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When Families Become the System: Family Care for Young Adults with Disabilities in Urban Ecuador

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This study examines how disability care is reorganised in adulthood within urban Ecuador, where formal disability legislation coexists with uneven institutional implementation. Drawing on semi-structured interviews with six parents of adults with disabilities[1] in Quito and analysed through reflexive thematic analysis, the findings demonstrate that adulthood constitutes a decisive restructuring moment. When educational support fades and job opportunities remain uncertain, families find themselves shouldering more responsibility, becoming the main coordinators, advocates, and planners for their adult children. Care thus becomes an intergenerational governance project in which mothers and, over time, siblings, progressively internalise functions typically associated with institutional infrastructures. Structural gaps are mitigated but not resolved through families mobilising informal networks, faith communities, and private resources. Engaging critically with feminist care ethics and Southern disability scholarship, the paper argues that care in this context may not be simply relational or culturally embedded, but also structurally imposed under conditions of governance displacement. By foregrounding adulthood in a legally progressive yet institutionally constrained middle-income context, the study refines debates on intersectionality, familialisation, and symbolic inclusion in the Global South. It concludes by calling for a life-course-oriented disability policy that redistributes, rather than formalises, intergenerational family responsibility.

Keywords: family caregiving; adult disability; disability policy implementation; intergenerational care; Ecuador.

Introduction

Ecuador is an upper-middle-income country in the Andean region of South America, with a population of over 18 million (World Bank, 2024). While official figures from the Consejo Nacional para la Igualdad de Discapacidades (*National Council for the Equality of Disabilities*) (CONADIS) register 487,542 people with disabilities (PWD), independent estimates suggest the reality is closer to 1.1 million, or around 7% of the population, revealing a significant "registration gap" (World Bank, 2024; CONADIS, 2024; Disability Debrief, 2024). Ecuador ratified the Convention on the Rights of Persons with Disabilities (CRPD) in 2008, committing to international disability rights standards. Since then, the country has introduced several national policies aimed at fostering inclusion, such as the Organic Law on Disabilities (2012) and the National Plan for Good Living, which places social protection and equity at the centre of national development (National Assembly of Ecuador, 2012). However, despite these legal advances, PWDs in Ecuador continue to face significant structural and attitudinal barriers in accessing education, employment, healthcare, and civic participation across the lifespan (Valdivieso & Lalama, 2017; Pinilla-Roncancio, 2018).

Under the leadership of Lenin Moreno, the Global South's first wheelchair-using president (LSE, 2017), Ecuador was positioned as a regional pioneer in disability legislation and increased access to services and support through disability identification cards issued by CONADIS. However, despite these symbolic and legal inclusion advances, scholars have argued that a significant gap persists between Ecuador's progressive disability rights discourse and the lived realities of PWDs and their families (Maldonado, 2018; Pinilla-Roncancio, 2018). Furthermore, critics note that Moreno's visibility, while politically significant, did not translate into structural changes that ensured sustained, equitable access to services for all PWDs (Mora & Jácome, 2019). This disconnect between disability as a political symbol and the everyday struggles of families navigating fragmented systems reflects a broader pattern in the Global South, where rights-based rhetoric often outpaces practical implementation (Grech, 2011; Soldatic and Grech, 2014).

In addition, when disability support is mediated through state agencies such as CONADIS, the process may frequently be subject to politicisation, bureaucratic inefficiency and corruption, as evidenced by the 2020 scandal involving the fraudulent sale of over 2,000 disability CONADIS identification cards (IDs) for tax benefits (Disability Insider, 2020). This scandal not only exposed systemic vulnerabilities but also eroded public trust in the very institutions designed to support PWDs and their families. In such a context, where the reliability of state-led disability support is compromised, families emerge as the primary, and often sole, source of care, advocacy, and support. This dynamic mirrors broader Latin American patterns, in which families shoulder caregiving responsibilities amidst fragmented public provision and inconsistent implementation of disability policies (Pinilla-Roncancio, 2018). Care work frequently falls on mothers and female relatives, reinforcing entrenched patterns of unpaid labour and exposing families to ongoing financial and emotional strain (Grech, 2019).

While much of the global disability studies literature has historically been shaped by frameworks developed in high-income contexts from Global North settings (Grech, 2015), critical disability scholars argue that these perspectives often fail to reflect the realities of care and exclusion in the Global South (Meekosha & Soldatic, 2011). In Latin America, recent studies from Guatemala (Grech, 2019), Brazil (Antunes & Dhoest, 2018), and Colombia (Magaña et al., 2019) have begun to document the contextual complexities of disability, care, and stigma. However, in Ecuador, research has primarily focused on the early years of parenting children with disabilities (Buffle et al., 2024; Huiracocha et al., 2017), leaving a critical gap in understanding the layered family experience of disability into adulthood.

As PWDs become adults, disability care becomes an intergenerational family governance project where families absorb the functions of a missing state, managing the mental, financial, and structural labour. Families raising adults with disabilities encounter compounded challenges, including the withdrawal of state services once children age out of school systems, persistent financial strain, deepening concerns about future care, and enduring social stigma (Mora & Jácome, 2019). This transition into adulthood is an intensification of earlier caregiving struggles in addition to a restructuring developmental moment that generates new parental roles and future anxieties not adequately captured by childhood-focused studies. These long-term dimensions of caregiving and their emotional, economic, and social implications remain underexplored. By foregrounding families' lived experiences, this study responds to Grech's (2019) call to move beyond individualised and decontextualised understandings of disability, illuminating how disability, care, and family intersect through deeply gendered and intergenerational dynamics that remain marginalised in both theory and policy.

This study centers the voices of urban, relatively well-resourced Ecuadorian parents, with a combination of middle and high-income families of adults with disabilities. In doing so, it contributes to wider calls to decolonise disability knowledge and attend to the specificities of Global South contexts (Meekosha & Soldatic, 2011), where adulthood marks a distinct site of institutional exit and further systemic withdrawal. In this article, decolonising disability scholarship entails challenging Global North epistemic dominance in knowledge production and, furthermore, interrogating policy imaginaries that assume the automatic translatability of rights-based legislation into institutional capacity. This research illuminates the family impact of the transition into adulthood, particularly the intergenerational gendered dimensions of caregiving (Torres & Ohajunwa, 2025). Much of the global discourse on disability and family caregiving assumes the existence of robust welfare systems, formal services, and legal protections. In contrast, caregiving in Ecuador, even amongst well-resourced urban families, commonly unfolds within stratified social structures shaped by informal care arrangements, over-reliance on families as care institutions, as well as enduring inequalities (Pinilla-Roncancio, 2018; Soldatic and Grech, 2014).

By focusing on parents of adults with disabilities, we focus on demonstrating that further withdrawal of the systems in adult life creates qualitatively intensified pressure on the family unit. This study offers a situated account of how families navigate disability in the absence of consistent public support towards adulthood, tracing how caregiving demands shift over time and what forms of support are necessary to accompany families beyond the early years of diagnosis and early intervention.

Methodology

This qualitative study explores the lived experiences of parents of adults with disabilities in the urban city of Quito, Ecuador. The research design followed an interpretive, exploratory approach, using semi-structured interviews guided by an interview schedule to elicit rich, in-depth narratives. Interviews were recorded through an encrypted voice recorder and transcribed verbatim. All interviews were conducted in Spanish by the bilingual researcher.

Sampling and Participants

Participants were recruited using purposive sampling (Etikan et al., 2016), with the support of disability-related organisations in Ecuador, who shared the study invitation with potential participants who met the inclusion criteria. Although the invitation was extended nationally, rural participation was limited due to technological and connectivity barriers. The inclusion criteria were: (a) parents or primary caregivers residing in Ecuador, and (b) caring for a young person over the age of 18 with a disability. The sample allowed for detailed, contextualised exploration of each family's narrative. Six participants (four mothers and two fathers) from urban and relatively middle to high-income areas of Ecuador took part in the study (see Table 1 below).

*Table 1. Family Vignettes**

Family 1 Participant: Ana, mother of Daniel	Daniel is 26 years old and is the eldest son of 3 boys who live at home with their parents. Their family is Afro-Ecuadorian and originally from a rural province in Ecuador. Daniel was diagnosed with hearing loss at age 4 after his school reported this observation. This family received financial support from their school church to buy Daniel a hearing aid. He then received a cochlear implant before age 18. His mother is a house cleaner, and his father is a plumber. He currently works and pays for his university studies.
Family 2 Participant: Sophia, mother of Carla	Carla is 30 years old and has an intellectual disability without a clear diagnosis. Carla grew up with her parents and her older half-sister who is 10 years older than Carla. When she was two years old, the doctor told her mother she had an intellectual disability. Carla has attended private special education schools and currently remains at home with her stay-at-home mother.

Family 3 Participants: Monica and Jonathan, parents of Chris	Chris is 32 years old and is the second son of four. He currently lives with his mum, dad, and youngest brother. His parents reported they were in search of a diagnosis for 14 years before finally being told that Rubinstein-Taybi Syndrome is the most approximate. Chris comes from a high-income family, and he attended several private special education schools during childhood and into adulthood, as he is not employed.
Family 4 Participants: Catherine and Oliver, parents of Nicole	Nicole is 18 years old and the youngest of two daughters. She lives with her mum, dad, and older sister. She has Down Syndrome. Nicole currently attends a Montessori special education school. Nicole's parents both work for state agencies and are of a *mestizo* heritage (*mestizo* refers to a person of combined European and Indigenous descent).

*Names have been changed to ensure the anonymity of participants

Data Collection

Data were collected via 90-minute semi-structured Zoom interviews, which followed a topic guide informed by relevant literature (Band-Winterstein & Avieli, 2017; Young & Koritsas, 2012). The guide explored the diagnostic process, family adaptation, interactions with systems, and caregiving across the lifespan. Open-ended questions allowed participants to narrate their experiences in their own terms, while the semi-structured format ensured coherence across interviews (Gill et al., 2008). The interview schedule was written in English and translated into Spanish by the bilingual researcher using a culturally sensitive adaptation of Brislin's (1970) back-translation method (Lopez et al., 2008). This ensured both linguistic accuracy and cultural relevance to Ecuadorian Spanish.

Remote interviews presented both opportunities and limitations. While they removed logistical barriers such as travel and scheduling, they also restricted the ability to fully observe body language and non-verbal cues (Seitz, 2016). To foster rapport, the researcher used supportive verbal prompts and allowed space for reflection (Weller, 2016). All participants provided written informed consent before the audio-recorded interview.

Data Analysis

Data were analysed thematically following Braun and Clarke's (2006) six-phase framework, using iterative coding and theme development. Transcript readings were undertaken to identify initial codes, which were then clustered into broader themes through an iterative, reflexive process (Terry et al., 2017).

Analysis was conducted in Spanish to preserve the nuance of participants' voices. The analysis process was grounded in a critical, context-sensitive reading of care and disability, informed by literature on the Global South and Latin American caregiving contexts. Themes were developed inductively and situated within Ecuador's social, cultural, and policy context. Selected excerpts were translated into English for inclusion in this manuscript, with care taken to preserve the meaning and tone of participants' original narratives. Trustworthiness was enhanced through verbatim transcription, iterative coding, and transparent documentation of analytic decisions (Nowell et al., 2017).

Ethical Considerations

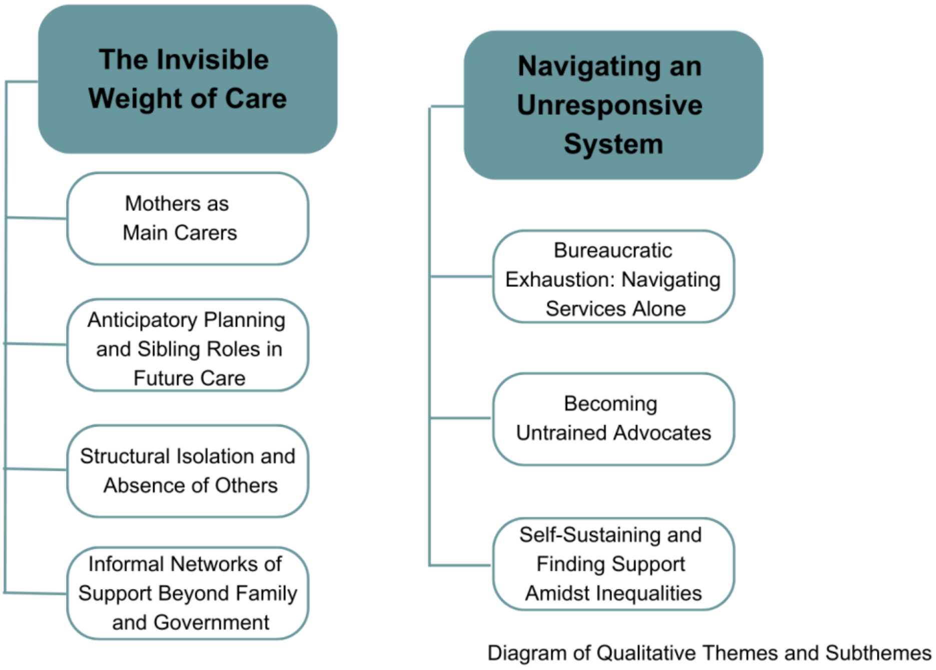
Ethical approval was granted by the University College London Research Ethics Committee. Participants could pause or discontinue the interview at any point. Pseudonyms were used, and all identifying information was removed to ensure confidentiality in the analysis and reporting of data.

Findings

Although parents recalled the moment of diagnosis marking a profound emotional impact for families, the significance of this became clearer over time. Parents described shock, guilt, and disorientation, 'like a tsunami,' as Sophia recalled when receiving their child's diagnosis, yet these early responses did not remain confined to childhood. Rather, they became sedimented into long-term caregiving arrangements that extended into adulthood. As children aged out of early intervention services and schooling, families encountered a structural vacuum where support systems that had been partially scaffolded during childhood did not translate into adulthood. It is at this moment that caregiving intensified and reorganised, revealing how responsibility for care becomes increasingly absorbed within the family across developmental cycles.

The findings are organised around two themes and seven subthemes that foreground this reorganisation across adulthood (see Figure 1).

Figure 1. Diagram of qualitative themes and subthemes



Theme 1: The Invisible Weight of Care

Across interviews, care was described as an act of love as well as a gendered and intergenerational responsibility. Even amongst relatively well-resourced urban families, caregiving was carried out mentally, financially, and structurally within the household, with a pervasive absence of consistent systemic support.

Subtheme 1.1: Mothers as main carers

All four families described how care fell almost exclusively on mothers from childhood into adulthood. The mothers' accounts portrayed how they coordinated therapies, managed education, navigated medical systems, and restructured daily life around their child's needs. Sophia described her routine as continuous movement between appointments: 'I was running all the time, one therapy in the morning, then another in the afternoon….' She added, 'No one will take care of her as I do.'

This dedication was often accompanied by enduring guilt. 'You feel a lot of guilt, even until today,' Sophia reflected. Guilt translated into heightened vigilance and overprotection: 'All this guilt makes you protect more.' Ana described herself 'like a hen taking care of her chick.' These metaphors reveal not only attachment, but an internalised sense of singular responsibility that is still present as their children become adults.

In most families, fathers assumed financial roles while mothers withdrew partially or fully from paid employment. ‘My husband worked all the time, I dedicated myself in body and spirit to Carla,’ Sophia explained. For some, maintaining employment became a strategy of psychological survival. Catherine recalled being advised by another mother of an adult with disabilities not to resign: ‘Work for us is therapy.’ Paid labour thus functioned ambivalently, both as constraint and refuge.

While some fathers remained involved, some participants noted that caregiving often isolates mothers. Ana observed that in hospital settings, she mainly saw mothers: ‘Fathers abandon their family when they see their child has some type of disability… mothers on their own fight.’ The gendered concentration of care was therefore not simply a cultural preference, but structured through institutional and network absence, which remained consistent towards adulthood.

Subtheme 1.2: Anticipatory planning and sibling roles in future care

As children became adults, maternal responsibility expanded into anticipatory governance. A central anxiety concerned the mother’s absence and death. ‘My biggest fear is that I die before him, who is going to take care of him with the love that his mom gives him?’ Monica rhetorically asked. Sophia echoed: ‘The constant worry if I am not here, what is going to happen?’

This anticipatory grief often leads to informal succession planning within the family. Future care was rarely imagined as state-supported. Instead, it circulated within the family. One mother described how her non-disabled daughter integrated her sister into her marriage plans: ‘If something happens to my mother, my sister comes as part of the package’ (Sophia). Another daughter internalised economic responsibility early: ‘She says, I need to have a good job because I have to take responsibility for my sister.’ (Catherine).

These arrangements were expressed as love and continuity, yet they also reveal transferred intergenerational obligation. Care moved from mother to daughter, often implicitly. Financial planning mirrored this transfer. Sophia explained purchasing property to ensure economic independence for her daughter’s adulthood when she is not present: ‘We want her to have her own financial independence, even if managed by her sister.’

These findings show how adulthood thus reorganised family roles and how care continues to circulate within the family, rarely extending into formal systems. Care became more about long-term risk management, including housing, financial planning, and care transfer to siblings. Even in families with economic resources, reliance on daughters as future caregivers persists, carrying this responsibility internally within the family rather than through institutional guarantees.

Subtheme 1.3: Structural isolation and absence of others

Some families described continuing to raise their children in relative isolation. Extended family members were often geographically distant, particularly amongst those who had migrated from rural areas seeking services in Quito: 'The extended family lives in Otavalo (*a rural province in northern Ecuador)* or the coast,' Ana noted, describing how urban relocation fragmented traditional support networks.

Stigma compounded this isolation. Monica recounted how other parents treated her son 'as if the *guaguas* (originating from the Kichwa word *wawa,* meaning child) had leprosy,' with one threatening to withdraw their child from school. Such reactions reinforced vigilance and withdrawal and forced some parents to isolate, especially as their children became adults, as Sophia clearly articulated: 'Honestly, I gave myself the support.'

While some fathers described 'teamwork as a good thing,' (Jonathan), parents consistently emphasised that reliable, sustained support rarely extended beyond the nuclear family. Even within urban settings and private institutions, families remained the primary coordinators of care in adulthood.

Subtheme 1.4: Informal networks of support beyond family and government

In the absence of consistent institutional support and limited involvement from extended networks, families constructed informal infrastructures. Relationships with other parents of adults with disabilities often became enduring sources of knowledge and emotional solidarity. 'When you find someone who went through the same thing, you rely on each other.' (Sophia)

Social bonds between families of adults with disabilities were frequently developed through informal school settings, such as art classes for adults with disabilities. Monica described how her son's art teacher and classmates became part of their informal support network: 'Anita María, the art teacher, is super important, her art friends too'. As their children entered adulthood, formal educational spaces occasionally provided meaningful support as well. Ana described her son's acceptance into a private university and stated, 'they didn't deny a spot, and that made Daniel feel more confident.'

Faith communities also functioned as parallel support systems. One church connected a family to 'foreign sponsors that send the money to get the (cochlear) implant.' (Ana). Yet faith operated ambivalently. Phrases given by priests to families, such as 'God gives a special child to special people' (Ana), provided meaning and endurance, but could also frame disability as divinely assigned responsibility, potentially softening structural support.

Some families expressed frustration at the lack of formal networks or accessible information. One father noted the difficulty of connecting with other families with the same syndrome, even now that their child is 32 years old: 'So far, I haven’t met anyone else who has the syndrome, to talk with their parents.' (Jonathan)

These experiences emphasise how informal networks supplemented, but did not replace, formal systems. They functioned as patchwork infrastructures in a fragmented landscape where government systems may be absent or insufficient.

Theme 2: Navigating an unresponsive system

If childhood provided partial scaffolding through schools and early services, adulthood exposed institutional fragility. This theme captures the complex and often frustrating experiences of families as they engage with Ecuador’s urban formal systems of disability support. Families repeatedly described encountering slow, bureaucratically dense, and inconsistently implemented systems.

Subtheme 2.1: Bureaucratic exhaustion: navigating services alone

Obtaining official recognition and benefits required sustained effort. Delays in obtaining crucial documents for their children occurred within a context where corruption and inequity undermined access. Such experiences compounded feelings of injustice and frustration.

Ana recalled the protracted wait for her child’s CONADIS disability ID, a crucial document for accessing government services for PWD in Ecuador, including formal employment as they reach adulthood: ‘You have to fight for the disability card.’ Jonathan recounted that disability vehicle permits and ID cards took two years: ‘The only ones with privileges are members of parliament,’ he added, expressing indignation for the corruption scandal with the CONADIS IDs, ‘I found it insulting, in my family, there is a person who truly needs it.’

Means-tested initiatives excluded families who did not meet extreme poverty thresholds. Sophia explained that the ‘Manuelas governmental aid programme’ targeted only those with ‘absolutely nothing’, excluding families from lower and middle-income households and thus reinforcing structural care on these families. Catherine described inclusion laws as ‘letra muerta’ (*dead letter*)- existing on paper but weakly implemented. Catherine reflected that while Ministries promote inclusion, ‘not all institutions are prepared.’

In addition, financial constraints also limited developmental opportunities:

> Financial resources limit PWDs who can’t continue developing…there’s a lack of support from the government. What our country still needs to develop is the creation of opportunities for adults with disabilities to develop themselves. (Oliver)

This subtheme reveals how systemic failings in Ecuador’s services impose additional burdens on families, with legal recognition not translating into coordinated infrastructure ‘for adults with disabilities to develop themselves.’

Subtheme 2.2: Becoming untrained advocates

Due to systemic gaps and professional unpreparedness, parents continuously assume roles as advocates during the life-span of their adult children. Ana described being at her son’s academic institution ‘every day, angry,’ confronting teachers and administrators over discriminatory practices.

The persistent need to 'fight' for their child’s rights was a shared experience, as parents also confronted a widespread lack of specialised knowledge among educators and healthcare providers. Sophia argued, ‘I was self-taught in all of this… they spoke from theory, I spoke from practice.’ The consequences of this unpreparedness were profound. Another mother reported abuse within specialised educational settings for PWDs: ‘they punished him by putting him in cold water.’ (Monica). This showcases how fragmented systems can become sites of abuse as ‘they are not properly prepared to handle people with intellectual disability.’ (Sophia)

A mother explained how advocacy was necessary but exhausting, reflecting how ‘nobody works with the parents, and this should be teamwork’ (Monica). Parents consistently sought services, educated professionals, contested decisions, and monitored compliance. This subtheme illustrates how these advocacy responsibilities did not end in childhood and extended well into adulthood as families pursued opportunities for their disabled adult son or daughter.

Subtheme 2.3: Self-sustaining and finding support amidst inequalities

Access to services and support was influenced by families’ socio-economic resources, with stark disparities evident in available resources; however, these resources did not eliminate structural gaps. Ana described how her family moved from rural settings to an urban city to attend public schooling and added that the family paid for therapies and ‘private tutors’, which were ‘too expensive.’

Another family, with greater financial means, was able to access private therapies, tests, and even travel internationally for diagnostic services during their son’s adolescence and early adulthood: ‘We even went to Cuba… the doctor went to a conference in Germany, and we finally got the information that it could be Rubinstein Syndrome.' (Monica)

Financial anxieties also shaped future planning. Sophia shared how ‘economically’ they ‘are very worried…’ and added that ‘when the time comes’ they want to ensure her disabled daughter will ‘have a monthly income to cover her expenses.’

Employment stability also influenced families’ capacity to provide sustained care. Oliver expressed, ‘we’re public employees… thank God we’ve been able to keep our jobs, that has allowed us to do everything possible for the development of our daughter.’ Conversely, another family with access to financial resources, extended support as sponsors of families in need, illustrating reciprocal social bonds within the disability community: 'we’ve been sponsors for children who don’t have the means to pay for therapy.' (Monica)

The contrast between families with financial resources who could afford domestic help and those who had to balance employment with full-time caregiving, underscores the economic disparities shaping access to support. One family with greater financial stability shared, 'There was a housekeeper, and (as business owners) we have the freedom to be at home’ (Monica). In contrast, Ana, who worked as a housekeeper herself, described the struggles involved in affording private services: 'I couldn’t afford to pay anymore' (Ana).

These quotes underscore how, even amongst economically stable households, adulthood required continued private investment: therapies, housing strategies, and financial planning. The presence of resources altered how families navigated the system but did not remove the underlying overload of responsibility.

Discussion

The narratives shared by urban families in Quito caring for their adult sons and daughters with disabilities showcase a shift that becomes most visible in adulthood. Over time, what emerges more clearly is the consolidation of caregiving within the family precisely at the point where childhood and educational supports recede. Adulthood thus becomes the moment where partially institutionalised support, through schools, therapies, and inclusion school units, fails to translate into coordinated adult infrastructure to support both adults with disabilities and their families. Therefore, the reorganisation of responsibility, including coordination, advocacy, financing, and long-term planning become increasingly internal within the nuclear family system. In this regard, the findings refine existing Southern disability scholarship by showing how governance functions are acquired intergenerationally during the young-adult phase of an adult with disabilities, even in legally progressive, middle-income contexts (Grech, 2015; Meekosha & Soldatic, 2011) such as the families interviewed in the urban area of Quito, Ecuador.

Emotional Transformations and Gendered Care

Consistent with prior research on the psycho-emotional dimensions of disability caregiving (Grech, 2015), mothers in this study described enduring guilt and vigilance extending beyond childhood. The persistence of maternal centrality in care during adulthood cannot be understood solely in terms of affective attachment and familial responsibility. Whereas literature from many Global North contexts showcases service and professional support for families (Hunt & Watermeyer, 2017), the Ecuadorian mothers in this study describe emotional work inseparable from logistical problem-solving and institutional advocacy in response to scarce state-supported services for adults with disabilities.

Feminist care ethics, particularly Kittay’s (1999, 2011) work on dependency as a morally and politically distributed condition, clarifies why care consolidates around women when institutional support is limited. As showcased by these mothers’ accounts, quitting jobs, coordinating multiple therapies, becoming advocates in educational and healthcare systems, and planning for future care when they are not present, compounded by anticipatory grief, instantiate Kittay’s (2011) view that dependency generates moral claims that are often not reciprocated by the state. Nonetheless, the urban Ecuadorian context further complicates an affirmative reading of care ethics. When caregiving unfolds in conditions of bureaucratic fragmentation and limited implementation, care risks becoming structurally imposed rather than only freely chosen. Withdrawal from paid employment or the internal reorganisation of work as ‘therapy’ illustrates the ambivalence of paid labour and gendered care. On one hand, it offers psychological refuge for some women carers, and on the other, it simultaneously reinforces the gendered concentration of unpaid labour. Thus, maternal care of adults with disabilities appears as both relational devotion and constrained obligation. This tension resonates with broader Global South research documenting the gendered informalisation of care economies (Mathias et al., 2018). Yet, the adulthood lens foregrounds how these arrangements solidify rather than dissipate over time, reinforcing the need for gender-sensitive social protection and disability-inclusive family support for adults with disabilities across generations.

Intergenerational obligation and anticipatory governance

Adulthood reorganises care temporally. Mothers’ pervasive concerns about what will happen 'when I am no longer here?' point to anticipatory grief as well as the emergence of what can be described as anticipatory governance within the family. Such findings resonate with Southern disability scholarship, which emphasises that care in Global South contexts is often a lifelong family responsibility, particularly in societies where formal supports are limited or unevenly distributed (Meekosha & Soldatic, 2011; Grech, 2019). Housing purchases, financial planning, and the early socialisation of daughters into future caregiving roles showcase how care responsibility is transferred across generations. This intergenerational transfer does not replace affection with coercion; rather, it coexists with it. Sibling incorporation is narrated as continuity and solidarity by these families; however, it also carries the possibility of curtailed autonomy and reoriented life trajectories. The expectation that a daughter will integrate her sister into her future marriage, or choose a financially stable career ‘to take responsibility’ suggests how disability in adulthood reorganises family futures. These arrangements align with previous Latin American disability research emphasising family centrality (Grech, 2019), but the present findings highlight how adulthood intensifies these dynamics as *intergenerational* family centrality, where parents age and institutional guarantees remain uncertain, thus families plan for succession of care and long-term risk management, showcasing a form of family intergenerational governance project of care. By intergenerational governance project, this study refers to the process through which families progressively internalise coordination, risk management, resource allocation, and succession planning functions that would otherwise be institutionally distributed, thereby reorganising governance within the family across time.

Family coping mechanisms

In the absence of formal and state support networks in adulthood, these families from urban settings transfer support to parent networks, faith communities, and informal education for adults with disabilities, such as art classes. These relationships provide emotional solidarity and, at times, material support. Structural isolation, particularly following rural-to-urban migration such as Ana's case, further consolidates responsibility within the nuclear family.

Becoming 'self-taught' advocates reflects both agency and systemic strain. Parents repeatedly confronted professional unpreparedness and, in some cases, abusive practices of their adult children. Their lived expertise challenged credentialed authority, resonating with Grech's (2019) call to centre family knowledge in disability policy. However, advocacy also carries emotional costs where families are 'supporting themselves.' Although this advocacy usually begins when parents are searching for academic inclusion, it does not end with school; it intensifies as families seek employment, adult education, and opportunities for their adult children to 'develop themselves.' Thus, advocacy becomes a coping mechanism that appears as both necessary and exhausting. It secures access but also reinforces the privatisation of governance functions. Without institutional partnership, advocacy risks becoming a permanent condition expected by families of PWDs rather than a transitional intervention.

In this regard, faith also emerges as a deeply ambivalent coping mechanism. While religious narratives can offer meaning and endurance to certain families, framing disability as divinely entrusted, 'Que Dios nos da un hijo especial a personas especiales.' (*God gives us a special child to special people);* this same framing may subtly reinforce care responsibility with the moral sphere of the family, softening societal and state redistributions of support. This ambivalence echoes scholarship on culturally embedded coping strategies in Latin American contexts (Magaña et al., 2019), whilst also cautioning against reinforcing spiritual and religious cultural values as the acceptance of a lack of institutional absence. In this regard, informal networks mitigate systemic and state limitations, but do not replace them.

Intersectionality as systemic reorganisation

Families in this study are situated within urban Quito and represent differentiated socio-economic positions: two families possess relatively high levels of economic and social capital, while the other two come from working-class backgrounds, including mestizo state employees and an Afro-Ecuadorian mother who migrated from a rural context in search of services. While the empirical material does not support generalisation to Indigenous or rural families beyond these accounts, it demonstrates how disability in adulthood reorganises gendered and classed relations within both family and institutional systems (Moya, 2020), in ways consistent with Latin American contexts where partial welfare provision intersects with gendered care economies (Hunt & Watermeyer, 2017; Magaña et al., 2019).

In this context, families in this study, with financial and social capital, can access private therapies, create support networks, or establish quasi-NGO initiatives, while less resourced households rely on charitable networks and external sponsorship from faith organisations for cochlear implants. Therefore, caregiving can be understood not just as a private act but as a social process whose costs and possibilities are distributed unevenly by intersectional identities.

Intersectionality, as originally articulated by Crenshaw (1991), showcased how multiple axes of power co-constitute experiences of marginalisation. In disability research, however, intersectionality is sometimes operationalised primarily at the level of the individual, adding disability to existing categories of gender, race, or class, without sufficiently examining how social institutions and family systems reorganise around disability. As Watermeyer and Swartz (2022) argue, much disability research has been constrained by 'lazy intersectionality', in which disability is added as a peripheral category rather than treated as constitutive. In contrast, this study centres disability within the family as the primary site of intersectional experience, where gender, ethnicity, and socio-economic status are not external modifiers but co-constructive forces that shape and are shaped by disability. The findings here suggest that in the transition to adulthood, intersectionality is not only embodied but structurally enacted. Disability reshapes mothers' labour trajectories, redistributes economic risk within households, and recalibrates siblings' anticipated futures. Gender, class, and disability do not simply intersect within individuals; they reorganise relational and institutional arrangements over time within the family system.

This systemic reading is particularly visible in how socio-economic resources shape, but do not resolve, governance displacement. Families with financial capital finance private therapies, travel internationally for diagnoses, or secure domestic help, partially buffering institutional gaps. Working-and-middle-income households describe reliance on faith-based sponsorship or the inability to sustain costly therapies. Yet, across these differences, families remain the primary coordinators of adult care. Economic resources alter navigation strategies, but they do not eliminate the structural burden to compensate for institutional gaps. These stratified yet consistently familialised arrangements underscore that economic stability should not be conflated with institutional support. Even relatively resourceful families organise housing strategies, long-term financial planning, and succession of care internally in anticipation of parental ageing. In this sense, intersectionality operates across family systems and state systems simultaneously, thus resonating with Grech's (2019) call to foreground family experiences in scholarship and policy, shifting the analytic lens from the individual body to the 'disabled family', whilst remaining attentive to the differentiated privileges and constraints shaping urban Quito families in this study. Therefore, this systemic intersectional lens may offer a more situated understanding of how disability reorganises family labour, dependency, obligation, and inequalities whilst interacting with limited institutional infrastructures in adulthood.

Navigating a limited and unresponsive system

Families' interactions with Ecuador's formal systems highlight how the bureaucratisation and politicisation of disability services, exemplified by the CONADIS ID scandal and protracted administrative procedures, exacerbate caregiving demands and often undermine, rather than facilitate, family support. Delays in CONADIS identification, inconsistent application of inclusion laws, patchwork of charitable and faith-based institutions, and exclusion from means-tested programmes reflect what Catherine described as 'letra muerta' (*dead letter*). This suggests that legal recognition alone does not automatically produce meaningful and coordinated adult inclusion. These experiences align with analyses of symbolic inclusion in Latin American social policy, where rights may exist in statute, yet remain uneven in implementation and sustained services (Monjes-Vargas, 2013).

In this regard, Ecuadorian disability policy has been formally progressive in law but remains limited in its application. The employment quota requiring companies with at least 25 employees to hire 4% PWDSs (Organic Law on Persons with Disabilities, 2012) signals formal commitment. However, as Caiche-Beltrán and Guerrero-Velástegui (2024) note, quota compliance does not guarantee meaningful inclusion in the absence of workplace accommodations, accessible transportation, adequate support services, and monitoring mechanisms. Participants' accounts of limited adult opportunities and persistent stigma suggest that legislative frameworks require sustained institutional infrastructure in order to translate into practice. Once educational scaffolding recedes, entry into stable employment becomes contingent on institutional readiness, which remains uneven and 'not properly prepared to handle people with intellectual disability'.

Within this small sample, only one adult with disabilities was formally employed, the Deaf participant whose cochlear implant had been financed through religious donations. The other adults remained in informal educational spaces, such as art workshops or within the home. While this study cannot generalise employment trajectories, these accounts are consistent with wider evidence that adults with intellectual disabilities in Latin America face disproportionately high rates of unemployment and labour market exclusion (Pinilla-Roncancio & Gallardo, 2023). Such exclusion constrains individual autonomy while redistributing financial and emotional labour back onto families, particularly mothers and, later on, intergenerational familialised care.

Policy and theoretical implications

If research is to remain relevant to families of adults with disabilities in urban Quito, it must move beyond normative endorsement of inclusion and confront the institutional conditions under which inclusion is governed. The findings call for greater precision in invoking 'decolonial' approaches. In this context, decoloniality does not refer to a wholesale rejection of global disability rights frameworks; rather, it entails interrogating the policy imaginaries through which disability is governed, specifically, the assumption that individual rights recognition, once legislated, will automatically translate into institutional capacity. The interviews demonstrate that adulthood reconfigures vulnerability: once educational scaffolding recedes, families encounter labour market precarity, bureaucratic fragmentation, and parental ageing without parallel state infrastructures to absorb these transitions.

Ecuador's rights-based disability architecture, including identification cards, employment quotas, and anti-discrimination mandates, has been symbolically significant. However, rights recognition does not, in itself, resolve enduring tensions of fiscal limitations and bureaucratic coordination. As scholarship on Latin American social policy has shown, formal legal expansion can coexist with uneven implementation and constrained state capacity, particularly in middle-income contexts (Huber & Stephens, 2012). The experiences described by families in this study reflect precisely this gap between formal inclusion and material support. A decolonial critique, therefore, requires attention to the political economy of implementation: who funds inclusion, who monitors it, and how durable these arrangements are beyond electoral cycles.

One pragmatic avenue lies in extending the institutional logic of Ecuador's *Unidades Distritales de Apoyo a la Inclusión* (UDAI) (District Inclusion Support Units), which currently operate within the education system to provide technical guidance and coordination for inclusive schooling (Ministerio de Educación del Ecuador, 2017). UDAI units have functioned as intermediaries between policy mandate and school-level practice, offering specialised personnel and inter-institutional coordination. An analogous structure within the labour and employment sphere, tasked with employer guidance, accommodation monitoring, mediation, and coordination with social and mental health services, such as the *Ministerio de Desarrollo Humano* (MDH) (Ministry of Human Development), in charge of executing social inclusion policies, could support adult inclusion beyond the formal 4% quota compliance or corporate DEI rhetoric. Such a structure could reduce the familial role as the only de facto case managers navigating fragmented systems. Nonetheless, this proposal must be considered within fiscal and political constraints. Cross-ministerial collaboration between labour, health, and social protection sectors would require sustained budget lines, trained personnel, and monitoring mechanisms, conditions that remain uneven in Ecuador's current economic landscape. Incremental implementation, piloting within urban districts such as Quito, where institutional density is higher, may be more feasible to begin with than nationwide expansion.

Importantly, recognising families as central actors in disability governance carries ambivalent consequences. While family-centred policy may acknowledge lived realities of interdependence, it also risks entrenching familism and legitimising further state withdrawal.

The findings illustrate that families already absorb long-term risk: financial, emotional, and structural; particularly as parents age and siblings renegotiate their futures. Policy recognition must therefore be paired with redistributive and service-based commitments that shift, rather than merely formalise, responsibility. Family disability care should take into account the *family* as a system of support that also needs systemic support. Family partnership models should invest in local professional capacity, accessible family mental health support, and parental networks that mitigate burnout and intergenerational strain, rather than presuming inexhaustible familial resilience and ongoing care across the lifespan of PWDs.

Within this framing, Kittay's (2011) reminder that all citizens are 'temporarily abled' underscores that disability policy is long-term social risk management in ageing societies rather than a minority protection. Read through this urban Ecuadorian family case, this insight reframes adult disability support as anticipatory governance: the infrastructure that sustains adults with disabilities today, constitutes preventative social policy for broader populations tomorrow.

Limitations and further research

This study reflects a small group of urban families in Quito. Whilst the small sample size limits the generalisability of the findings across the broader range of family experiences of adulthood disability care, the analytical contribution lies in showcasing how families with adults with disabilities face systemic gaps within relatively middle-high income urban resourced households. If governance displacement is visible even amongst relatively resourced urban families, the implications for less-resourced households may be more severe, though this is not empirically demonstrated in this study. Thus, future research should examine how these dynamics unfold in more marginalised and rural Latin American contexts and evaluate the effectiveness of adult inclusion infrastructures outside of urban areas.

Conclusion

The experiences of these Ecuadorian families illustrate that adulthood is not a neutral developmental phase in disability care, but a decisive restructuring moment in which governance displacement becomes fully visible and tangible. As formal education recedes and parental ageing advances; coordination, financing, advocacy, and long-term planning consolidate within the family. Care circulates intergenerationally, shaped by gendered labour, classed resources, and institutional fragility and bureaucracy.

This study, therefore, advances Southern disability scholarship by demonstrating that disability in adulthood reorganises not only individual life trajectories, but family systems and governance arrangements over time. In urban Quito, even relatively resourced families absorb functions typically associated with state infrastructure, transforming care into an intergenerational governance project. If disability policy is to move beyond symbolic inclusion, redistribution must address access for PWD and the long-term structural reorganisation of care within families. Without such institutional recalibration, the invisible weight of adult disability care risks remaining a private inheritance rather than a collectively sustained social responsibility.

Notes

[1] Terminology: This article uses person-first language (e.g., persons with disabilities, PWD) unless a specific community identifies a preference for identity-first language (e.g., Deaf individuals), following the guidelines of the American Psychological Association (APA, 2020).

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