

ANNE F. FARRELL *University of Connecticut*

GLORIA L. KRAHN *Centers for Disease Control and Prevention**

Family Life Goes On: Disability in Contemporary Families

Disability is part of life for most contemporary families, but to date the literature on disability in families is fragmented and narrow. This editorial commentary introduces the content and findings of peer-reviewed articles appearing in a special issue of Family Relations. The editors outline unanswered but core research questions and preview the themes present in the issue: families with disabilities are diverse; economic hardship disproportionately characterizes their lives; family life with disabilities is a journey that includes stress and resilience, with support contributing significantly to the latter; and that work benefits and taxes family life. Articles extrapolate beyond findings to explore implications for family policy and practice. The editors assert that developing understanding of how disability influences families requires a more diverse and rigorous research portfolio. They further cite the need to embed disability as a variable in a range of family studies and advocate more outlets for publication.

With about 15% of people experiencing significant disabilities in the United States and globally, disability is or will be part of life for

Human Development & Family Studies, One University Place, Stamford, CT 06901 (anne.farrell@uconn.edu).

*Division of Human Development and Disability, National Center on Birth Defects and Developmental Disabilities, 1600 Clifton Road, NE, MS E 88, Atlanta, Georgia 30333.

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most contemporary families. The odds are that nearly every member of the *Family Relations* readership has an extended family member, colleague, or friend who has a disability. Most of us will find ourselves living with disability at some point in our lives. In spite of this, we observed the research literature on disability within a family context to be fragmented and narrow in scope. That observation led to our Call for Papers in June 2012 for a special issue of *Family Relations* to focus on families and disabilities, one we hoped would address some important questions. How do families welcome a child with significant disabilities into their family? What promotes optimal family quality of life if a member has a disability? On balance, what is the role of work among families with a member with disabilities? How do adults with paralysis or traumatic brain injury resume the multiple roles of parent, spouse, and employee? What supports are most helpful as families care for aging members with limitations? What implications do research findings hold for policies and programs to support family life? Most important, what tangible steps might help families to capitalize on their own capacities and those of the community to cope, adjust, and thrive in spite of multiple challenges?

We set out with ambitious intentions. Principally, we wanted to document the status of current research on disability and families. In doing so, we wanted to explicate the multiple roles of people with disabilities within families and demonstrate how families experience and adapt to disabilities across the life course.

We hoped that submissions would embrace contemporary changes in society's view of persons with disabilities as fully participating members of their families and communities. We began with the intent to demonstrate how theoretical models and empirical scholarship have evolved to mirror the paradigm shifts evident in the move from institutionalization to special services to an expectation that individuals with disabilities can and do and will participate fully in society, fulfill valued roles, and live long, healthy, and integrated lives.

We aspired to explore the intersectionality among racial and ethnically diverse families and the health disparities that characterize the population of people with disabilities. We aimed to advance the field's understanding of how formal and informal supports affect the routines, challenges, and functioning of persons and families. Importantly, we invited each article to explicitly address the policy and program implications of their findings. We hoped that this issue would not just summarize the state of the science but also stimulate discussion, anticipate new perspectives, shape the emerging scholarly agenda, and influence policy and practice.

Consistent with these aims, we identified leaders in the field to anchor the issue with reflections on key topics. To frame the issue in demographics of disability within family, Glenn Fujiura agreed to describe the arithmetic of disability within the family context. For a scientific grounding in genetics and early identification of disability, Don Bailey and colleagues presented and reflected on issues in the field of genetic testing for disabling conditions. Given the critical role of self-determination in empowerment of youth and adolescents with disabilities, Michael Wehmeyer agreed to summarize his seasoned perspectives about research that examines self-determination of youth with disabilities and implications for all families. We also intended to provide a broad overview of programs and policies for people with disabilities and their families that might frame and inform research. Sue Swenson and Charlie Lakin agreed to reflect on their perspectives as influencers of federal disability policy—its effects, and its potential. Unfortunately, despite active solicitation and searching internationally, we were unable to identify a scholar whose writing would fully encompass the multiple family roles that persons with disabilities currently fill—that of parent, spouse, breadwinner, and member of an

extended family. Our difficulties in this effort presaged what would emerge as the current state of research in the field.

The response to the Call for Papers was gratifyingly strong; we received more than 50 manuscripts. Clearly this response signifies a need for publication outlets and expanded scholarly exchange on families and disabilities. In considering articles, we sought to provide a diverse collection framed by features such as family roles, cultural and cross-cultural issues, content emphasis, and study design (quantitative, qualitative, mixed methods, reviews). We were privileged to review an array of manuscripts that indeed spanned the life course and provided nuanced portraits of individuals and families. Scholars with an impressive array of expertise and disciplinary backgrounds served as careful reviewers of these many submissions. We owe a debt of gratitude to the dozens of reviewers whose expertise and care helped shape the content and style of each contribution to this volume. The journey from that initial Call to this final collection of articles has been rich and rewarding. Along the journey of developing this issue, we shifted our own view from “families and disabilities” to that of “disabilities within families.”

As the issue took shape, a few themes became evident. Glenn Fujiura's opening demography article establishes the universality of disabilities by reviewing the prevalence of families who have members with disabilities. Writing with authority and elegance, he informs us that the overwhelming majority of individuals with disabilities live in family settings, and that families with disabilities represent a significant proportion of today's families. He concludes that “there is no prototypical family type; the structure of households is variable and interacts in a complex fashion with key characteristics of its members” (p. 13, this issue). To expand on this, the Altman and Blackwell article provides numerous tables that document the status of disability within U.S. households; these data should prove an invaluable resource for many researchers and policy makers. Their article reveals the finding that one fourth of all households with an adult with a disability are one-person households, a percent that is comparable to one-person households for the entire population. Further, 43% of households with elders (age 65 and older) have members with disabilities. We came to understand that numerous

surveys of disability have omitted persons living alone or with unrelated persons. Whereas it seems clear that “nonfamily” households are worthy of being counted, these authors raise concern about the policy, planning, and human implications of excluding them. The message extends beyond an embrace of wider social changes in family structure to involve the caregiving implications of community members who reside a distance from biological relatives or in isolation. These individuals may be particularly vulnerable to policy changes that affect the availability of critical supports. Taken together, these two articles convey disability as a normative part of the family experience and begin to portray the array of family settings that include disability.

A second critical theme is that poverty is more frequently a characteristic of families with disabilities compared to the general population. Economic hardship is more evident among racial and ethnic minority households, single-parent families, and households that have multiple members with disabilities. Poverty is a major social determinant of health and quality of life. Morris informs us of a “strong, independent association between mental well-being and income, with poorer parents experiencing significantly higher rates of anxiety and depression” (p. 118, this issue). As Swenson and Lakin articulate so eloquently, the dual impact of the stresses of poverty and the challenges of accommodation to the disability have clear implications for policy and programs to support families. The unfortunate but robust coincidence of disability and socioeconomic stress presents consistently.

Consistent with the field’s movement away from remedial to strengths orientation, we begin to see that living with disabilities has life-enhancing and life-affirming aspects. Despite the increased stresses of living with disability within a family, individuals and families are remarkably resilient to the challenges that temporary and lifelong disabilities present. The interdependent nature of individual, family, and community life is an important subtext illustrated in several articles. The articles in this issue reflect and call for a more fine-grained, ecologically based understanding of the complex ways that stressors and assets; individual, family, and community characteristics; and formal and informal supports combine to affect the way families live. Family interconnections are forged through learning to manage the life

challenges that having a disability can bring, and the sense of belonging we derive through family relationships. Research paradigms have yet to fully realize salutogenic perspectives; yet the articles here represent movement forward in exploring a positive agenda.

Following these foundational contributions, the study by Woodman employs data from the Early Intervention Collaborative study to present longitudinal (early childhood through adolescence) and dyadic (mother–father pairs) trajectories of parenting stress among parents whose children have developmental disabilities. In examining how parenting stress changes over time in response to developmental changes, behavioral and related features of child disability, and family resources, this article is a significant contribution to the literature. Woodman provides a much-needed depiction of the prototypical trajectories of stress by family climate and social support. Importantly, most parents in the sample did not experience clinically significant parenting stress, and when stress was present, social support typically served to buffer it to help families cope.

Similarly, Farrell, Bowen, and Swick report that military families who have children with special health care needs demonstrate resilience in the face of challenge. These authors examined the support experiences and perceived resilience of mothers whose children have special health needs. Informants were mothers who serve as Key Spouses (supports) for other families experiencing the exigencies of military life, including parenting children with developmental and health concerns. Mothers whose children have special health needs experience significantly less support than their counterparts, and yet they are equally resilient overall. Increased formal and informal network support was associated with greater resilience. The implications of this work, which is embedded in the social organizational theory of community action and change, are significant for the armed forces and may extend beyond, particularly as the field looks to understand processes that support family resilience.

Smith, Ronski, Sevcik, Adamson, and Barker examine differences in parent stress and parent perceptions of language development between parents of young children with Down syndrome and parents of children with other disabilities such as genetic syndromes, cerebral palsy, and pervasive developmental disorder. Parents of children with Down

syndrome experienced lower levels of total stress, child-related stress, and stress related to parent-child interactions. Across diagnostic groups, parents felt successful in their ability to affect their children's communication development, again illustrating that families of children with disabilities are characterized by normative and adaptive responses. Despite similar measured language skills, parents of children with Down syndrome perceived their children's communication difficulties as less severe than parents of children with other disabilities. These authors frame their discussion in terms of the need to consider etiology and other variables in understanding family responses and highlight social cognitive processes that might influence how parents construct their own understanding of their children's strengths and needs.

Don Bailey and colleagues provide an intriguing and instructive cross-condition review of population-based carrier screening that illustrates how testing has the potential to inform the reproductive decisions of prospective parents and help families prepare for life with a child who has a significant health or developmental condition. This article raises, but does not pretend to resolve, important questions, such as when and to whom should screening be offered, and for what conditions. How can families living in poverty or with limited access to care be afforded the same choices as families with greater resources? How might this technology affect family policy and how might policy affect the use of this technology? Bailey et al. convey the weighty consequences of these deeply personal decisions while contextualizing them in an interdisciplinary, evidence-based review that illuminates a range of concerns facing professionals and families in the genomic era.

Three articles address the influence of work in families where one or more members have disabilities. Morris extends prior examination of the impact of work on the psychological well-being of parents who have children with disabilities. Using representative data from the National Survey of American Families, she finds that work provides particular mental health benefits ("positive spillover") for parents of children with disabilities, yet these benefits are most evident under specific conditions and disappear at high levels of work. Morris cautions the reader that the magnitude of effects was modest, that a number of social and contextual variables influence the experience of work, and

that further inquiry is needed. She observes that supporting families is important beyond the short- and long-term economic effects.

In a similar vein, Song, Mailick, and Greenberg examined the effects that work stress had on the health of parents providing care for their adult children with serious mental illness. Work-to-family spillover and working in a position with schedule inflexibility was more detrimental to the health of parents of adult children with serious mental illness than to comparison parents. Their findings of somewhat different effects for mothers and fathers contribute to a finer-grained understanding of the relationship of work, disability, and family roles.

Comparing how work stress is experienced among mothers with and without children with disabilities, Wong, Mailick, Greenberg, Hong, and Coe examine daily work stress and awakening cortisol in mothers of individuals with autism spectrum disorders and Fragile X syndrome. When mothers of individuals with developmental disabilities experienced work-related stress, their awakening cortisol level was significantly higher on the subsequent morning, but this effect was not observed among their counterparts who did not have children with disabilities. There appear to be chronic differences in the physiological functioning of mothers who have children with disabilities, particularly as this role interfaces with work. Wong and colleagues assert that low cortisol may be an adaptive compensatory response, in essence an emotion regulation strategy with cognitive and affective components. A unique contribution of this study is its combination of naturalistic (maternal diaries) and physiological measures.

Together, these three articles reveal that, regardless of phase of life, work appears to benefit and tax families and that the conditions of benefit vary. They further underscore the need to consider the interaction of employment contexts and policies, the nature of caregiving demands and supports, gendered aspects of work and parenting, shared and unique sources of stress and resilience within families and communities, and economic, cultural, and familial factors. The policy implications are many and much more work is needed if families are to experience tangible benefits from the fruits of scholarship.

The rich literature on family relationships of adults with disabilities is presented in two articles and the Wehmeyer commentary. In their exploration of sibling relationships and

disability, Burbidge and Minnes compare the contact adults maintain with their sibling with disabilities compared to another sibling without disabilities. Participants reported more contact with the sibling with a developmental disability, in-person and telephone, and of particular note, more positive feelings about that relationship compared with their relationship with a sibling without disabilities. In a complementary second study, these authors interviewed adults with developmental disabilities to report their perceptions about their sibling relationships. Adults with developmental disabilities reported that they provided support to and received support from their adult siblings and expressed a desire to spend more time with them. Sibling relationships that include disability are rich and meaningful components of family life.

Zehner, Ourada, and Walker remind us that family caregiving is not a “family problem,” given the great benefits that society derives from its reliance on family caregiving for family members with disabilities. In their comparison of a representative sample of caregiving parents with caregiving adult siblings of persons with disabilities, they document a strong association between perceived family demands with the number of health conditions for both groups. Parents in particular report negative consequences on their health, likely due to the number of years in which they provide care. In this study, social support was not a strong mediating factor to ameliorate this impact. This work echoes themes explored by Swenson and Lakin, Farrell and colleagues, and Morris: the inevitability, costs, benefits, and compelling need to understand the contextualized nature of care provision in families.

Although response to the Call for Papers was notable for sheer volume of submissions, the content reflected gaps in the current fields of study, or at least submissions to this special issue. Our editorial approach of matrixing manuscripts by content area, age of sample with disabilities, and study design was revealing. Virtually all of the submissions related to offspring with disabilities, as young children or as adult children, and the concomitant stresses on families. The singularity of this research perspective likely reflects the status of current research, which is somewhat mismatched when demography is considered. As such, the singularity points to the need for a concerted and deliberate expansion of how we conceptualize the family roles of persons with disabilities.

In terms of study design, the preponderance of research submitted represented cross-sectional quantitative studies. Many studies used sophisticated analysis methods to explore relationships among variables at a single point in time. An exception is Woodman’s study of parenting stress that is longitudinal in design. Although many submissions were based on convenience samples, for example, Altman and Blackwell used population-based national data, whereas others (Song, Mailick, & Greenberg; Wong et al.; Zehner, Ourada, & Walker) were based on sampling methods representative of defined populations. We received a number of studies that relied on qualitative methods; many were of scientific merit and yet did not qualify as significant, novel contributions to the literature. The good news contained in that observation is that the existing body of research captures fairly well the contextualized nature of disability and family when individual families are the unit of analysis. Consequently, there is limited need for studies with restricted external validity and a burgeoning need for studies that enable population-level inferences about families with disabilities, subgroups of the population, and how disability interacts with family characteristics and services over time to affect individuals and families.

As guest editors, we experienced continuous tension between our desire to expand the type and scope of articles while also ensuring that each study reflected sufficient scientific rigor for inclusion. For example, submissions from the voice of persons with disabilities were very limited, and the few submissions received were not sufficiently developed to survive the review process. One exception was the Burbidge and Minnes article that collected information on sibling relationships from the perspective of adult siblings with and without intellectual disabilities. Finally, despite our efforts to solicit contributions from multiple countries, the vast majority of submitted studies were conducted with U.S. families. Were a similar issue to be compiled in several years’ time, we would look forward to seeing more attention to policy analyses, systematic literature reviews, and longitudinal studies from different countries that could demonstrate how different policies in different countries determine practices and influence outcomes.

This special issue of *Family Relations* reminds us that disability is a universal aspect

of life, that families who have members with disabilities are more different than alike, that most families are resilient in spite of stress, and that families contribute to and derive benefit from engagement in work. We celebrate the emerging knowledge on disability in families. Together, the scholars who contributed to this issue lay out the challenge for the future in four notable ways. First, the issue unveils the need for expanded publication outlets to serve as forums for scholarly research and dialogue on disability in families. Without one or two journals designated to disabilities in families, the corpus of knowledge for this field will remain fragmented. Second, there is a need for family scholars to more intentionally embed disability concerns into ongoing inquiry into the nature of contemporary family life. Although this may seem to contradict the first direction we recommend, we argue that the absence of disability as a common variable of interest in family studies limits the field's understanding of important sources of family diversity, strain, and resilience. To understand the influence of family life on disability and disability on family life, the scholarly lens needs to focus on disability both as a defining and as a common characteristic.

Third, and important, we call for a more diverse research portfolio to develop the understanding of how disability is a part of our family lives, contributing to the experience of family stresses and satisfactions. We call for more variation in study foci, research designs, populations, measures, and voices. In particular, research needs to be conceptualized with the explicit intention to inform practice and policy, including partnering with policy makers to anticipate and address needed knowledge, and produce studies with results that are easily translated into actionable steps. Research needs to capture the inter-related longitudinal and interactive nature of disability and family, and the "nestedness" of children in families, families in communities, and communities within service systems. Multilevel modeling will be critical to capturing the complexities inherent to understanding what families need, their preferences, and the responsiveness of supports that are intended to promote well-being. Important questions to consider include: What are the values underlying the critical research foci? What are the overarching questions that need to be asked and investigated? What methods are best suited to address the

compelling questions that need answering? What theories or conceptual frameworks are best used to frame research? What voices are missing? Are concepts and measures adequate to the task of portraying diverse cultures and perspectives? Is the research conversant enough with policy opportunities to result in tangible steps toward change? Are findings disseminated and translated with sufficient breadth and depth to cause ripples across constituencies, including scholars, policy makers, practitioners, educators, advocates, and families?

A fourth and final challenge is to infuse disability more meaningfully into undergraduate and graduate curricula across disciplines. The rich complexity of family lives and family relationships is relevant for many disciplines. The addition of disability only increases that complexity. Preparing students for their varied future roles as professionals requires preparation that embraces disability as a form of family diversity, builds skill, and enhances confidence to tackle these complex issues to map new directions for disability within families. We are confident that the articles in this issue will stimulate rich dialogue within and outside the classroom and we hope they will spawn new inquiry as well.

We invite readers to read each of these contributions, recognizing the expanding perspective and rigorous methodologies that contribute to advancing knowledge of disabilities within families. We greatly appreciate Ron Sabatelli's invitation to develop this special issue, the confidence with which he entrusted the issue to us, and his sage guidance and encouragement as the issue took shape. As well, Lindsay Edwards gently prompted action and ably supported our careful deliberation throughout this process. We have learned so much in the process of developing this issue. We extend the challenge to you, the readers of *Family Relations*, to critically examine the perspectives, methods, and findings of these articles, and to apply them to your work. Doing so can meaningfully impact scholarship, policy, and practice, hopefully to the ultimate benefit of families.

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