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Experience Report

Inclusive parenting and occupational therapy: experiences and challenges from the South

Parentalidad inclusiva y terapia ocupacional: experiencias y desafíos desde el Sur

Parentalidade inclusiva e terapia ocupacional: experiências e desafios desde o Sul

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Abstract

This experience report analyzes the challenges and opportunities faced by women with disabilities in the Magallanes, Chile as they exercise their parenting roles, based on the systematization of two cases supported by NGO REPRODIS. Among the main obstacles are ableism, attitudinal barriers, and the lack of accessibility in judicial and healthcare systems, which limit their rights and perpetuate structural discrimination. From a qualitative and situated feminist perspective, the experiences of women who, despite these adversities, strive for autonomy and the full exercise of their motherhood are explored. Occupational therapy plays a key role in this process, offering interventions that strengthen parenting skills, structure daily routines, and promote self-determination. The findings highlight the urgency of inclusive policies that remove barriers and promote accessible environments. They also underscore the importance of community and professional support as essential elements to ensure the active and effective participation of these women in raising their children.

Keywords: Persons with Disabilities, Parenting, Human Rights, Architectural Accessibility, Occupational Therapy, Disability Discrimination.

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Resumen

Este relato de experiencia analiza los desafíos y oportunidades que enfrentan mujeres con discapacidad en la región de Magallanes, Chile al ejercer su parentalidad, basado en la sistematización de dos casos atendidos por la ONG REPRODIS. Entre los principales obstáculos se destacan el capacitismo, las barreras actitudinales y la falta de accesibilidad en los sistemas judiciales y de salud, los cuales limitan sus derechos y perpetúan discriminaciones estructurales. Desde un enfoque cualitativo y feminista situado, se exploran vivencias de mujeres que, pese a estas adversidades, luchan por su autonomía y el ejercicio pleno de su maternidad. La terapia ocupacional desempeña un rol clave en este proceso, ofreciendo intervenciones que fortalecen habilidades parentales, estructuran rutinas diarias y promueven la autodeterminación. Los resultados enfatizan la urgencia de políticas inclusivas que eliminen barreras y promuevan entornos accesibles. Asimismo, destacan el apoyo comunitario y profesional como elementos esenciales para garantizar la participación activa y efectiva de estas mujeres en la crianza de sus hijos.

Palabras clave: Personas con Discapacidad, Responsabilidad Parental, Derechos Humanos, Accesibilidad Arquitectónica, Terapia Ocupacional, Capacitismo.

Resumo

Este relato de experiência analisa os desafios e oportunidades enfrentados por mulheres com deficiência em região de Magalhães, Chile, ao exercerem sua parentalidade, com base na sistematização de dois casos acompanhados por uma Organização Não Governamental (ONG) REPRODIS. Entre os principais obstáculos estão o capacitismo, as barreiras atitudinais e a falta de acessibilidade nos sistemas judiciais e de saúde, que limitam seus direitos e perpetuam a discriminação estrutural. A partir de uma abordagem qualitativa e feminista situada, exploram-se as vivências de mulheres que, apesar dessas adversidades, lutam por sua autonomia e pelo pleno exercício de sua maternidade. A terapia ocupacional desempenha um papel fundamental nesse processo, oferecendo intervenções que fortalecem as habilidades parentais, estruturam rotinas diárias e promovem a autodeterminação. Os resultados enfatizam a urgência de políticas inclusivas que eliminem barreiras e promovam ambientes acessíveis. Além disso, destacam o apoio comunitário e profissional como elementos essenciais para garantir a participação ativa e efetiva dessas mulheres na criação de seus filhos.

Palavras-chave: Pessoas com Deficiências, Parentalidade, Direitos Humanos, Acessibilidade Física, Terapia Ocupacional, Capacitismo.

Introduction

Parenting among women with disabilities has historically been an invisible topic in public policies and academic research, especially in contexts like Chile, where structural barriers perpetuate social exclusion. According to the Third National Disability Survey (Servicio Nacional de la Discapacidad, 2022), 21.9% of Chilean women live with some type of disability. However, their needs and rights in terms of parenting and reproductive health have historically been neglected (Pino-Morán & Rodríguez-Garrido, 2019). This phenomenon reflects the absence of inclusive policies and the entrenched ableist attitudes that undermine the autonomy of these women.

The study of parenting among women with disabilities reveals a gap in the existing literature, challenging hegemonic narratives that perpetuate stigma and discrimination (Tarleton & Heslop, 2020; Strnadová et al., 2018). In Chile, the lack of adapted services and training exacerbate this problem (Herrera, 2022). Along these lines, Ferrante & Tiseyra (2024) analyze motherhood and disability from a Latin American perspective, identifying common patterns of exclusion and structural barriers that women with disabilities face when exercising parenthood. Their findings reinforce the idea that these barriers are not isolated or exclusive to Chile, but rather respond to structural dynamics in the region, which allows this study to be placed within a broader context of inequalities and resistance in Latin America.

Women with disabilities continue to face widespread stigmas that portray them as incapable of independently caring for and raising their children (Rodríguez-Garrido et al., 2024). This perception is reinforced by multiple barriers such as high unemployment and poverty rates, lack of access to public transportation, limited access to quality healthcare, lack of recognition of their parenting skills, excessive scrutiny by child welfare institutions, and lack of professional support (Frederick, 2014; Janeslätt et al., 2019; More & Tarleton, 2021).

Atkin and Kroese (2021) emphasize the fundamental role that professional human rights defenders play in supporting and accompanying parents with intellectual disabilities, particularly in contexts where child protection institutions often question their parenting capabilities. In addition, both families and professionals frequently experience isolation and a lack of support from the broader protection system when navigating the challenges of inclusive parenting. This role of independent defender is extremely relevant in social intervention processes; however, it lacks state recognition and remuneration (Atkin & Kroese, 2021). In Chile, the absence of formal recognition for support services and personal assistance in the context of parenting further underscores the need for independent defenders who can safeguard the rights of people with disabilities and their families. It is essential to include a feminist approach in Occupational Therapy to highlight and address the structural inequalities that affect women and other marginalized groups, thereby fostering a more inclusive and critical practice (Morrison & Araya, 2018).

In Chile, research on access to and use of support services during motherhood and parenting for people with disabilities remains limited (Herrera, 2022). The absence of social and institutional support and the failure to create public policies that safeguard the rights of mothers with disabilities have fostered these violations (Dehays et al., 2016; Yupanqui-Concha et al., 2022).

This experience report analyzes two cases of women with disabilities supported the NGO REPRODIS in southern Chile dedicated to fostering the rights of persons with disabilities through community interventions and a human rights approach.

The Magallanes Region, in the far south of Chile faces unique challenges stemming from its geographic isolation and extreme weather conditions, which significantly affect access to health services, justice, and support networks. Long distances between cities hinder consistent medical care, access to disability specialists, and legal assistance in custody or reproductive rights disputes. Additionally, the limited availability of specialized professionals restricts the institutional response to the needs of mothers with disabilities. In this context, judicial decisions and assessments of parental suitability do not always consider these barriers, reinforcing the structural exclusion and vulnerability of these women (Dehays et al., 2012).

The inclusive parenting program provides professional support, with a focus on the self-determination and autonomy of persons with disabilities. Its goal is to strengthen parenting skills, ensure the full exercise of rights, and promote independence in family decision-making.

It includes home adaptations to identify risks and foster family autonomy. It also connects families with support networks, provides accessible materials on sexual and reproductive rights, and applies a gender and disability perspective. The program offers personalized resources and reasonable accommodations to promote the exercise of rights.

Driven by the absence of state policies, REPRODIS established itself as a recognized organization in the community with an approach that goes beyond reporting violations to empowering women's autonomy and legal capacity in the exercise of parenthood. Since its inception, the initiative has been led by occupational therapists, who have designed and implemented the Inclusive Parenting Support Program. With the support of the Department of Occupational Therapy at the University of Magallanes, the program seeks to eradicate barriers, strengthen parenting skills, and promote self-determination among mothers and fathers with disabilities. This effort proves the transformative impact of occupational therapy in adverse contexts, highlighting its contribution to social inclusion and the full exercise of parenthood.

Through case analysis, the initiative seeks to highlight the structural barriers imposed by the justice system and institutions, but also to highlight the empowerment and emancipation strategies that have allowed these women to exercise their rights. This paper proposes a reflection on the need for intervention models that strengthen the agency of mothers with disabilities within a rights-based framework.

Within this framework, two cases are presented with fictitious names inspired by the Selknam culture, an indigenous people who inhabited Patagonia for almost[1] 10,000 years. This experience report is part of the research project entitled *"Support Services and Transformative Experiences in Motherhood and Parenting of Women with Disabilities,"* Funded by the University of Magallanes. This study has been approved by the Scientific Ethics Committee of the same university.

Story 1 KOSPHY

A 34-year-old woman from Magallanes region, Chile. She was born with hearing loss. Her native language is sign language, and despite facing multiple barriers, she completed her education with the support of her mother, Xalpen, and her siblings. Always sociable, she has strengthened ties, especially with the deaf community.

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[1] It is worth noting that the choice of names inspired by the Selknam culture reflects the recognition of the territorial identity of the southern region of Chile, without implying that the cases presented correspond to individuals belonging to this ethnic group. This tribute seeks to highlight the cultural richness of the territory where these experiences take place.

At 30, seeking independence, she moved to the Chilean capital, which strained her relationship with her mother due to her overprotective nature. There, she started a family with Ulen and had her son, Kren. However, after the relationship broke up, she returned home with Kren, reuniting with a mother eager to welcome them, but with whom conflicts soon arose, mainly over Kren's upbringing.

Koshpy decided to seek her own space with support from the deaf community, but Xalpen took the case to court, alleging parental negligence and arguing a possible violation of her rights, claiming that she had developmental delays, primarily in language acquisition and cognitive skills. She alleged that Koshpy lacked the skills to foster the child's proper development and that she posed a risk to him. Given this situation, the court judge decided to grant custody of the child to Grandmother Xalpen, without evaluating Koshpy's parental skills, denying Koshpy the right to exercise the role of mother.

Kosphy faced multiple barriers in her motherhood, constantly questioning her ability to provide care. The intervention of the judicial system conditioned her right to parenthood, imposing requirements that did not apply to other mothers. "*I was told that if I didn't comply with certain programs, I wouldn't be able to have him with me. They sent me to programs and made me sign things I didn't fully understand. I just wanted to be with my son, but it seemed like they had to prove me better than other mothers*" (Koshpy). These demands reinforced the idea that she had to constantly prove her suitability as a mother, rather than receiving effective parenting support.

Ableism (Campbell, 2008; Lapierre, 2022) structures inequalities that undermine the autonomy of people with disabilities, particularly in the exercise of motherhood. Professional accounts reveal the restriction and denial of the full exercise of this occupation, as in the case of Koshpy, who faces structural barriers in her fight for custody of her son. Occupational apartheid (Kronenberg & Pollard, 2006) describes this systematic exclusion, reinforced by structural ableism. From an intersectional feminist perspective (Crenshaw, 1989), we notice how gender and disability intersect in justice, health, and social care, where decisions can be questioned or made by third parties. Instead of strengthening effective support, institutions impose substitute measures for parenthood, perpetuating exclusion and dependency.

This highlights the constant and emancipatory struggle we are part of as occupational therapists in the Global South (Galheigo, 2020).

> *What I observed through the exercise is that the courts, the different institutions, both public and private, immediately apply this discriminatory bias to an issue such as ignorance. They assume that these mothers' disabilities would violate and harm the physical integrity of their children. Of course, that is not the case, and that was the work we had to do in court: demystify this and reverse these measures of separation of children from their mothers due to disability* (Lawyer, 35 years old).

The parenting skills of women with disabilities are questioned, as they are constantly compared to hegemonic models of daily life, despite existing legislation regarding care, well-being, autonomy, and participation (Rodríguez-Garrido et al., 2024). Courts of justice are sites of structural violence and social injustice. They have been founded on patriarchal structures that contribute to the marginalization of people with disabilities, excluding a gender and intersectionality perspective from their processes and decisions.

> *There are many situations in which the State is indebted to the protection and ensuring equal conditions for people with disabilities. In other words, the courts act, based on reports from the network that serves people with disabilities, from the conviction that these people are not fit to provide care* (Lawyer, 47 years old).

The constant lack of protection by the State and its neoliberal and patriarchal institutions are the main causes of violations of the sexual and reproductive rights of women with disabilities. From this, structures of oppression are framed, perpetuating forms of domination from which stigmatization and ableism are deployed among professionals (Lapierre, 2022). These factors constitute barriers to the full exercise of the human rights of women with disabilities.

> *It is important that the State and professionals understand—because at the end of the day, we are public officials, we are public policy. Public policy is implemented through us, and because we make the decisions, it ultimately determines how friendly or not people's lives can be* (Social Worker, 45 years old).

By court order, Xalpen is granted custody of Kren. Meanwhile, Koshpy is placed under a supervised visitation and communication arrangement, with the requirement to participate in intervention programs aimed at strengthening her parenting skills and demonstrating her ability to care for her son.

Initially, Koshpy's visits with Kren are restricted to the intervention program facilities, where professionals supervise each encounter. Over time, thanks to her empowerment and support networks, Koshpy obtains permission to take Kren to spaces outside the program. As part of the process, the court orders the promotion of sign language communication among Koshpy, Kren, and Xalpen, thus encouraging more inclusive interaction within the family.

Koshpy's strongest protective factor is the bond she has built with Kren, despite the restricted nature of their visits. Despite the adversities in her context, Koshpy lives independently.

Upon entering the program of the NGO REPRODIS, the professional team demonstrates that the Court fails to implement procedures with universal accessibility measures to guarantee due process for persons with disabilities. Assessment instruments with reasonable accommodations were not applied, nor was a permanent sign language interpreter available, limiting their rights and opportunities.

Faced with these barriers, the NGO team implemented a comprehensive plan focused on promoting and exercising their rights and personal autonomy.

After completing the intervention process, the Court decided that Kren's personal care remain with her grandmother, Xalpen, arguing that Koshpy "*does not have enough capacity to act as a mother.*" However, she is allowed to maintain regular visits and communicate in sign language with her son without constant professional supervision.

Despite this ruling, Koshpy disagrees with the court. Although she does not have legal custody of Kren, she continues to work to strengthen her role as a mother.

Story 2 KOIN

Koin was born in the Magallanes region, Chile, the daughter of Shinka, a person with an intellectual disability. She raised her daughter alone after her husband abandoned her. When Koin was one year old, Shinka married and gave birth to her sister, Shioon, who has a physical disability and requires care. However, this relationship did not last, and the family unit formed by Koin, Shinka, and Shioon became consolidated.

During school, teachers detected learning difficulties in Koin and recommended that she continue her studies at a special school, where she successfully completed them. She then entered a job workshop to develop independent living skills, where she met Shénu, beginning a teenage relationship. Concerned about a possible unplanned pregnancy, Koin was taken by Shinka, her mother, to a health center for sex education. However, the information was not tailored to Koin's needs, which limited her understanding.

After several years of dating, Koin and Shénu decided to start a sexual relationship. Fearing she would run out of contraceptive pills, Koin took them irregularly, every other day, as she thought the health center would no longer provide her with contraceptives, which led to an unplanned pregnancy. Upon learning this, the health center's professionals expressed concern, questioning Koin's ability to care for a baby because they are a family with disabilities, assuming the child would be at risk of rights violations from an ableist perspective.

When her baby was born, the professionals considered giving the baby up for adoption as a protective measure. Ultimately, Koin became a mother to Wikayen, taking on his care with the support of her mother, as Shénu, the father, did not participate in his upbringing due to opposition from his family, who questioned his paternity, citing his alleged asexuality due to his disability.

Koin becomes the head of the household, responsible for domestic duties and caring for her severely disabled sister and her son, Wikayen. Despite feeling overwhelmed by her responsibilities and the opposition to her motherhood, Koin faces the challenge of proving that her disability is not a reason to lose legal guardianship of her son.

The intervention of the NGO REPRODISbegan by strengthening Koin’s empowerment and validating her right to motherhood. Her support networks were also trained to ensure equal opportunities, facilitating a more inependent and fulfilling motherhood.

The approach included education on sexual and reproductive rights, structuring essential routines for motherhood, adaptations and accessibility measures at home to create a safe environment and foster the baby’s holistic development. In addition, daily habits that enhance the well-being of both Koin and Wikayen were reinforced, strengthening her occupational performance.

During her pregnancy, Koin did not imagine the barriers she would face in motherhood. The NGO identified discriminatory treatment and an ableist perspective among professionals that threatened the exercise of her motherhood. For this reason, support was requested from the National Disability Service (SENADIS) to establish an intersectoral support network.

The hospital team attempted to detain Koin and her newborn son, arguing that her disability made her incapable of caring for him. The support network intervened, reporting this violation of rights and ensuring they were allowed to leave the hospital. However, the hospital filed a protection order claiming a violation of the child's rights, based solely on prejudice and ableism.

This episode marked the beginning of years of legal proceedings, interrogations, and abuse. Various professionals questioned Koin's parenting skills, her love for Wikayen, and her autonomy, while denying her accessibility and support measures. They constantly suggested institutionalizing Wikayen as the best option, perpetuating violent and discriminatory discourses toward Koin.

Koin clearly expresses what motherhood means to her: "*I love having a son, I'm so happy. I'm a mother. When he was born, they said I wouldn't be able to take care of him. That's when the problems began. Thank God, some therapists helped me rescue him." With a ticket, I won, I fought... I said: 'Yes, come on, you can become a mother.*'" This testimony shows how mothers with disabilities face barriers imposed by institutions that, instead of providing support, tend to question their parental suitability.

Women with disabilities who decide to become mothers in Chile are victims of discrimination and extreme surveillance by the courts (Rodríguez-Garrido et al., 2024). This constant questioning is based on stereotypes and prejudices about disability, which makes it impossible to exercise their legal capacity (Yupanqui-Concha et al., 2022).

> *Especially in the field of health, the attitude toward motherhood for a person with a disability always begins from a place of discrimination — the idea that, because she has a disability, she shouldn't be a mother... Courts usually associate disability with diminished parenting abilities, which is not necessarily — we could say — a general rule* (Lawyer, 47 years old).

There are multiple barriers to accessing comprehensive and quality healthcare for women with disabilities, such as the lack of reasonable accommodations in information delivery, attitudinal barriers like stigma and discrimination, questioning the reasons behind seeking medical care, and the lack of training among social and healthcare professionals regarding disability. These factors limit women's full participation in decisions about their own health (Hichins-Arismendi & Yupanqui-Concha, 2022).

> *Ultimately, it was prejudice and value judgments from the professionals themselves that were at play across the different institutions. They essentially measured motherhood using the same standards by which they probably exercised their own motherhood — with more tools, more resources, even more money — we could say a freer motherhood from another perspective. So, the negative shift lies in how public policy was implemented* (Social Worker, 45 years old).

The speech on disability among professionals within the social and health network is biased and limits the exercise of women with disabilities' rights to have and be part of a family (Dehays et al., 2016). Ignoring current theoretical approaches and disability legislation, they question their capacity and autonomy to exercise their parental role.

> *People don't know, they don't study, or make the effort to delve into the reality of things. So these actors, simply from their bias, from their misguided approach, applied what they considered safe, legal, legitimate, etc., without realizing that*

> *what they were doing was, from then on, discrimination, a denial of human rights. I remember that in many hearings I had, I had to start by explaining the basics, that is, people with disabilities have the right to have a family. The problem is that when it's put into practice, these actors question it. And if a child whose mother has an intellectual disability falls, they immediately assume, from their approach, from their bias, that the child fell and hand him over to someone who is qualified* (Lawyer, 35).

The judge rules that the temporary personal care of her son, Wikayen, is in the care of his maternal grandmother, Shinka, for a period of six months. This is because the health center's professional team reports that Wikayen could be at risk. They establish the need to evaluate possible measures to adopt for the child's protection.

After three years of working with the NGO team and its support network, Koin has made significant progress in her role as a mother, reflected in Wikayen's development and their mother-son bond.

The strength of this family lies in mutual support and the reduction of environmental barriers. Koin's progress is visible in her occupational performance and independence, both in her own activities and in caring for her son, who has regained legal guardianship.

Key Learnings and Challenges

The experiences of Koshpy and Koin highlight the importance of ensuring that women with disabilities can exercise motherhood with autonomy and dignity. This underscores the need for interventions grounded in human rights, universal accessibility, and gender perspectives to eliminate discriminatory practices. Community networks are fundamental in supporting these mothers, strengthening their parenting skills, and providing them with the necessary resources to exercise their rights. In addition, occupational therapy emerges as a key discipline for empowerment, supporting the exercise of rights, structuring routines, developing skills, and promoting self-determination in the context of inclusive parenting. However, significant challenges persist, including systemic and institutional barriers reflected in ableist attitudes within healthcare and justice systems, where mothers with disabilities are often seen as incapable, leading to their exclusion and excessive surveillance. The lack of inclusive public policies in Chile further exacerbates the barriers these women face, perpetuating structural discrimination. These difficulties are intensified by the absence of accessibility measures, such as reasonable accommodations and adapted information, which limit their opportunities for full participation in their parental role.

Final Reflections

Throughout this article, the aim has been to shed light on the structural barriers faced by mothers with disabilities in exercising their parenthood, within a context of structural ableism and social exclusion. It has been shown how the justice, health, and social welfare systems impose restrictions that limit their autonomy, reinforcing guardianship logics instead of offering effective support. Likewise, through the analysis of specific cases, strategies of resistance and empowerment have been identified, highlighting the role of women in defending their rights and the work of organizations in promoting legal capacity and emancipation. These findings make it clear that the exercise of parenting among women with disabilities continues to be shaped by prejudice and exclusionary norms, reinforcing the urgent need to rethink public policy from an intersectional and human rights-based approach.

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Melissa Hichins-Arismendi, Daniela Mandiola-Godoy and Juan Pablo Obilinovic-Rivera contributed equally to the development of the article. All authors approved the final version of the text.

Data Availability
The data that support the findings of this study are available from the corresponding author, upon reasonable request.

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