

# DISABILITY AND THE CHANGING CONTEXTS OF FAMILY AND PERSONAL RELATIONSHIPS

**Edited by** Gabriele Ciciurkaite  
and Robyn Lewis Brown

RESEARCH IN SOCIAL SCIENCE  
AND DISABILITY

**VOLUME 15**

DISABILITY AND THE CHANGING  
CONTEXTS OF FAMILY AND  
PERSONAL RELATIONSHIPS

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VOLUME 15

**DISABILITY AND THE  
CHANGING CONTEXTS OF  
FAMILY AND PERSONAL  
RELATIONSHIPS**

EDITED BY

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INVESTOR IN PEOPLE

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# INTRODUCTION TO THE VOLUME: TOWARD AN UNDERSTANDING OF DISABILITY AND THE CHANGING CONTEXTS OF FAMILY AND PERSONAL RELATIONSHIPS

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The past 50 years have witnessed a transformation in the structure and function of personal and family relationships (Cherlin, 2010; Martin, 2006). The social and demographic catalysts for these changes – including but not limited to delayed marriage, the legalization of same-sex marriage, women’s increased labor force participation, and declines in fertility and mortality – have further impacted norms governing our relationships and the ways in which we carry out formal and informal family and social roles (Cherlin, 1983, 2010; Risman, 1998). Despite these radical shifts, the general consensus of social science research and the population at large is that relationships remain desired and beneficial as well as challenging and constraining (McLaughlin, 2019; Risman, 1998). Within and beyond the context of disability, relationships often represent a complex balance between our aspirations and mundane tasks, our professional and personal lives, and our embodied desires and demands. How do we, as disability researchers, balance both the strains and resources conferred through relationships, much less the cultural ideals, economic constraints, political divides, and social policies with which they are intertwined?

There is no integrated framework for addressing these complexities in disability scholarship or family studies scholarship, which are fields with very little conceptual overlap (Bixby, 2023; Carey et al., 2020; McLaughlin, 2019; Stevens, 2021). The limited attention people with disabilities have received in family studies overwhelmingly problematizes disability, which is evident in the

predominant focus on difficulties, hardship, despair, etc., families may experience as a result of a family member's disability. In the study of disability, a number of family-related topics, and particularly those related to custody and caregiving, also remain fraught, and rightfully so because research has so often advanced the priorities of those without disabilities. History reminds us that this approach doesn't bode well for people with disabilities. Scientific research and expertise have been used to justify institutionalization, eugenics programs, and enforced marriage restrictions on the basis of disability, after all, and the wants and needs of non-disabled family members have supported such harmful treatment (Longmore, 2003; Nielsen, 2012; Schweik, 2009).

In counterpoint to work that has undermined growth and perpetuated both interpersonal and structural violence, research that centers the experiences and claims of people with disabilities is critical. The need for such research is further bolstered by Hughes and colleagues' (2011) observation that the "discovery" of intimate partner violence risk among women with disabilities was not even by design because scholars previously thought women with disabilities were unlikely to be in intimate relationships. The study by Sobsey and Doe (1991) that first documented patterns of sexual abuse and assault among women with a diverse range of physical, psychological, and intellectual disabilities was a follow-up study on childhood disability.

In the interest of expanding scholarship on personal and family relationships from the perspective of those with disabilities, our approach to this volume of *Research in Social Science and Disability* was rooted in a sociological and anti-ableist understanding of families which recognizes that families are not only shaped by individuals and individual relationships. Adding a consideration of the social contexts in which relationships exist shifts our focus away from individuals and allows us to engage with the social structures and status hierarchies that may privilege or undermine different types of relationships to varying degrees.

Each of the 11 chapters included in this volume challenges us in some way to revisit dominant perspectives on disability and the contexts of family and personal relationships in the current moment. One of the submissions we received, an autoethnographic examination of the decision to become a parent by the artist Molly Joyce, further provides a disability-centered organizing framework for conceptualizing how various social forces converge on relationships. In brief, Joyce's examination of disability, family, and artistry encourages us to linger in the ambiguities of relationship processes and not shy away from concerns related to (1) vulnerability and dependency, (2) embodiment and care, and (3) identity and creativity. This chapter is included in the Introduction section of this volume because it orients the reader to these key themes, addressing them through a narrative of discovery.

The considerations discussed in this chapter extend beyond artists and the art world, however. This begins with an appreciation of the wiliness and tenacity with which many people with disabilities have forged new paths in a variety of contexts that have not met their needs. From this point of origin, our focus shifts, first, in considering vulnerabilities attendant to diverse bodies and minds, through recognition of the role of autonomy and creativity in navigating circumstances of

constrained choice. This has implications, for example, for understanding why workplace accommodations for disability and family responsibilities such as childcare remain a persisting source of vulnerability. This orientation also provides insight into how embodied experiences influence care work. This is reflected in the link between an individual's own bodily awareness and their understanding of the changing needs and corporeal realities of others, among other topics. Furthermore, this reorientation is useful for addressing ways in which relationships both allow us to challenge aspects of identity and are a conduit through which identity can be challenged.

Each of the subsequent chapters included in this volume elaborates on these themes. On the subject of vulnerability and dependency, Agnès Berthelot-Raffard challenges the false dichotomy of addressing care providers as individuals with autonomy and care recipients as individuals who lack independence or agency, noting that this dichotomy disregards the fluidity of disability, overlooks the many people with disabilities who are providers of care, and fails to recognize that informal caregivers often constitute a socially disadvantaged and vulnerable group. Drawing on a legal case study of a court case heard by the European Court of Justice in 2008 concerning employment discrimination faced by the mother of a child with a disability, Berthelot-Raffard's analysis addresses the difficult balance between informal care work and employment in a market economy and calls for a more comprehensive examination of power relations resulting from care activities, such as those among informal caregivers and care recipients.

Darcy L. Sullivan, Noelle K. Kurth, Jean P. Hall, and Kelsey Goddard further challenge dominant notions that dependency is largely negative in the context of relationships by examining variation in household food insufficiency, or limited access to an adequate and nutritious diet, during the COVID-19 pandemic. Their analysis of data from a nationally representative survey of adults in the US with a self-reported disability provides compelling evidence that a lack of dependence, as indexed by living alone as well as lacking companionship and being socially isolated, increased risk for food insufficiency. Next, Nicole Ineese-Nash and colleagues Kathryn Underwood, Arlene Hache, and Patty Douglas scrutinize constructs framed by colonial narratives related to disabled childhoods, notions of disability, the "best interest of the child" trope, the archetype of the "good parent," and the designation of custodial "status." Utilizing data from a 9-year longitudinal study across three Canadian provinces and one territory, they document the experiences of 41 families who have interacted with the child welfare system, which emphasize the challenges and instability stemming from government interference in family relationships. Along with illustrating how family relationships can be undermined by state forces, this work demonstrates the utility of institutional ethnography as a method for deconstructing systemic influences.

The chapters included in the next section of this volume extend an understanding of embodiment and care. Justin T. Maietta's investigation of people living with Type 1 diabetes explores how disability transforms and redirects the embodied experience of reproductive trajectories. Ioanna Georgiou and Stavros

K. Paralalis next address how social services and support structures in Cyprus inform expectations of care among adults with an autism spectrum disorder and their families. The in-depth interviews they conducted highlight unmet service and support needs – as opposed to relationship and personal needs – that undermine quality of life. Then, Zachary Hart’s work on parents of children with intellectual and developmental disabilities in the US emphasizes the centrality of emotions in informational processing and sensemaking and ways in which emotions are embodied and underrecognized in health care decision making. Expanding on the shortcomings of health care contexts emphasized throughout this section, Kevin Hans Waitkuweit’s analysis of the Proceedings of the American Medical Association documents how physicians describe and view family care over time in the US. Utilizing longitudinal content analysis, this study highlights cases in which the medical establishment recognizes itself as a potential source of burden, ways in which support systems are framed by clinicians, and the medicalization of family relationships in the context of disability.

The chapters included in the third and final section of this volume address themes and processes associated with identity and creativity. Research by Eun-Jeong Lee, Sang Qin, Arshiya A. Baig, Jennifer Dongha Lee, Patrick W. Corrigan, and a community-based participatory research team expands upon dominant individualist narratives of agency and self-determination to incorporate cultural perspectives that emphasize group cohesion over individual autonomy. Their assessment of treatment options for Type 2 diabetes in Korea identifies a preference for involving family members in diagnosis and decision-making processes, as opposed to receiving information from clinicians and making health care decisions alone, which has important implications for how we conceptualize understandings of the self and personal identities in disability research. Judith Tröndle, Lisa Pfahl, and Boris Traue then draw from research on couples parenting a child with a disability in Germany and a conceptual framework of *subjectivation* to analyze the positionality of couples as “special parents” – a medicalized identity often at risk of being othered. The authors demonstrate examples of personal and institutional ableism and sexism in navigating parenthood, as well as a need for less sexist labor market expectations, less medicalized support systems, and access to emancipatory discourses. Finally, Alan Santinele Martino’s chapter closes the volume by introducing a framework for raising awareness about and acknowledging agency among people with disabilities in relationships, love, and sexuality. This framework invites further discourse on joy, desire, and pleasure in the study of personal relationships.

As a whole, the chapters in this volume remind us of the complexities of contemporary family and personal relationships and underscore that we cannot ignore disability in addressing them. They advance a conceptual understanding of relationships and the contexts within which relationships exist that integrates considerations of vulnerability and dependency, embodiment and care, and identity and creativity. Through empirical insight drawn from a diverse range of social science research methods, ultimately, the authors call for an empowered reconsidering of disability in the context of family and personal relationships that transcends disciplinary bounds. As editors, it is our hope that this volume will set

the stage for further work that prioritizes disability as central to an understanding of relationship processes and contexts.

*Robyn Lewis Brown and Gabriele Ciciurkaite*  
Volume Editors

## REFERENCES

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# CHAPTER 1

# DISABILITY, FAMILY, ARTISTRY: A SEARCH FOR BALANCE AND ACCESS

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## ABSTRACT

*This article features four disabled artists who are parents and center on their balance of artistic practice and family. As a disabled artist considering starting a family and becoming a parent, the question of balancing artistry with a child has been a consistent thought and inquiry. Especially as a disabled artist wrestling with the realities of managing one's bodily needs with a career and personal life, I realize it will be a challenging yet rewarding adjustment. Furthermore, artists often lead atypical work lives with atypical working hours, which can sometimes lend itself to parenting and take away from it in other ways. With the resultant interviews and article, I aim to provide critical insights into practicing disabled artists' viewpoints on parenting, ranging from the challenges to the dividends. I hope these insights will support a singular view of disability parenting and artistry, as well as the Journal's goal of a new paradigm in disability scholarship overall.*

**Keywords:** Disability; artistry; family; balance; access

## INTRODUCTION

Disability—like gender, class, and race—is a social force that affects the world in a pervasive manner. —Sunaura Taylor, 2017

When you become a mother, you engender life, endless possibilities. Mothering is creative in a very literal sense—it is cultivating all that potential, bringing a small person into consciousness. —Angela Garbes, 2022

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Art is two things: a search for a road and a search for freedom. –Alice Neel, 2007

As a disabled artist, balance is a continual line of inquiry. Balance of my work and personal life, balance of disability and artistry, balance of art and activism, and the literal, physical balance of my unbalanced body, which is stronger on the right side due to an impaired left hand. Through this search for and questioning of balance, I have embraced the quest to enact balance between these facets. With this, I have benefitted from conversing with collegial disabled artists in their pursuit of balance. By balance, I infer not equalizing two competing forces but recognizing the inevitable ebb and flow between them. Identifying how they can inform rather than resist each other, such as disability rights activism informing artistic work promoting disability awareness.

More recently, the question of balance has come to the forefront as I have considered becoming a parent. For a long time, becoming a parent was not something I seriously considered. During my early career, I focused almost exclusively on art, as if it was a “child” of mine. However, turning 30, reckoning with the biological realities of having children as a woman, and being with a supportive partner to go on this journey together have made me consider starting a family.

As a disabled artist managing one’s bodily needs with a career and personal life, I realize it will be a challenging yet rewarding adjustment. In addition, artists often lead atypical work lives with atypical working hours, which can lend itself to parenting and take away from it. Therefore, for this article, I interviewed collegial disabled artists who are parents on their viewpoints of balancing their disability, family, and artistry, ranging from the challenges to the dividends. To protect anonymity, the names of respondents and their children have been changed, while other details such as artistic media have been retained: They are:

- Fiona – Artist and writer with low, fluctuating vision and one son (Felix, age 12)
- Claire – Deaf visual artist and three sons (John, age 24; Tim, age 21; Oliver, age 18, Grandson Andrew, age 3)
- Steven – Actor with cerebral palsy and one son (Ben, age 4)
- Cody – Media artist with a visual impairment and one son (Liam, age 18).

I chose these artists because their practices span disciplines and disabilities, and represent different gendered and racialized experiences. While these viewpoints are not holistic representations of the disability community, they offer insights into working disabled artists with families. Their insights highlight the importance of balance and access in consideration of disability, family, and artistry, namely the balance between these points and their opportunities and the extension of accessibility to family and childcare.