

Resilience as Authoritative Knowledge

The Experiences of Single Mothers of Children with Disabilities

There is a substantial body of literature that explores family adaptation within the context of childhood disability. However, closer analysis indicates that the primary focus of this research has concentrated on two-parent family systems. Despite evidence to suggest that single mothers are more likely to be parenting children with disabilities, their experiences have received minimal attention within social science research. Furthermore, when single mothers do become the focus of study, much of the attention is directed toward identifying the deficits within their family systems. Grounded in family resilience theory, the intent of this study was to explore the family adaptation of single mothers of children with disabilities within a longitudinal framework, and to identify the individual, family, social, and environmental factors that contribute toward resilience within this population. Concepts of family resilience were revealed by mothers who challenged definitions of single mothers as inadequate, who disputed the definition of their children as “disabled,” and who moved from a position of received to authoritative knowledge. The study demonstrates in contrast to public perceptions, single mothers of children with disabilities view their experiences as personally transformative and as means of building confidence that empowers them to further disrupt negative expectations of their families.

The label “authoritative” is intended to draw attention to the status of a body of knowledge within a particular social group and to the work it does in maintaining the group’s definition of morality and rationality. The power of authoritative knowledge is not that it is correct but that it counts.

—Brigitte Jordan, 1997

Although contemporary discourse asserts progression in terms of expanding the construct of family, there are residual beliefs regarding appropriate family

structures and the quality of caregiving within families. The socially-constructed ideal of the “good” family does not typically evoke images of families headed by single or lone mothers, and consequently, caregiving within these families remains vulnerable to greater public scrutiny. The discourse around mothering continues to reflect the pervasive influence of psychoanalytic orientations on how society constructs the institution of motherhood (Read, 2000: 9). Essentially, mothers are synonymous with family, and there is an intrinsic linkage between the personality and psychological functioning of mothers and the health and well-being of children. Although in the past two decades there has been a significant increase in the number of families that are headed by single mothers, the term remains a demographic risk factor that excludes exploration of the social, emotional and cultural strengths that single mothers manifest on a daily basis.

The epistemological frameworks for understanding issues related to single mothers have both formed and been formed by upholding the traditional, heterosexual two-parent family as the norm. These parameters are routinely re-constituted in childhood disability research. Families who differ from the normative construction are typically omitted from the discourse of childhood disability, and consequently, the experiences of families that do not conform to this idealized norm are either rendered invisible, or in comparative analyses, labeled as problematic. Social processes and contexts have worked to negate the construction of knowledge that challenges dominant ideas about single mothers, with the result that mothers’ subjective *knowledge* of caregiving for children with disabilities is neither acknowledged nor incorporated into service provision. This has critical implications for social policy formation as Philip Cohen and Miruna Petrescu-Prahova (2006: 630) suggest that gendered living arrangements among children with disabilities are a neglected aspect of inequality in caring labour. Thus, in the absence of specific knowledge regarding single mothers of children with disabilities, service models based on the two-parent family structure are extrapolated onto lone mothers. This “one size fits all” approach suppresses knowledge-building regarding the needs of single mother families, and constrains the capacity of social service administrators to create meaningful social policies that address the needs of diverse family structures and consequently, practitioners’ abilities to provide appropriate service to these families.

This article describes the phenomenological experiences of 15 women to explicate an epistemic framework through which social service professionals can develop alternative understandings of single mothers of children with disabilities. It argues that mothers’ caregiving abilities are frequently challenged by dividing practices wherein professionals’ knowledge about women’s lives is privileged over lone mothers’ personal, subjective, and experiential knowledge. Through the examination of the experiences, social contexts and subjective meanings of parenting children with disabilities, women’s capacities to retain their perspectives as authoritative emerged as the critical indicator of resilience.

The socially constructed assumption that single mothers are inadequate conceals the complexity of issues related to parenting children with disabilities, and these decontextualized analyses fail to incorporate the socio-environmental factors that contribute to perceptions of risk in the first instance. It is this circumstance that provides the rationale for developing a new proactive framework for working with women within these families.

Single mothers of children with disabilities

There is evidence to suggest that the number of single parents of children with disabilities is increasing, and current data indicates an increase in the prevalence of childhood disability in groups specifically defined by poverty and female-headed, single-parent family status (Fujiura and Yamaki, 2000: 191; Lloyd and Rosman, 2005: 186). Although all mothering entails a variety of caregiving and advocacy tasks, mothering a child with special needs has been described as “mothering plus extras” (May, 1997: 18). The extras include needing to inform themselves about their children’s diagnoses, educating others about the individualized needs of their children, and adapting both the social and physical environment to facilitate the development of their children. Single mothers assume these additional challenges in the absence of a second parent.

Studies exploring caregiving in families of children with disabilities historically concentrated on issues of unresolved grief, caregiver burden, chronic sorrow, and general family dysfunction (Seligman and Darling, 1997: 1-35). This context of negativity is particularly true for single mothers of children with disabilities. In comparison to partnered mothers, single mothers of children with disabilities have been noted to be more vulnerable to depression, express greater concern and worry about the future, be at a higher risk of child neglect or abuse, experience increased stress related to lack of time and meeting family commitments, and access support services more than their married counterparts (Cigno and Burke, 1997: 181; Floyd and Gallagher, 1997: 369; Grant and Whittell, 2000: 270; Olsson and Hwang, 2001: 536; Salisbury, 1987: 157; Schormans and Brown, 2004: 1-3). At a macro level, the inevitable conclusion is that single mothers of children with disabilities are inherently more problematic than families with children with disabilities in which there are two parents. The question arises however as to whether these beliefs are reflected in single mothers’ perceptions of themselves as caregivers. Feminist standpoint theory challenges the premises of universality and objectivity, and offers a framework for analysis that emphasizes situated knowledge grounded in women’s experiences (Hartsock, 1999: 227; Smith, 1987: 19). Standpoint theory suggests that documenting the decisions, goals and expertise of lone mothers of children with disabilities will not only shape service providers’ relationships with women, but that this knowledge is essential in order to challenge the dominant and repressive social practices to which women have been subjected.

Authoritative knowledge

Authoritative knowledge may be described as knowledge that originates within mainstream scientific inquiry and is therefore held as legitimate, valued and universal. In essence, it delineates Foucault's parameters that limited what can be said or thought, as well as who can speak, when, where, and with what authority (Philip, 1985: 69). Thus, meaning and knowledge arise not from language or subjective experience, but from institutional practices, from power relations, and from structural factors.

The socially sanctioned processes of transmitting authoritative knowledge are privileges accorded to those in positions of power and authority over women, including medical, psychological and social service professionals. These profound power differentials result in women being placed in positions of "received knowledge" wherein individuals are more likely to accept others' knowledge as being more trustworthy, valid and authoritative in relation to their own knowledge or experiences (Belenky, Clinchy, Goldberger, and Tarule, 1986: 35-51). This is perhaps most evident in women's relationships with the medical profession (Pringle, 1998: 45). Given its etiology in medicine, it is not surprising that the disability service system replicates the dominant medical model. The historical legacy of disability as shame is a powerful influence that shapes relationships among mothers with their families and friends as well as the various professionals. As an artifact of the charitable model, the parent-professional relational dynamic has historically limited mothers' roles to being passive, unquestioning and grateful recipients of service. These interpersonal relationships were translated into attitudes toward mothers in which they were often characterized as "change resistant," considered a part of the problem rather than the solution, and were viewed as targets for service from professionals who knew best, rather than parents with power and expertise.

The binary nature of gender highlights power and control as important factors in knowledge creation and transmission, yet does not fully explain existing discrepancies. Women have made enormous inroads in terms of contributing to the academic discourse in all disciplines, yet this knowledge remains subject to other categorical divisions, of which class is only one, that have a profound influence on what constitutes valid knowledge. Women who are educationally advantaged may have the power to speak authoritatively about other women, yet experiential, subjective knowledge created by poor, single mothers remains invalid. Thus, despite the proliferation of studies on women and the increasing visibility being accorded to issues related to women, there remains divisiveness between accepting knowledge produced by privileged women and knowledge created by poor women. By virtue of their gender and social location, single mothers' authority is not recognized and we have yet to move to the position that invites marginalized women into the discourse. What has come to be accepted as authoritative knowledge about caregiving, disability, and family functioning is inextricably linked to the hegemonic views of family, ability, and social class. This means that experiences of single

mothers and the standpoints from which they speak are not incorporated into knowledge. However, in this research context it was important to ensure that “other” women’s voices were heard, and although some may interpret the findings from this study as counter-intuitive, it is critical that this knowledge become part of the discourse. When authoritative knowledge intersects with women’s experiences, the result is a more critical perspective of the status quo that allows us to think about knowledge in different ways.

Study methods and context

This study was located within a research project entitled “Family Strengths in Childhood Disability” (Trute, Hiebert-Murphy, and Wright, 1999). This was a three year project that explored families’ experiences with Children’s Special Services, the Manitoba government agency whose mandate is to coordinate the provision of therapeutic and support services for families of children with disabilities. The study had two phases: Time 1 occurred approximately 6 months after families’ entrance into the service system and Time 2 occurred approximately 12 months later (18 months after intake). At each phase, parents completed a series of standardized measures that assessed parenting stress, family needs, family support, the impact of the child’s disability on the family, and the family’s relationship with service providers. In addition to the standardized measures, approximately one-third of the families were interviewed about their experiences entering the service system and their relationships with service providers. This study focused on the sample of fifteen single mothers that were part of the initial study, who were interviewed approximately four years after their first contact with the service system. Mothers completed a third set of standardized measures and individual interviews based on a semi-structured questionnaire were used as a means of exploring women’s experiences as single-parents of children with disabilities.

Participants and their children

Twelve of the 15 women resided in an urban centre and three resided in a rural area. Seven women were employed on a full-time basis, one woman was attending a post-secondary institution and worked part-time, five women received income assistance as their primary source of income, one woman worked part-time, and one woman was employed part-time and received income assistance as a supplement.. Their ages ranged from 30 to 47 years. Ten women described themselves as never-married, four women described themselves as divorced, and one woman described herself as widowed. None of the participants had remarried, however four women described themselves as having relationships with non-resident partners.

Twelve of the children with disabilities were male and three were female. Their ages ranged from 6 to 20 years. Seven children were diagnosed on the Pervasive Developmental Disorder spectrum. Three boys and one girl were diagnosed with Autism, and two boys and one girl were diagnosed

with Asperger's Disorder. Six boys and one girl were diagnosed as developmentally delayed, not otherwise specified. The oldest child in the study was a young man diagnosed with congenital toxoplasmosis that presented itself as cognitive and developmental delays. It is important to note that none of the children in these families had multiple or severe disabilities or were considered medically fragile. All of the children were physically mobile, none had significant hearing or vision loss, and all were capable of some form of verbal communication. The children's disabilities were manifest primarily as behavioural difficulties, cognitive impairments, poor social skills and speech and language delays.

Analysis

This study incorporated the "purposeful" approach described by Hennie Boeije (2002: 391) wherein the analysis process begins with comparison within a single interview, and then shifts to comparisons between interviews within the same group. Therefore, each interview was analyzed prior to conducting the next in order to identify important areas for exploration that the researcher had not initially identified in the interview guide. As new information emerged from later interviews, four mothers who were interviewed at the start of the study were contacted for follow-up interviews.

Data analysis was completed using the constant comparative method of analysis (Glaser, 1965: 437). This method was originally suggested as an approach that is inclusive of the need for explicit coding procedures and as a foundation for theory development. The principle of constant comparison is used for all analytic tasks: forming categories, establishing the boundaries of the categories, assignment of the interview segments to categories, summarizing the content of each category and finding negative evidence (Yin, 1989: 32).

Findings

In this study, mothers' resilience became manifest through their mindful rejection of the dominant positions on single parents, childhood disability, and caregiving decisions, and by acceptance of their situated, subjective knowledge as authoritative. The data analysis revealed the sequential strategies wherein mothers began from positions that internalized/mirrored the dominant discourse to those that represented a conscious paradigm shift from accepting professional *knowledge* as propriety to positions that legitimized their own experiences.

First, mothers consciously rejected the "stigma of the single mother" and transformed it into the position of "mother-presence." Women described how they had either initially accepted the dominant discourse that values two-parent families, or had been a recipient of the negative portrayals of single parents. As one participant stated:

I was raised by two parents; they were together for 41 years when my dad died.... they were together forever. And so when I had (child) I was willing

to deal with anything so that my child would be raised with both parents. And I would put up with crap because I was raised with two parents.

For another participant, the “stigma of the single parent” began with her pregnancy:

I find that really hard, just knowing that society really views me differently, seeing me as a high risk for abuse or whatever and I don't feel that that label is fair or right. When I was pregnant and I told people that I was pregnant and the situation the way it was, I was actually happy and excited to be pregnant even though I was puking my guts out. And people said, people said, “Oh no! How awful.” And I thought to myself, you know, my sister-in-law who's married to my brother, when she announces that she's pregnant, everybody's like so happy and so overjoyed, and for once I would just like someone to be happy for me.

The stigma of the single mother is predicated on a state of father-absence that has been re-constituted into the “pathology of patriarchy” (Biblarz, 1999: 321). As women, the participants in this study were never free from the historical and socially reinforced judgments that assert children are significantly worse off in single mother families. However, these positions do not recognize the strengths of single mothers, disregard fathers who have “no contact” orders due to histories of violence or incarceration, and ignore fathers who choose to sever contact with their children. Furthermore, the participants were clearly aware that single caregiving is not inevitably different from two-parent situations and recognized that that marital quality is more important than marital status. As another participant noted, “Depending on your relationship, it can be no different. Lots of men don't help around. And in fact they add to the workload.”

Of the 15 women who participated in this study, only three fathers maintained some form of contact with their children. Being unconditionally physically and emotionally available to their children became the essential component of their role as single-parents, as they rejected the discourse of “fatherlessness” (Daniels and Gutterman, 1998: 28) and transformed this into a position of “mother-presence.” As Marilyn described:

I'm the one who gives him breakfast, getting him up in the morning, and getting him out the door, and I'm going to be there when he comes home from school. That's a big thing. You never miss, you never miss anything. You're always there.

For these women, the recognition that their subjective experiences as single caregivers was superior to many other families reflected two levels of awareness: their stigmatized location as single mothers within the social structure,

and the location's relationship to their own experiences. Although participants were aware that lone mothers are not considered ideal family types, they chose not to accept the essentialist notions of single mother families as inherently flawed by creating positive meanings of caregiving and by acknowledging that the physical presence of partner does not automatically provide emotional support or result in a shared workload, and in fact can exacerbate the burdens on mothers who are parenting children with special needs.

Mothers' situated knowledge was further denied in their interactions with the social service system. At the time of referral to the disability support system, mothers had instinctively known that their child was different. However, others adamantly disputed their concerns and subjective experiences regarding their children. Several participants described how fathers consistently denied that there was a problem, even when it became apparent that their children's development was clearly atypical.

I saw a program when (child) would have been about five or six and it was about people, or young men, who had no social capabilities. I don't think I knew about Asperger's, the name, but I watched this program. I kept saying, you know that's like (child). (Father) kept telling me, don't be so bloody stupid. I don't know whether he saw images of himself and didn't want to accept it or whether he just thought I was grasping at straws to find out what was wrong with (child).

Resilient mothers trusted their inner instincts that further intervention was warranted, and sought out professional consultation, even when blamed for their children's conditions. As Donna described, several professionals had labeled her as "interfering" in her attempts to access appropriate intervention services.

"Don't make so much fuss and let go the apron strings and you've got to let him go." I even had a psychiatrist tell me I was too domineering and I had to let him live his own life. I was "an interfering mother" and I had to learn to let go of the apron strings.

After diagnosis, mothers' knowledge regarding their children continued to be challenged by others. Decisions made by single mothers that do not conform to what is expected of them are vulnerable to critiques, and tension was created when participants challenged professional, i.e., authoritative knowledge, regarding their caregiving practices. This was most apparent in mothers' interactions with educational systems. Participants expressed how school staff minimized mothers' knowledge about the educational needs of their children and adopted the position of "expert." One mother, whose son had been diagnosed with Asperger's Disorder (difficulties in navigating social relationships being a primary diagnostic criterion), described how her son

failed physical education because he was not able to answer the questions on a test that focused on initiating friendships.

He failed PE because the teacher was not tuned into him. He received only 1 out of 30 on the tests. I said, but what were the tests on? "Well, how to make friendships and develop relationships." And I just threw my hands up in the air and said, "He doesn't get that. He makes friends a different way than you make friends." "Oh" she said, "but he's got to know this."

Mothers' decisions regarding their social and economic welfare were further subject to criticism. Sarah chose to return to post-secondary education as part of her long-term plan to secure better employment and lessen her financial stress, but was met with considerable resistance by her case-worker.

When I first started the course I was taking, I was really having a hard time financially because you fall behind in things and I wasn't able to work as much as I had hoped. I wasn't impressed with the way this one lady dealt with me. She was like, "We never sent you to school. You should quit if you're this early into the program and you're having financial problems. It's not like you're a couple of months from finishing and you know there's other people out there that have children with disabilities or whatever who are working."

Her experience illustrates how others constructed the "problem" as her decision to attend post-secondary school, which speaks to the power of professionals to objectify single mothers. Even when they are acting in opposition to the dominant images, single mothers are penalized for their efforts. In contrast, Lori's experience highlighted the discrepancies within the system wherein her case worker took the position that any job would be of greater benefit to her family than the care she provided at home. She described how her choice to remain at home with her children was severely criticized by her income support worker, with the implication being that she "lacked motivation."

And I do want to go back to work. That's the thing. I do want to go back to work, but it's, I feel it's not feasible 'cause by the time I pay my babysitter, pay my gas, pay my registration, I'm no further ahead. I'm more in the hole. Especially a babysitter. You have to have one here that's on call all the time when you're at work. Then there's your gas, and your registration. There's medication. Medication alone for the three kids plus myself, I'm looking at \$300 a month. And then that's not including eyeglasses for (child), and then with dental costs, you know, it's not feasible.

Social workers and other professionals continue to perceive lone mother families to be victims of their own choices, and thus, their interactions with

single mothers are more punitive, rather than supportive (Rhodes and Johnson, 2000: 443; Schmitz, 1995: 427). One mother was criticized for acting in opposition to stereotypical images, and another for conforming to them. These findings support Jacquelin Scarbrough's contention (2001: 266) that frequently, the most responsible decision for a single mother is welfare, rather than a paying job and unstable employment. However, making the "right" choice continues to distinguish the "civilized" (i.e., the good mother who accepts the expert advice) from the marginalized (Dean, 1995: 561).

A third area that demonstrated mothers' shift from received to authoritative knowledge was represented by the transformation of the dominant position of "child as disabled" to "disability as normal." Although there is a general trend to move toward a social model of disability where structural barriers and not individual characteristics are considered disabling, there remain beliefs about disability that are simplistic, one-dimensional, or contemptuous. For mothers whose children have behavioural issues, negotiating public spaces can be extremely difficult due to environmental and structural constraints. In response to these challenges, mothers undertook specific adaptations to emulate a normal appearance of family life through inclusion in activities in public spaces. They acknowledged that although spending time together may be accompanied by public disapproval, it was important for them to tackle these challenges and not internalize others' perceptions. As Sherry stated,

You can't even worry about that. Like who cares what other people think. I mean I don't care. We just have to get through this. It just doesn't bother me what people think.

In opposition to images of disability that predict enduring emotional responses of denial, anger, and depression, participants described how they had created their own meanings of disability, through redefining, accommodating, encouraging, negotiating and interpreting their children's behaviours in ways that extended well beyond parameters of normalcy. Carolyn summarized the "disability as normal" position when she stated, "Disability is not the term I use when thinking about my child."

Discussion

For lone mothers of children with disabilities, it was clear that resilience was best defined as the process in which "knowing" through listening to others was replaced by the process of constructing "knowing" in the context of listening to self. When mothers encountered situations in which others enacted positions of authority, professing to know what was socially, economically and politically correct, they responded by defining for themselves and their children what constituted family, ability and caregiving. We continue to reside in a society "that supports and rewards the maternity of some women, while despising or outlawing the mother-work of others" (Ginsberg and Rapp, 1995:

16). Even when confronted with a multitude of negative and forceful messages that reinforce stereotypes of single mothers as poor, welfare-dependent, and educationally disadvantaged, resilient mothers do not internalize the social problem perspective of their family structure, nor did they accept the constraints of their children's prognoses.

Valuing mothers' knowledge regarding their families challenges a legacy of professional helping beliefs that have served to dis-empower single mothers and their children. In many ways, the public service system that is tasked with the mandate to assist families often magnifies mothers' feelings of powerlessness and shame. As professionals, we need to examine social processes and interactions that enable single mothers' experiential knowledge to share in the body of knowledge that counts as authoritative. Four years earlier, others' voices dominated. Family members', friends', and professionals voices were typically negative, and highly critical of mothers' choices, abilities and caregiving. However, four years later, mothers revealed how they managed the dual burden of lone parenthood and childhood disability as practices of thoughtful, responsive and strategic decision-making within their individual contexts. Cheryl Gibson (1999: 310) described the process of empowerment for mothers of critically ill children as one in which mothers become aware of their personal strengths, abilities and resources. This may suggest that although it is important for service providers to acknowledge mothers' strengths, their abilities to do so for themselves is a much stronger influence on their well-being. Single mothers of children with disabilities are entitled to define themselves, their families and their children as normal, to make decisions around caregiving practices that reflect individual family needs, and to be respected for their strengths and initiative demonstrated on a daily basis. If we are to shift toward the position that acknowledges single mothers of children with disabilities as both creators and enactors of knowledge, as experts in terms of what it means to be a member of this community, and to refuse to define their lives according to others' standards, then we must accept that they also have the power to change and to redefine, in our context, what it means to be resilient.

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