DISABILITY AND THE FAMILY

CONTEMPORARY PERSPECTIVES IN FAMILY RESEARCH

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VOLUME 27

DISABILITY AND THE FAMILY: CHALLENGES, RESOURCES, AND RESILIENCE

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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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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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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.

Patricia Neff Claster
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CHAPTER 1

COPARENTING A CHILD WITH DISABILITIES: SELECTED DETERMINANTS

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ABSTRACT

Coparenting is a complex construct showing the quality of parental beliefs, motives, and actions related to cooperation in the child-rearing process. Its important role has been proven in child development and in shaping parents' quality of life outcomes or marital satisfaction. This chapter presents the results of a study aimed at exploring the significance of selected parenting and child-related variables for the various components of coparenting in families with a child with disabilities. Material was collected in a group of 118 parenting couples using The Coparenting Relationship Scale. It was found that fathers scored higher in Coparenting Undermining and Endorse Partner Parenting. The variable of education was significant: parents with higher education showed the highest parental compatibility, and mothers also showed relatively highest satisfaction with the division of responsibilities. Parental age, age, and gender of the child with a disability were not significant. Difficult behaviors in the child correlated negatively with favorable coparenting components in parents and positively with unfavorable ones. Functional status was negatively associated with Coparenting Agreement and Endorse Partner in fathers. The complementarity of parental roles must be taken into account in the process of specialized support from psychologists, school counselors, social workers, etc.

Keywords: Child with disability; coparenting; mothers and fathers; parental cooperation; marital support

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INTRODUCTION

A child's disability and related special developmental needs pose challenges for parents in many dimensions of their functioning (Saini et al., 2015). This issue has been relatively widely recognized in the literature. The research perspective for a long time was limited to the negative aspects of parenting describing the consequences of the burden of responsibilities and stress in the form of depression, anxiety, and fatigue. Contemporary research trends, embedded in the positive paradigm, use the concept of post-traumatic growth (Calhoun & Tedeschi, 2006; Tedeschi & Calhoun, 2004), organismic valuing (Joseph, 2009; Joseph & Linley, 2005), or transformation (Scorgie et al., 2004) as theoretical frameworks for explaining the beneficial changes occurring in the functioning of parents who have a child with a disability. Research results demonstrate the positive changes perceived by parents of children with disabilities in themselves, in their relationships with the environment, and in their life philosophy. Mothers and fathers perceive personal growth indicated by the acquisition of a range of instrumental and personality competencies related to raising a child and functioning in other roles (Byra & Parchomiuk, 2018; Laufer & Isman, 2022; Mitchell & Lashewicz, 2019; Potter, 2017; Pryce et al., 2017; Sheldon et al., 2021; Takataya et al., 2016; Young et al., 2020, among others). The understanding of parental adaptation to life with a child with a disability has changed. It is no longer framed as a process consisting of closed stages but as a dynamic construct triggered by important life and developmental events (Lee et al., 2015). Empirical evidence confirms the need to study parenting in a multifaceted way, including negative and positive experiences. It is also important to include both parents, given the complementarity of experiences and their importance to the development and functioning of their child with a disability.

The Essence of Coparenting

The construct of coparenting helps explain how parents coordinate their joint responsibility for raising their children, supporting or undermining each other's parenting efforts (Lau & Power, 2020). Its theoretical roots come from several complementary sources, including the systemic family theory (Bloom, 2019), the ecological theory (Feinberg, 2003), and the transactional theory (Norlin, 2017). Over time, various concepts emerged to explain its essence (Feinberg, 2002, 2003; McHale et al., 2004; Van Egeren & Hawkins, 2004) pointing to specific components of coparenting, its actors, correlates, and mechanisms. What they have in common is the assumption that coparenting is not a homogenous construct – it is composed of positive and negative elements. Coordination, cooperation, and support are central to coparenting as they ensure the well-being of all members of the family system. The concept of coparenting by Feinberg (2002, 2003) is central to this study. Feinberg points to other roles undertaken by mothers and fathers (e.g., professional roles) that may be relevant for families with a child with a disability. Moreover, he embeds his concept in the ecological theory, which is considered important in explaining the functioning of a family with a child with a disability (cf. Portes & Vieira, 2020).

In Feinberg's concept, coparenting consists of four elements: (1) agreement in child rearing, signifying the degree to which parents share values, expectations, and parenting styles; (2) division of duties involving childcare tasks and responsibilities with the key role of being satisfied with it; (3) support, especially affirmative support, showing recognition of the other parent's competence and efforts; (4) joint management of the family, and therefore, family interactions, behaviors, and communication (Feinberg, 2003; Feinberg et al., 2012). These components have been supplemented over time by parenting-based closeness found through qualitative studies with parents (Feinberg et al., 2012; Feinberg & Kan, 2008). The authors distinguish it from support, writing that "parenting-based closeness derives from shared celebration of the child's development, working together as a team, and witnessing one's partner develop as a parent" (Feinberg & Kan, 2008, p. 254).

Qualitative research with parents of children with disabilities demonstrates that their parenting experiences, both positive and negative, can be captured in specific elements of coparenting, confirming the utility of this theory as one of the multidimensional explanations of parental adjustment to life with a child with a disability (May et al., 2017; Mendez et al., 2015; Portes & Vieira, 2020; Rafferty et al., 2020).

To understand the essence of coparenting in families with a child with disabilities, it may be useful to refer to the Continuum of Dependent Care Model theory, whose authors use the social model of disability (M. Oliver) and the model of family adjustment to chronic illness (J. S. Rolland), to explain the essence of family functioning in the face of taking on special care responsibilities (Stewart et al., 2018). According to the theory, dependent family care responsibilities include the physical, emotional, social, and financial support provided to a dependent person, such as a child or an adult related to the caregiver. This type of family care is situated on a continuum, beginning with typical caregiving responsibilities and ending with exceptional responsibilities, that is, those that caregivers undertake for a family member with a disability or chronic illness. Family caregivers can be placed on this continuum, depending on the intensity, type, and complexity of care, but also the resources at their disposal (including environmental resources such as formal and informal support) (Stewart et al., 2018). This model is useful insofar as it makes it possible to capture in parents' experiences both typical care associated with the course of life (care of young children or the elderly), "normative" so to speak, and exceptional care associated with the trajectory of disability. The latter is characterized by the increased physical, emotional, social, and financial demands faced by families. According to the life cycle concept, family life and the individual development of its members are characterized by alternating phases with changing developmental tasks (Rolland, 2012) that also impinge on the greater or lesser intensity of caregiver cooperation (Feinberg, 2002; Riina & Feinberg, 2012). Families with a child with a disability have different configurations of needs in this regard, resulting, for example, from the fact that there are also non-disabled children in the family but also from the diverse developmental and special needs of children with disabilities. From a long-term perspective, exceptional caregiving requirements are unpredictable and recurring,

but they also do not end when the caregiver becomes incapacitated or dies (Stewart et al., 2018).

The variety of tasks involved in raising a child with special needs, often very specific compared to tasks undertaken by parents of children without disabilities (e.g., rehabilitative, therapeutic, and advocacy tasks resulting from extended time/specialized care and nurturing) raises the need for coparenting in many areas, such as socialization, education, rehabilitation, and contact with specialists (Meadan et al., 2015; O'Hare et al., 2023; Schippers et al., 2020; Smith & Samuels, 2021). Parents may have different competencies required for performing these tasks since their participation and responsibility for these tasks may vary. Research shows, for example, that mothers take on more child-rearing tasks, which is not uncommon because fathers are more involved in maintaining the family (Hartley et al., 2014; Pancsofar et al., 2020; Schippers et al., 2020). Empirical evidence also suggests that fathers want greater involvement in caregiving tasks and collaboration with specialists (Rafferty et al., 2020), and their involvement depends on their partner's attitude but also on the non-family environment (Mavrogianni & Lampropoulou, 2020; Pancsofar et al., 2020; Potter, 2017). Cooperation with the partner is an important factor in strengthening paternal involvement (Brągiel & Kaniok, 2014; Sato & Araki, 2022).

In conclusion, such trends may be relevant for the child-rearing agreement and child-rearing labor: broadening the areas related to child rearing that require cooperation, compatible expectations and priorities, and a division of responsibilities in these areas that is satisfactory to both parents.

In families of children with disabilities, mothers' attitudes and beliefs about their irreplaceable role and dominant involvement in caregiving tasks can be a problem (Kaji et al., 2021; McAuliffe et al., 2019). Kaufman and Pickar (2017), characterizing the functioning patterns in families of children with special needs, write about the parent who considers themselves an expert and the only capable parent. Both patterns include beliefs and behaviors that interfere with positive coparenting, such as considering oneself a dominant knowledgeable authority, being an expert on the child's issues, or assuming sole responsibility for coordinating care and collaborating with others (specialists). Among other things, the authors write about a lack of trust in the competence of the other parent, which is not based on a realistic assessment of their capabilities. In conclusion, such tendencies can impact the joint management of family relations, just as the above-mentioned ones.

The developmental progress of a child with a disability may be less visible compared to that of their peers without disabilities, and achieving developmental milestones may be delayed or impossible (Crown, 2009). This will play a role in the smaller gratification of parental caregiving activities. Importantly, however, over time, parents may learn to assess their child's development based on individual criteria, allowing them to focus on their child's achievements, sometimes small, and create a vision for the future based on the child's abilities (Kirby et al., 2021; Park & Chung, 2015). In conclusion, such tendencies may be particularly relevant to the component of parenting-based closeness, which includes, among other things, celebrating the child's milestones together.

The social model of disability (Oliver, 2004) and the biopsychosocial model (WHO, 2013) explain the nature of the parental experience of caring for a child with a disability. Both see the environmental context as crucial for differentiating the adverse consequences of limitations and dysfunctions in health and fitness (Stewart et al., 2018). Some studies show lower availability of support and satisfaction with it in parents of children with disabilities and point to the phenomenon of social isolation and self-isolation in families (e.g., Boehm & Carter, 2016; Byrne et al., 2018; Laslo-Roth et al., 2023; McCafferty & McCutcheon, 2021). In conclusion, the ecological model assumes that environmental conditions are important for the quality of coparenting. Presumably, the lower availability of informal and formal support will impact particular dimensions of the construct.

We have relatively scarce and diverse material illustrating the problem of coparenting in families with a child with disabilities. Studies have included parents of children with autism spectrum disorders (ASD), intellectual disabilities (IDs), and cerebral palsy (CP). Certain variables describing the child's functioning were found to be significant, such as the child's challenging feeding behavior (Thullen & Bonsal, 2017), the level of motor skills (De Souza et al., 2019), the severity of ASD symptoms (Chang & Leung, 2020), and the diagnosis (Sim et al., 2017). A mediating role of coparenting for self-efficacy and stress has been shown (May et al., 2015), and a moderating role for time spent with the child (during the pandemic) and parental stress (Bentenuto et al., 2021). Coparenting was important for parental well-being over time (Sim et al., 2017) and linked to the quality of the marital relationship (Chang & Leung, 2020; Leung, 2020) and fathers' involvement. Interestingly, the patterns of connectedness varied, depending on the coparenting component.

The Context of Family Care and Coparenting

Coparenting does not imply equal distribution of power or equal contribution of parental responsibility (Feinberg, 2003). Their level depends on factors from the broad socio-cultural context and parents' context. According to the ecological model, coparenting is influenced by individual, family, and non-family factors (Feinberg, 2003). These include (a) environmental support/stress originating from the environment (e.g., stress from financial difficulties, stress at work, work–family conflicts); (b) parents' characteristics such as attitudes, for example, gender role expectations, or mental health; (c) characteristics of the child, such as their temperament; and (d) the overall relationship between parents. These factors are interdependent. The model points to the mediating and moderating role of coparenting, which manifests itself in the relationship between the aforementioned environmental and personal factors, the parents' adaptation, the child's adaptation, and parenting (Feinberg, 2003).

Several factors, including personal and environmental, increase the likelihood of taking on the role of a caregiver, assuming the role of a lead caregiver, but also modify the course of care (Stewart et al., 2018). Factors that increase the likelihood of taking on the role of a lead caregiver for a dependent person, also a child with a disability, include female gender, younger age, and being married

(Stewart et al., 2018). The trend for mothers of children with disabilities to assume the role of a primary caregiver may be due to internal intra-family arrangements under which couples are more likely to exhibit a distinct division of responsibilities, with mothers contributing more to the tasks of caregiving and education and fathers to economy and security (Portes & Vieira, 2020). Depending on how well this division of responsibilities is accepted, the level of parental satisfaction can vary, which will affect coparenting experiences (Feinberg, 2002, 2003).

Over the family life cycle, the demands of dependent family members will change (Rolland, 2012), but we can expect them to be more intense during the younger phases of family life and parental age due to caregiving needs for young children. As previously mentioned, exceptional caregiving requirements may not be similar in terms of this pattern due to the prolonged dependency of family members with disabilities. Data on parental age for coparenting are not uniform. Longitudinal studies have found that the older age of mothers promotes positive aspects of coparenting, but this trend has been established in a group of mothers who are not in direct contact with the child's father (Choi & Becher, 2019).

Previous research indicates a negative role of adolescence for positive aspects of coparenting, which may be caused by the fact that parental demands increase during this developmental time (Han et al., 2023; Riina & Feinberg, 2012) even though the demands of normative care should be lower than in the previous period due to children's greater independence (Stewart et al., 2018). Such a trend, however, has been established in studies with parents raising non-disabled children and may not be found in parents of children with disabilities, especially complex ones, where the disorders largely determine the scope and severity of developmental needs. On the other hand, these children also reach a difficult period of adolescence, and for parents, it can be a critical period, not only in terms of increased parenting challenges (attempts to increase autonomy) but especially in terms of realizing differences from non-disabled peers (failure to reach milestones) (Crown, 2009; Winning et al., 2022). Some studies do not confirm the significant role of age and gender of non-disabled children (Han et al., 2023; Stright & Bales, 2003) and children with ASD (Sim et al., 2017). Others point to the possible differentiating contribution of the gender of a child with a disability: negative for girls and positive for boys. Such a gender contribution has been found in the context of other variables, such as the child's age, whether they attend a school, and the family or economic situation (de Souza et al., 2019).

Parental and family experiences of caregiving, including its typicality-exceptionality and demand for resources (e.g., spousal support), differ depending on the intensity, type, and complexity of demands (Stewart et al., 2018). From the perspective of raising a child with a disability, the characteristics of the disability, such as the causes (how it originated), course, and symptoms, will determine the demands (cf. Rolland, 2012). The complexity of the disability, but also the greater severity of its symptoms, will imply the need to undertake more specialized and complex care services, requiring greater cooperation between caregivers and the community, including the specialists (Stewart et al., 2018). The evidence gathered so far has largely included parents of children with ASD. Data show the severity of the symptoms may be detrimental to some positive aspects of coparenting

(Downes & Cappe, 2021) and reinforcing the negative ones (Chang & Leung, 2020). Importantly, the quality of parental cooperation creates certain conditions for the development of the child and the realization of their special needs, which may be evident in the results confirming the mediating role of coparenting between the child's difficult behaviors and parental stress (Sim et al., 2017). Difficult behaviors of the child can trigger negative parental reactions and behaviors, which, in turn, is a potential factor for escalating such behaviors (Mendez et al., 2015).

Caring for dependents will require, as already mentioned, various resources, including knowledge and skills, and access to various forms of support (Stewart et al., 2018). One such personal resource is education. Empirical evidence gathered in studies with parents of non-disabled children indicates a more favorable contribution of higher levels of education (compared to lower levels) in shaping coparenting outcomes, regardless of the age of the non-disabled child (Han et al., 2023; Stright & Bales, 2003). This trend is explained by predicted greater parental competence relevant to specific demands and expectations in the relationship with the child, and with the partner in more educated parents.

Aim

Given the importance of the construct in many dimensions of parents' and children's functioning, the lack of interest in analyzing it among parents of children with disabilities, especially in Poland, is surprising. In the case of families raising a child with a disability, there are many specific areas where mothers and fathers must cooperate at the decision-making and operational levels. Examples include therapeutic strategies aimed at dealing with the child's difficult behaviors (e.g., in ASD), or the design and implementation of individual educational programs, which require parental cooperation with specialists (Kaufman & Pickar, 2017; Thullen & Bonsal, 2017).

Raising a child with special needs brings many challenges and requires undertaking various tasks (Saini et al., 2015). Parental cooperation is one of the aspects that determine the conditions for a child's socialization and prepare them for adult life (Norlin, 2017). Coparenting can be the subject of interventions aimed at strengthening its positive aspects, also for parents of children with disabilities (Mendez et al., 2019; Yingling et al., 2020). Data show that access to specialized support, including informational or instrumental support, can facilitate parents' ability to build consensus on child rearing (Rosencrans & McIntyre, 2020).

The analyses were aimed to find out the importance of selected parenting and child-related variables in terms of the various components of coparenting in families of children with disabilities. Based on the assumptions described above regarding the context of caregiving and coparenting, referring to the dependent family care model (Stewart et al., 2018), the following hypotheses were formulated:

H1. The intensity of each dimension of coparenting, including positive and negative coparenting, will be related to the sociodemographic characteristics of the caregiver, including their gender and age.

Table 1.1. Variables and Their Indicators.

Variables	Variable Indicators
Dependent variable	
Coparenting	Intensity (average results): Coparenting Agreement, Coparenting Closeness, Exposure to Conflict, Coparenting Support, Coparenting Undermining, Endorse Partner, and Division of Labor
Independent variables	
Sociodemographic characteristics of the caregiver	
Gender	Female (mothers)/male (fathers)
Age	Mothers' average age; fathers' average age
Characteristics of a dependent person	
Age	Average age of a child with a disability
Gender	Female/male
Multiple disabilities	Presence/absence of multiple (1–0) disabilities (at least two disabilities) in the child
Functional status	Average determining the level of independence of a child with a disability in basic self-care activities and locomotor skills
Difficult behaviors	Average determining the range of occurrence of difficult behaviors in a child with a disability
Caregiver resources	
Education of mothers and fathers	Primary and basic vocational education; secondary education; university degree

H2. The intensity of each dimension of coparenting, including positive and negative coparenting, will be related to the characteristics of the dependent (a child with a disability), including age and gender, the presence of complex disabilities, functional status, and the occurrence of difficult behavior.

H3. The intensity of each dimension of coparenting, including positive and negative coparenting, will vary depending on the caregiver's resources manifested by their education level.

Undoubtedly, an important resource potentially differentiating the parenting experience in the area studied here is the caregiver's employment (Stewart et al., 2018). Still, this variable takes on a specific distribution in the population of Polish mothers of children with disabilities: most mothers do not take up employment (give it up) because they take care of the child with a disability.

Table 1.1 presents the variables and their indicators.

METHODS

The material was collected using The Coparenting Relationship Scale by Feinberg et al. (2012) in a Polish adaptation by Więsyk et al. (in press). The scale (35 items) identifies the following dimensions of coparenting: Coparenting Agreement,