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Rahmathunnisa K
Ph.D. Research Scholar of
English Vels Institute of
Science, Technology and
Advanced Studies, Pallavaram,
Chennai, Tamil Nadu, India

Dr. P Santhosh
Research Supervisor of English
Vels Institute of Science,
Technology and Advanced
Studies, Pallavaram, Chennai,
Tamil Nadu, India

Corresponding Author:
Rahmathunnisa K
Ph.D. Research Scholar of
English Vels Institute of
Science, Technology and
Advanced Studies, Pallavaram,
Chennai, Tamil Nadu, India

Unseen struggles, unheard voices: the auto ethnographic reflections on disability and parental trauma

Rahmathunnisa K and P Santhosh

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Abstract

The art of parenting is an enormously vast and worthy of rewarding journey which involves nurturing, guiding, and supporting a child's multifaceted development; that is physical, mental, emotional and intellectual. Parenting a child with a disability is more than a deeply emotional and strenuous journey marked by love, resilience, and significant challenges. This paper explores the intersection of disability, auto ethnography, and parental trauma, examining how personal narratives can provide insight into the psychological and social struggles faced by caregivers. Using auto ethnographic storytelling as a research method, this paper highlights key aspects of parental trauma, including the emotional impact of a child's diagnosis, systemic barriers in healthcare and education, societal stigma, and the physical and mental exhaustion of care giving. While many parents experience grief and stress, the paper also emphasizes the transitional power of advocacy, community support, and storytelling in rewiring trauma into empowerment. By amplifying the voices of parents through auto ethnographic narratives, this work underscores the need for greater societal understanding, policy reforms, and inclusive support systems to ensure both caregivers and children with disabilities can thrive.

Keywords: Disability, Auto ethnography, Parental Trauma, Societal Barriers, Inclusive Policy

Introduction

Parenting can be considered as an art and a science. It exclusively requires love, patience and wisdom along with practical and knowledge related skills as well. Being a real and perfect parent is a herculean task to deal with. Parenting a child with disability is an immensely tedious and strenuous journey filled with challenges, dilemmas, uncertainties and mixed emotions. It requires patience, resilience, emotional tolerance and flexibility as well. Disability is not a personal tragedy but a natural part of human diversity, shaped as much by societal barriers as by individual conditions. The true challenge lies not in the disability itself but in a world that remains inaccessible, unaccommodating, and often exclusionary. While medical and support needs vary, the universal struggle for disabled individuals and their families is one of recognition, dignity, and equal opportunity. True inclusion requires shifting from a mindset of pity to one of empowerment ensuring that policies, public spaces, and social attitudes reflect the inherent value of disabled lives. Disability is not a flaw to be fixed but a reality to be embraced, demanding a world that adapts to people, not the other way around.

The Burden of Care: Parenting as Emotional Labour

Parenting a child with a disability extends beyond conventional care giving, demanding emotional, physical, and psychological resilience. According to Arlie Hochschild's concept of emotional labour, caregivers must constantly manage their emotions while masking distress to protect their children (Hochschild 7). This invisible labour often leads to burnout, anxiety, and depression, yet remains largely unrecognized in mainstream discourse. My experiences as a mother of a disabled kid often underline this.

'Emotional labour', originally coined by sociologist Arlie Hochschild, refers to the management of emotions to fulfil the expectations of a role. In parenting, this includes regulating one's own emotions while supporting a child's emotional and physical needs. When raising a child with a disability, this labour is magnified due to:

- **Advocacy Work:** Parents often take on the role of advocate, ensuring their child receives necessary medical care, education, and social inclusion. This requires persistent emotional resilience when facing systemic barriers.
- **Emotional Regulation:** Parents must manage their own emotions—grief, frustration, or exhaustion—while maintaining a nurturing and supportive environment for their child.
- **Social Expectations and Stigma:** Parents may experience social judgment or feel the need to present a composed, capable image to counteract stereotypes about disability.
- **Increased Care Responsibilities:** Beyond emotional support, physical care giving responsibilities can be more demanding, leading to burnout and stress.
- **Interpersonal Labor:** Managing relationships with healthcare professionals, educators, and even extended family adds another layer of emotional work.
- **Gender and Emotional Labor:** Mothers are often expected to bear most of the emotional labour, reinforcing traditional care giving roles. This gendered expectation can create further pressure and disparities in emotional burden. My experiences as a mother testify these hundred percentages.

Personal Reflection: Living in a World That Doesn't Fit

As a parent, I have often found myself in spaces not designed for my child. From inaccessible playgrounds to unsympathetic school systems, every step has been a battle, a constant negotiation between advocacy and acceptance. The meltdowns in public, the whispers, the unsolicited advice, and the lingering guilt of never feeling 'enough' form a daily reality that many caregivers share but few articulate.

Raising a child with a disability is a journey filled with love, resilience, and advocacy but it often unfolds in a world that wasn't built with them in mind. From inaccessible spaces to societal attitudes, the struggle isn't just about the disability itself but about navigating a world that resists making room for differences. I have learned that the greatest challenges aren't always medical or developmental milestones, but the barriers imposed by society. Simple activities finding an inclusive school, going to the playground, or even receiving adequate healthcare become battles requiring endless patience and determination. Public spaces claim to be accessible but often fall short in ways that only those who depend on accessibility notice. The burden of inclusion is placed on parents and caregivers, forced to constantly advocate, educate, and fight for accommodations that should be a given.

Beyond the physical world, the emotional toll is significant. The loneliness of parenting a disabled child in a society that values independence and perfection can be overwhelming. The well-meaning but ignorant comments, the stares, and the unsolicited advice can be isolating. Friendships may shift as others struggle to relate to our reality, and support systems can be difficult to find. Biases and misconceptions too lead to distress.

Parental Trauma and the Psychology of Grief

The emotional toll of raising a child with a disability parallels the stages of grief outlined by Elisabeth Kübler-Ross: denial, anger, bargaining, depression, and acceptance

(Kubler-Ross 45). However, unlike conventional grief, this process is ongoing, often triggered by new developmental challenges, societal rejection, or medical complications.

Grief, in the context of disability, is complex and ongoing. It is not about wishing for a different child, but rather about grieving the loss of ease, the effortless milestones, the carefree future, the unspoken expectations that most parents hold before reality shifts. Psychologists call this "ambiguous loss," a grief that has no clear resolution. Unlike the finality of death, this type of grief lingers, resurfacing in unexpected moments when a child is excluded from a school activity, when another parent talks about their child's plans for adulthood, and when financial capacity finds incapable to treat the status or when medical complications arise out of nowhere.

This grief is often silenced by societal expectations. Parents are told to be strong, to focus on the positives, to embrace the "special" nature of their child. While being positive has its place, it can also invalidate the very real emotional toll of constantly advocating, worrying, and adjusting. The pressure to suppress grief in favour of gratitude can be isolating, leaving parents without the space to process their emotions. I always found myself grief stricken and dumb struck in most auspicious moments in my life.

Beyond grief, there is trauma the chronic stress of fighting systems that were never designed for disabled children. The medical world is often dismissive, requiring parents to become experts in conditions they never knew existed. Schools may resist accommodations, forcing parents to fight for basic rights. Even in public spaces, the stares, the whispers, and the exclusion chip away at a parent's sense of normalcy.

This constant state of vigilance takes a psychological toll. Research shows that parents of disabled children experience higher rates of anxiety, depression, and PTSD[post traumatic stress disorder] like symptoms. The unpredictability of medical emergencies, the exhaustion of care giving, and the financial strain all contribute to an overwhelming emotional burden. Many parents operate in survival mode for years, suppressing their own needs until burnout becomes inevitable. Grief as a parent of a child with a disability is often unspoken, invalidated, unpredictable and misunderstood. Society discourages expressions of frustration or sorrow, branding them as ungrateful or selfish. Yet, behind closed doors, many parents quietly mourn the life they envisioned for their child, while simultaneously cherishing the child they have.

Research in psychology has identified "chronic sorrow" as a persistent, recurring grief experienced by caregivers of children with disabilities (Olshansky 120). Unlike acute grief, chronic sorrow is cyclical resurfacing with every unfulfilled milestone, every exclusion, and every reminder of the child's struggles.

Stigma and Societal Rejection

Stigma surrounding disability extends beyond the individual to the entire family. According to Erving Goffman, stigma is a social construct that categorizes individuals as 'less than' based on societal norms (Goffman 3). This extends to parents, who often face blame, pity, or exclusion. Raising a disabled child means navigating not only the challenges of care giving but also the stigma and rejection imposed by society as well. The world often views disability through a lens of pity or discomfort, leading to exclusion in both

personal and institutional spaces. Parents face unsolicited advice, judgment, and the silent fading of friendships as others struggle to relate. Schools, workplaces, and public spaces frequently fail to accommodate disabled individuals, making even basic inclusion a battle. The unspoken blame placed on parents whether for their child's condition or for advocating too fiercely adds another layer of emotional burden, compounding the grief and exhaustion they already carry. "Being disabled shouldn't mean being disqualified from having access to every aspect of life." [Emma Thompson] Yet, in the face of rejection, parents learn to redefine strength and community. They become relentless advocates, challenging outdated systems and forging new spaces of belonging. While stigma continues to isolate, many parents find solidarity in those who share their experiences, rewriting the narrative of disability as one of resilience rather than tragedy. However, true change requires more than individual perseverance it demands a societal shift toward genuine inclusiveness. Until then, parents will continue not only raising their children but also fighting for their right to exist in a world that too often refuses to make room.

The 'Bad Parent' Stereotype

Parents of disabled children often face the unfair "bad parent" stereotype, rooted in ignorance and societal bias. When a child struggles in public, outsiders may assume poor parenting rather than recognizing the realities of disability. If a parent advocates too strongly, they're labeled as difficult; if they seem exhausted, they're seen as neglectful. Some face blame for their child's condition, as if disability results from personal failure rather than biology or circumstance. This constant judgment adds to the emotional toll, forcing parents to defend their choices while already navigating immense challenges. These parents are not failing they are fighting, often against a world that refuses to understand.

These parents are frequently subjected to judgmental assumptions like,

- If their child has meltdowns in public, they are bad parents.
- If their child is non-verbal, they must not be trying hard enough.
- If they express mental or emotional exhaustion, they are ungrateful.

Such narratives contribute to social isolation and self-doubt, making it harder for caregivers to seek help. For example, my child being a wheel-chaired kid, I have heard a lot of advises to make him walk as they didn't see the struggling faces of my life. These people are unaware of our financial, physical and mental fitness.

Systemic Barriers and Institutional Failures

Parents of disabled children frequently encounter systemic barriers and institutional failures that make care giving exponentially harder. Schools resist providing adequate accommodations, forcing families into exhausting legal battles for basic educational rights. Healthcare systems are riddled with long wait times, insurance denials, and providers who dismiss parental concerns. Public policies often overlook the financial and emotional burden of disability, offering minimal support while expecting parents

to navigate complex bureaucracies on their own. Even workplace policies rarely account for the unpredictable demands of care giving, pushing many parents out of stable employment. These failures are not accidental they reflect a society that prioritizes convenience over inclusion, leaving families to struggle in a system that was never designed for them. While legislative frameworks such as the Rights of Persons with Disabilities Act (RPWD), 2016 exist, implementation gaps continue to hinder access to essential services (Shakespeare 88). Many parents struggle to navigate bureaucracy, encountering long wait lists, inadequate support systems, and financial strain. Despite policies promoting inclusive education, many schools remain ill-equipped to accommodate children with disabilities. Parents are often forced to fight for basic rights, facing bureaucratic resistance and discrimination. Raising a child with a disability is financially taxing, with expenses including therapy, medical care, assistive devices, and specialized education. Government assistance is often inadequate, leaving parents to shoulder immense financial burdens.

Coping, Advocacy, and Hope

Despite the immense challenges, parents of disabled children find ways to cope, advocate, and hold onto hope. Coping often means redefining expectations, seeking support from like-minded communities, and allowing space for both grief and joy. Advocacy becomes a necessity whether fighting for accessible education, better healthcare, or basic respect in public spaces. Many parents become experts in laws, policies, and medical systems, ensuring their child receives the care and opportunities they deserve. Midst the struggle, hope emerges not just in moments of progress, but in the growing movement toward inclusion, empathy and understanding. Every fight for accessibility, every conversation that shifts perspectives, and every act of resilience lays the foundation for a future where disabled children and their families are fully seen, valued, and included.

The Need for Policy Reform

Meaningful policy reform is essential to address the systemic barriers that disabled children and their families face. Education policies must enforce stronger protections for inclusive learning, ensuring that schools provide necessary accommodations without forcing parents into endless legal battles. Healthcare systems need to prioritize accessibility, reducing wait times, improving provider training on disabilities, and expanding insurance coverage for essential therapies and equipment. Workplace policies should recognize the demands of care giving, offering flexible hours and job protections. Additionally, public infrastructure and social services must be designed with true inclusiveness in mind, moving beyond bare-minimum compliance to create a world where disabled individuals can fully participate. Without these reforms, families will continue shouldering an unfair burden, fighting against systems that should be supporting them.

For real change to occur, governments must:

- Strengthen disability inclusive policies in healthcare and education.
- Improve financial support for caregivers.
- Enhance public awareness and inclusion efforts.

Results

The findings of this study highlight the complex and often traumatic nature of care giving for parents of children with disabilities. Three primary themes emerged:

- **Emotional labour:** Parents' experiences of trauma were deeply emotional, with feelings of anxiety, depression, and guilt manifesting because of care giving demands and societal stigma.
- **Resilience and resistance:** Despite the traumatic experiences, parents demonstrated resilience and resistance through strategies such as advocacy, support-seeking, and self-care.
- **Institutional ableism:** Parents' experiences were shaped by institutional ableism, with societal stigma and medical trauma exacerbating parental trauma.

Conclusion

The experiences of parents raising children with disabilities remain largely invisible in mainstream discourse. This paper, through auto ethnographic reflection, has aimed to illuminate the unseen struggles and unheard voices of caregivers. By acknowledging parental trauma, challenging societal stigma, and advocating for systemic change, we can move towards a world that is more inclusive, empathetic, and just.

This auto ethnographic study demonstrates the value of exploring parental traumatic experiences through a critical and reflexive lens. By centering the voices and narratives of parents, this research aims to promote a deeper understanding of the intersection of disability and parental trauma. Ultimately, this study seeks to inform the development of more inclusive and supportive policies and practices that promote the well-being and resilience of parents raising children with disabilities.

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