

# Unveiling Perceptions of Disability Through The Disabled Child: Memoirs of a Normal Future

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## Unveiling Perceptions of Disability Through *The Disabled Child: Memoirs of a Normal Future*

Review of Amanda Apgar's *The Disabled Child* by Karla Armendariz

Karla Armendariz is a first-generation Mexican who has dedicated her career to helping children with complex communication needs. Along with being a certified bilingual speech-language pathologist, she is pursuing a doctorate at Pennsylvania State University. Her research focuses on addressing multicultural issues in augmentative and alternative communication and implementing intersectionality within advocacy for culturally and linguistically diverse children with complex communication needs. Email: kpa5178@psu.edu

Amanda Apgar's *The Disabled Child: Memoirs of a Normal Future* (University of Michigan Press, 2023) calls the reader's attention to the commonly accepted notion surrounding independence and disability. This is done within the context of parental narratives. These memoirs provide valuable insights into the experiences of families with disabled children, yet Apgar argues that they also perpetuate a narrow understanding of disability as a problem that must be overcome in order to achieve a "normal" life. Throughout the book, Apgar presents various perspectives on disability and critiques the current societal perception of it, highlighting the need for growth and change in how we think about and support disabled individuals and their families.

Apgar sets the stage by examining the American cultural notion of disability. This framing of people with disabilities is shaped by ideas of disabled people working on obtaining normalcy, developmental growth, independence, and advantage. Accomplishments in these areas typically are heteronormative or dominant notions of developmental milestones, such as getting married or obtaining employment. Adherents to this concept portray their child as a valuable member of society that enriches the lives of others around them. Heteronormativity in these instances operates as a narrative device to mitigate the negative effects of disability and position disabled children within dominant discourses of childhood and adulthood. The author argues that by doing so, parent memoirists disavow all things queer and the queerness of disability.

The book later transitions into deconstructing the idea of a linear, age-specific developmental process that is fundamental to the camps of childhood development and neoliberal rationality. Apgar argues that developmental discourse should not only focus on the physical and cognitive aspects of development but should also include the individual's personal experiences and the social and cultural context in which they occur. Furthermore, she demystifies the widespread belief perpetuated in public health that age-specific child development is a universal phenomenon, demonstrating how it is a more recent concept initiated during the 20<sup>th</sup> century. This includes the Center for Disease Control's (CDC's) current milestone chart and the creation of the IDEA Act. From a feminist/queer/crip (FQC) theory of narrative, Apgar then examines developmental rhetoric in popular child-rearing texts such as *Dr. Spock's Baby and Childcare* (10<sup>th</sup> edition updated and revised by Needlman, 2018). For example, the authors of *Dr. Spock's Baby and Childcare* emphasize homogeneity in child development and the idea of achieving independence. Apgar uses the example of the usage of present progressive language throughout the book such as "your baby will do ..." (p. 32). This language, in turn, constantly generates a binary between what the child is going to do rather than what they might do. This distinction does not always apply to disabled children. This language perpetuates independence as a linear goal and sidelines the experiences of disabled children. On the other hand, there are memoirs that promote a more fluid approach to development, one being *Hole in the Heart: Bringing Up Beth* (Beaumont, 2016). Henny Beaumont's memoir provides readers a more realistic idea of what development consists of through visual and verbal storytelling that challenges dominant templates and boundaries in disability narratives.

Apgar branches from a broad societal impact to a more intimate perspective captured through the lens of parental narratives. She details that these narratives, rather than being revolutionary, are recuperative in nature. By this, Apgar means that parents' narratives push against the often-faced rhetoric of exclusion and demonstrate how their child was able to overcome obstacles in order to live a "normal" life. In addition, parent memoirists as a collective recognize how their children are excluded from commonly accepted ideas of what it means to be a child or an adult in society. However, Apgar argues throughout this book that these memoirs fall short of effectively challenging ableist attitudes and beliefs. Parents then weave a story where their child has generated a full and meaningful life and created an envisioned parenthood, yet from Apgar's perspective, the stories fail to challenge societal biases and prejudices.

Out of the 300 unique memoirs Apgar found, 25 were about children of colour. The bulk of the memoirs were authored by abled, white, middle- and upper-class heterosexual parents. The findings highlight the extreme overrepresentation of white parents in the genre, and in who shapes "positive" portrayals of disability more broadly. This has far-reaching implications for disabled children and their families and the limits of inclusion that need to be addressed. The genre is also dominated by white children, which has implications for inclusion of disabled people of colour and perpetuates settler colonialism (p. 62). The narrative of overcoming challenges is seen as *claiming one's place* in the world and *possessing a right to belong*. This narrative results in the false legitimacy of families of white disabled people belonging because of whiteness. These narratives distinctly overlap with ableism in denying subjugated populations self-determination, with white settlers' sense of entitlement to determine who belongs and the mechanisms of privilege and exclusion. The overcoming narrative reinforces American meritocracy. Apgar emphasizes that this can lead to a situation where people of colour with disabilities are further excluded from the social world and denied the right to fully participate in society, which reinforces the idea that they are somehow inferior or less deserving of respect and dignity.

The overwhelming whiteness of the "special needs" parental memoir genre comes as a result of the material and discursive privileges of white settler colonialism. This whiteness contrasts with the intersectional realities of many disabled adults and children of colour. A discussion is consequently opened with regards to the underrepresentation of families and children with disabilities of colour in memoirs and popular media. Apgar highlights that many memoirs and positive portrayals of disability in video media and literature have a strong focus on white male children. This is mainly due to the discursive and material privileges of whiteness and the one-dimensional representation of Blackness in the predominantly white publishing industry. On a more encouraging note, Apgar presents a refreshing perspective with *The Broken Cord* (Dorris & Erdrich, 1990) which features an Indigenous child without an overcoming narrative. She also discusses independent and small press published memoirs written by families of colour about their disabled children. These memoirs present a unique opportunity to challenge the genre's typical appeals to normativity and the overcoming narrative.

Overall, the memoirs analyzed within the book share some common attributes, including how parents' lives have been impacted by having a special needs child. Common themes found throughout memoirs include: how their child has taught them how to love, the diversity of the human experience, or learning about an obscure truth. Apgar argues that these narratives provide an enriching perspective on parents' emotional growth but continue to feed into the assumption that children with a disability have compromised the parents' quality of life (p. 83). On the other hand, parental memoirs about raising a child with a disability often touch on how negative feelings about a disability are overcome, with parents portraying their children as exceptional. This narrative reinforces the idea that disability is something to be overcome and that success in life is possible through hard work and determination. However, this approach ignores the systemic barriers and discrimination that people with disabilities face and may reinforce the idea that those who are not successful are to blame for their own lack of achievement.

Moreover, children in these narratives are often portrayed as agents of positive change in their parents' lives. These memoirs typically depict disabled children as catalysts for growth, challenging the notion that they necessarily diminish their parents' quality of life. They may also depict disabled children as spiritual gifts where they help the parents or the community come closer to a spiritual being. Within these experiences parents argue that their child with a disability has aided them in parental growth rather than hindering it.

*The Disabled Child* provides a thought-provoking exploration of the impact of parental memoirs on our understanding of disability. As a Hispanic certified speech-language pathologist in a doctoral program, I appreciate how the book not only challenges us to promote more diverse voices in the genre but also encourages us to think more openly about how policy and parental narratives can contribute to views on disability. Although a complex read, this book provides insights appropriate for a graduate seminar. Readers who engage with this book will gain insights regarding parental memoirs as valuable within disability studies for sharing experiences about the complexities of living with a child with a disability. In addition, readers can recognize the value in considering the inclusion of the untold stories of families of colour, primarily because their absence from the genre raises questions about who is being represented. Likewise, readers will learn how the current narratives often challenge or contribute to stereotypes about disability. This then prompts reflection on how both material and discursive factors contribute to the construction of disability in our society.

The book also brings into question the autonomy of the person with a disability. In many parental memoirs, parents position themselves as spokespersons for their child's disability. This raises inquiries about parents' authority to speak on behalf of their child, as well as the power dynamics that exist between children and adults, disabled and nondisabled individuals. Through parental memoirs, there exists the possibility of perpetuating unequal relationships of power and reinforcing stigmatizing attitudes towards disability.

To conclude, *The Disabled Child: Memoirs of a Normal Future* interrogates the existing discourse on disability as promulgated through parental memoirs. Apgar encourages readers to recognize the complexity of the experiences of families with disabled children and to embrace an inclusive and nuanced approach to disability narratives. The book emphasizes the importance of rethinking the idea of independence through its showcasing of a variety of memoirs. *The Disabled Child* promotes increased awareness and sensitivity towards the experiences of families with disabled children and highlights the need for a more empowering discourse surrounding disability.

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