intellectual disabilities.

Intellectual disability, ableism and maternal care

The Association where I met Dione was founded in the city of São Paulo by employees of a financial institution in the late 1980s. Parents of people with disabilities, they met to share their experiences and, faced with the lack of resources for their children, they started the organization to help their families. Over time, the initiative was replicated by employees in other locations. Nowadays, the Association, a philanthropic institution that serves the community, operates in thirteen states and the Federal District. The national board and regional councils, however, are still composed of bank employees. Given its history and scope, the Association participates in national, state and municipal councils on the rights of people with disabilities. My fieldwork was carried out at the Rio Grande do Sul headquarters, which was founded in 1999. In 2017 and 2018, it served 200 families in the city of Porto Alegre, most of them with no connection to the bank, and offered classes in judo, capoeira, music therapy, art therapy, theater, swimming and sports. As one of the few institutions that offers activities for adults, and due to its policy of adjusting the monthly fee according to monthly family income, the Association serves people from different

² Translation Note: The English version of this paper reflects a few issues Brazilian scholars in Disability Studies have been facing in international dialogues. In Brazil, ableism was translated as *capacitismo* since, in Brazilian Disability Studies, we use the category of *capacidade* to refer to the classificatory and ordering system of disability [*deficiência*]. In this sense, *capacidade/não-capacidade ou deficiência* reflects the able/not able or disabled divide. As such, *capacidade* would be closer to the category of ability.

However, *capacidade* is also a key category for the experience of disability in Brazil - as a legal and medical category, and also in the imaginaries of disability in the country. When used in this manner, *capacidade* refers to being capable [*capaz*] of doing something or having the capacity to do so. The divide, then, is *capacidade/incapacidade* or capacity or capability/incapacity - incapability. Evidently, both usages are intertwined. To better express how they affect the experiences of people with intellectual disabilities and the care practices of their mothers/caregivers in Brazil, and the theoretical dialogues being made in Brazilian academia, I chose to use the Portuguese categories of *capacidade*, *incapacidade* or *não-capacidade*, *capaz* and *incapaz* throughout this paper.

paths and socioeconomic backgrounds. Its central location also means that families from various parts of the city participate in the activities, most of whom use public transportation to get there.

Attending the Association weekly allowed me to spend time with the mothers and their children, especially those waiting while their sons and daughters took judo and music classes on Thursday afternoons or played sports on Fridays. Of all the students who participated in the activities, only two went to the Association alone. The others were accompanied by adults who were responsible for their care, which meant that almost all participants were accompanied by their mothers, many of whom would wait for them throughout the entire duration of the classes (Helena FIETZ, 2023b). The Association also promotes activities aimed at family members, such as lectures, support groups and discussion circles, in which I had the opportunity to participate. Although I also spent time with their children, it was with these women that I spent most of my time, and it is their experiences that I share in this article. I will focus on those with whom I developed a closer relationship, who had all come from the middle or lower working classes and were, as I said, the main caregivers for their adult children with intellectual disabilities.

The Association's mission is to work towards inclusion and the promotion of autonomy and independence for people with disabilities, and to provide support to them and their families. This "dual mission" reflects what is required of mothers as caregivers: to ensure that their sons and daughters have as autonomous and independent a life as possible, while at the same time protecting and supporting them when necessary. The work of the Association's professionals is essential in this dynamic, especially that of the four people responsible for its day-to-day management: the physical education teacher and coordinator of leisure and sports activities, the social worker responsible for welcoming the people with disabilities and their families, the administrative assistant, and the regional manager. In addition to these, the Association has a number of teachers and interns responsible for providing activities. Attentive to the most recent discourses on the rights of people with disabilities, these professionals' priority is to promote the "autonomy and independence" of their students. I will not delve into the extensive discussion on notions of autonomy and independence here, but I like to point out that, in the Association's day-to-day activities, "autonomy-and-independence" appear as a compound word, referring both to the right to make one's own decisions and to the opportunity to carry out activities only with the support that is in fact necessary and no more. According to them, one of the obstacles to this are the mother-caregivers, whom they consider to be **overprotective**. Therefore, a central part of supporting families is working with the families, so that they "let their children grow up".

Accusations of **overprotection** are common in the lives of my interlocutors and refer to practices that restrict their children's learning opportunities, producing unnecessary dependencies that prevent them from experiencing their lives apart from their families. In other words, as I once heard from one of the professionals, mothers end up not letting their children **grow up**. Rafael, the coordinator of leisure and sports activities, illustrated this need with a short anecdote about a mother who claimed that her daughter could not put on her socks by herself. However, when given the opportunity, the young girl did so. Of course, Rafael recalled, this took longer than it usually did when her mother did it for her and she sometimes ended up putting her socks on inside out. Still, she not only learned how to do it, but now did so regularly. This very simple example refers to the need to recognize different ways and time periods for performing tasks and, moreover, for the mothers not to assume that their children are not able to complete them.

By pointing out the need for mothers to recognize their children's *capacidade* to perform everyday tasks and value their ways of doing so, the Association's professionals discuss, albeit not in these terms, the ableism that often prevents the social participation of people with disabilities.

The researcher Fiona K. Campbell (2001; 2009) defines ableism as "a network of beliefs, processes and practices that produces a particular kind of self and body (the corporeal standard) that is projected as the perfect, species-typical and therefore essential and fully human" (CAMPBELL, 2001, p. 44). The logic of ableism, in turn, organizes society into a binary system of able-body and disabled or less abled bodies and, similarly to what racism does with race, leads to the devaluation of disability being internalized by everyone, including people with disabilities (Dan GOODLEY, 2009). In short, it involves presuming the inferiority and *incapacidade* of people due to their disability and organizing society in terms of the *capaz* and *incapaz* binary. It is a way of ordering society in which persons with disabilities are viewed as less of a person, a lesser state of human being (CAMPBELL, 2009).

Within the logic of ableism, disability is nothing more than what is lacking in relation to a non-disabled body. As Campbell (2009) explains, the hierarchization and subalternization of bodies and minds that constitute the production of disability as "other" takes place in relation to a "self" (normative body and mind) that is never made explicit. The "able body," that is, what is "normal," is produced in relation to the disabled body from the relationship with the disabled, in an oppressive and productive ordering that determines what bodies should do and how people should be. The notion of ability is neither explicit nor fixed. Even so, it "operates as a structural norm, informing [the] ableist cultures" (SMILGES, 2023, p. 4). Hence the need to understand the

political dimension of disability and to question how ableism acts as a producer of a common sense, whose characterizations are naturalized, and the effects of these on the lives of those who experience disability (KAFFER, 2013). After all, the idealization and valorization of certain *capacidades* to the detriment of others, such as the centrality of autonomy and independence for the ideal modern subject (Nikolas ROSE, 2007; Emily MARTIN, 2007; Paul RABINOW; ROSE, 2006) are always situated (Sunaura TAYLOR, 2017).

The term **ableism** didn't come up in any conversations I had with the mothers I met at the Association. Still, they all shared situations of violence and oppression they had experienced with their children. It was common for me to hear about places they couldn't go to because they lacked the necessary infrastructure for their children, parties they weren't invited to, or the looks they received when using public transport, for example. It was just as common for them to be faced with the assumption that their children were incapable of carrying out ordinary activities, even those expected of people their age. In these cases, unlike the story shared by Rafael, my interlocutors acted to fight the prejudice against their children. This often involved pointing out **overprotective** attitudes in other mothers, as happened with Dione at the cooperative where she presented the movie I mentioned at the beginning of this article.

Dione is a white woman in her 50s, who used to own a restaurant, is an actress, and worked in an NGO for underprivileged children on the outskirts of Porto Alegre's south side, where she also lives. After a troubled marriage, she divorced her first husband when Raul, her only child, was just a baby and ended up raising him on her own, even though she had some help from her parents. At the time we met, Raul was 30 years old. He is a tall, white man who gets around easily and communicates well, with a thinner voice than most men his age. Raul needs support to carry out some everyday activities such as shaving, due to fine motor skills difficulties, or crossing the street, for example. As a child, he was diagnosed with "mental retardation," a recurring diagnosis among my interlocutors, and attended a special school until he was twenty-one. When he reached this age, he had to leave school, which prompted Dione to create the aforementioned cooperative so that "these young people would be productive and produce for society and not just sit around all day." More than that, she hoped that the workshops and activities offered would make Raul and his classmates "independent, have a role, produce, enjoy more autonomy and learn things."

However, according to her, many parents diverged from this view and opposed even the simple changes, such as asking that they serve themselves at lunchtime, eat without assistance – even if it meant making more of a mess than when their parents helped them – and washing up after the meal. The resistance of certain parents was seen by Dione as the result of mothers who didn't want to "let their children grow up." In a similar way to Rafael, Dione said: "Every mother is overprotective. All of them. So, for those mothers, having a child "like that" is like winning the lottery. "My son will never leave me. He'll never leave me." According to her, many mothers like "their child to be dependent." The constant disagreements over what their sons and daughters could or should do meant that Dione ended up leaving the cooperative.

Given this context, I propose that it is essential to understand the practices of the mothers of adults with intellectual disabilities from the point of view of a "politics of disability," in other words, to question how such assumptions and common sense regarding intellectual disability shape maternal care. The presumed *incapacidade* and inferiority of people with disabilities is at the heart of ableism. In the case of intellectual disability, it is connected to the idea that there is a difference in relation to other people in the same age group, which is perceived as a "lag". As mentioned above, this difference is recognized in early childhood, when mothers realize that their children's times or ways of doing things are different from those of children of the same age. Throughout life, the idea of falling behind is constantly reinforced by the notion of a "mental age" that is always lower than the chronological age. Throughout my research, it was common to ask how old their children were and hear their mothers say things like "he's thirty-one, but mentally he's eight or nine," in reference to phrases they would have heard from professionals they consulted with, such as educators and psychologists. The words of these professionals are striking because they make explicit the ideal of a linear developmental progression which means that at each life stage we are expected to do some things and stop doing others. Idealizations about what an adult should do, or what a child is, are permeated by the notion of *capacidade*. The constant comparisons with this "ideal adult" reinforce the idea that their sons and daughters will always remain children. It is an imaginary that shapes maternal care practices. After all, the type of "protection" expected from a child's mother in relation to her children is different from that of the mother of an adult.

Paradoxes of mothering adults with intellectual disabilities

Reaching adulthood causes some confusion as to what is expected of mothers in terms of caring for their sons and daughters. How can they act as promoters of their "autonomy-and-independence" and at the same time guarantee the well-being of their adult children who need

support to carry out a range of activities? It's an alleged paradox that reflects the ways in which the constitutive binaries of "*capacidade/não-capacidade*" and "adulthood/childhood" intersect and are present in the daily lives of the mothers I worked with. On the same day that she told me about the cooperative and her annoyance at seeing mothers who wouldn't accept their children growing up, for example, Dione complained that her current husband accused her of spoiling their son and treating him like a child. Her response to this "insult" was to say that Raul was like a child and that it was up to her to protect him. This statement, which went against everything Dione had said before, came when we were talking about what had happened when we arrived at a barbecue.

That morning, we had met at the home of Maria, the mother of José, a young man with Down's syndrome. They live in a "vila" located in a central neighborhood of the city, which might be considered dangerous by those who don't live there. When we were already at her house, Margarete called to say that she and her son Igor were in front of a store and asked us to pick them up. She lives in the south of the city and it took her over an hour to get there by bus. Also, as she told us afterward, she first went to the health center to get a prescription for Igor and then to the Popular Pharmacy to pick up the free medicine, causing them to be late. Igor is an autistic man in his thirties. He is white, short, wears glasses and walks with a slight stoop. He usually doesn't speak much and has a thin voice. That day, he was walking a little ahead of us as we headed towards the entrance to the "vila.". At this point, a speeding car swerved onto the sidewalk and crashed into a dumpster, almost running him over. Unlike the people around him, Igor didn't move even though the car was coming towards him. His reaction could be the result of a lack of exposure to situations like this, but according to his mother, when faced with circumstances that make him nervous, he often stays still, without communicating or moving. That's why his mother doesn't allow him to walk around unfamiliar areas of the city unaccompanied, nor does she allow him to stay at home alone for too long. This attitude has led her to be accused by many, including her psychiatrist, of being "overly concerned" about her son and smothering him. It was because she agreed with her friend, believing that Raul also needs the same protection to get around the city, that Dione categorically stated that her son, a man in his thirties, was indeed a child. According to her, this was corroborated by the fact that Raul would never finish college, get married or have children, and that he still needed his mother's help to do certain tasks. Raul, according to her, had reached his learning limit.

Dione, by evoking the image of her son as a child, is guided by a rigid division between what it means to be an adult and what it means to be a child, which is permeated, as already mentioned, by the notion of *capacidade*. It is no coincidence that the term **infantilization** is commonly used to refer to practices that mean that the opinion, desire or will of adults with disabilities are not taken seriously or considered when making decisions (LOPES, 2015; Fernanda NUNES, 2014; Julian SIMÕES, 2014; 2019). This term reiterates the idea that the child is an adult in formation and, for this reason, incomplete and *incapaz*. This idea has long been refuted by the Social Sciences. The field of anthropology of childhood, for example, questions the division between the world of adults and that of children and points out how this supposed separation reinforces dichotomies, placing the children as the "other" in relation to the adult world (Fernanda RIFIOTIS *et al.*, 2021; Claudia FONSECA *et al.*, 2018). It is an adult-centrism that ends up universalizing the experience of childhood and depriving children of their power as agents and subjects of rights. It is clear, however, that when these logics are produced and reproduced by state and family governance practices, they have effects (Clarice COHN, 2013; Fernanda RIBEIRO, 2011; Patrice SCHUCH *et al.*, 2014). Among these, we have the idea that children, or those who have not yet reached the legal age of adulthood, should be more protected and guarded (Philippe ARIËS, 1978; Adriana VIANNA, 2002; FONSECA *et al.*, 2018). At the same time, these conceptions produce and reproduce the image of the "ideal adult": the autonomous and independent subject, endowed with reason and volition, capable of producing, consuming and participating fully in society. Anything that deviates from this adult "us", or the norm, becomes closer to the "other" child.

When Dione talks about her son reaching his learning limit, she is referring to expectations of what an adult should be. An adult is someone who is considered fit to take on residential, professional, marital and family responsibilities (Elaine Muller, 2013). As we know, not all 30-year-olds get married, graduate from college, have a job that allows them to support themselves or live away from their parents' house. Many will never even reach these milestones. Even so, they are all considered developmental milestones linked to adulthood. When it comes to intellectual disability, not achieving these "milestones" is quickly understood as an *incapacidade* to do so. As anthropologist Pedro Lopes (2015) reminds us, chronological age is important for considering bodies and minds that deviate from the norm. According to the author, "the fact that turning 30 can mean fulfilling different roles in different societies does not detract from the fact that, precisely for this reason, when 30 one must meet certain social expectations" (LOPES, 2015, p. 156). Life stages are institutional processes of synchronization and expectations for the future

based on trajectories that are always situated in a certain time-space (Jennifer JOHNSON-HANK, 2002) and people's lives often overlap them (Guita DEBERT, 1999). However, despite the consensus within the social sciences that age groups are social constructions, and therefore relational, in common sense, and also in the biomedical field and often in education, they are perceived as natural, as something that is given and self-evident (FONSECA *et al.*, 2018).

The transition to adulthood is therefore a challenge for families, who once again have to reconfigure their expectations and their daily lives. After the age of 21, their sons and daughters have to leave school and there are far fewer services for adults than for children. Furthermore, since the idea of being able to work or live independently, two common paths for people who reach adulthood, is linked to a model of the ideal adult, people with disabilities find it difficult to access these activities. As the work of anthropologist Valéria Aydos (2016; 2021) shows as she followed the daily lives of two autistic young people entering the Brazilian job market, the lack of support for them to carry out their work activities leads to a series of violent acts. This reinforces the assumption of incapability when what is lacking is precisely the support needed to carry out their work. Similarly, "living alone" or away from their families is also seen as an unlikely reality by many, largely due to the lack of adequate infrastructures to enable this to happen (FIETZ, 2023a).

The fact that *incapacidade* is presumed is both a cause and an effect of inaccessibility and, in the case of intellectual disabilities, it is especially associated with the idea that they are "eternal children". This association, as I said, has an effect on mothers' care practices. After all, as Sara Ruddick (1995) pointed out in her classic work on mothering, there are three main demands when raising a child: ensuring its survival, promoting its growth and development, and preparing and socializing this child so that it is accepted in the world. When Dione and Rafael talk about mothers who don't let their children grow up, they are pointing to these women's "failure" on these last two demands. The presumed *incapacidade* is an assumption of the impossibility of growth. Moreover, it means that people with intellectual disabilities are not even given the opportunity to learn from their mistakes, to try to find the most efficient way to carry out tasks and to figure out how much time they need to develop certain skills and abilities. However, we mustn't forget mothering's first demand, which is to protect her children, nor overlook the fact that, when it comes to disability, children are being socialized into a world that is unwilling to live with their differences (KITAY, 1999; 2019).

Maternal responsibility, *capacidade* and "Good care"

By establishing the parameters for what it means to be an adult, ableism makes the adulthood of people with intellectual disabilities seem unachievable, while acting on maternal care practices and producing mothers who are more *capazes* or less *capazes*. The familiarization and privatization of care, the result of austerity policies put in place in different countries since at least the 1990s, have transferred or consolidated the family as responsible for providing care, especially for those considered more dependent (DEBERT, 1999; Cintia Liara ENGEL, 2022; Camila FERNANDES, 2017; FONSECA, 2012a; 2012b; YAZICI, 2012). When it comes to childcare, these austerity policies have further centralized the role of the mother, who is even held responsible for the cognitive development of her children, especially in early childhood (FONSECA, 2012b). Strongly linked to markers of race and class, maternal childcare practices are constantly under the scrutiny of third parties – whether family members, neighbors or even the state – who evaluate their *capacidade* as mothers. Another form of control over female bodies, the moralizations surrounding maternal care shape policies and legislation which, in turn, reinforce the idea of what constitutes a "good mother." In addition, they produce non-ideal motherhood categories linked to the use of violence, neglect or abandonment, for example. It is a reality that particularly affects Black women from peripheral regions of the country (FERNANDES, 2017). The balance between promoting the proper development of their children and protecting them is constant in mothering and the search for it takes place in the midst of continuous judgments and surveillance.

The care relationship between mother and child is one that extends over time and it is marked by reconfigurations of practices and expectations. The need for protection diminishes as the child becomes more prepared and socialized in the world to which they belong. It is in this sense that I propose that ableism, by shaping the notion of ideal adulthood, also produces the idea of a mother *capaz*, especially when we talk about adults with intellectual disabilities. After all, in these cases, ableism also works by equating the experience of people with intellectual disabilities with that of children. It is an equalization that always takes place in relation to this idealized adulthood and is most easily translated by the aforementioned notion of "mental age" to which their children are constantly imposed, placing them in a particular social position in terms of the necessary protection and care for their survival and development.

This equalization is often complicated by the fact that sometimes the wishes and desires of children can put them at risk. Similar to the mother of Jack, the boy in the movie, *Miriam*, a white woman in her 50s, married and the mother of two adult children, who also took part in our weekly

volleyball games, dealt with this dilemma on a daily basis. Stefani, who was 25 at the time, is an energetic and sociable woman who loves taking part in activities with lots of people and doing sports at the Association. After suffering three strokes at the age of seven, she was diagnosed with Moyamoya Syndrome. The mobility restrictions caused by the strokes, which also resulted in brain damage that causes learning and communication difficulties, do not prevent her from taking judo, capoeira and swimming classes, although in her own time and way. However, the seriousness of the syndrome means that Stefani is at constant risk of developing new strokes and dying or being left with new and perhaps more serious sequelae. Miriam says that, over the years, she has seen her daughter “die” three times in her arms, but she had managed to get medical help in time so that nothing worse had happened.

Even though she no longer attends school because of her age, Stefani does activities such as swimming, capoeira, judo, sports and art therapy in different organizations at least one session a day, five days a week. Because they live on the outskirts of a city in the metropolitan region of Porto Alegre known for its high rates of urban violence, Miriam accompanies her to all her activities, even if it means spending more than two hours on public transport. Stefani also attends the Association’s winter and summer camps without Miriam, and has had several boyfriends whom she met during the many activities she takes part in. Stefani is very sociable and loves talking to everyone she meets. She makes friends easily and is always willing to help her classmates with their activities when they have difficulty doing the exercises. At the parties I attended, she was always the first to hit the dance floor and the last to leave. For Miriam, ensuring that her daughter has the opportunity to do the activities and experience the intense social life she enjoys so much is a central part of her role as mother and caregiver. However, this comes with some inherent risks. The risk of further strokes, for example, is high if she hits her head. Her daughter is aware of this fact, since her mother taught her to be as careful as possible from an early age. Miriam, however, believes that Stefani’s friendships, experiences and satisfaction are worth the risk. Even though it is her daughter’s wish, this decision has been criticized by friends and relatives who believe that the role of a “good mother” is to protect her daughter, even if this means ignoring her wishes.

When talking about the constant accusations and questions about the way she looks after her daughter, Miriam is emphatic that she has to let her live. As she told me once when we were talking about it: “Otherwise, what’s the point? Always being cooped up, not knowing anything, not doing anything. She has to live, she has to enjoy herself, she has to do her own thing.” Assuming that it’s up to the mother to decide what her adult child can or can’t do is a specificity of disability – and especially intellectual disability – that directly dialogues with the confusion caused by the ways in which the notions of adulthood and childhood are mobilized as categories of accusation for these women. After all, their *capacidade* for motherhood involves either guaranteeing greater “autonomy and independence” for their children, ensuring their adult status, or guaranteeing their protection and development, a requirement that brings their maternal experience closer to that of mothers of children. This is often also a legal matter. Like Stefani, it is common for people with intellectual disabilities to be “legally incapacitated [*legalmente incapaz*]” after an extensive judicial process of civil interdiction in which they are assessed by medical experts and a judge who deems them unfit to make certain decisions and manage aspects of their lives (SIMÕES, 2019; 2022). Miriam is also her daughter’s legal guardian, i.e. she is legally responsible for making decisions about her life, medical treatments, finances, among other things. This is a legal measure that reflects and produces the ableist logic that guides our society and, at the same time, creates a responsibility for these mothers who, if considered “incapazes” of such management, could face legal sanctions and, ultimately, even lose custody of their children.

The ableist logic that permeates our society affects my interlocutors in a different way to the way it affects the lives of their children. What is at stake is their “*capacidade* to mother” in a society where ableism permeates all our relationships and where interdependence is not recognized or valued. Hence the apparent paradox between being simultaneously responsible for protecting their children in a world that is commonly hostile to their differences and acting as a promoter of their development, which is also measured by metrics based on the ideal of adulthood. This is why dismantling the presumption of *incapacidade* involves not only recognizing the possibility of adulthood for people with intellectual disabilities, but above all challenging the assumptions linked to the rigidity with which we understand the adulthood/childhood binary.

The confusion caused by this division is constant in the lives of my interlocutors, as I hope to have made clear throughout this text. As one of the mothers told me during one of Rafael’s talks about the importance of families working to promote the autonomy and independence of people with disabilities, she knew that many people looked down on her daughter because of her disability. Even Gabriela’s grandmother, who had been her main carer until she was 16 so that her mother could work, kept her from helping with housework, despite the young woman’s insistence. With an air of indignation, her mother said that she knew Gabriela could always do what she set her mind to, even if it sometimes took her longer to learn. When she stopped working outside the home and was able to spend more time with her, Gabriela took on more responsibilities,

including the one she had always wanted: feeding her dogs. Her mother's speech reinforced the need to recognize that, albeit in a different way to that which we expect, people with intellectual disabilities can carry out the tasks they set themselves, if they have the necessary help to do so. But the conversation didn't end there. Looking at her daughter who was sitting in front of us, the mother went on to say that, to celebrate her 29th birthday, she had asked for her birthday party to have the theme of Fiona, a character from a Disney cartoon. Looking down, her mother said: "Just when you think she's improved, that she's grown up, she asks for children's princesses. Last year it was Frozen and I was happy, because she's for older girls, but this year it's back to Fiona. What can I do?" Like Gabriela, many of the adults I met didn't conform to an idealized adulthood, which didn't stop them from doing other activities considered "adult things." The same young man with significant work experience, for example, still believed in Santa Claus, while another woman in her 30s loved Disney cartoons and was in a long-term relationship with a man of the same age who also attended the Association.

Allowing people with disabilities to have contact with films, characters and situations that many consider to be "inappropriate" because they equate them with children is key. It requires an effort and often causes conflicts, as was the case with Dione at the cooperative where she worked. Respecting children's wishes and choices, however, also means accepting that sometimes they will choose activities that are not in line with what common sense deems appropriate for an adult. The tension between protection and overprotection is constant in the care practices of my interlocutors, largely because of the ways in which ableism operates by rendering modes of being an adult that defy the common sense or idealized expectations unimaginable. This is why it's important not to equate tastes or behaviors considered childish with a supposed inability to carry out different tasks attributed to adult life, such as working, living alone, or having romantic or sexual relationships, for example. Rigid notions of what it means to be an adult hierarchize bodies and underpin our criteria of *capacidade*. Therefore, at the same time as they prevent bodies and minds that defy these criteria from accessing certain spaces, they place them in a position of lesser value precisely because they don't perform adulthood by participating in these spaces or by carrying out activities attributed to adults. In other words, the supposed **disharmony** between the chronological age and the "mental age" of people with intellectual disabilities is produced by logics that are as abstract as they are unrealistic. Even so, it informs the care practices of my interlocutors in a very concrete way, causing them to be constantly judged as more *capazes* or less *capazes* mothers.

Final considerations

Throughout this article, I have focused my analysis on maternal care practices for adults with intellectual disabilities and their relationship with the ableist logic and the binaries of *capacidade/não-capacidade* [able/non-able] and adulthood/childhood as a privileged place to analyze the tension between protection and overprotection. The goal is to look at the ontological problem of ableism, at what underpins our criteria of *capacidade* (CAMPBELL, 2009), and to ask in what ways the notion of *capacidade* acts as a structuring norm (SMILGES, 2023). In this sense, I highlight three ways in which ableism operates in the lives of people with intellectual disabilities and their families. Firstly, by making people believe that the failure to reach certain life stages or courses is the result of disability as a condition of physical and mental difference and not of the specific characteristics of each individual, their families and the different historical, social and economic contexts in which they live. Secondly, through barriers that prevent disabled people from accessing and participating in society. And lastly, by making a "normative future" unthinkable for people with disabilities and, at the same time, impeding futures that deviate from this normative way of experiencing the world from being deemed less desirable or even possible.

It is in this sense that, in addition to guaranteeing the possibility of being in the world in an autonomous and independent way by creating and maintaining the necessary infrastructure and support, it is important to look at the category of adulthood as restrictive, limiting, and hierarchically applied in the classification of people. Society is prejudiced against all those who do not conform to the ideal of adulthood. Although it wasn't the focus of this article, markers of class, race, gender and sexuality also inform this hierarchization of bodies. Rethinking what it means to be an adult or a child is necessary if we are not to reproduce violence and oppression beyond disability. What I propose is that this idealization and classification is even more evident in the case of intellectual disability precisely because of the idea of a **disharmony** between chronological age and the abilities and *capacidades* expected of people in that age group. It is a presumption that is informed by the ableist logic that devalues people with disabilities, but also produces it. As I have argued throughout this text, this has a direct effect on care practices for this population.

Many of my interlocutors are beginning to think about the possibilities of getting their sons and daughters out from under the constraints of **overprotection**, something that is linked to

advances in the rights of people with disabilities and their greater social participation. However, they often find themselves limited by conceptions of good care tied to binary classifications and reinforced by notions of “mental age” or expectations of what an adult should do. The arrival of adulthood and the many forms it can take brings with it new discoveries, challenges, limitations and developments that don't fit into ready-made ideas about what and how an adult should be, what an adult should believe in, and what they should like. Defining ways of experiencing adulthood is counterproductive and erases the multiplicity of ways of being in the world. This is even more serious in the case of intellectual disabilities, since failure to meet certain developmental milestones is linked to a presumption of *incapacidade* that prevents social participation.

Beyond recognizing the need for support and care to carry out activities and consequently valuing interdependence as a universal characteristic of living beings, cognitive difference requires a second step that can be more difficult to reconcile with the notion of “adult”. This is because, although it is often the lack of incentive for them to gain access to practices, actions or entertainment that match their chronological age, sometimes such practices or tastes do not really appeal to them. Rigid and fixed notions of what it means to be an adult prevent us from conceiving of the multiple ways of being an adult, such as men and women who like Disney princesses, prefer children's films or need help counting money, shaving or getting to their workplace, and who also have emotional and sexual relationships with other adults, work in a job that guarantees them some income, and who make decisions about what they want or don't want to do. This ends up situating them in a liminal space which means that, most of the time, their wishes are not recognized or they are not offered the necessary conditions to exercise them. This reality of violence and segregation ends up generating real risks to their well-being and, sometimes, to their safety and survival. By setting the parameters for what it means to be an adult, ableism means that the adulthood of people with intellectual disabilities is perceived as unachievable, while at the same time impacting maternal care practices, producing mothers who are more *capazes* or less *capazes*.

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Helena Moura Fietz (helenafietz@lsu.edu; helenafietz@gmail.com) holds a doctorate and a master's degree in Social Anthropology from the Federal University of Rio Grande do Sul. She is an Assistant Professor at the Department of Anthropology and Geography and is linked to the *Women's, Gender and Sexuality Studies Program* of the Louisiana State University.



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