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“Others”: Identity of Mothers of Children with Disabilities and Adult Education Discourse

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Abstract: This literature review explores the experiences and identity development of mothers of children with disabilities within the discourse of adult education, disability studies, informal education, and identity development.

Keywords: disability, identity, adult education discourse, informal education

Introduction

Discovering how mothers of children with disabilities socially construct a parental identity through interaction with family, school, and community can lead to an understanding of the ways that lifelong learning can foster positive identity construction.

Disability in Adult Education Discourse

Brookfield’s (1985) critical definition of adult education is that it “assist[s] adults in their quest for a sense of control in their own lives, within their interpersonal relationships, and with regard to the social forms and structures within which they live” (p. 46). Mothers of children with disabilities may feel a lack of control as their parenting faces challenges and constraints within school, medical, and community settings due to the disabilities of their children; therefore, addressing these relationships, social forms and structures is an appropriate topic for adult education. Societal definitions of the good mother or the bad mother are not truths, and these descriptors can be changed through collective enterprise. If “[d]eveloping in adults a sense of their personal power and self-worth is seen as a fundamental underpinning ... of adult education” (Brookfield, 1985, p. 47), then the lives of mothers of children with disabilities should be considered worthy of discourse, yet adult education academic journals reveal a lack of attention to parenting and disability.

Rocco (2011) highlighted the paucity of adult education articles on disability beginning in 1960, reflecting the historical focus on the medical viewpoint of disability. Articles on diagnosis and training illustrate this perspective. She suggested moving the discussion of disability in adult education “from a medical or economic concern to a social justice concern” (p. 1-2). Still, it seems as though this suggestion has not been acknowledged.

A current review of adult education journals revealed few articles on disability, with only one directed toward parents of children with disabilities. Adult education research related to parenting revealed articles on parental cultural capital, education and health training, financial literacy, immigrant parent participation in their children’s education, depictions of the ideal parent in the media, and mothers in multiple academic, work, and family roles. However, little attention was given to parents of children with disabilities.

Currently missing from adult education discourse are articles that critically examine the practices and policies of educational, medical, and social communities as seen through the eyes of mothers of children with disabilities. New research in this area will allow exploration of the structures of power and privilege that affect the identity development of these mothers. Creating counter-narratives through research would aim “not simply to understand the contradictions and oppressions within particular groupings, but ... to promote empowerment” (Goodley, 2003, para. 11), while highlighting the fallacy of the myth of the good mother. Clark (2006) argued for interdisciplinary research that connects adult education and disability studies as “an enticing lattice for the examination of issues that produce discomfort of the deviant and differently other as well as those views that simultaneously malign and positionalize disabled people to the outside of normal” (p. 318).

Disability Studies Discourse

Goffman (1963) defined stigma as “an attribute that is deeply discrediting” because the individual is tainted in some way (p. 3). Goffman acknowledged three types of stigma including physical deformities, character flaws, and identity group stigma. The term normal is applied to individuals without a stigma. Connected to identity group stigma is courtesy stigma, described by Green (2003) as “a complex and often subtle phenomenon [where] ... family members experience different degrees of stigmatization” (p. 1362). Green described her experiences as the mother of a child with a disability who encountered a span of reactions from kindness to cruelty, from ignorance to understanding. She has conducted several studies using her insider status to investigate the effects of stigma experienced by family members of children with disabilities (2003), both the positives and the difficulties experienced by caregivers of children with disabilities (2007), and the value of sharing narratives of mothering experiences for women

whose children have disabilities. The importance of the community is clear as families of children with disabilities must deal with courtesy stigma.

Within the field of disability studies, there are certainly limitations of the social and civil rights models, because they appear to fall short of capturing the entire picture. These perspectives do not allow for full understanding of the complexity that happens in educational settings or social spaces; they seem to miss the intersectional nature of human lived experience. More recently, the field of disability studies has found critical social theory to be an important influence and has made a turn toward a more critical study of disability in our society (Goodley, 2017). McDermott and Varenne (1995) argued that “[d]isabilities are less the property of persons than they are moments in a cultural focus” (p. 324); the social model of disability supports the notion that culture has the power to disable individuals through socially constructed obstacles and established norms.

This is consistent with Goodley’s postulation that “disability is a social, relational, political and cultural entity that is lived through as a very personal experience though shaped by some very public encounters” (Goodley, 2017, p. xi). He explicitly injects the relational and political components of disability into the previously discussed social model. Meekosha and Shuttleworth (2009) pointed out that the emerging focus on critical disability studies has been heavily informed by “intersectionality”, “critical race theory”, and “feminism”, because it has made apparent the issue of power (p. 62). It seems that when power dynamics are unequal, people with disabilities may have to negotiate not only the inequitable relationship, but also have an additional barrier placed in their path. Providing mothers of children with disabilities, through their counter-narratives, the opportunity to resist “what they cannot ignore [and] also reveal the hegemony of all the institutions that originally constructed their problems” will add to the discourse on disability and culture (McDermott & Varenne, 1995, p. 345).

Informal Education

Mothers’ experiences with informal education activities may provide insight into effective supports for more positive identity development. For example, in her work with a support group for parents of children with autism, De Wolfe (2014) described the communicative activities of these parents as educational. She explained how the way that they talk about their children and their own parenting experiences with family members, educational and medical professionals, and community members is indicative of informal education; parents were constantly engaging in the “process of educating others ... in order to seek support, locate resources, ask for help, fight for their children’s rights, teach others who had never had such

experience, or relate to those who had” (p. 137). Support group meetings offered parents the opportunity to learn from each other, group outings provided parents with a chance to educate members of the public about autism, and their activism and published narratives shared on social media expanded educational opportunities. Through their informal learning, “parents practice activities of education and communication, they come to live the life of educative, communicative autism warriors” (De Wolfe, 2014, p. 160).

Shilling, Bailey, Logan, and Morris (2014) suggested that potential benefits of informal learning activities such as peer support networks are reciprocal; they are realized by parents providing support, as well as those receiving it. This indicates that peer support networks are an effective means of fostering positive identity construction in the social realm for mothers of children with disabilities. Similar benefits may be possible within the educational realm; Bal (2017) advocated for implementation of “parent/staff dyads” as a way to foster more positive collaboration and connection between schools and parents, and to give credence to the expertise of the parent within the educational system (p. 22). In addition to peer support networks, interventions such as this aid in development of socially just counter-narratives of mothering children with disabilities.

Identity Development

The identity development of mothers of children with disabilities reflects Mead’s (1929/2013) claim that the social group defines the individual. “By taking the attitudes of other individuals toward himself within a social environment or context of experience and behavior” identity is developed (Mead, 1929/2013, p. 163). He highlighted the importance of communication where our thoughts and actions during discourse contribute to who we are.

In their review of critical disability theory, Procknow, Rocco, and Munn (2017) argued that while individuals with disabilities “do not have singular, unitary identities” (p. 365), they are still primarily viewed through the prism of their impairment; the parenting of mothers of children with disabilities is viewed through a similar lens. Although “one identity dominates an experience and at other times multiple intersecting identities influence an experience” (Procknow et al., 2017, p. 366), and mothers of children with disabilities may identify with different races, classes, sexuality, ethnicity, religion for example, the connection to disability is often the significant factor used to view them as mothers. Disability is a dominant descriptor for these mothers, not personally, but through group identity.

Freud’s (1917) work on self-reproach and self-reviling, feelings experienced by both children with disabilities and their families when the stigma of the disability leads to an

internalization of the negative reactions of others who view the disabled body as deficient, provides an area for considering the relationships between disability and identity. The connection between disability and grief/grievance has been explored by practitioners in psychology and disability studies scholars. Bartram (2013) discussed the importance of psychotherapy for dealing with disability, as the loss felt when disability occurs is complicated by self-accusations, Freud's notion of self-reviling, particularly for those who acquire disability and for the parents of children with disabilities; they must deal with the loss of "the anticipated and imagined well baby" (Bartram, 2013, p. 170) and experience chronic sorrow; therefore, these parents must contend with melancholia. Their reactions to their child involve Freud's elements of melancholia such as low self-esteem and self-hatred. Parents direct their hatred towards themselves so as not to exhibit "'bad' thoughts about their disabled children" (Bartram, 2013, p. 173), and individuals who become disabled through an accident may see their new limitations as a moral failing rather than just a physical one and become melancholic, blaming themselves for their condition (Bartram, 2013, p. 172). Other researchers have also examined parental grief, loss, and disability.

In 2011, Goodley argued against the pathologizing of disabled individuals in psychoanalysis that "reduce[s] the problems of exclusion, marginalization and oppression ... to the level of the individual person and their damaged psyche" (p. 716). He explained how the reactions of non-disabled individuals to persons with disabilities (PWD), from altruism to rejection, present a situation similar to the self recognizing the good mother and the bad mother as the PWD experience "the tendencies of disabling and ableist cultures to split the disabled subject" (Goodley, 2011, p. 722). Goodley saw the social psychoanalytic ideas as a way to understand the conflicts within both disabled and non-disabled individuals that stem from societal and cultural interactions (2011).

Watermeyer and McKenzie (2014) argued that frequently research on psychoanalysis and parenting a child with a disability focuses on a pathologized view of disability centered on parental grief or a social model of disability directed toward the societal context that creates inequality, "stances [that] are located at opposing ends of the individual-social continuum, and are, in [their] experience, often applied in clinical practice as if mutually exclusive" (p. 406). They introduced a more nuanced position that "attempt[ed] to develop a unified position to support parents in forming psychologically healthy relationships with their children, while remaining cognizant of a broader social context characterised by ongoing discrimination" (Watermeyer & McKenzie, 2014, p. 406). Despite the varied viewpoints on the nature of disability and the disagreements on whether the focus should be exclusively on the socially constructed barriers to equality, or whether attention to an individual's impairment should be

part of the approach, “social exclusion and deprivation have a psychological face, for disabled and nondisabled people alike. We need to understand the ways in which ongoing assaults on identity limit the imagining of a different social organization” (Watermeyer, 2017, p. 146). The connections between the body and the psyche must be considered.

The difficulty for all parents, but particularly parents of children with disabilities, is the guilt they feel when acknowledging their negative feelings toward their child when dealing with the challenges of parenting. Watermeyer and McKenzie (2014) proposed an integrated view of disability that sees both the effects of individual impairments and the results of societal obstacles. Goodley & Runswick-Cole (2011) also described the magnifying glass under which mothers feel scrutinized by professionals with whom they must interact, which likely has an impact on identity development. “The prolonged interaction with services beyond the early years of a child’s life means that for families of disabled children the scrutiny of the mother–child dyad goes well beyond the early years” (Goodley & Runswick-Cole, 2011, p. 82). The development of the mother’s identity is tied to disability.

Conclusion

This review fills a gap in the literature on parenting and disability in adult education as it investigates the experiences and identity development of mothers who are not themselves disabled, but who are intimately affected by disability. The literature considers the impact of stigma on the identities of mothers of children with disabilities, the practices and policies of school and community as seen through the eyes of mothers of children with disabilities, and how the structure of power and privilege affect the identity development of these mothers. It is clear that areas of opportunity exist for enhancement and improvement of informal adult education practice around communication between and among parents, schools, communities, and families. However, it is crucial that practice and future research consider the intersections between adult education and critical disability studies perspectives.

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