

Forum: Global Families

Introduction: Writing the Global Family, International Perspectives on Disability Studies and Family Narratives

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We live in the Golden Age of the memoir. Everyone has a story to tell, and a growing number are finding their way to publication. The disability memoir has certainly been a part of this growth. It is refreshing to note how many of these recent narrative accounts of living with a disability have been written from what might be broadly termed a “disability studies perspective” taking on a more critical, socio-cultural orientation than the traditional ‘inspiration in the face of personal tragedy’ motif. The list of such accounts is growing (a very short and incomplete list would include works by Anne Finger (2006), Simi Linton (2006), Harriet McBryde Johnson (2005), Eli Clare (1999), Rod Michalko (1998), and Stephen Kuusisto (1998). Beyond the personal memoir, there has been a similar explosion of memoirs written by family members of individuals with disabilities (parents, siblings, and children). However, unlike the personal memoir, relatively few of these “family narratives” have adopted a clear disability studies perspective. There are, of course, important exceptions: Lennard Davis’ (1999; 2000) personal and socio-cultural examination of *normalcy* as a child of deaf parents; Michael Berubé’s (1996) powerful account of discovering the history of a label as he engaged with the reality of his son’s Down syndrome; or Ralph Savarese’s (2007) distinct but equally powerful accounts of fatherhood, adoption, and the meaning of neurodiversity.

We also aspire to live in a Global Age for disability studies. Of course, there is no area of academic study that should not be in such a “global age.” We are long past the time where assumptions, hidden or explicit, that “West is Best” and “White is Right” can go unchallenged. Still it is important to recognize that it is families everywhere, from the Global South as well as the North, whose voices about the experience of disability must be heard in greater number. If disability is unavoidably cultural, then our search for family voices must also reflect the international – and intra-national – diversity that contributes to that cultural context. As Goodley puts it, the literature emerging from “global disability studies” must be “pan-national” in perspective as much as “cross-disciplinary” (Goodley, 2011, p. 1). Yet, here as well, the burgeoning literature of personal and family narratives has remained predominantly white and western in origin and perspective. Even the selections that follow might be said to show a somewhat “westernized” overall tone. A truly global disability studies remains as much aspiration as reality. It is this personal and socio-cultural negotiation with the (re)interpretations of disability from various family perspectives that we focus on in this special issue of the *Review of Disability Studies*(RDS).

In our call for proposals for this special issue, we sought a global perspective representing a variety of cultures and traditions. The response was overwhelming, making the selection difficult, but we hope representative of ways in which gender, race, class, disability and culture intersect with family systems. While a unifying theme is the combination of the personal

with the scholarly using a disability studies orientation, we organized the manuscripts into two parts: the first group of articles places special emphasis on narratives where disability is located *within* a family context. This emic perspective includes primarily autoethnographic work of mothers, daughters, sons and “the othered sister.” The second group of articles consists of studies conducted by disability studies researchers *about* family systems, thus providing more of an etic (outside the family looking in) perspective. We are the first to admit that this emic/etic distinction is not a clean separation, but it provides a useful way to think about singular experiences as opposed to socially organized structures. As Mark Sherry (2008) points out, “disability is always a sexed, gendered, racialized, ethnicized, and classed experience...[that] operates within a framework of multilayered and complex patterns of inequity and identities” (p. 75). Considering all of the articles together, we think this collection of family narratives and narratives on family provides intersectional sites for critique of the ways in which history, geography, culture, gender and religion mix with the disabled experience.

The first set of articles includes narratives written from the direct personal perspective. Um and Won’s account, written by a South Korean daughter and her mother who has a visual impairment, draws upon Toni Morrison’s approach of reconstructing past realities to interrogate their memories. They include partial transcriptions from distanced conversations to construct a dialogue in order to illustrate their interrogation process. This unusual form for presenting their experiences and analysis responds to disability studies scholars who argue for the importance of using experimental qualitative designs: “Diverse ways of writing reports can meaningfully convey ideas about social situations and contexts” (Brantlinger, Klingner, & Richardson, 2005, p. 104). The authors acknowledge how their process of reflexivity was accompanied by tension as they became increasingly aware of their different positionalities within the experience.

Youssef, a young adult woman with a visual disability describes how her Egyptian Coptic Orthodox Christian community plays a role in her emerging identity. This personal narrative provides “insider knowledge” on ways in which religious and cultural traditions traverse the globe in an immigrant family. Her story illustrates the role of mothers as advocates indicative of the privileged parents Ong-Dean (2009) describes in his socio-cultural analysis of the special education system in the United States. Acknowledging the less than straightforward negotiation of a disabled identity, Youssef describes both her achievements and struggles that led her to a sense of empowerment as well as pain. When she moves away from her protective family to attend university, Youssef shares some of her own trepidation as she endures discrimination in her daily life. She explains how these experiences informed her career decisions “to become an agent for education and change.”

Jones writes about being the ‘othered’ sister, noting that the “biases toward individuals with disabilities do not occur in a vacuum affecting only those with a disability.” Like Um and Youssef, Jones uses the reflective process of autoethnography to situate her family’s story within the public sphere. Jones discloses “family secrets” that were created in response to “the public stare, segregation and isolation” she and her family experienced having a member with an intellectual disability. She describes her process of understanding growing up with -- and the subsequent loss of -- her brother who died nearly three decades ago. Jones’ story emphasizes the importance of hearing the lived experience and the lasting impact society has on these families. In reference to Garland-Thompson (2006), Jones suggests her essay “is meant to be

generative...toward social change in perception...unmasking and reimagining disability 'not only for people with disabilities but for everyone' (p. 259)."

In an American mother's search for an "Inclusive Oz", Sauer describes how these social perceptions and disability constructs are revealed in what Gee (2005) calls people's "storylines" or "habits of conversation." By documenting and analyzing the discourse of the people her family encounters when they move across the country, Sauer shows how her son *becomes disabled* when confronting a new set of social and cultural constructs reminiscent of Mercer's (1973) classic study of the "6-hour-a-day retarded child." While highlighting the increasingly mobile world in which we live, Sauer calls for a more thorough examination of socio-cultural influences on family's experiences, with particular attention on the power of economic and cultural capital.

We conclude the first part with an Iranian journalist's (Goodrich) description of a family's experience over a thirty year period, beginning in 1980 when their son, Mohsen, was born with cerebral palsy in a city under attack by Saddam-Hosseini's army. Goodrich explains how she first met Mohsen H. Taha at the newspaper office when the young man offered his writing samples to the journalist in an effort to seek employment as a contributing author to their journal. Taha's voice begins the piece where he writes, "The tragedy happens in a society who treats persons with disability like unhumans. Our life tragedy is made by our society, not by our disability..." Goodrich honors Taha's voice throughout the manuscript, but she also gives voice to Taha's mother, father, sister, and brother including many quotes taken from years of interview transcripts. Their mixed experiences include feelings of "shame" reflected in some of the other stories in this issue and so they are not wholly owned by those in so-called less developed countries. These shared human experiences are meant to provide readers with a chance to reflect upon our own storylines and the roles we may play in the lives of disabled people and their families.

In the second grouping of manuscripts we see the influence of historical and political legacies on disability experiences for British Pakistani families and American immigrant mothers from Japan, the Philippines, and the Dominican Republic, as well as for a group of Ecuadoran men with physical disabilities who come together to play basketball. Extended families in both the genetic sense and in the social structural sense are shown to play an important role in providing support for families. Goodley, Runswick-Cole, and Mahmoud, employ the complicated notion of diaspora as it plays out in the lives of three British Pakistani families. The authors use the voices of their participants to explore the often liminal status of these families as they negotiate their place within multiple communities while seeking the best for their disabled children. The second article, by Wilgus, Valle, and Ware, continues this exploration of the immigrant experience by recounting the stories of three mothers living in New York City with their disabled children. Coming from three different backgrounds – Japanese, Dominican, and Filipina – these mothers tell stories that are both similar and different. As with the British Pakistani families, these mothers also reported a life of complicated interactions with the educational and social institutions of the dominant society. The authors describe a process through which disability, race, class, gender and other signifiers of identity were used to create a kind of cultural calculus that gave different results to each family. What was common was the influence of this social

formula, or algorithm of access, by which intricate formal and informal bureaucracies drew upon multiple factors to shape the lives of these mothers and children.

The following article, by Rattray, reminds us that the very notion of “family” itself is mutable and contextualized. Using the concept of “segunda familia” or second family, Rattray examines how the identities of wheelchair athletes in Ecuador were importantly shaped by the close, familial relationships that they formed with the other members of their team. In these extended, second families, his participants came to embody lives that identified as disabled and proud, strong in both their individual achievements and their collective sense of purpose.

It is our hope that these family narratives offer a contribution to the authentic voice of the disability experience in today’s societies. This is an effort to privilege the voices of the lived experience of disabled people and their families from a variety of ‘locations’ both geographic and metaphoric. We acknowledge the risks involved for some of the families as they made the personal public and appreciate what in some instances involved emotional upheaval in the telling. The topography of these stories offers an opportunity to examine the intersection of societal structures that impact disabled people and their families. For instance, material and cultural capital played an important part in the opportunities and choices afforded to the Sauer family as they relocated across the country, while it could be argued a lack thereof restricted Taha’s choices.

As is often true with story-telling of any kind, these narratives leave readers with as many questions as answers. As researchers, our first responsibility is to “ensure that these stories are valued and gathered and told in ways that are culturally respectful, recognizing the potential the stories have to bring about social change” (Stienstra, 2012, p. 386). One of the ways we hope to fulfill that responsibility is to let the stories mainly speak for themselves. The questions they raise should prompt us to continue to listen, not rush to answer. In that spirit, we end by mentioning some of the more provocative questions that we take away from the stories that follow:

- How have family experiences with disability changed over time?
- How do the functional implications of specific impairments shape the family experience of disability?
- How does the location of a disability within a family system (i.e. who is the person with the disability label – father, mother, brother, sister, son, daughter) shape the experience?
- How relevant and helpful is a disability studies lens to understanding family experiences in developing countries?
- How do race and culture intersect with family systems to shape the meaning of disability?

In raising these and other questions, the authors help remind us that even within the global context there are at least a few common places to begin the quest for answers. Not only is disability a universalizing context, both in concept and in experience, but so is family. It is at the intersection of both within a global perspective that further voices must be heard; further questions must be sought.

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