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Family and disability: aesthetic relations as mediations[1]

Família e deficiência: as relações estéticas como mediações

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ABSTRACT
This study aimed to analyze the meanings attributed by parents of people with intellectual disabilities in relation to their aesthetic experiences in a social inclusion program. The field of study is the "Arts for All Program", which aims to promote the social inclusion of people with disabilities from different artistic modalities. The program counts on the involvement of six parents of people with intellectual disabilities in this process. The data construction process took place through semi-structured interviews, carried out in a virtualized way and taking place through the social network WhatsApp. Data systematization was developed from content analysis, based on (MORAES, 1999; BARDIN, 2016). The theoretical framework was supported by cultural-historical psychology, with Vygotsky (1997; 2001) and Sawaia (2001) as the main authors. The results of this research show that parents of people with intellectual disabilities notice the importance of spaces that promote the development of their children, for example the program under study. The research subjects emphasize that the possibility of participating in art classes with their children allowed the construction of new perspectives towards themselves and their children. It can be seen in the parents' statements that participation in classes

RESUMO
Este estudo teve por objetivo analisar os sentidos atribuídos por pais de pessoas com deficiência intelectual em relação às suas experiências estéticas em um programa de inclusão social. O campo de estudos é o "Programa Artes para Todos", que tem como objetivo promover a inclusão social de pessoas com deficiência a partir de diferentes modalidades artísticas. Nesse processo, o programa conta com o envolvimento de seis pais de pessoas com deficiência intelectual. O processo de construção dos dados ocorreu por meio de entrevistas semiestruturadas, realizadas de modo virtualizado e ocorrendo por meio da rede social WhatsApp. A sistematização dos dados foi desenvolvida a partir da análise de conteúdo, com base em MORAES, 1999; BARDIN, 2016. O referencial teórico teve sustentação na Psicologia Histórico-Cultural, tendo Vygotsky (1997; 1999) e Sawaia (2001) como principais autores. Os resultados desta pesquisa mostram que os pais de pessoas com deficiência intelectual notam a importância de espaços que promovam o desenvolvimento de seus filhos, a exemplo do programa em estudo. Os sujeitos da pesquisa enfatizam que a possibilidade de participar das oficinas estéticas propostas pelo programa junto aos seus filhos permitiu a construção de novos olhares para com eles próprios e com seus filhos. Constata-se nas falas dos pais que a participação nas oficinas produziu efeitos

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produced important effects in looking at their children and the bonds between them. This study also discusses how the impasses experienced by families of people with disabilities are permeated by political and social factors, which indicate the need for Psychology to produce more critical readings about the relationship between family and disability.

Keywords: Aesthetic Relations; Family; Intellectual Disability.

importantes no olhar para com seus filhos e os vínculos entre eles. Este estudo problematiza ainda o quanto os impasses vividos por famílias de pessoas com deficiência são permeados por fatores políticos e sociais, os quais indicam a necessidade da psicologia em produzir leituras mais críticas acerca da relação família e deficiência.

Palavras-chave: Relações estéticas; Família; Deficiência intelectual.

1 Introdução

Individuals with intellectual disabilities are often excluded from spaces and environments due to their particularities, which become more evident than in cases of individuals considered within the standards set by society. Despite being supported by a set of legal advances in favor of rights guarantee, which has been gaining ground in recent decades, dominant conceptions circulating in society still reproduce a perspective that marginalizes these individuals. Consequently, the potential present in them and what can be developed in them are not observed (RAGAZZON, 2018; KLAZURA & FOGAÇA, 2021).

According to Ragazzon (2018) and Klazura & Fogaça (2021), since birth, individuals with disabilities and their families have to deal with medical reports and diagnoses that, although in certain circumstances enable the guarantee of rights, can also hinder the social participation of individuals. This results in a stigma of "incapacity" or permanent limitations produced by the very conditions of disability in its biological dimension. With changes in conceptions about what it means to be a person with intellectual disabilities, it is evident that there have been divergences over the years regarding the condition of these individuals.

Each historical period, within its context, presented different views on the theme of disability, but for the most part, negative conceptions about this condition prevailed. In antiquity, the Middle Ages, during industrialization, and during the World Wars, what is evident is the repetition of segregation practices outlined according to each historical period. Nevertheless, one continuous element that transcends each of these moments is the logic of marginalization and incapacity overshadowing the human dimension of people with disabilities (RAGAZZON, 2018; KLAZURA & FOGAÇA, 2021).

It was in the 20th century that studies and research on intellectual disability began to be conducted in the field of psychological science. Among the theorists of the time, one of the main figures who gained prominence in research related to disability and the ways of development of individuals with intellectual disabilities was Lev Semionovitch Vygotsky (1896-1934). This psychologist conducted studies with these individuals regarding their educational and social experiences, and these studies contributed to a critical perspective on how psychology observed the process of human development in these individuals. Vygotsky emerged as a researcher armed with a critical perspective regarding the processes of measuring intelligence quotient that categorized individuals as "abnormal" or "incapable." According to this Soviet psychologist, psychology should think about how to intervene with these individuals not in the direction of measuring their difficulties but in the construction of mediations that promote the development of their potential.

Through studies such as that of Vygotsky (1997), it is known that individuals with intellectual disabilities are not in a condition of lower intellect but, rather, in a qualitatively differentiated development process with a unique pace of learning and development. Vygotsky's scientific legacy marks the fact that when social practices, such as education and psychology, guided by a quantitative, pragmatic, and immediate perspective, they limit the possibilities for these individuals to achieve more autonomous conditions and effective social participation.

For Klazura & Fogaça (2021) and Ragazzon (2018), the passing years have brought significant changes, but it was in the 1990s, through the "Salamanca Statement," that a more comprehensive discussion of inclusion and the introduction of the term "person with disabilities" were initiated. It shifted the focus from a biomedical, clinical perspective to one centered on citizenship and opportunities for social participation.

In Brazil, the Brazilian Inclusion Law No. 13,146 (2015) states that every person with a disability has the right to freedom of expression and equality of opportunities, meaning the right to access public spaces that should be prepared to accommodate diversity. However, when analyzing the concrete reality of many public services and spaces, there is a need for not only structural advancements but also changes in societal attitudes that promote inclusion, whether through cultural shifts or more effective government involvement.

Vygotsky's contributions to the study of disability allowed for an articulation between the development of these individuals and the objective conditions of existence, namely, social opportunities. In this regard, Mata (2018) and Dias & Oliveira (2013) discuss how conditions and opportunities are circumscribed by the way society conceives disability. These authors point out the dominance of perspectives that still focus on the limitations and impossibilities of these individuals even in contemporary times, highlighting that negative conceptions about the possibilities of people with disabilities continue to prevail with meanings that circulate dominantly in the social fabric.

Vygotsky (1997) situated the development process not only in quantitative and isolated terms but also considered the qualitative complexity of human development and its cooperative and mediated social nature. This allowed him to understand disability not only in individual terms but also in social terms. His discussions on the relationship between disability and society delineate the existence of a "primary defect" and a "secondary defect." The former relates to the biological dimension, while the latter relates to the social dimension, constituted by the quality of mediations, experiences, and lived experiences. Vygotsky (1997) realized that the primary defect will only be prominent when the secondary defect is not the primary one. In other words, the biological dimension will take precedence over an individual when mediations, interactions with other individuals, and experiential learning did not facilitate the development of their potential.

The research presented here had as its field of study the "Art for All Program," which operates within the framework of the Institute of Art through Movement Research (IMPAR). Its objective is to contribute to the development of individuals and society, with one of the fundamental principles being the involvement of parents in the workshops provided. The artistic processes that are part of the activities produced at the institute are conceived as instruments for promoting social inclusion. In terms of the program's objectives, it is evident that mediations occur within the artistic processes produced in the program, enabling individuals to develop sensitive perceptions and new ways of observing and experiencing the world. According to Camargo & Bulgacov (2008), individuals develop new perceptions through aesthetic experiences, constructing different perspectives and viewpoints on their daily surroundings, allowing them to expand their ways of relating to themselves, others, and life.

The work involving families of individuals with intellectual disabilities, as reflected by teachers involved in the program, indicates the possibility of constructing new perspectives on the condition of individuals with disabilities, in this case, the children of the participants. Therefore, practices involving families, through mediations guided by an aesthetic education perspective, can break away from the hegemony of the biomedical view of disability, which tends to reduce these individuals to a place of incapacity and lower worth (FURLAN, 2020).

It is relevant to understand the family as a symbolic space intertwined with society and culture. In this sense, the family is permeated by the meanings of a specific time and weaves plural ways of relating among its members, but organically linked to what circulates discursively in the social fabric (Guarido, 2015). When it comes to families of individuals with disabilities, it is important to consider the presence of the biomedical perspective as the hegemonic social meaning of our time, even with legal frameworks, public policies, and scientific productions aligned with the central role of the social dimension.

Analyzing the role of the family in the process of forming the subjectivity of individuals with disabilities implies acknowledging it as a social institution sensitive to how life is produced, organized through social, political, economic, and cultural factors. The family is recognized as an institution that interconnects the individual with society, not as an autonomous and independent group from what is historically produced (SAWAIA, 2018).

Analyzing the family from a historical perspective implies conceiving it as a diverse and multifaceted institution. Barroco (2012, p. 160) points out that: "Each person has not one but several families. He has the family of his childhood, the family through marriage, parenthood, and the setting sun family [...] One can also add the 'parallel families' that individuals may form [...]." It is a space for sharing bonds, affections, care, and where what is observed in society is expressed. Therefore, it is important to observe the social position of this family. According to Sawaia (2018), in a neoliberal scenario where the state is becoming less participatory, institutions end up not promoting measures that favor the construction of bonds and increasingly occupy individualistic spaces. Thus, families are often blamed, and it is expected that they can provide all the necessary measures of social and psychological support for the individual.

In light of the above, considering the process of developing the capabilities of individuals with disabilities leads us to acknowledge the social function of the family as an institution that promotes the first and most significant but non-deterministic mediations, which enable certain paths of development. However, by acknowledging this fact, it is also considered that the possibilities of these relationships that unfold as mediators of the development process of individuals with disabilities are influenced by broader issues, such as social, cultural, political, and economic processes, which serve as determinants of the various possible configurations invented by families.

The objective of this work was to analyze the meanings attributed by parents of individuals with intellectual disabilities regarding their aesthetic experiences in a social inclusion program. This was done in consideration of the importance of social practices involving families to ensure spaces of belonging and rights guarantees. It aimed to explore alternative ways to observe in their children something beyond the biological dimension, delving into the social realm of emotions and bonds.

2 Method

This research was approved by the Ethics Committee under opinion number 4,687,694, issued through the Plataforma Brasil. The field of study was the "Art for All Program," which is part of the Institute of Research through Art in Movement - IMPAR, a non-profit association with the aim of broadening people's perspectives on others and demonstrating that art is a means of enhancing empathy and relationships.

The research participants were six parents of students enrolled in the program who provided semi-structured interviews. According to Manzini (2003), these interviews are based on flexible scripts that involve questions but also allow for open-ended dialogue and investigation based on the responses and statements.

Due to the research being conducted during the pandemic in mid-2021, the interviews were conducted via WhatsApp, scheduled in advance, and carried out individually. Each interview was conducted through audio calls, recorded on a mobile device, with each session lasting from 30 minutes to 1 hour. Prior to the interviews, the participants were presented with the "Informed Consent Form," and the interviews took place only after obtaining their signatures.

Following the interviews and transcription, data were organized for content analysis. According to Bardin (2016), content analysis refers to techniques that seek to describe and systematize the raw material collected during data collection. This process involves procedures to classify the information gathered from participants to enable interpretation (MORAES, 1999). Considering the above discussions, the analysis process involved grouping elements from the material, considering their similarities and shared features, which led to the development of analytical categories.

Subsequently, the treated material underwent theoretical discussion using the framework of Historical-Cultural Psychology. This theoretical-methodological perspective is grounded in Historical and Dialectical

Materialism, a method for producing scientific knowledge that starts with the examination of humanity, considering that the materiality of life precedes the construction of human consciousness (TRIVIÑOS, 2007). Anchored in this view, Historical-Cultural Psychology emphasizes the importance of history and objective reality in explaining the development and psychological processes of human beings, assuming that the psyche is formed through the raw material objectified in social practice (BARROCO, 2007). With this theoretical-methodological approach, the objective was to analyze the participants' statements within their relationship with belonging to the social totality, which organizes human phenomena, in this case, the capitalist mode of life production.

Next, the data analysis process is presented, along with the results and discussions. To protect the privacy of the participants, all names were safeguarded and modified. Family members were assigned the names of famous artists, while other names, including those of the children and program coordinators, were given different pseudonyms.

2.1 Results

To provide the reader with context about the research participants, we organized a table presenting some data that contributes to a better understanding of what will be discussed in the analytical categories.

Table 1
Participants

Participant	**Name**	**Gender**	**Education**	**Marital status**	**How they learned about the program**	**Duration of participation**
1	Lauren Potter	Female	High School Completed	Married	NAIPE	3 years
2	Madeline Stuart	Female	High School Completed	Single	TV	6 years
3	Katelyn Reed	Female	Bachelor's in marketing	Single	NAIPE	2 years
4	Breno Viola	Male	Up to 6th grade	Divorced	NAIPE	2 years
5	Jamie Brewer	Female	Ph.D. in public health	Divorced	NAIPE	2 years
6	Chris Burke	Male	Business administration	Married	NAIPE	2 years

Source: SCHEUER and FURLAN, 2022

In the interviews, we aimed to understand more about the participants, including their age, education level, and marital status. Furthermore, in line with the objective of this article, we asked about the "Art for All Program," how they came to know about it, and how long they have been participating along with their children.

The table above is divided by gender, with the majority being female participants (four women and two men). Among the participants, one of the relatives was a sister, while the others were two fathers and three mothers of program participants. Regarding age and education, the average age was 54.8 years, and among the six participants, two completed university degrees, two completed high school, one completed up to the sixth grade, and one of the participants had obtained a Ph.D.

It's notable that five of the interviewees learned about the "Art for All Program" through a referral from the Comprehensive Care Center for Individuals with Intellectual Disabilities and Autism Spectrum Disorder (NAIPE).

The information presented in Table 1 reveals a greater presence of females compared to males in the study. According to data from the Center for Civil Registry Information, it was observed that in the first half of 2020, over 80,000 children were registered with only the mother's name. Furthermore, the Brazilian Institute of Geography and Statistics (IBGE) reported that over 26% of families consist of only one parental figure, with mothers being the majority (GUIMARÃES, 2021).

In light of these data, it can be inferred that parental abandonment is prevalent in Brazilian society, including in families with children with disabilities. The consequences of this can lead to issues such as a lack of financial resources to provide for the children's care, the alienation of paternal responsibilities, and mothers becoming overwhelmed, as they are often required to work to meet basic needs while also actively participating in work, household tasks, and motherhood. Some studies have highlighted the absence of male presence in child-rearing, indicating a lack of male involvement in caregiving (GUIMARÃES, 2021).

Analyzing the absence of males in the caregiving process from a critical perspective, it stems from the consideration of Federici (2021) that the construction of a patriarchal culture aligned with the capitalist mode of production established the social division of labor not only in terms of intellectual and manual work but also from a gender perspective. This reduces women's roles to childcare functions, which evidently have adverse effects on other aspects of their social lives.

The composition of the sample underscores this tendency of placing responsibility for childcare on women, especially when it comes to children with disabilities, as only two of the participants are men. While this aspect is questioned in quantitative terms, it is essential to understand how both fathers and mothers make sense of their experiences with their children, who are situated in a condition that often requires specialized care and a social support network due to the complexity that can, in certain circumstances, extend beyond maternal and paternal roles.

2.2 Shared Mediations: What Parents Say About the "Art for All" Program

Through the interviews, it is observed that mothers often perceive their children as dependent on them, and at times, they end up losing their personal space or foregoing activities they consider important. Women can become trapped in a patriarchal society, as Federici (2021) suggests, where activities such as domestic work and motherhood lack social value, especially within the context of capitalism, where productive work is considered the foundation for an individual's existence. According to Paugam (2003), recognition is achieved through the value that others place on an individual based on their presence, characterized by the quality of social participation and belonging. This is evident in the statements made by Lauren Potter and Katelyn Reed when Lauren gave up her job to become her son's caregiver, and Katelyn expressed her desire to be part of the workforce and have a place in society, but she ends up solely in the role of a mother, not receiving the recognition she deserves from others: "[...] I worked as a cook, and when Bruce began to require our care, I took four years off to stay at home (Lauren Potter)"; "I am retired, not by choice, I am out of the job market due to problems, and I dedicate my time to Miles (Katelyn Reed)."

Throughout the interviews, family members highlighted how the workshops in the "Art for All" Program triggered moments of listening and support. It is a place that offers comfort, making them feel like they belong to something. According to Sawaia (2001), spaces that promote meetings and dialogues about the feelings caused by the suffering of exclusion enhance bonds through common affections. In many cases, family members end up losing their own place with the arrival of their child, and especially women, who already experience the effects of a patriarchal culture more intensely, become even more imprisoned in these roles, losing spaces and support, dissolving relationships that once supported their existence. Thus, it is important to seek places that foster encounters with family members and allow them to feel part of a network of welcoming and supportive relationships, ensuring that motherhood is not a solitary experience but one that can be shared and built collectively.

The discussions raised about the roles of men and women in caregiving, as well as the feelings of isolation and loneliness experienced by many family members of individuals with disabilities, need to be analyzed within the context of politics that shape their lives. Therefore, it is essential to recognize that in Brazil, as well as globally, there is a growing advancement of neoliberal logic, which reduces investments in social policies and places unilateral emphasis on the individual, evading the responsibility of creating social actions that could alleviate what Sawaia (2001) terms as ethical-political suffering. The conceptual category of ethical-political suffering points to the experience of suffering not as something originating internally, even though it is lived individually, but rather as woven into the fabric of contradictions within an unequal society founded on exploitation and oppressive mechanisms that gradually erase bonds and relationships of belonging between individuals.

Due to the fact that this study takes place in an institution related to the arts, it is essential to mention how the government has been exempting itself from creating consistent policies to guarantee the right to access art and culture. Thus, the advancement of Non-Governmental Organizations (NGOs) is evident, which, according to Macalini (2012), play a significant role in providing art and culture in Brazil. These organizations operate through social projects, and some of them aim to accommodate people with disabilities, focusing on development through art. In the case of the field of study in question, art, through aesthetic workshops, serves as a mediator that enhances work with people with disabilities and their families, providing a space for speaking, listening, and expressing emotions.

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Within this context, it is evident that IMPAR is an NGO where practices mediating the construction of citizenship occur through the strengthening of bonds between parents, children, and society. The existence of the "Art for All Program," which aims to promote the social inclusion of people with disabilities through art and engage parents in this process, signals the creation of a space of relationships in which the family's encounter with a person with a disability is organized based on a different logic. The statements of family members regarding the importance of the "Art for All Program" point to the establishment of a time for meeting, welcoming, and collaboration: "[...] So, it was good because of that, I had the availability for both of us to stay [...] (Jamie Brewer)."

> [...] All the children there interact very well. They are doing good work with the children and with us, the mothers, and the siblings. My daughter, when she participates at home... For us, mothers, fathers, it's very well developed (Lauren Potter).
>
> [...] I try to work with him, record audio, do voiceovers, try to get him moving, and then I send the video for people to see, and there's an exchange of experiences, and it's quite interesting. And the person in charge of IMPAR is a wonderful person; he manages to bring out what we have [...] it's hard not to be captivated by him (Katelyn Reed).

When analyzing these statements, we turn to Vygotsky (1997), who considers the social dimension and collaborative relationships as a decisive factor in the construction of individual capabilities. In this sense, based on a proposal grounded in the perspective of aesthetic education, which uses art as a mediator and promotes relationships that break away from utilitarian connections and are shaped by emotions, which bring forth words, looks, attitudes, and perceptions, constructing spaces where family members, along with their children, can discover new forms of relationships and bonds, both with each other and with others: "She didn't speak outside the house, didn't go to the mall, now she does, she talks and plays (Madeline Stuart)."

> [...] He was an extremely shy child when he started, and nowadays, he joins the theater's live events, smiling [...] the

> change in this matter is quite significant; I feel that it has improved a lot, socialized more with this interaction, with the theater friends, as he says (Katelyn Reed).

Through their participation in the "Art for All Project," family members describe a process of learning, discovery, and meaningful encounters in their statements. Being with their children, exchanging looks with them, listening to them, listening to themselves, getting to know the experiences of other people with disabilities and their families—here is an arena in which diversity, collaboration, and discoveries transform time into a place that is experienced through emotional bonds that facilitate the emergence of mediations that are now shared.

2.3 Aesthetic Relationships: Mediations through Art

The participants' recognition of the importance of the effects caused to their children and themselves by participating in the “Art for All Program” enabled them to make some considerations regarding what constitutes the mediating resource that makes the work proposal possible: art.

> Art is very important because it's in everything we do, everything we think about doing. Even in a home, it's art; it really opens our minds. How important art is in our lives, for everyone. It opens our minds to many things (Lauren Potter).

Vygotsky (1999) considers art as the social technique of feeling. His insights into this essential aspect of human development are based on the idea that the creation of works of art and the relationship people establish with art mobilize emotions. He further suggests that the emotional dimension of art evokes and activates elements of movement related to the reality in which an individual lives, a reality that is reconstructed and transformed: "He started showing things through gestures, by counting on his fingers, and then IMPAR helped a lot (Lauren Potter)"; "She had a fondness, and she started having dialogues with friends, shared laughter that nobody else understood, it was just between them. So I see that it was a space for fulfillment and belonging (Jamie Brewer)."

For Vygotsky, art is associated with imagination, facilitating the emergence of personal experiences and emotions (Vygotsky, 1999). The participants' statements resonate with Vygotsky's ideas as they highlight that art brings to life the aspects that elicit emotions:

> The dance, art, you know they go hand in hand. Just to give you an idea, this dance festival, I couldn't take my daughter, but I was there every night, every day I was at the dance festival, and it brought her great joy to see it (Breno Viola).
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> And the dance, for her, is ballet. It enchants her, fills her soul. She loves going to the dance festival when it's on. So we have a marathon of being there every day, because it brings her back full (Jamie Brewer).

According to Barroco (2014), Camargo & Bulgacov (2008), and Vygotsky (1999), the capacity for creation and expressiveness is a characteristic of the human race that can be enhanced through mediation. During the interviews, the family members raised concerns about how each experience has its uniqueness and that the moments with their children evoke emotions that only art was able to provide.

In other words, art is a part of the human being and their development as a subject in society. It constitutes culture, serves as a form of mediation, composed of signs, meanings, connections, feelings, and emotions, but also capable of generating personal meanings. It is a source of creativity and imagination, self-knowledge, and understanding of others with whom one experiences art and shares their experiences. It is possible to recognize these issues in the statements made by parents when they express that art is "joy," an essential part of a person's life that "fills the soul," and that "you can't be without music, it does me good," in addition to art providing parents with the opportunity to experience and observe "his feelings," referring to their child.

It is observed, therefore, that art as a mediator used in the aesthetic workshops of the "Art for All Program" ends up favoring the construction of unique bonds between parents and children, as well as for each individual with themselves. Due to the aesthetic experiences, it can be seen that artistic expressions mediate the relationship between parents and their children. Through shared moments, parents recognize common issues and grow closer to their children, as in the case of Chris Burke, who saw a passion for car racing in his son, and Jamie Brewer, who perceives that music and movies are intertwined in their relationship, and the activities they do together, be it walks or movie nights, are interwoven with art.

According to Barroco (2014), art fosters affection and other human potentialities. Through the interviews, it was noted how art serves as a mediation for the relationship between parents and their children, connecting them and enhancing moments spent together, where they end up getting to know each other more, experiencing and experimenting with artistic relationships. In addition to the activities that become unique in the relationships between parents and children, art triggers new memories, feelings, and emotions among them: "She has some very interesting things: the songs she listens to with me and the ones she only listens to with her sister, and she has those she likes and no one else does. [...] Sometimes, we sing a song to each other. (Jamie Brewer)."

> [...] we record video clips, dub music, I put on a wig and give him the guitar, and we do music dubbing [...] we make the video, I ask if it's good, and he says: do it again, and then we do it several times. [...] (Katelyn Reed).
>
> Another thing that I love and that he also likes to watch is Formula 1 car racing. [...] so these are things that I've always liked, I've always been passionate about car racing, and Andrew is too. [...] (Chris Burke).
>
> We did a performance there at Sesi, that really marked me, because the father participating alongside, the most beautiful thing in the world, I was so happy. It was me and her on stage, together (Breno Viola).

Through the parents' statements, it can be seen that art provides a different way of being with their child, where they can find similarities between themselves, recognize and embrace differences, and also create together. Through this, they suspend the pragmatism of everyday life, delving into emotions and feelings that sometimes do not find expression in a society that prioritizes productive and order-replicating practices.

With the rise of neoliberal ideology, the intensified spread of capital's logic, which currently determines the course of the Brazilian state, art not only lacks investment but also recognition. Spaces like the "Art for All Program," although not constituting a social policy but rather a civil society initiative, have the effect of sensitizing those involved to social needs, which are partially addressed but, due to their significance, should be guaranteed by the state as an accessible right for all. Given this, the third category addresses the themes of families and perceptions regarding disability, society, and the state.

2.4 What do families of people with disabilities say about the relationships between disability, society, and the state?

The data discussed in the previous categories and some statements from the participants that will be presented in this third category of analysis indicate the need to think about the relationships between family and disability based on the questioning of social, cultural, and above all, political issues. This is because understanding the complex dynamics of human relationships involves the necessary examination of how the state, as the regulator of society, has been managed and involved in matters related to family and disability.

Problematising the role of the state in directing the course of society implies that we are talking about the capitalist state managed from a neoliberal perspective. Therefore, while the guarantee of rights and citizenship is provided for in legal mechanisms, we can critically discuss a term that has long been used to assert the rights of people with disabilities: "inclusion." Although this expression is more intensively used in policies for people with disabilities, it is important to consider that it is inherent in liberal democracies to formulate affirmative policies that reduce the impacts of inequality. In light of the above, it is relevant to analyze not only the formal mechanisms but also how the contradictions between the capitalist state, the guarantee of rights, and the lives of individuals are pursued. For this, we turn to Sawaia (2001, p. 08):

> Society excludes in order to include, and this transformation is a condition of an unequal social order, implying the illusory nature of inclusion. We are all included in some way, not always decent and dignified, in the reproductive cycle of economic activities, with the vast majority of humanity included through insufficiency and privation that extend beyond the economic.

The problematization of the exclusionary nature of the capitalist society is reflected in the statements of the participants: "[...] As for going out with him, unfortunately, there is a certain restriction; when I go out with him to the mall, there's always someone who looks as if they've never seen someone special [...]" (Chris Burke).

> [...] I've been on a pilgrimage in this city to see if I could get Hope into a school that was truly prepared for her, prepared for everyone, prepared to embrace differences, but there isn't [...] (Jamie Brewer).

The statements made by these participants highlight how the social position of people with disabilities and their enjoyment of fundamental rights, such as education and access to public spaces, can be a costly process, even for parents who express a sense of helplessness in their quest for the minimum rights for their children.

These situations narrated by the parents attest to the existence of social processes that legitimize inequality and do not favor the civic social participation of people with disabilities. Moreover, in Brazil, the support structure for individuals with intellectual disabilities has been largely confined to charitable institutions and non-governmental organizations for decades. It is evident that the city of Joinville - SC presents different conditions from other states, with provisions of public services for individuals with intellectual disabilities through NAIPE and third-sector spaces such as IMPAR, which focus on rehabilitation and providing support to people with disabilities and their families (TOMAZ *et al.*, 2016).

Within IMPAR, through the "Arte para Todos" program, opportunities are offered, providing spaces for support and the creation of bonds among peers and for the families accompanying them on this journey. It should be noted, however, that there have been no significant advancements regarding the formulation of national public policies, and new public or third-sector bodies aiming to provide spaces for families and individuals with intellectual disabilities have not been created (TOMAZ *et al.*, 2016).

It is important to consider that although there is a discussion about expanding the rights of people with disabilities and their families, there are still vulnerabilities in such programs due to the lack of guarantees for their continuation. Through the statements of the family members, it is evident how important the program is and how they fear its closure, as well as the despair of not having places that are committed to welcoming families of people with disabilities: "What I have to say is that this shouldn't end, you know. It helps a lot for the children, the parents, and this was a good development in Brazil (Lauren Potter)"; "I wish there were a headquarters [...] Before, there were more students, other classes, it was very interesting. But it is difficult to obtain funding and investment, the (coordinator) faces a lot of difficulties. (Madeline Stuart)".

The statements of the participants about the possibility of the "Arte para Todos" program ending generate suffering, fear, and hopelessness, relating to ethical and political suffering. According to Sawaia (2001, p. 103), the suffering experienced by individuals is not purely an internal process but is shaped by social and political issues. In light of the above, the participants' statements highlight how caring for individuals with disabilities, especially working mothers, can be costly when experienced in isolation without support networks. Thus, their "pilgrimages" in pursuit of better living conditions for their children become an individual and solitary task, lived in a society that, by standardizing existence, produces situations of segregation for the different. The sense of loneliness and helplessness of the participants becomes a political issue, as this is about the denial of basic rights for their children, which are not concretely guaranteed by the state (SAWAIA, 2001; VYGOTSKY, 1997).

It can be observed through the statements of Jamie and Chris that families narrate experiences of seeking citizenship rights for their children marked by failure, not because of their actions as parents, but due to the state itself failing to provide such provisions. Thus, the parents are left despondent and question the future prospects for their children (MATA, 2019):

> Look, I think that if we analyze and expect something from our leaders to provide an improvement for special children, it's kind of difficult because if someone wanted to do it, they would have done it a long time ago, but they do very little, we practically don't feel it (Chris Burke).
>
> This journey of ours is very lonely. I think that if public policies, along with the education sector, could take care of some things, help us improve their autonomy, it would be a different story. It's not about giving up, it's not that, but this space that we as mothers lose (Jamie Brewer).

When families intertwine society with their children, they realize the lack of participation by public policies. There is a fear of what might happen, as, if anything is lacking for their children, the responsibility falls on the families. Situations known as negligence vary and are controversial because they are based on subjective and often condemning judgments of certain family profiles. At times, families suffer from the negligence of the state, while in other cases, they may be accused of negligence. Legal means reinforce the responsibilities of the state, society, and families, but the expectations of care and the judgments of caregiving methods fall upon the families (MATA, 2019).

The issues raised by the participants indicate a lack of faith in the political actions that could provide favorable social conditions for family care. Thus, on one hand, we see the state failing to concretize what is established by law, while on the other hand, there is a social voice that has fallen into what is called fatalism. This concept from Social Psychology refers to the idea of an inevitable destiny. Oliveira and Schlosser (2020) argue that individuals from marginalized classes, who experience domination and suffer from social injustices, tend to feel paralyzed by a suffering that seems perpetual and for which nothing can be done to bring about a transformation.

Through the interviews, the need for further discussions about disability-related issues and families became apparent in order to establish a foundation for parents in the context of caregiving for their children, to enhance bonds and relationships, and to understand the family/disability relationship as a process that is constructed socially, historically, and politically. It was observed that the possibilities of workshops with art led to dialogues and the creation of ways of relating to life that go beyond pragmatism.

These opportunities for dialogue emerged through art workshops, leading to ways of connecting with life that transcend pragmatism. However, even though families understand how social conditions impact their lives and the development of their children, there is still a sense of hopelessness about changing these social conditions. Alienating conditions appear in everyday life just like the measures to overcome them. Therefore, processes must be built to enable these families to break through the barriers of alienation, fostering imagination and the ability to dream and create (MATA, 2019; OLIVEIRA; SCHLOSSER, 2020).

3 Final Considerations

This study addressed the experience of parents of people with intellectual disabilities who participated in a social inclusion program focusing on aesthetic activities. The results of the interviews revealed that participation in the program had a significant impact on both children and parents, highlighting the importance of art in creating family bonds and transforming parents' perceptions of their children's disability.

Aesthetic education, characterized by its participatory nature and the expression of affection, played a crucial role in improving the relationship between parents and children, transcending the practical concerns of everyday life. The "Art for All" program offered a collective space that allowed parents to recognize suffering and explore new perspectives on parenting children with disabilities.

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However, parents expressed discouragement regarding public policies and the lack of investment in the program. They also expressed concerns about the possible interruption of the program due to a lack of financial support. The study emphasized that interpersonal relationships and connections occur in a context of social inequality, affecting both people with disabilities and workers. The study highlighted the importance of programs such as "Art for All", even if they are not officially recognized as social policies, as they provide collective and public experiences. Research participants highlighted the relevance of collective spaces, collaboration and affective relationships in reflecting on broader social issues, including the State's neglect of people with disabilities.

These considerations are of the greatest importance for the practices of psychology, as thinking about professional performance, which is based on the social commitment of the profession, is carried out through considerations of the society in which we live. The social commitment of psychology refers, here, to the production of knowledge and creation of practices that enhance the achievement of citizenship, encouraging these people to understand that their experiences occur in a condition of belonging to a broader social, economic and political structure. than the everyday dimension of their private existences.

Familia y discapacidad: las relaciones estéticas como mediaciones

RESUMEN

Este estudio tuvo como objetivo analizar los significados atribuidos por padres de personas con discapacidad intelectual en relación a sus experiencias estéticas en un programa de inclusión social. El campo de estudio es el “Programa Artes para Todos”, que tiene como objetivo promover la inclusión social de personas con discapacidad a través de diferentes modalidades artísticas. En este proceso, el programa cuenta con la implicación de seis padres de personas con discapacidad intelectual. El proceso de construcción de datos se dio a través de entrevistas semiestructuradas, realizadas de forma virtualizada y a través de la red social WhatsApp. La sistematización de datos se desarrolló a partir del análisis de contenido, con base en MORAES, 1999; BARDIN, 2016. El marco teórico se sustentó en la Psicología Histórico-Cultural, teniendo a Vygotsky (1997; 1999) y Sawaia (2001) como autores principales. Los resultados de esta investigación muestran que los padres de personas con discapacidad intelectual notan la importancia de espacios que promuevan el desarrollo de sus hijos, como el programa en estudio. Los sujetos de la investigación destacan que la posibilidad de participar de los talleres estéticos propuestos por el programa con sus hijos les permitió construir nuevas perspectivas sobre ellos mismos y sus hijos. De las declaraciones de los padres se desprende que la participación en los talleres produjo efectos importantes en la forma en que miran a sus hijos y los vínculos entre ellos. Este estudio también problematiza en qué medida los impasses vividos por las familias de personas con discapacidad están permeados por factores políticos y sociales, que indican la necesidad de que la psicología produzca lecturas más críticas sobre la relación entre familia y discapacidad.

Palabras clave: Relaciones estéticas; Familia; Discapacidad intelectual.

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