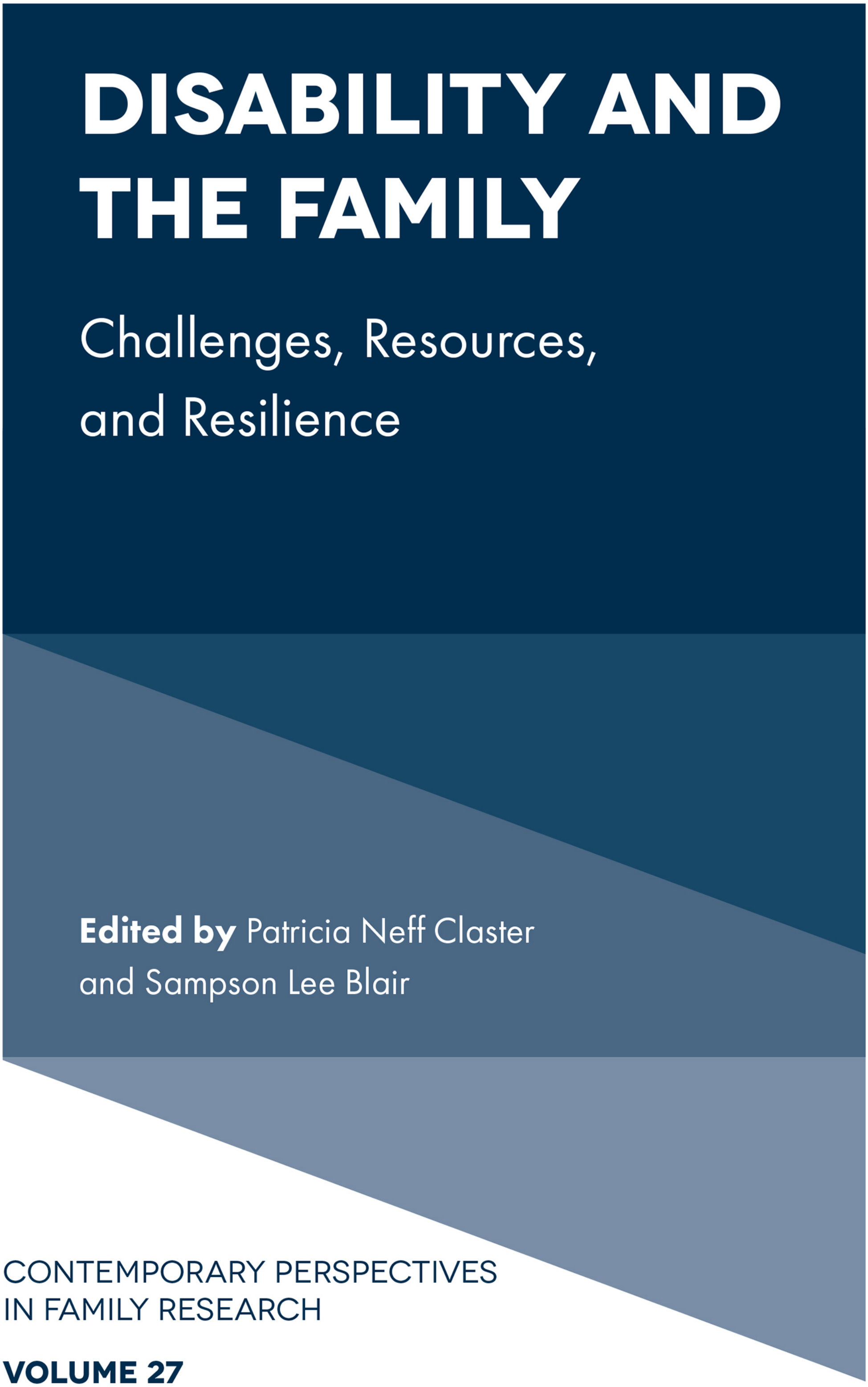

DISABILITY AND THE FAMILY

Challenges, Resources, and Resilience

Edited by Patricia Neff Claster
and Sampson Lee Blair

CONTEMPORARY PERSPECTIVES
IN FAMILY RESEARCH

VOLUME 27

DISABILITY AND THE FAMILY

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DISABILITY AND THE FAMILY: CHALLENGES, RESOURCES, AND RESILIENCE

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INVESTOR IN PEOPLE

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ABOUT THE CONTRIBUTORS

Eileen M. Brennan has concerned about improving the life experiences of families that have young people with disabilities as members. She has worked to gain a more accurate and compassionate understanding of the cultural dilemmas that they face and the opportunities that improve their lives. While studying for her Doctoral degree in Psychology at the University of Notre Dame, she became intrigued with the possible discrimination that people with accented speech encountered. After joining the social work faculty at the University of Kansas, she studied how families managed discrimination they encountered based on the emotional or behavioral difficulties their children experienced. Later, at Portland State University School of Social Work, she was part of a team of researchers supported by major grants from the National Institute of Mental Health. She and her collaborators examined ways that parents could maintain their employment while they struggled to support children and youth with serious mental health challenges. *Work, Life, and the Mental Health System of Care: A Guide for Professionals Supporting Families of Children with Emotional or Behavioral Disorders,* which she and Julie Rosenzweig co-authored in 2008, was one of the first books examining the work and family lives experienced by parents caring for children with disabilities. This was followed by research that examined more effective ways to care for children with disabilities in childcare settings. Later work included research that led to the development of guidebooks for parent support providers that examined ways to improve work–family balance and for human resources specialists to help them work more effectively with employees raising children with disabilities. Recent work has also examined the importance of social sustainability in building systems that will support families experiencing work–life challenges as they balance family demands and seek workplace support (ORCID: 0000-0002-2816-7836).

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Jessica Lukefahr, having been born with a physical disability herself, she started advocating for others with disabilities as early as her teens. She struggled in joining activities and making sure her needs were met both in and out of school. She soon expanded her advocacy, speaking out for students with mental health needs. From firsthand experience, she witnessed the work–family struggle, through her employed parents, who were her caregivers growing up. They had difficulty in simultaneously raising a child with a disability and managing work (ORCID: 0000-0002-4350-1759).

In college, she continued her advocacy work, helping construct an American Sign Language course in which students with physical disabilities could participate. She also ensured that students with visual impairments had an accessible website from the student housing organization. In 2011, she graduated Summa Cum Laude from the University of Illinois at Urbana-Champaign with an English degree. After college, she held various jobs, some of which included diversity and inclusion components. She even testified before the Texas State Senate's Finance Committee, advocating raises in attendants' wages. Since 2021, she has worked for Portland State University's School of Social Work's Regional Research Institute. She currently writes and edits articles for journals and conferences involving work–family integration, especially for caregivers of children with disabilities and/or mental health needs and participates in related conferences. Her preferred research interests are those that involve achieving better equity for those affected by all types of disabilities, specifically to improve equity in areas concerning public accessibility, educational opportunities, professional opportunities, work–family balance, durable medical equipment, and access to the tools needed to receive attendant care while also maintaining a full-time job. Her passion is ensuring that people with special needs can live independently in a welcoming society.

Janelly Macias-Martinez is an Entry-level Occupational Therapy Doctoral student at the University of Illinois Chicago, expected to graduate in May of 2025. She holds a Bachelor of Science in Rehabilitation Sciences. As a first-generation Mexican American, her research interests encompass several areas, including culturally competent and advocacy approaches to disability services, family-centered care, and diversity in pediatric occupational therapy. She is particularly focused on promoting inclusion and cultural considerations in occupational therapy for Latinx individuals with or without disabilities, as she is equally committed to extending these efforts to benefit all communities. (ORCID: 0009-0004-0206-1605)

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So far, she has published 25 scientific papers in national and international journals and scientific books and actively participated in a number of scientific conferences. Most of her papers deal with the topic of interpersonal relations. Her current scientific interests relate to the well-being of parents of children and adults with disabilities. She was until recently a Member of research team of an institutional research project entitled "Well-being of Working Parents of Children with Disabilities," led by Ana Slišković (Full Professor at the Department of Psychology, University of Zadar) (ORCID: https://orcid.org/0000-0002-3416-6303).

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Mariela Saenz is an Entry-level Occupational Therapy Doctoral student at the University of Illinois Chicago, expected to graduate in May of 2025. As a Future Occupational Therapy Practitioner, she plans to utilize her bilingual and bicultural skills to deliver culturally relevant services to her clients from historically marginalized groups, especially the growing heterogeneous Latinx population. She also strives to promote diversity within the occupational therapy profession. She has had the privilege of working closely with the Latinx population within her own community and through various job positions in school and healthcare settings. These experiences have fueled her passion to advocate for the unique needs of Latinx individuals, particularly in increasing access to healthcare services. Currently, she is a Graduate Research Assistant for PODER Familiar, a study that tests the efficacy of a bilingual intervention designed to promote the health and well-being of Latinx caregivers of children with disabilities. She is interested in the development and implementation of culturally tailored interventions and hopes to address barriers that the Latinx community often faces.

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Ana Slišković is a Full Professor at the Department of Psychology at the University of Zadar (Croatia). She graduated from the Faculty of Philosophy in Zadar in 2002 with a degree in Psychology. She received her master's degree

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She has published about 50 scientific papers in national and international journals and scientific books and actively participated in a number of scientific conferences. Most of her papers deal with the topic of stress at work and the well-being and psychophysical health of workers in different work environments. Her current scientific interests relate to two specific areas. The first area is maritime psychology, where she has conducted several studies on the health, well-being, and motivation of seafarers; the motivation of maritime students to work in the maritime industry; and the well-being of partners and spouses of seafarers. Another area she is interested in is the challenges and stressors faced by parents of children with disabilities, with a particular interest in factors related to work and organization, that is, work–life balance. She recently led an institutional research project entitled "Well-being of Working Parents of Children with Disabilities" (ORCID: https://orcid.org/0000-0002-5621-648X).

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She is a Fellow of the American Psychological Association and past President of the Society for Community Research and Action (SCRA, APA, Division 27). She was the 2021 recipient of the Distinguished Alumna Award, University of Kansas, Department of Applied Behavioral Science, and a 2022–2023 University Scholar recipient at UIC (ORCID: 0000-0002-1963-3129).

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Her work is focused on exploring challenges of parents of prematurely born children as well as parents of children with disabilities, and she has also participated in various competitive and institutional projects (both domestic and international). She is a regular reviewer for several Croatian and foreign journals. During her years of work at the Department of Psychology at the University of Zadar, she has taken part in numerous educational workshops, seminars, and summer schools. She has presented over 40 papers at domestic and international scientific-professional conferences. Since the beginning of her employment at the Department of Psychology (2007), she has been a permanent member of the organizational and program committees of the international scientific-professional conference “Psychology days” and has repeatedly participated in the organization of the Summer Academy for Neurodevelopmental Rehabilitation. Since December 2017, she has been the Head of the Premature Baby Parents Club (Zadar branch) providing daily support and counseling to parents of prematurely born children. In October 2019, she was appointed as the Head of the Student Counseling Center at the University of Zadar. She is a Member of the Coordination of the Ombudsperson for Persons with Disabilities for the area of higher education. She is the President of the Quality Committee of the Department of Psychology. She is a Collaborator on a scientific research project: “Identification of key factors for the implementation of educational inclusion of students with disabilities” (ORCID: https://orcid.org/0000-0002-1559-6826).

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FOREWORD

For most of us, disability will inevitably impact us or those we love. Interest in the dynamics between disability and family relationships dates back to Greek mythology and the story of Hephaestus, the Greek god of fire, blacksmiths, and craftsmen. Hephaestus was the son of Hera, the queen of the gods, and Zeus, the king of the gods of Olympus. As the story goes, upon his birth, horrified by the sight of Hephaestus and his physical deformities, Hera threw him into the ocean from the top of Mount Olympus. Surviving the fall, Hephaestus is rescued by the goddess of water, Thetis, and raised on the island of Lemnos where he became a skilled craftsman and went on to design impressive inventions, weapons, and jewelry. Despite his hardships, Hephaestus garnered much respect and admiration from the other gods for his clever creations. He is often depicted with curved feet and portrayed high up on a wheeled chair or a chariot of his making which he used to maneuver around. Different versions of his complicated relationship with his mother have been characterized in various myths. According to one version, seeking vengeance against his mother, Hephaestus concocts an elaborate plan to humiliate her and make his return to Olympus. He constructs a majestic golden throne for Hera and tells her that it is a gift. But when she sits on the throne, she is trapped by invisible chains which no other god is able to free her from. In return for releasing his mother from her captive throne, he negotiates with Zeus to marry the stunning Aphrodite, the Greek goddess of beauty and love. Yet, despite his adoration for Aphrodite, Hephaestus' relationship with his wife also proves to be arduous. Not thrilled with her arranged marriage to Hephaestus, Aphrodite often entertains other lovers and enters into a relationship with Ares, the Greek god of war. In another pivotal act of revenge, Hephaestus creates a trap to ensnare the love making couple in an unbreakable chain and shame them in front of the other gods, but the other gods just laughed at the sight of the entangled naked lovers. In these mythical stories, Hephaestus's disability is often presented as both a source of struggle and strength, overshadowing the dynamics of his intimate and family relationships.

Many cultural stereotypes associated with disability can be traced back to different accounts of Hephaestus. The narrative surrounding his family interactions implies that they are fraught with conflict. His relationship with his mother is laced with negative emotions which range from scorn, resentment, and embarrassment to feelings of neglect, rejection, anger, and humiliation. His relationship with Aphrodite is colored by jealousy, suspicion, rejection, and betrayal. He is not warmly accepted or lovingly embraced by either woman, but rather he is seen as a burden and a barrier to overcome. Tropes such as these continue to play out in modern day depictions of disability within literature and popular culture, impacting our understanding of the experience of living with disability. Yet, it is important to recognize that disability is not understood or treated uniformly across cultures, and the experiences of families vary considerably across social class, race, ethnicity, and gender. Myths and stereotypes often oversimplify the complex realities of living with disability.

The purpose of this volume of *Contemporary Perspectives in Family Research* is to provide a broad examination of disability and the family. Families are impacted in a multitude of ways by disability throughout the life course. The new presence of a disability can lead to major shifts in the roles and responsibilities of family members and intimate partners. Frequently, family members, often women, play an essential role in the care of other family members who experience disability. This service can involve physical assistance, emotional support, advocacy, financial aid, or just adjustment to their lifestyles or routines to accommodate the disability. While support can be reciprocal, it can also place a great deal of stress on family members and cause strained relationships. In addition to the demands caused by role changes, individuals caring for a child, parent, or partner with a disability also may face guilt or blame, fear, anxiety, communication challenges, intimacy issues, financial strain, and social isolation among other issues. Disability can change the nature of relationships across and within generations, with older individuals caring for younger ones, younger members caring for older members, and, in some cases, siblings caring for other siblings. Ultimately, disability may affect those in spousal and intimate relationships, especially as couples age together and concerns related to physical and cognitive abilities become more problematic. The impact of disability can vary considerably depending on a variety of factors including the severity of the disability, the dynamics of the family, the coping mechanisms of individual family members, and the availability of support systems. Balancing work, household duties, personal needs, and caretaking responsibilities can be overwhelming. But caring for a person with a disability can also lead to a heightened sense of empowerment. Caretakers may experience hope, strength, growth, and resilience. Couples may feel stronger in the face of diversity as they overcome obstacles and adapt to change together. Families may become closer and more cohesive.

Across societies, there are numerous social factors that impact rates of disability as well as the experience of disability. Differences in cultural beliefs, access to healthcare and services, poverty and economic inequality, opportunities for education and employment, and differing legal frameworks will invariably impact the needs and ability of members of a society to provide care to their loved ones. Barriers to economic resources and opportunities mean that marginalized or disadvantaged groups are disproportionately affected by disability. Natural disasters as well as conflict, violence, and war in a society can also lead to increased rates of disability. Worldwide, the prevalence of disability is on the rise. Many societies have expanding populations of individuals with disability and chronic conditions, especially as the global population continues to age. Improvements in diagnostic technology also mean more individuals are being diagnosed and recognized as having a disability. Environmental factors like air and water pollution and more sedentary lifestyles and unhealthy diets can also lead to increased rates of disability. Clearly, disability and its related consequences have moved to the forefront of family concerns. In this volume of *Contemporary Perspectives in Family Research,* researchers from around the globe provide us with a more comprehensive understanding of how families are impacted by disability. The work presented here highlights the challenges, coping, resources, and resilience of families.

Caring for a child with a disability can be hard enough, but trying to coparent can complicate matters even more. In Chapter 1, "Coparenting a Child with Disabilities: Selected Determinants," Monika Parchomiuk examines the process of coparenting a child with disabilities using "The Coparenting Relationship Scale" with 118 coparenting couples in Poland. Parental age, gender, and education and the age and gender of the child were also taken into consideration. While the gender and education of parents proved to be significant, their age did not play as great of a role in their perception of parental agreement or satisfaction with the division of labor. Understandably, the findings also indicate that children display less difficult behaviors when parents are able to coparent cooperatively and support each other's efforts. As the author emphasizes, a better understanding of how parents of children with disabilities in coparenting relationships interact with one another, cope with stress, and share responsibilities can help school counselors, social workers, and psychologists in the process of developing plans of intervention and specialized support.

Having a sibling with a disability can affect a child in various ways, both positive and negative. The question of how parents of a disabled child divide up their time among siblings is addressed in Chapter 2, "Childhood Disabilities and Differential Parental Time Investments in Siblings." In this chapter, Jocelyn S. Wikle, Ashley Forbush, and Alexander C. Jensen utilize a longitudinal sample from the nationally representative American Time Use Survey (2008–2019) to analyze parental time investment in disabled children as compared to children without disabilities. The results indicate that nondisabled youth may not be getting the same kind of attention that their siblings with disabilities are receiving. This disparity can lead to jealousy, resentment, and difficulties for nondisabled siblings such as poor educational outcomes. The authors illuminate how negative consequences can be mitigated by providing nondisabled siblings with a greater understanding of the reasons for the differences in parental time investment.

The experience of role reversal between parents and children in at-risk families is explored in Chapter 3, "A Qualitative Analysis of the Experience of Parentification." Barbara Chojnacka utilizes the autobiographical narrative interview method to gain better insight into the process parentification, whereby the child takes on the roles and responsibilities of the parent, often due to the incapacity or unavailability of the parent. In some cases, this might mean children making significant decisions that affect the household or taking on responsibility for instrumental tasks. This could include performing household chores like laundry, cooking, cleaning, and caring for other family members. In other cases, this might also involve children taking on expressive functions or an emotional support role for the parent. Findings from interview data with 17 female and 18 male participants reveal a pattern or processual model of parentified childhood. In other words, parentification does not just happen overnight. As illustrated by Chojnacka, this role reversal is a complex, multi-stage process which can lead to negative consequences for family dynamics and relationships.

To better understand the way chronic illness shapes the lived experiences of individuals and their families, Allison Jendry James employs the autoethnographic and social constructionist approach in Chapter 4, "What 'Normal' Means to My Family and I: Life as a Young, Chronically Ill Person." Reflecting on her own experience and daily encounters, the author provides readers with a glimpse into the day-to-day difficulties of living with chronic illness and how it impacts her marriage and family relationships. She delves into various emotions and considers how these feelings contribute to her identity. This introspection also involves self-reflection about the influence of her social location and a discussion about varying intersecting social statuses that may influence the experience of stigma. James concludes by advocating for more research that explores the various intricate ways chronic illness impacts the daily living and functioning of families.

Individuals with disabilities are not the only ones who may face stigma. Parents caring for a child with a disability like a mental health or a behavioral condition may contend with heightened judgment in the workplace due to the invisibility of the disability as well as the public stigma associated with mental illness in American society. In Chapter 5, "Navigating Stigma and Discrimination at Work While Parenting a Child with a Mental Health Disability," Lisa M. Stewart, Claudia Sellmaier, Marin Henderson-Posther, Jessica Lukefahr, and Eileen M. Brennan conduct a literature review of 26 research articles and 12 websites dealing with the subject mental health stigma and discrimination in the workplace experienced by parents of a child with a mental health disability. While research on the subject is limited, their review reveals the widespread and multifaceted occurrence of stigma and discrimination. The authors also highlight the dearth of resources that are available to combat the potential stigma and discrimination encountered by parents. They conclude by discussing opportunities for implementing organizational strategies and policy reform to help create more supportive and family-friendly work environments.

Disability can affect family planning in a variety of ways. Fredinah Namatovu, Erling Häggström Gunfridsson, Johan Junkka, and Lotta Vikström evaluate the relationship between the use of disability benefits and the likelihood of becoming a parent in Chapter 6, "The Dynamic Association Between Disability and Parenthood in Sweden." Using longitudinal data from the Swedish national registers with a sample of over 440,000 individuals, the authors use descriptive analysis, heatmaps, and multinomial logistic regression analysis to demonstrate a bidirectional relationship between the age at starting to receive disability benefits and the age of having a first child. More specifically, receiving disability benefits at a young age appears to significantly reduce the chances of becoming a parent, while becoming a parent at a young age appears to increase the likelihood of receiving disability benefits. These results demonstrate there is a dynamic interplay between disability and parenthood.

Language, cultural, and economic barriers can make navigating the healthcare system, finding appropriate services and interventions, and advocating for children with disabilities a significant challenge. For Latinx, the elevated risk or experience of racism and discrimination can also discourage families from seeking necessary services. In Chapter 7, "Latinx Families of Children with

Disabilities: Challenges, Supports, and Empowerment Interventions," Yolanda Suarez-Balcazar, Isabella Rosas, Mariela Saenz, Janelly Macias-Martinez, and Sandy Magaña delve into the unique struggles faced by Latinx families of children with disabilities. In addition to describing some of the common obstacles that are encountered, the authors provide context about the support systems and available resources. Various empowerment-focused interventions intended to improve advocacy skills and enhance the health and well-being of Latinx families are also highlighted. The authors summarize their work by making policy suggestions and recommendations for future research and practice.

Annaliese Grant and Rachel Litchman tackle the issue of social class as it relates to disability care in Chapter 8, "Caring Through It: Mothers' and Daughters' Perspectives on Disability and Interdependence in Financially Struggling White Families." Intergenerational poverty, poor or dangerous living conditions, occupational hazards, limited access to healthcare, and chronic stress are just some of the different factors that contribute to higher rates of disability among low-income groups. Disability can also create significant additional expenses for families which can lead to even greater financial strain. Based on 31 in-depth interviews with mothers and daughters across the United States, Grant and Litchman's research takes a look at how financial struggles and disability care are intertwined and how this entanglement often necessitates cooperation and interdependence between mothers and daughters. Unlike in families with more resources for support, mothers and daughters in financially struggling families may have no other choice but to rely on each other.

Attention is devoted to coping strategies and the influence of social support on parents caring for children with severe disabilities in Chapter 9, "The Well-Being of Croatian Parent Caregivers: Testing the Role of Cognitive Emotion Regulation Strategies and Social Support." In this chapter, Jelena Ombla, Marina Vidaković, and Ana Slišković collect and analyze online survey data from 210 Croatian parents of children and adults with disabilities. In addition to assessing the mental health and well-being of caregivers, the researchers addressed life satisfaction, parental stress, social support, and cognitive emotion regulation strategies. Consistent with past research, the findings illustrate the potential remedying effects of social support and positive refocusing for parental well-being, life satisfaction, and the experience of stress. Considering the various demands faced by parent caregivers, learning strategies for emotional regulation and having adequate social support appears to be crucial.

In Chapter 10, "Improving Family Resilience through Parent to Parent Support: A Pilot Study on Culturally and Linguistically Diverse Families of Children with Disabilities," Yali Pang and Dana Yarbrough also unpack the influence of social support and investigate ways to support diverse parents of children with disabilities. In this pilot study, the researchers paired two cultural brokers with six different parents to determine the efficacy of evidence-based peer support practices that have been developed by Parent to Parent USA. Cultural brokers can act as an intermediary between different cultural groups, facilitate a mutual understanding, bridge cultural differences, and provide advocacy, support, education, training, and access to other resources and connections. This chapter is focused on the observations of the cultural brokers collected through interviews and surveys conducted after daily interactions with the assigned parents over a period of three months. The results suggest there is a great deal of value in promoting the use of parent to parent support in culturally and linguistically diverse families of children with disabilities.

In Chapter 11, "Disability Is a Family Affair," Rhoda Olkin emphasizes the intertwined nature of individual disability and the family and examines the responses of family to the needs of those with disabilities. She focuses upon the role of clinicians and practitioners, who need to be keenly aware of how their care choices and recommendations can affect not only the disabled person, but may have substantial consequences for the rest of the family. Disability, quite simply, affects everyone within the family, and the delicate balance of maintaining the well-being of the individual and the well-being of the family is often difficult to achieve. She also discusses Medical Family Therapy, and the ways in which it can aid in our understanding of the contextual and environmental factors which can affect the functioning of families, along with their capacity to properly aid and assist those with disabilities.

The aim of this volume of *Contemporary Perspectives in Family Research* was to examine how disability affects family processes and relationship dynamics. Around the world, as demographic and societal shifts occur and life expectancy continues to rise, we can expect to see more disability and a greater need for healthcare and caregiving services. Families will likely incur additional financial, physical, and emotional costs, particularly if the family member with disability is unable to work or faces education or employment barriers. Addressing obstacles, promoting social inclusion, and enhancing access to resources can help families cope with potential challenges and maintain healthy relationships. An enhanced understanding of disability within the family context can lead to new directions for research and new ways of assisting individuals with disability and their family members. The studies included in this volume demonstrate that disability has far and wide-reaching affects, not just impacting those with disability but the whole family system. We extend our most sincere gratitude to all of the authors for their important contributions to this volume as well as the anonymous reviewers who provided thoughtful and constructive reviews.

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