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Disability and the Self-Reliant Family: Revisiting the Literature on Parents with Disabilities

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Abstract

An estimated 8.4 million adults with disabilities have children under age 18 living with them. Despite the large number of adults with disabilities engaged in parenting, studies of parents with disabilities have been relatively scarce, though the number is growing. This paper reviews the literature on parents with disabilities as a whole and elaborates three themes relevant to parental support and care: parental capacity, “young carers”, and social networks. Also discussed are key concepts from the feminist and disability studies literatures that can form the basis for a theoretical framework to guide research on parents with disabilities.

Keywords

Sociology of Disability; Disability Studies; Parents with Disabilities; Care-Giving

An estimated 8.4 million adults with disabilities have children under age 18 living with them (McNeil, 1993), of which between 2.6 and 4.7 million (depending on the measure of parental disability used) are raising adolescents aged 11 to 17 (Olkin, Abrams, Preston, & Kirshbaum, 2006). Despite the large number of adults with disabilities engaged in parenting, studies of parents with disabilities are relatively scarce, though the number is growing. Many have attributed the recent expansion of this literature – and of the literature on parents with intellectual disabilities in particular – to the growth in opportunities for people with disabilities to become parents due to deinstitutionalization, improved prospects for independent living, and changing attitudes about the sexuality of people with disabilities (e.g., Booth & Booth, 1998; Llewellyn, McConnell, Cant, & Westbrook, 1999).

Parents with disabilities are vital to understanding the nature of care-giving, dependency and self-reliance because they simultaneously occupy two subject positions that we usually treat as distinct from one another; they act both as the recipient of care (the role in which people with disabilities are typically considered) and the care-giver (Morris, 1993; Walmsley, 1993). They must continuously negotiate the tension between these roles in the face of challenges related to their disabling conditions and, more importantly, to barriers and

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stigmatizing attitudes posed by the broader community. Consequently, the study of parents with disabilities, traditionally located at the margins of mainstream social science inquiry, has the potential to significantly contribute to our understanding of all families. As Booth and Booth (1998) point out, “Looking at out-of-the-ordinary families throws new light on taken-for-granted assumptions about the process of parenting. Parents who break the rules help to define them more clearly. Observing children under pressure shows up the extent of their adaptability” (p. 1). Contemporary studies of care-giving demonstrate that, in spite of shared ideals about family self-reliance, reliance on paid and unpaid parent-figures outside of the nuclear family for childrearing assistance is widespread. Moreover, at least one study suggests that families who actually practice the ideal of family self-reliance are those under the greatest strain (Hansen, 2005). Such insights help us understand that interdependence is not limited to parents with disabilities, but rather is characteristic of a much broader segment of families.

The aims of this paper are to provide a review of the literature on parents with disabilities and to illustrate the contributions that can be made by integrating feminist scholarship on care-giving with research on parents with disabilities to develop a new framework in which care-giving is central. In this paper, I first provide an outline of the literature on parents with disabilities and elaborate on three major themes relevant to care-giving in particular: parental competence, young carers, and social networks. Next, I briefly highlight the conceptualizations of the relationship between disability and family in the literature on parents with disabilities. I then discuss key concepts in both the feminist and disability studies literatures that together can form the building blocks of a theoretical framework in which care-giving is central. This will guide future research on parenting by adults with disabilities, and perhaps parenting more generally. Last, I suggest a rough sketch of what such a care-giving framework might look like and highlight the issues that become critical under such a framework and what research questions might arise as a result.

THE LANDSCAPE OF RESEARCH ON PARENTS WITH DISABILITIES

Despite the large number of parents with disabilities, the literature on parents with disabilities is sparse. Of the literature that does exist, studies frequently focus on a narrowly defined subgroup typically defined by a shared medical diagnosis. Although some authors have made arguments against considering all parents with disabilities together (e.g., Kirshbaum & Olkin, 2002), I find that many of the same themes, concepts, and research problems were repeated throughout the literature, regardless of parents’ medical diagnoses, functional limitations or impairments. Therefore, scholarship on parents with different medical conditions and functional limitations is considered together for the purposes of this review.

In order to locate studies of parents with disabilities, I relied on the SocIndex research database and limited findings to articles, books, conference papers, or dissertations that were theoretical and/or empirical in nature and located additional studies through the bibliographies of studies identified in the original search. I considered all studies published in or before August 2008 but excluded from consideration descriptions of program interventions, policy prescriptions that did not include original theoretical or empirical work,

or personal narratives that were not tied to a research agenda. Because of my own limitations, I also excluded articles published in a language other than English. After imposing these parameters, I coded studies according to whether they were mostly theoretical or empirical, the country of research, and whether the research methodology (if applicable) was qualitative, quantitative, or a mixture of both.

An outline of the scholarship on parents with disabilities

Some general observations can be made about the landscape of scholarship on parents with disabilities. First, the majority of extant work has been published within the past ten years. The tenor of scholarship published in the past ten years is also substantially different than that of earlier literature. Much of the recent literature demonstrates a strong motivation to rebut the clinical nature and deeply negative appraisals of parents with disabilities and their families found in earlier literature (Aldridge & Becker, 2003). Second, over half of studies center on parents with intellectual disabilities, in part because these are the parents most likely to have their children taken from their custody. Accardo and Whitman (1990) report that 46% of parents with intellectual disabilities in the U.S. have had their children taken away and others suggest that children are frequently removed from their parents with little or no grounds to do so (McConnell & Llewellyn, 2000). Similar statistics do not appear to be available for parents with other kinds of disabling conditions.

Third, although a number of countries are represented, the current literature is dominated by studies conducted in the U.K. and U.S., and to a lesser extent, Australia and New Zealand. This is partially an artifact of limiting the search to English-language articles and the geographic location of some prolific researchers, but it is worth noting that all studies I was able to uncover take place in developed contexts with liberal welfare states. Fourth, theoretical and empirical works are both well-represented, with a diverse set of theoretical frameworks and research methodologies (quantitative, qualitative, and occasionally multi-method) available. Fifth, conceptualizations of disability used in this literature generally fall into one of three broad categories: (1) as a specific diagnosis or group of related diagnoses, such as multiple sclerosis or mental illness (e.g., Katz, Pasch, & Wong, 2003), (2) through receipt of professional services targeted to people with disabilities in accordance with Mercer's (1973) social systems perspective (Booth & Booth, 1998; Llewellyn et al., 1999), and (3) as systematic disadvantage (Olsen & Wates, 2003).

Sixth, a number of methodological challenges still face researchers working in this area. Although there are exceptions, the vast majority of empirical studies recruit participants through social service organizations and professionals rather than from the community or general population, heightening the potential for selection bias. In addition, most studies – qualitative and quantitative – rely on fairly small sample sizes, many with around 30 or fewer parents. Perhaps as a consequence of small sample sizes, many quantitative studies fail to control for important confounding factors like socioeconomic status. The greater part of empirical studies on parents with disabilities is cross-sectional in design, though a handful employs retrospective data collection using the recollections of children of parents with disabilities (e.g., Booth & Booth, 1998).

Last, most studies are published in disability-specific journals. The publication of studies in these journals has multiple implications, including that studying parents with disabilities is an interdisciplinary endeavor, that service professionals working with parents with disabilities are often the target audience and, to some degree, that publishing in disability journals furthers the political project of creating a more prominent place in the academy for disability studies as a discipline. Publication in disability-specific journals may also reflect the marginal status of the research with respect to the mainstream of social science inquiry. This is not to say that parents with disabilities never appear in non-disability specific journals, but this work tends to cast parents with disabilities as “problematic others” – for example, as the mothers who fail to transition off of welfare into work (e.g., Hardina, 1999), or as the parents who are overrepresented in child abuse cases (e.g., Taylor et al., 1991).

What don’t we know?

Despite the rapid growth in research on parents with disabilities, there are still a wide range of topics we know little about. For example, we still do not know much about the aspirations to parenthood held by adults with disabilities, or about the pathways they travel to achieve parenthood and how they compare to those of parents without disabilities. We also do not know much about the meanings of parenthood to parents with disabilities, and most of what we do know is focused on mothers with disabilities. Overall, there is a conspicuous absence of research on fathers, despite the fact that 75% of families parented by adults with disabilities have fathers present (Olkin et al., 2006). There is also a noticeable absence of research motivated by the core questions of family sociology, including those centering on the impact of family structure on child wellbeing, how parents negotiate the demands of work and home, the impact of community context on family wellbeing, or how race, class, and gender shape the experiences of parents with disabilities and their children.

CARE-GIVING IN THE STUDY OF PARENTS WITH DISABILITIES

In this section I discuss three thematic areas of research in the study of parents with disabilities directly relevant to our understandings of care-giving: parenting capacity, “young carers”, and social networks. In enumerating these themes, the focus is on how researchers frame the research problematic of parents with disabilities, the concepts they use to understand the relationships between parents with disabilities and their children and between parents with disabilities and the broader community, and the causal models and mechanisms they implicitly or explicitly pose.

Parenting Capacity

One recurring theme in the literature on parents with disabilities is that of parenting capacity. In many studies, parenting capacity is a key causal mechanism in the relationship between parental disabilities and poor parent and child outcomes; in other words, parental disabling conditions lead to potential deficits in parenting capacity, which in turn lead to high levels of parental stress and social isolation, and increased risk of developmental delays, neglect, and abuse of children (what Wolin and Wolin (1995) refer to as “damage model thinking”). However, parenting capacity is defined and measured in multiple, frequently incongruous ways.

Broadly speaking, parenting capacity has been defined in two ways: as *parenting efficacy*, and as *parenting competence*. *Parenting efficacy* is generally understood in instrumental terms. For example, Evans, Shipton and Keenan (2005) define parental efficacy in terms of “day-to-day childrearing tasks” such as “lifting, feeding and transporting children” (p. 685) among a sample of women experiencing chronic pain and “pain-free” controls. Katz, et al. (2003) use a similar measure of parenting capacity in their study of mothers with rheumatoid arthritis. Using these measures, the authors of both studies find that mothers’ disabling conditions and the attendant psychosocial distress are significant predictors of mothers’ parenting efficacy. This version of parenting capacity is quite limited because it fails to consider that parenting frequently involves more than lifting, feeding, transporting, and opening pill bottles for children. Regarding parenting capacity in this way is not only indistinguishable from the conceptualization of impairment, but also fails to consider that care-giving includes a substantial emotional component. Furthermore, the role of adequate support and accommodations may render such childrearing tasks incidental to the business of parenting.

A more significant collection of studies identify parenting capacity with *parental competence* in the context of child protection hearings. This literature documents discrimination by the courts against parents with intellectual disabilities and mental illness in the assessment of their parental competence and subsequent custody decisions. It also attempts to uncover the processes contributing to observed inequality in outcome. McConnell and Llewellyn (2000, 2002) maintain that many parents with intellectual disabilities and mental illness are presumed incompetent a priori and that, rather than being a true investigation of evidence, child protection hearings often become a means by which to certify parental incompetence. Furthermore, the effects of poverty, inadequate housing, and social isolation are frequently attributed to parental disability (Swain & Cameron, 2003). McConnell and Llewellyn (2000) describe court proceedings in which children were removed from their parents’ custody without evidence of neglect, when parental adequacy was acknowledged by the court, and in the presence of evidence that parents were addressing the difficulties leading to child removal (p. 885). Other barriers parents with disabilities face in child protection hearings are the lack of suitable support services, the inability to procure adequate legal representation (McConnell & Llewellyn, 2002), and the imposition of time limits that may prove burdensome to people with disabilities (Booth, McConnell, & Booth, 2006).

Much of this literature is silent as to what objective parental competence entails (though it is unequivocally against measures relying on IQ alone). However, based on the findings of several studies conducted by different researchers in the U.S., U.K. and Australia, some suggest that parents with intellectual disabilities or mental illness are held to a different and higher standard of parental competence than parents without disabilities. Moreover, given the same level of assessed parental competence, parents without disabilities are less likely to have their children removed from their custody (McConnell & Llewellyn, 2000, 2002; Swain & Cameron, 2003). As a result of observed inequity in the assessment of parental competence, some authors advocate for an understanding of parental adequacy that both acknowledges the resilience of children as well as the role of other parent figures in childrearing (Booth & Booth, 1998).

Care-giving role reversal and the problem of young carers

Another strong theme in the literature on parents with disabilities is a concern with the likelihood that children of parents with disabilities will assume care-giving responsibilities for their parents. Some studies express concern that individuals with disabilities make less capable parents, principally because of what LeClere and Kowalewski (1994) call the *burden of care*: the view that individuals with disabilities have the potential to negatively impact families because they require care and support but generally cannot provide care and support in return. As a result, family care-givers must invest time, energy and material resources into caring for and supporting family members with disabilities, in addition to forgoing the receipt of such care and support for themselves. Within this view, parents with disabilities are problematic because not only do they fail to provide adequate care for their children, but their children may be forced to assume age-inappropriate care-giving responsibilities for their parents – becoming “young carers” – which may, in turn, result in negative consequences for their intellectual, social, and academic development. A large body of work on parents with disabilities, known as the “young carers” literature, adopts a child-centric approach that is primarily concerned with documenting the adverse consequences that children of parents with disabilities can face as a result of assuming care-giving responsibilities for their parents. Olsen (1996), Newman (2002), and Olsen and Wates (2003) provide comprehensive overviews of the young carers literature.

The existing “young carers” literature has come under considerable scrutiny. Some identify weaknesses in the “young carers” literature on methodological grounds. Aldridge and Becker (1993) remark on the failure to compare “young carers” to other children who do not have parents with disabilities, or to children responsible for domestic tasks and care-giving under different circumstances. Olsen (1996) wonders how “young carers” can be labeled as “at-risk” by virtue of adopting care-giving and domestic tasks when no shared standard of reasonable involvement in domestic tasks and care-giving for children exists and moreover, when such a standard can vary by social class, gender, and cultural practices.

Others criticisms are made of the emphasis on children of parents with disabilities rather than the parents themselves. Olsen (1996) and Newman (2002) argue that investigating the relationship between parental disability and children’s care-giving responsibilities have considerable political implications, particularly in the U.K., where significant pieces of “young carers’ s” rights legislation have been passed. Newman (2002) also notes the difficulty of applying an individual rights framework to relationships between family members, particularly when, as in the case of the disability rights movement and efforts to protect “young carers”, the individual rights of family members come into conflict. Olsen (1996) worries that a focus on children rather than parents can also undermine the provision of supports to parents and the family as a whole in favor of supporting only the child. Despite the initial development of the “young carers” literature as separate and sometimes at odds with the literature on parents with disabilities, Olsen and Wates (2003) remark that “analysis by researchers coming from a disabled parents’ perspective on the one hand, and a ‘young carers’ perspective on the other, increasingly appear to reach similar conclusions in terms of how and why young people become involved in caring roles” (p. 30).

Social Networks

In recent years, a promising body of work on the role of social networks in the lives of people with disabilities has developed, some of which focuses on how these networks affect parents with disabilities and their families. Krose, Hussein, Clifford, and Ahmed (2002) examine the role of social networks in the psychological well-being of mothers with intellectual disabilities. Working from the concept of *distributed competence*, Kroese et al. maintain that many service providers share “the common misconception that parenting is carried out in isolation” despite the fact that “in most families other people, besides the parents, have a significant contribution to make to the child’s development and well-being” (p. 325). Accordingly, they find that mothers reporting more helpful network contacts have higher self-esteem and are less likely to feel that parenthood is burdensome. However, most mothers report having no friends in their social network and persistent fears that they will lose their children. Similarly, Feldman, Varghese, Ramsay, and Rajska (2002) find that social support plays an important role, although they find that mothers’ networks are more likely to contain social workers or friends than family members. In their study of mothers with intellectual disabilities, Llewellyn and colleagues (1999) also find support professionals have a strong presence in mothers’ social networks. However, they find that the share of mothers’ social networks containing support professionals vary by mothers’ living arrangements, where mothers living with their parents demonstrate the least amount of contact with support professionals.

Evidence of whether the strong presence of support professionals in mothers’ social networks is good or bad for parents with disabilities is mixed. On the one hand, Llewellyn et al. (1999) find that informal supports from friends and family are more likely to involve direct care for children and help with housework, but that support professionals are also likely to support parents in maintaining and improving their community involvement. On the other hand, Krose et al. (2002) point out that relationships between mothers and support professionals are non-reciprocal, making these ties more unequal and fragile than informal ties with family members and friends (Pescosolido, 2001).

HOW DO RESEARCHERS CONCEIVE OF THE RELATIONSHIP BETWEEN DISABILITY AND FAMILY?

Olsen and Wates (2003) classify existing research perspectives on the relationship between parental disability and family in three ways: (1) Personalized, (2) Ecological, and (3) Organizational. Under this classification, personalized perspectives consider disability as a personal characteristic and are concerned with the consequences of parental impairment for parents and children. In the relationship between parental disability and family outcomes, therefore, symptoms associated with disabling conditions or the severity of impairment are given a central explanatory role (Olsen & Wates 2003: p. 13). An example of one such study is Thomas and Kalucy’s (2003) study of parents with mental illness, in which they interview parents with diagnosed mental illness about the impact of their symptoms, medication, and frontal lobe dysfunction on childrearing and domestic tasks. Olsen and Wates (2003) note that studies conducted from within this perspective frequently fail to account for the role that poverty, inaccessible housing, or stigmatizing attitudes might play (15).

The ecological perspective draws on Bronfenbrenner's (1979) seminal work about the social and institutional contexts of human development. Bronfenbrenner critiqued context-free approaches to human development, asserting that such approaches "typically employ a scientific lens that restricts...the researcher's vision of environmental obstacles and opportunities and of the remarkable potential of human beings to respond constructively to an ecologically compatible milieu once it is made available," concluding that, "as a result, human capacities and strengths tend to be underestimated" (p. 7). Thus, in many ways, the ecological perspective is consistent with a social, rather than medicalized, view of disability. However, Olsen and Wates (2003) argue that when this perspective is applied to parents with disabilities, it continues to "focus on impairment and parenting 'deficit', although it has moved towards placing this within social contexts" (p. 16).

The organizational perspective specifically acknowledges the importance of service professionals in the lives of parents with disabilities and, as such, focuses its analytical lens on the aspects of service delivery which can "expedite or hinder the development of supportive practice in relation to disabled adults with parenting responsibilities" (Olsen & Wates, 2003: p. 31). Such an approach is certainly timely and necessary, as accessing needed support proves challenging for many parents. Both Harris and Bamford (2001) and Morris (2004) talk about the difficulties parents with disabilities face in accessing parenting supports. Harris and Bamford (2001) focus on accommodations, documenting the need of Deaf parents for equipment such as vibrating pagers or flashing lights to alert them to their babies crying or the telephone and doorbell ringing, and interpreters for their participation in school activities and teachers meetings. Yet they also find that many parents face difficulties in convincing social services and school staff of the importance of these technologies and services to their ability to parent.

Morris (2004) discusses the fears held by some parents that the act of seeking parenting supports may invite social services personnel to question their capacity to parent or to label their children as at-risk. Indeed, she notes, in order to access certain publicly-provided parenting supports, parents must first have their children officially labeled as "needy". Parents are also resistant to the stigma associated with receiving services from child protection authorities and the possible intrusion of child services personnel. Olsen and Wates (2003) remark, "Although social services departments are aware that disabled adults are wary of approaching social services for support with parenting, few measures are taken to allay these fears [or to design] services [to] lessen anxieties and/or increase access" (p. 33). While this work has the potential to help minimize the invasiveness of service provision by identifying ways to make service delivery more effective, there is also danger that such work will provide justification to widen surveillance and intervention in the lives of parents with disabilities.

POTENTIAL FOR INTEGRATION WITH THE LITERATURE ON CARE-GIVING

In this section, I discuss concepts from the feminist literature on care-giving, followed by a discussion of care-giving concepts from the literature on parents with disabilities and disability studies more generally.

The Self-Reliant Family: Problematizing Self-Reliance, Advocating Autonomy

In her 2005 study of families with children, Hansen identified a persistent disjuncture between the ideology of family independence, wherein responsibility for all domestic tasks and childrearing is assumed by members of the nuclear family unit, and the actual practice of interdependence, reflecting the lived reality of parents reliant on a host of others outside of the nuclear family to accomplish the everyday tasks of parenting (2005: p. 3). Although, when interviewed, parents consistently characterized themselves as the only ones raising their children, in her time as a participant-observer, Hansen found that parents' ability to rear their children actually hinged on the assistance of extended family members, friends, neighbors, and paid helpers. In spotlighting the contradiction between the ideology of independence espoused by parents in her study and their practice of interdependence, Hansen's study epitomizes a growing body of largely feminist scholarship on the family. This growing body of work stresses how the changes in family form and function over the last half of the twentieth century have uncovered essential contradictions between practices by and ideologies about normal families. In order to understand the coexistence of these contradictions and suggest alternative ideals, Hansen and other scholars interrogate and redefine the concepts of dependency, autonomy, and self-reliance/self-sufficiency – concepts that several authors have observed are also intertwined with understandings of disability (Barton, 1989; Morris, 1993; Hansen, 2005; Young, 2002).

Researchers and service professionals alike have problematized parents with disabilities on the basis of their perceived overdependence on others to raise their children. As McConnell and Llewellyn (2000) note, the “expectation that families should be autonomous and self-sufficient contributes to the marginalization of many parents with intellectual disability. For many of these parents ‘independent’ parenting may not be readily achieved” (p. 887). At the same time, “reliance on family members or professionals may penalize parents with intellectual disability as their ‘dependence’ can be seen as a breach of the social contract or as confirmation of parental incompetence” (McConnell & Llewellyn, 2000: p. 887). Young (2002) identifies self-sufficiency as a mostly unattainable state of living without help from others to support oneself or one's loved ones. Instead, Young advances the alternative ideal of autonomy, which she defines as the ability “to determine one's own projects and goals, how one will live one's life, without having to answer for those goals to others, and without having to obey the orders of others about how one will live” (p. 43–44). Young maintains that the danger of emphasizing self-reliance/self-sufficiency – particularly when employed in the implementation of public policy – is that it “operates further to close the universe of discourse about the respect people deserve...and aspirations for autonomy” (p. 42). Note that the definition of autonomy does not preclude the receipt of assistance in achieving one's goals – in this case, of successful parenting – but rather relocates the emphasis to maximizing self-direction.

Feder and Kittay (2002) describe one of the most valuable contributions of the recent feminist literature on care-giving as the development of a “framework within which to reconsider independence and dependence...to identify a moral language to describe...the ethical dimension of interactions of unequals, attending...to the inequality between caregiver and the dependent...[because] relations among unequals in fact dominate our social life” (p.

1). Using such a framework, those working within this tradition have been able to argue that (1) dependency is an inevitable facet of the human experience: most individuals spend the majority of their lives either as a dependent, a care-giver, or someone responsible for supporting a dependent and care-giver, and (2) that whereas some are “inevitably dependent” (Feder and Kittay (2002): p. 2) – i.e., those who are unable to meet essential needs by themselves, such as children, the elderly, and people with disabilities – care-givers are often also made dependent as a result of social relations that render them so. Furthermore, care-givers (or as Feder and Kittay refer to them, “dependency workers”) are more often than not women who are also subject to social relations that serve to exclude them on the basis of class and race.

Although the potential contributions of the feminist care-giving framework are numerous, it is not clear if, as it stands, it can accommodate parents with disabilities. As Walmsley (1993) and Morris (1993) also observe, the existing theoretical framework of care-giving automatically casts people with disabilities in the role of care-recipient, and therefore as “not care-giver.” Thus, they fail to acknowledge the possibility that care-giving and receiving can be conceived of as a continuum rather than a mutually exclusive dichotomy (Walmsley, 1993). Additionally, though there are exceptions, the current literature is generally concerned with elucidating the ways in which care-givers – women in particular, and more recently, low-income women, women of color, and/or immigrant women – are multiply oppressed through existing social arrangements that simultaneously depend on their caring labor and fail to assign it adequate value (as evidenced by its generally low or unpaid nature). While valuable, the work as it stands has not sufficiently investigated the role of those who are “inevitably dependent” nor has it fully explored the implications of their automatic and complete assignment to “inevitable dependency”, not just in research, but also in social and public policy arenas.

Successful Parenting, Resilience, Supports and the Possibility of Oppressive Care

The study of parents with disabilities and disability studies more widely has several valuable insights to offer the study of family more generally. One of these is the importance of highlighting accounts of successful parenting among parents that are highly vulnerable to being labeled unfit (Olsen & Wates, 2003). Key to such accounts is the concept of *resilience*. Wolin and Wolin (1995) define resilience as “successful adaptation despite risk and adversity” (p. 418). Unsurprisingly, the concept of resilience is generally employed only in studies of “problematic” parents, including parents with disabilities, low-income parents, and single parents. However, as Olsen and Wates (2003) point out, the study of parenting in general can also benefit from accounts of successful parenting, and thus, from an understanding of the role and factors that cultivate resilience among children.

Parenting support also fulfills a pivotal role in the literature on parents with disabilities. In many ways, parenting supports are one answer to Feder and Kittay’s (2002) question: “How...can the consequences of human dependency be equitably borne by all, so that some do not experience themselves as intolerably dependent in order for others to experience themselves as fully independent?” (3). Numerous observers have documented the critical nature of supports to enable successful parenting by adults with disabilities (Morris, 1993,

2004; Booth & Booth, 1994; Harris & Bamford, 2001). Some observers have focused on enumerating the types of supports that parents need (Harris & Bamford, 2001), while others investigate the nature of supports, who provides them, and the difference between supports that enable and supports that oppress (Morris 1993, 2004; Swain & French, 1998).

Acknowledgement that care-giving can be oppressive to its recipients is a significant contribution of disability studies scholarship, but it has not been routinely applied to the situation of parents with disabilities. Feminist scholarship on care-giving has appreciated how the context and social organization of care-giving can be oppressive, but has demonstrated little insight into how care and support itself can be oppressive. Observers such as Morris (1993) and Swain and French (1998) discuss how adults with disabilities can be dominated by their care-givers, paid or unpaid. Thus, parents with disabilities may find themselves ceding control over their lives to care-givers instead of receiving support to achieve self-direction.

The meaning of care is shaded with intimacy when it is received from a loved one, and it is all the more fulfilling to both parties when reciprocal care-giving can be cultivated. However, exclusive reliance on loved ones for needed care and support can strain relationships, lead to social isolation, and increase vulnerability to emotional and physical abuse. Morris's (1993) informants discuss the need to blend paid and unpaid supports in order to maintain good relationships with their loved ones and retain control over which tasks care-givers will complete and which ones parents will do themselves. Importantly, parents discuss the need to control supports so that the care-giver does not co-opt the parenting role. For example, Lauren, one of the mothers Morris interviewed explains:

I first got PAs when Molly was very small...I didn't want my mother doing the things that I would have done...I didn't want Molly running to her instead of me... So that's when I [hired the PAs] and I could tell them exactly what to do...you know, like if she fell over and hurt herself then they were to pick her up and put her on my lap so it was me that did the kissing better. (p. 92).

Similarly, another mother, Jackie, relates her experience of receiving assistance from her friend and expressed her angry response when her "friend was willing to help but acted in such a way that her own relationship [with Jackie's son] got in the way of Jackie's relationship with him," describing her friend's actions as those of "a stupid, taking-over, able-bodied, not-a-brain-cell-in-the-head person" (p. 92).

PIECING TOGETHER A NEW FRAMEWORK

A comprehensive framework to guide future research on parents with disabilities must include the concepts of autonomy, resilience, support, reciprocity, dependency. It must also allow that care can be negative as well as positive. One hope is that consciously incorporating such concepts can assist in resolving the divide between parent- and child-centric approaches. Another is that such a framework will help us to think through what we mean by successful and/or adequate parenting. Further, it will also help us conceptualize and measure the related concept of parenting capacity in a way that transcends a focus on deficits.

Integrating the feminist care-giving literature with scholarship on parents with disabilities also opens up new possibilities for the kinds of questions we can ask. One set of questions relates to how we can understand the impact of service professional involvement in the lives of parents with disabilities and their children. For example, does the kind of professional involvement matter? How can we usefully classify types of professional involvement? And what about the extent to which they are involved? How do they become involved in the first place? How can we effectively blend formal and informal supports? Furthermore, we need to ask questions about the application of professional judgment. Even if measures of parental capacity used by researchers and by child protection authorities are similar, what institutional conditions are most likely to engender the fairest application of them to parents with disabilities? How do such conditions come about?

Another set of question relates to the provision of care by loved ones. In some ways, the questions raised here build on those articulated by Morris (1993) more than a decade ago: “What is it like receiving assistance from those you love? What effect does it have on your relationships? How does it compare with receiving help from those who are paid to give it?” (p. 72). However, we can also integrate understandings of autonomy into the questions we ask: How can autonomy for parents with disabilities be facilitated so that they may in turn provide care to their families? Under what conditions is such an achievement feasible? What kinds of ideological changes would this require in the discourse about autonomy and about parents with disabilities? What kinds of policy changes would this require? What kinds of changes in practice would this require on the part of family members, parents with disabilities, and service providers?

Much of the scholarship on parents with disabilities to date has documented the potential or actual disadvantage experienced by parents and their children. In setting the agenda for future research, it is imperative that we seek to balance the search for negative consequences with empirical investigations into family arrangements characterized by the presence of adequate formal and informal parenting supports, that identify the predictors of parental success, and that give us a clearer picture of the average parent with disabilities in addition to the most disadvantaged parent with disabilities. Also, we must continue to recognize the implications our research has for policy-making and service provision, and help provide the evidential basis for policy recommendations that can assist parents in achieving autonomy and self-direction. Last, we must continue to pursue research providing critical insight into the development of a fairer standard of parental capacity that both acknowledges that successful parenting often includes reliance on paid and unpaid helpers outside of the nuclear family, and that minimizes the effects of prejudicial attitudes towards parents with disabilities.

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