

Disability and Shame Special Issue Forum: Introduction

Disability and Shame

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In July 2016, a man entered the Tsukui Lily Garden in suburban Tokyo in the middle of the night and stabbed over 40 people. Nineteen died. The Tsukui Lily Garden specializes in caring for adults with cognitive impairments. Satoshi Uematsu, a former employee of the facility, turned himself in to the police shortly thereafter and confessed his crime. "It is better that disabled people," he told them, "disappear."

When one of the editors of this series, John Jones, expressed his dismay about the attack on the listserv of the *Review of Disability Studies: An International Journal*, he noted in the local response to the tragedy a reflection of Japanese culture: after the attack, many of the victims' family members did not want it publicly known that one of their loved ones was involved.¹ The requests for anonymity, and in some cases flat refusals of acknowledgment, were grounded in the shame that would attach to the families who had relatives residing at the Tsukui Lily Garden. Shortly after sharing his thoughts, the *Review of Disability Studies Journal* reached out with a suggestion to initiate a special forum on the topic of shame and disability. This issue is the result of that suggestion.

Shame, like any human emotion, finds expression in a number of ways. Moreover, manifestations of shame are tempered by a wide range of factors, from the broader culture of the person or persons experiencing shame to the microcultures of the person's family dynamics and immediate social milieu, as well as the source of the shame itself. This special forum addresses this last point: disability and its relationship to shame.

For this issue, we sought as broad a range of scholarly perspectives as possible and we were not disappointed. The goal was to include a wide selection of international views and diverse disability experiences. The articles that follow examine the intersection of shame and disability through a variety of frameworks. Articles discussing the complexity of shame in East Asia and the Middle East share space with intimate first-person narratives grounded in ethnographic scholarship. Some articles are broad and theoretical, others offer a more practical perspective. Submissions focus on the effect of shame not only on the disabled individual, but on families, as well. Together, all showcase a rich diversity of ongoing scholarship in a field deserving our full attention.

Embracing a broad range of perspectives includes acknowledging differences in contemporary preferences regarding the language of disability. Toward the end of the

twentieth century a majority of disability scholars and advocates encouraged use of person-first language. A core explanation for this preference asserted that because the fundamental humanity of people with disability had long been denied and ignored, those wishing to contribute to the end of ableism should acknowledge the person before any difference in capacity relevant to their experiences. By the turn of the twenty-first century, the dominance of person-first language became so pervasive that many scholarly journals and public agencies around the globe required its use.

Even as the popularity of person-first language rose, some hesitated to transition from traditional language forms which lists disability as a primary characteristic of the individual in question. Others found the person-first language unnecessarily cumbersome. Finally, and most importantly, some disability activists stressed that the differences in capacity called disabilities played so central a role in their identity that disability (or identity) first-language was not only preferable but the only truly appropriate language form given a goal of respecting diverse identities.

Debate remains regarding disability language. Given that disability reflects interaction between capacity and infrastructures and that contemporary identities are multifaceted, personal language preferences vary across time, spaces, and interactions. In order to work most positively and proactively with the topic of shame, the following articles contain authors' own language choices.

We begin our special forum with "The Intersections of Culture, Disability, and Shame: The Experiences of Emerging Adults with Developmental Disabilities and their Families in South Korea" by Mina Chun and Diana Ferguson. This article examines how culture and shame effect the lives of 12 families of adolescents with developmental disability. "Three Dimensions in the Register of Shame" by Jean-Pierre Tabin, Monika Piecek, Célin Perrin and Isabelle Probst follows—an article that discusses the effects of shame on disabled recipients of Social Security benefits in Switzerland.

"The Cultural and Religious Production of Disability Shame and the Saving Power of Heretical Bodies" by Michelle Mary Lelwica continues the discussion of the effects of shame created by cultural and religious beliefs about physical disability. In "Dealing with Shame: Saudi Mothers' Responses to their Children's Diagnosis of Autism Spectrum Disorder" by Mona Sulaimani and Dianne Gut, we return to the effect of disability shame on families, examining how the degree of parental shame and stress is proportional to the severity of children's symptoms and behaviors.

"Mental Health Disabilities, Shame and the Family: The Good, the Bad, the Chosen, and the Imagined" by Cassandra Evans is an ethnographic research study exploring shame through the lens of mental health issues related to deinstitutionalization and community-based mental health care. And finally, we complete our forum with an article by Maggie Bartlett, "A Counter-Narrative to Shame in Namibia" evaluating her experiences interviewing families of disabled children in Namibia, Africa.

In an effort to expand our understanding of shame related to disability, in addition to our literary offerings, we are fortunate to include artistic expressions about the topic. We have works from artist Ann Millett-Gallant, illustrator Anna Faroghi, and poems from Lisa Boskovich and David Isaac Hernández-Saca.

The issue of shame coupled with the problems of ability and disability remain an area rich for future scholarship. The authors in this issue have invested an immense amount of work into the articles that follow. In many ways, however, the broader work is just getting started. We hope that this humble beginning will stimulate our readers to both think deeply about this pressing issue and consider examining the intersection of shame and disability in their own scholarship.

We are profoundly grateful to have had the opportunity to work with authors who have given so generously of themselves to this effort. We are also thankful to the editorial team at the Review of Disability Studies Journal for shepherding this project along.

We wish to close by noting that the subject of shame itself can be a depressing one to contemplate. When we consider the many manifestations of shame, most of which are less tragic than the killings in Tokyo but nonetheless painful for those experiencing them, despair sometimes follows. Our intention in compiling this series of articles is to provide a forum for discussion, raise insights, and share perspectives to help scholars and laypersons counter that despair and instead find reasons for optimism and hope. That so many scholars wanted to contribute their work to this issue gives us reason for great optimism, indeed.

Stephanie Patterson, MLS has expertise in the field of disability and employment as a result of integrated experiences in disability studies, higher education, disability services, career services, human resources, and labor relations. Some of her research endeavors include publishing her new book *Disability and Employment in the United States* with Cognella Inc., and co-editing a Special Forum on Disability and Employment in the Review of Disability Studies that highlighted her article entitled, “A Historical Overview of the History of Disability and Employment in the United States (1600–1950).” In 2014, she published a book chapter, “Working 9 to 5... or Not: Historical Origins of Disability Discrimination in the U.S. Workplace” for Piraeus Books.

Dana Lee Baker, PhD has expertise in disability policy, with emphasis on neurodiversity, neuroethics, and autism. Dana brings considerable experience as a peer reviewer from a number of scholarly journals such as *The Social Science Journal*, *Journal of Public Affairs Education*, *Journal of Public Policy Analysis and Management*, *Social Problems*, *Educational Policy Journal*, *Scandinavian Journal of Disability Research*, *Journal of Autism and Developmental Disabilities and Emotion, Space, and Society*. Dana has also served as an ad-hoc reviewer for the National Science Foundation and for the Social Sciences and Humanities Research Council of Canada. Dana edited a two-volume book series entitled *Disability and U.S. Politics: Participation, Policy, and Controversy*, published in 2017.

John Jones, PhD has expertise in disability policy with an emphasis on special education

policy, eugenics, and the history of special education. He has served as a reviewer for American Educational Research Association, the History of Education Society, and the American Library Association. He was invited to create this call for papers by the editorial staff of the *Review of Disability Studies: An International Journal*.

Endnotes

1. It should be noted that John Jones is himself of Japanese descent and that his parents and grandmother reside a few miles from the location of the attack.



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Disability and Shame
Special Issue Forum: Research Article
A Counter-Narrative to Shame in Namibia

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Abstract: Fewer than 20% of children with disabilities (CWD) in Namibia attend school. One meta-narrative proposes CWD are being hidden from societal spaces, including school, due to shame. This study foregrounds stories of CWD and their access to societal spaces. It interrogated meta-narratives and uncovered a counter-narrative that illustrates hybridity.

Keywords: Disability Studies; Namibia; Culture

Introduction

There is no lack of stories and other evidence illustrating that children with disabilities are routinely excluded from all spheres of life in the so-called Global South. One marker of inclusion/exclusion is the school-attendance of children with disabilities in Namibia. Despite strides in the implementation of inclusive education, only about 18% of children with disabilities in rural Namibia attend school (Namibia Statistics Agency, 2016). In comparison, depending on the age of the student, between 66–89% of non-disabled children in Namibia attend school (Republic of Namibia & UNESCO, 2015). The literature reports that exclusion is fueled by complex factors, one of which is shame (Haihambo & Lightfoot, 2010, Zimba, Mowes, & Naanda 2007). While shame about a family member with disabilities may trigger reactions that entail limiting access to social, academic, and economic spheres, it does not tell the full, complex story. These study results agree that in some cases shame may lead to the exclusion or hiding of the family member, but as told from families of children with disabilities in rural Namibia, part of the exclusion comes from families' good intentions to protect their child.

The purpose of this ethnographically informed study was to listen to the voices of families of children with disabilities, and provide, via phenomenological interviews, a localized counter-narrative from individual vantage points as they relayed lived experiences. Throughout the study, families describe ways in which children were included in local contexts and how the desire to protect them from outside negativity and harm was a factor in the ways in which they lived their lives.

Background

The Republic of Namibia has been legally free from apartheid since 1990. From the first contact with Portuguese explorers in 1488 until 1990, when Namibia became independent, the country had been wrought with oppression and murder of its people, international treaties, and armed struggles that finally led to UN-supervised elections (BBC

New, 2018).

Currently, the 2.3 million people in the thriving and diverse country sparsely populated it's mostly desert landscape. Over half of the people in Namibia identify as Ovambo, an ethnic group that is largely situated in the north-central region of the country. These individuals are the focus of the study. Additionally, about 80–90% of Namibians identify as Christians. Many live in rural areas and can be faced with challenges such as access to safe drinking water, electricity, and cell phone coverage.

About 98,000 citizens identified as having a disability that causes “difficulties engaging in any learning and/or economic activity” (Namibia Statistics Agency, 2016, p. xii). As with many societies, people with disabilities are more likely to experience poverty, marginalization, limited access to formal education, unemployment, and violence (Grech & Soldatic, 2016; Namibia Statistics Agency, 2016, pp. xii-xiii).

After gaining freedom from South Africa in 1990, Namibia has prioritized its growth and progress in all facets. In 2014/15 about 9% of its Gross Domestic Product (GDP) is allocated toward education (Republic of Namibia and UNICEF, 2017). In addition to putting money into the education system, the Ministry of Education, Arts, and Culture has created and adopted multiple policies that are paving the way for better access to quality education for children with disabilities.

The policies that provide a foundation for the development of inclusive education for children with disabilities began when the founders of Namibia wrote the constitution in 1990. The constitution puts forth in Article 20 that all persons shall have the right to education, and that primary education shall be free and obligatory for all children up to the age of 16. Building on that foundation, Namibia has adopted international covenants such as the 1989 UN Convention on the Rights of the Child, 1990 Jomtien World Declaration on Education for All, the Salamanca Statement and Framework for Action (UNESCO, 1994), Dakar Framework for Action (Dakar World Education Conference, UNESCO 2000), and 2006 UN Convention on the Rights of Persons with Disabilities.

In addition to being a signatory on international agreements, Namibians have crafted national laws and policies that guide the implementation of inclusive education. These include the 1997 National Policy on Disability, 2000 National Policy Options for Educationally Marginalised Children, 2000 Namibian National Plan of Action for EFA 2001-2015, 2004 Namibia Vision 2030: Policy Framework for Long-term National Development, 2004 National Disability Council Act, 2007 Education and Training Sector Improvement Programme (ETSIP), 2008 Education Sector Policy for Orphans and Vulnerable Children, 2012-2017 Ministry of Education Strategic Plan, and 2013 Sector Policy on Inclusive Education.

Exclusion

Despite the policies that guide Namibia toward providing education for all children,

including those with disabilities, most disabled youngsters are not accessing formal education (Namibia Statistics Agency, 2016). Educational exclusion is a complex construct that is fueled by cultural models, unquestioned ways of knowing, and systemic deficits such as the lack of resources. It is also an important signifier of inclusion in society. Cultural models (i.e. cultural beliefs about disabilities) and institutional deficits are driving forces that perpetrate notions of shame. Shame, or the pain that is caused by “disgrace” (“Shame,” 2018) in some cases may cause African families to ‘hide’ and not allow the individual with a disability access to social, educational, and economic spaces (Abosi, 2007; Abosi & Koay, 2008; Chireshe, 2013; Haihambo & Lightfoot, 2010).

Such hiding possibly stems from shared cultural assumptions, or cultural models, that are ideologies and cultural understandings that have become deeply embedded within people/society and leave no space for alternative thoughts about people with disabilities (Strauss, 2005). However, people can hold both positive and negative views, as well as, complicated perspectives that take into account for biological and indigenous ways of understanding (Danseco, 1997; Groce, 1999). The notion of hybridity, or a view of these ideas not mutually exclusive, allows us to see a more complex picture of exclusion. The mixture of the cultural models of families of children with disabilities holding a notion of shame, while simultaneously believing that children need protection from the outside world, demonstrates that it is not an either or dichotomy.

The meta-narrative in the small body of literature focused on Namibia is that the cultural models, or ways of thinking, typically evolve from spiritual, supernatural, and mythic ways that support peoples’ thoughts of shame. For example, witchcraft, punishment from God, a curse, missteps of the mother, and myths about disabilities have been noted as ways of thinking about children with disabilities (Haihambo & Lightfoot, 2010). Because “ideologies and cultural understandings have power over thought and expression,” these cultural models, or ways of thinking, and other complex factors, arrange for exclusion for children with disabilities (Strauss, 2005, p. 203). The discourse of belief in the supernatural that in some cases may lead to shame and exclusion, is a part of a complex picture. A picture that considers multiple barriers, beliefs, religions, and cultural models.

Other factors that lead to exclusion of children with disabilities from formal education are the attitudes of teachers and society, teacher training, perceptions of education, curriculum, financial resources, and materials (Zimba et al., 2007).

The National Report of Namibia (2008) identifies the main barriers to inclusive education as: 1) economic, 2) political, 3) after-effects of apartheid, 4) social, 5) teachers’ education, 6) physical, and 7) communication. In addition to these obstacles, and in spite of educational advances, children with disabilities continue to be relegated to the margins. “Despite the advances in the expansion and provision of basic education, a remaining major challenge is to address the needs of educationally marginalized children and young people” (Ministry of Education, 2013, p. 2).

Addressing the needs of children with disabilities relies on the notion of inclusion. Shame that leads to exclusion of children with disabilities in Namibia is a widely accepted construct. The study suggests, however, that in its small sample, families of children with disabilities did not hide offspring due to feelings of shame. In fact, the children were able to navigate the rural community and some attended school. By continuing to sustain the discourse of shame/stigma, without a reframing, allows people with disabilities to continue to be seen as separate and marginalized. The notion that shame leads to exclusion and hiding can be reframed to a discourse that posits, in some cases, that protection is the driving force in the perception that the child with disabilities is being hidden.

Such a counter-narrative is a different way of viewing the exclusion of children with disabilities in rural Namibia. While shame and hiding are still real and prevalent, they are not the only narrative.

Theoretical Framework

This study is grounded in the use of critical global disability studies perspective (CGDS) and postcolonial theory. Both of these lenses explore the families' perspectives in non-binary, social, political, cultural and critical ways.

Critical global disabilities studies, coined by Grech (2015), has its base in disability studies and critical disability studies. The foundation of these theories is to understand the lived experience from the perspective of the person who experiences it (Linton, 1998). Additionally, power issues must be explored and problematized. Specifically, in terms CGDS, Grech posits that, in the past, scholars have often transferred and applied their epistemological underpinnings to a multitude of contexts—even when the contexts have different ways of knowing and being (2015). Thinking through such a frame means problematizing transference of “discourse, epistemologies, and methods” (Grech, 2015, p. 384). It also means that working in the Global South, the histories of oppression and colonialism, and neocolonialism must be remembered. More specifically, honoring the cultural complexities and identities; and seeking to understand and conveying ways of interpreting and knowing “their own world” (Grech, p. 384, 2015).

This study is also influenced by postcolonial hegemony including its political and economic effects that have marginalized people, cultures, languages, and indigenous ways. In addition, a primacy is set for the essential need for people—indigenous and/or people with disabilities—to claim their rightful place in society.

In postcolonial theory, hybridity, as described by Bhabha (1994), speaks about the complex, mutually constructed ways of being that were inherent when colonization occurred and continue to be lived vis-à-vis imperialism and diffusion of western thought. The resulting space of intersection produces a tangle of thoughts, beliefs, behaviors, policies, languages, and ways of schooling, which are negotiated by local actors. In this study, a tension between indigenous ways of knowing and being with western ways illustrates a hybridity of existence.

Methods

Ethnographically informed qualitative field research was used to uncover the cultural complexities of shame and protection as they relate to exclusion. Methodologically, interviews were used to gain an understanding of the interplay among cultural models and human motivations that arrange for children with disabilities to be excluded from societal spaces and opportunities. An overlay of analysis methods were employed to mine the breadth of data. First, analysis began with uncovering phenomenological themes and then moved to discovering deeply held cultural models vis-à-vis non keyword analysis (Seidman, 2006; Strauss, 2005).

Participants

The current study, part of a larger study, foregrounded the life stories of five children and one adult, in which the five families living in rural northern Namibia shared the lived experiences of disabled family members with openness and candor as participants names have been changed. Mrs. Ipinge (age 38), the mother of Armas (age 7), shared her son's story through her lenses as a teacher and mother. Ms. Elago (age 27), the mother of Indila (age 8), shared her daughter's story through her lenses as a retail worker and mother. Mr. Angula (age 62), the father of Toivo and Magano (age 8), shared his twin children's stories through the lenses of a farmer and father. Mrs. Haufiku (age 38) relayed her thoughts about her daughter Ndahafa (age 16). Tangeni's (age 36) story was shared from the view of his aunt Mrs. Paulus (age 62).

A purposeful sampling method was utilized to "intentionally select individuals and sites to learn or understand the central phenomenon" (Creswell, 2013, p. 194). Connections were made within the researcher's network that allowed recruitment of participants. After contact was initiated, consent was provided, and the interviews commenced.

The actual number of participants was an important decision. First, logistical transportation was taken into consideration to accommodate the ability to travel during the rainy season. Because travel during the rainy season, either by foot and/or truck, to different parts of the region is difficult, if not impossible. Therefore, the sample had to be accessible. Additionally, when considering an *n*, Seidman (2006) hesitates to establish a number that indicates "enough" participants (p. 55); while Creswell (2013), suggests a variable number between "3 to 4 individuals to 10 to 15" (p. 78).

This study purports to be counter-narrative that is representative of the participants. While generalization is not the aim of the work, opening a space that leads to discussion about possible alternative and complex views of shame and exclusion is a focal point.

The Interview Process

The three-part unstructured interview session/s engaged the participants in telling the stories of their family members with disabilities. The method utilizes a storytelling approach about lived experiences and how they, themselves, interpret it (Seidman, 2006). As Seidman

(2006) says, “individuals’ consciousness gives access to the most complicated social and educational issues, because social and educational issues are abstractions based on the concrete experience of people” (p. 7). Therefore, listening to the stories of people allows for insight into a phenomenon based on the interviewee’s experiences. Furthermore, the meaning of the words and experiences is a co-construction between the interviewee and interviewer.

Interviews included three parts, in which some were carried out over three sessions while others took place in one session. Each of the three interview parts are distinct in structure, as advocated by Seidman (2006). The first part one of the interviews captured the focused life history. Next, interviewees were asked to share the details of daily lived experiences. The third part or final portion of the interview explicitly asked the participants to reflect on the significance of their experiences (Seidman, 2006).

Throughout the planning and execution of the interviews, language differences and interpreting/translating was a vital consideration. The researchers gave each participant was given the option to conduct the interview in English or Oshiwambo. Only one participant opted to conduct the interview in English. During the Oshiwambo language interviews, an interpreter or translator that was familiar with educational jargon was employed.

Data Analysis

Data collected from interviews were analyzed with methods selected to expose cultural notions that have all emerged from Ovambo beliefs. According to Strauss (2005), there are multiple ways that cultural understandings and ideologies exert force on human thought and action. For example, a cultural model where beliefs that are so deeply internalized and these assumptions are so ingrained, that one is not aware of holding the belief and does not consider there to be any alternatives (Strauss, 2005). To uncover the intricate workings of culture embedded in talk, Strauss’ method was utilized to understand, “ways in which ideologies and cultural understanding have power over thought and expression” (2005, p. 201). Furthermore, cultural models exert power on how people think about children with disabilities, their school-going abilities, and how those beliefs manifest as participation in society.

To bare the shared cultural assumptions among a community, the data was mined for cultural models through thematic analysis using three distinct phases. In the first phase, data were reduced and summarized into individual profiles. In the second phase, profiles were compared for connections and themes. Third, profiles and interviews were analyzed with methods selected for the ability to expose cultural notions.

More specifically, the profiles were created to reduce and then shape the material “into a form in which it can be shared or displayed” (Miles & Huberman as cited in Seidman, 2013, p. 121). In this first step, individual profiles of each child with disabilities was created based on the interview with their family member. The profiles contained demographic information, health history, lived experiences of the child, and school experiences, if applicable. Once the data were ready for analysis, the profiles were grouped, coded, and categorized based on

themes (Seidman, 2013). The themes emerged to show connections and common understandings.

Trustworthiness

Presenting research that allows the reader to believe in it, called trustworthiness by Lincoln & Guba (1985), was addressed in the study through the use of triangulation of data. The triangulation for corroboration or validation of data (Creswell, 2002) was done using multiple voices that all generally pointed to the same outcomes. In the larger study, multiple voices from parents, grandparents, childcare providers, and professionals working in nonprofit organizations were incorporated into the data set. Next, recent literature from other educational stakeholders and families was sought to determine whether it supported the findings. Finally, observational data were collected as the researcher conducted the study as a way to further corroborate the data.

The incorporation of trustworthiness through member-checking and peer debriefing also took place. Member-checking was done with two of the families, such interaction invited the families to read the data collected and correct for any misunderstandings and/or for clarity. Peer debriefing occurred at a Namibia international conference, this allowed for comments or questions from Namibian and international professionals working with children with disabilities.

Findings

Throughout the research, two themes emerged that illustrate people with disabilities engage freely in rural and known locales, while families discourage navigation of more urban, populated spaces. In the study children with disabilities were able to access the local community and were not hidden from social spheres and in some cases had access to formal education. The children traversed to neighbors, school, and church, and conducted daily chores that required them to leave their homestead. In contrast, it also emerged that families were fearful of the individual navigating more populated areas (i.e. town, urban setting, roads).

Navigating Rural/Known Spaces

As children were able and old enough, they would visit neighbors, play with other children, and interact with the local community. For example, Indila had built a relationship with her neighbors—adults and children alike. Her mother said, “In her community, especially the neighbors, they welcome her and she goes and plays with them. She go [sic] herself even. And can go ... and they welcome her anytime.” She played “with the children who are around ... [the] same game, like building small houses with sand and sometimes chasing one another.” During these play opportunities, Indila is constantly laughing and enjoying her time.

The welcoming and acceptance of Indila by neighbors, and her ability to make connections, illuminates the capacity of the community to be open and accepting of children

with disabilities. Such receptivity was also demonstrated in Tangeni's village. Mrs. Paulus shared that at about age 10, he began to go out of the homestead alone, "to go visit neighbors sometimes ... just go and sit ... he sometimes didn't talk to them." She continues to explain that he also regularly interacted with people in the village community, "People know him, talk to him, and he likes [sic] people"

In addition to social spaces in the community (i.e. neighbor's house), the children with disabilities accessed more institutional settings such as church and school. These settings, especially schools, are not always a space of welcome and acceptance for children with disabilities (Haihambo & Lightfoot, 2010). However, in this study it was seen that some children and families found them to be a place for spiritual and educational growth.

Armas's mother, after trying out a few churches, found one where her family and especially Armas was accepted and welcomed. After one Sunday of not going to church, she said Armas missed it and then imitated what his experiences were while in the church:

even [though] I failed to take him to the church last Sunday but I found him just starting to clap hands like in the church because the people in church clap hands, singing ... but there are many be memories and he can remember start clapping hands but cannot able to sing but to make loud noise[s].

In addition to church being a place of acceptance for Armas and his family, Toivo, Magano, and family have found acceptance at school. As the Namibia Statistics Agency (2016) notes it is highly unusual that children with disabilities, especially children with down syndrome, attend school, Toivo and Magano were learning alongside their non-disabled peers.

As Toivo and Magano are from a family with four other siblings, there was never a second thought by the parents to send the children to school. However, the children's performance in school was reported to be quite different from peers'. For example, Toivo "was able to play, [but] not ever able to use [a] pen." and away from school, Toivo "likes to be with goats and cattle." In contrast, his twin sister Magano can write her name, but is unsure of her use of basic information, also, "if asked which village [she is from], she doesn't know." Mr. Angula continues, "She is making progress, needs special education, encouragement, and support."

In the study, families expressed that their child/ren was able to be in the local, rural community in terms of visiting neighbors, going to church, attending school. They also noted that completing family chores that require the children to venture into the community are required and vital. For example, Tangeni cares for the family's cattle, in doing so, he walks them to the watering hole where other boys/young men take the cattle. Additionally, he fetches water at the local tap, thus illustrating that his disability and shame is not a powerful cultural model for the family. Toivo, as a boy, has the same responsibility that Tangeni has and is able to pilot himself and cattle within his local community. Like many African cultures, Namibian families highly value the contributions the children make to sustain the household

(Ingstad & Whyte, 2007; Marfo, Walker, & Charles, 1986; Reagan, 1996). Mr. Angula noted that his children with disabilities are “very supportive to the family,” he illustrated this by sharing how the children are, “responsible for the field, house, and tell if visitor come. [They can] relay message and can run errands.”

While this small sample illustrates children with disabilities are accessing their local, rural communities, it is also a demonstration that in these cases, they are not being hidden within that community. As the literature has shown it is a widely held belief that they are being hidden out of shame and embarrassment. The parents in the study paint a different picture (Abosi, 2007; Abosi & Koay, 2008; Chireshe, 2013; Haihambo & Lightfoot, 2010).

Exclusion from Urban/Unknown Spaces

In accessing the wider community—moving outside the rural, local community, children with disabilities face greater challenges. While children with disabilities in the study traverse local communities, they are seemingly being protected from other spaces because of fear for their safety.

Toivo and Magano’s father, Mr. Angula, said the family has hope for each of the children’s future, yet still is fearful about each of them being in the urban and the less immediate community. Mr. Angula said there are “some challenges” to having children with disabilities, like “your heart is not free because we are worried [for them] to go out, for fire, getting lost, or doing something incorrect.”

Tangeni’s aunt agrees that being in the urban setting is worrisome for her in regard to how her nephew would be protected. While he moves freely around the village, he does not go to town because Mrs. Paulus is “afraid for him to be in town and hit by a car.” Mrs. Haufiku, Ndahafa’s mother, shares the same sentiment, “I fear for my child’s safety,” she goes on, “...many things to can happen to Ndahafa in a place that does not know her.” Mrs. Haufiku point of view concurs with what all families expressed, in spaces where the individual with disabilities is known, there is less opportunity for them to navigate safely. There is constant worry and fear that the children will be susceptible to harm.

All families of children and adults with disabilities shared stories that illustrate they were able to access the local community, but fear and protection is what kept them from being able to access the larger community (i.e. town).

Discussion

In this study, counter to the meta-narrative of shame, participants did not hide family members from the rural community; in fact, all people with disabilities that were of an age to leave the homestead and travel to other homesteads and rural community spaces did so. Chimedza (2008) supports such an idea, as he claims some Africans with disabilities actually experience more acceptance in home-based, local communities in comparison to the communities where the individual is not known. In locales where the individual is not known,

literature supports the assertion that shame and embarrassment does play a role in exclusion. One international aid organization published, “disabled children may be hidden away by their families who have little to no understanding of disability and in some cases, they are considered by being ‘cursed’” (Leonard Cheshire Disability, n.d.). A previous study on Namibian teachers’ beliefs reported that children with disability most often did not come to school because their parents were ashamed and hid them at home (Bartlett, 2003).

Contrasting evidence presented here suggests that people with disabilities are not being hidden, but are being protected by family members. It is evident that children with disabilities do have access to rural community spaces and have limited access to other spaces. From the discussion with the participants, it was not out of shame and embarrassment that the family member with disabilities was not taking transportation to/from the rural areas to urban spaces, or grocery shopping in town, or going to school; family members wanted to protect the person with disabilities from harm, stigmatization, and harassment.

Mrs. Lipinge described what challenges that she and Armas encountered when they went to the hospital, “sometimes he wants to play with them [the other people in waiting room] ... and touch them ... but you have to explain, this one is somehow [sic][because] some people can say, ‘hey ... what is wrong with these people’” (Armas and mother). Therefore, out of fear of what he may do, others’ interpretations of him, and any other negative backlash they may experience, “when we go to the hospital, we only keep him in the car just to avoid...maybe one of us in the queue while the other staying in the car with him until I join the queue to the doctor and then I become the second or third to go in, I have to come back to get him.” Ingstad and Whyte (2007) discussed reframing of the hiding of children with disabilities to a more probable reason of protection and care for the child; and this study supports that assertion.

It is not a binary notion that either people with disabilities are able to access public spaces or are hidden due to shame. The idea has a hybridity of influences and actions. The space of hybridity allows for a “third space of enunciation” (Bhabha, 1994, p. 37), a space where multiple histories and influences arrange for different and new cultural understandings and actions. In the case of Namibia, many things must be considered: its colonial past, European and South African influences, and the current state that includes influences from international aid organizations. Such a discussion must also consider the inequity of power—power among which voices are elevated, which voices are not, and which voices are actively silenced.

The mutuality of influences have arranged for children with disabilities to be seen and taught in different ways over the years. Chimedza (2008) documents that education existed before colonization, but we do not always recognize that, “indigenous knowledge seems to have potential as a solution to some problems of great magnitude experiences in Southern countries” (Mkosi, 2005, p. 89).

Yet, hybridity suggests that the space in which culture exists as it has become ‘mixed’

with the influences from the colonized and colonizer. However, as Abagi (2005) argues, Africa's development and schooling "must be reconceptualized and redefined by Africans - based on Africa's environment, experiences, and needs" (p. 297). The complexity of the exclusion of people with disabilities in Namibia is rooted in a past and present that posits shame is the driving force for exclusion. However, the families in this study did not hide the person with a disability. Instead, the individual was embraced by the local community. It was when they went into the urban setting that stigmatization occurred.

Conclusions

Social realities illustrate that people with disabilities are coming out to freely navigating within local societies. This study demonstrates that some individuals with disabilities in rural communities in Northern Namibia are accessing their regional communities. More importantly, the results posit why they are not accessing more of the wider community. Protection and care, not shame and embarrassment, keep people with disabilities from freely accessing the urban environment in rural Northern Namibia.

Furthermore, the findings speak to the need for interrogation of the meta-narrative around children with disabilities allowing for the hybrid nature of influences to be recognized, while continuing to honor and respect different ways of being as people with disabilities step out from the margins and into societal spaces. Culture is dynamic and is changing, albeit slowly, in Namibia as it relates to children with disabilities. This is evidenced from the national policies and actions that are occurring as a product of the policies. One of these policies led to a pilot project of implementing 'inclusion education' in a few select schools. The actualization of creating a more inclusive communities and demonstrating progress for children with disabilities demonstrates progress. As progress for children with disabilities continues, we hope that one day the meta-narrative becomes one of acceptance and inclusion that leads to high quality education for all learners.

References

- Abagi, O. (2005). The role of school in Africa in the twenty-first century: Coping with forces of changes. In A. Abdi, & A. Cleghorn, *Issues in African education*. (pp. 297–315). New York: Palgrave Macmillan.
- Abosi, O. (2007). Educating children with learning disabilities in Africa. *Learning Disabilities Research & Practice*, 22(3), 196–201.
- Abosi, O., & Koay, T.L. (2008). Attaining development goals of children with disabilities: Implications for inclusive education. *International Journal of Special Education*, 23(3), 1-10.
- Bartlett, M. (2003). Inclusive education in Namibia, Africa. Unpublished master's thesis. University of Texas, El Paso.
- BBC News. (2018). Namibia profile-timeline. Retrieved from <https://www.bbc.com/news/world-africa-13891138>

- Bhabha, H. K. (1994). *The location of culture*. London: Routledge.
- Chimedza, R. (2008). Disability and inclusive education in Zimbabwe. In L. Barton & F. Armstrong (Eds.), *Policy, experience and change* (pp. 123–132). Dordrecht: Springer Science + Business Media.
- Chireshe, R. (2013). The state of inclusive education in Zimbabwe: Bachelor of education (special needs education) students' perceptions. *Journal of Social Science*, –(3), 223–228.
- Creswell, J. (2002). *Educational research: Planning, conducting, and evaluating quantitative and qualitative research*. Upper Saddle, NJ: Pearson Education, Inc.
- Creswell, J. (2013). *Research design: Qualitative, quantitative, and mixed methods approaches*. Thousand Oaks: Sage.
- Dakar World Education Conference & UNESCO (2000). *World education forum, Dakar, Senegal, 26-28 April 2000: Final report*. Retrieved from unesdoc.unesco.org/ark:/48223/pf0000121117
- Dansecu, E. (1997). Parental beliefs on childhood disability: Insights on culture, child development and intervention. *International Journal of Disability, Development and Education*, 44, 41–52.
- Grech, S. (2015). From critical disability studies to critical global disability studies. In I. Parker (Ed), *Handbook of critical psychology* (pp. 376–385). New York: Routledge.
- Grech, S., & Soldatic, K. (Eds.). (2016). *Disability in the Global South: A critical handbook*. Switzerland: Springer International Publishing.
- Groce, N. (1999). Framing disability issues in local concepts and beliefs. *Asia Pacific Disability Journal*, 10(1).
- Haihambo, C., & Lightfoot, E. (2010). Cultural beliefs regarding people with disabilities in Namibia: Implications for the inclusion of people with disabilities. *International Journal of Special Education*, 25(3), 76–87.
- Ingstad, B., & Whyte, S. R. (Eds.). (2007). *Disability in local and global worlds*. Berkeley: University of California Press, Ltd.
- Leonard Cheshire Disability. (n.d.). *Frequently asked questions*. Retrieved from www.lcdisability.org/?lid=8045
- Lincoln, Y., & Guba, E. G. (1985). *Naturalistic inquiry*. Newbury Park, CA: Sage.
- Linton, S. (1998). Disability studies/not disability studies. *Disability & Society*, 13(4), 525–539.
- Marfo, K., Walker, S., & Charles, B. (Eds.). (1986). *Childhood disability in developing countries*. New York: Praeger.
- Mkosi, N. (2005). Surveying indigenous knowledge, the curriculum, and development in Africa: A critical African viewpoint. In A. Abdi & A. Cleghorn, *Issues in African education* (pp. 85–99).

- Namibia Statistics Agency. (2016). Disability Report. Retrieved September 2017, from https://cms.my.na/assets/documents/Namibia_2011_Disability_Report.pdf
- Reagan, T. (1996). *Non-western educational traditions*. Mahwah: Lawrence Erlbaum Associates, Inc.
- Republic of Namibia & UNICEF. (2017). A public expenditure review of the basic education sector in Namibia. Retrieved September 2019, from <https://www.unicef.org/esaro/PER-of-Education-in-Nambia-2017.pdf>
- Republic of Namibia & UNESCO. (2015). School drop-out and out-of-school children in Namibia: A national review. Retrieved from http://uis.unesco.org/sites/default/files/documents/rws_windhoek2016_national-experience-sharing-on-oosci_namibia.pdf
- Seidman, I. (2006). *Interviewing as qualitative research: A guide for researchers in education and the social sciences*. New York: Teachers College Press.
- Seidman, I. (2013). *Interviewing as qualitative research: A guide for researchers in education and the social sciences*. New York: Teachers College Press.
- “Shame.” (2018). In Merriam-Webster.com. Retrieved May 8, 2018 from <https://www.merriam-webster.com/dictionary/shame>
- Strauss, C. (2005). Analyzing discourse for cultural complexity. In N. Quinn (Ed.), *Finding culture in talk: A collection of methods*. New York: Palgrave MacMillan.
- UNESCO (1994). The Salamanca statement and framework for action of special needs education. Retrieved September 2019 from unesco.org/education/pdf/SALAMA_E.PDF
- Zimba, R. F., Mowes, A. D., & Naanda, A. N. (2007). Inclusive education in Namibia. In P. Engelbrecht & L. Green (Eds.), *Responding to the challenges of inclusive education in southern Africa* (pp. 39–51). Pretoria: Van Schaik Publishers.



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Disability and Shame Special Issue Forum: Research Article

Dealing with Shame: Saudi Mothers' Responses to Their Children's Diagnosis of Autism Spectrum Disorder

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Abstract: Autism is a disorder affecting individuals' academic, communication, and social development. The findings of this qualitative study report 15 Saudi mothers' responses to their children's diagnosis of autism spectrum disorder and provide insights into mothers' experiences and responses to stigma in the context of the Kingdom of Saudi Arabia.

Keywords: Autism Spectrum Disorder; Stigma; Mothers' Perceptions

Introduction

Individuals diagnosed with autism spectrum disorder (ASD) have difficulties when communicating and often show repetitive interests and behaviors. Therefore, mothers of children with this condition have encountered many problems when raising them. How ASD manifests depends on the chronological age and developmental level of the children. Symptoms of ASD include delayed toilet training, temper tantrums, self-injurious behavior, aggression, impulsivity, and hyperactivity (Duarte, Bordin, Yazigi, & Mooney, 2005). On the other hand, mothers of children diagnosed with ASD are more likely to experience depression, higher pessimism about their children's future, and reduced quality of life (Cappe, Wolff, Bobet, & Adrien, 2011; Johnson, Frenn, Feetham, & Simpson, 2011). According to previous research, it is evident that parents of infants diagnosed with ASD experience more parenting stress relative to other individuals (Hayes & Watson, 2013), indicating that having children with ASD can strongly impact the health and well-being of parents. Consequently, the degree of parental stress is proportional to the severity of children's behaviors and symptoms of autism (Davis & Carter, 2008; Ingersoll & Hambrick, 2011; Lyons, Leon, Phelps, & Dunleavy, 2010). When children manifest poor behavior and severe symptoms, their parents subsequently experience higher parental stress.

Furthermore, parents of children diagnosed with ASD often feel shame. For example, they may experience disapproval and criticism from neighbors as they are perceived as being unable to control their children (Gray, 1993; Mak & Kwok, 2010). Due to this stigma, children diagnosed with ASD are perceived as behaving inappropriately of their own volition. As a result, many individuals think that parents are to be blamed for using ineffective parenting styles when raising their children (Fernandez & Arcia, 2004). Consequently, mothers might feel they are not utilizing appropriate interventions or treatments, specifically when their friends advise them about various other treatments or interventions they should use (Miller, Schreck, Mulick, & Butter, 2012). Additionally, mothers may blame themselves for

not being able to help their children develop properly (Kuhn & Carter, 2006). They might even blame themselves for being the reason for their children's diagnosis. Therefore, these experiences of self-blame, shame, and guilt are the major causes of anxiety, depression, and parenting stress (Cappe et al., 2011; Mak & Kwok, 2010).

The shame, blame, and stigma experienced by individuals with disabilities and their families are reflected in the moral and medical models of disability where fault is attributed to the individual or his/her family and not to society (Olkin, 2002). Olkin (2002) proposes in the moral model of disability, that disability "is a defect caused by moral lapse of sins, failure of faith, evil, test of faith...brings shame to the person with the disability and his or her family" (p. 133). The moral model results in individuals "being ostracized from family and community, having profound shame, having to hide disability symptoms or the person with a disability" (Olkin, 2007, p. 6).

Review of the Literature

This study examined mothers' responses to the cultural stigma associated with their children's diagnosis of autism and the role institutions play. Individual interviews with mothers allowed for an examination of these women's experiences navigating issues of stigma related to autism in the Kingdom of Saudi Arabia (KSA). Goffman's (1963) theory of stigma as a theoretical framework underpinning this research review and stigma is examined in relation to culture, paying particular attention to the role that the Saudi culture plays in the lives of mothers whose children have been diagnosed with autism.

Culture

Culture plays a role in shaping the way individuals see, think, and understand the world. It comprises "a dynamic yet stable set of goals, beliefs, and attitudes shared by a group of people" (Gurung, 2006, p. 172) and even though some beliefs are fluid, "the general level of culture stays stable because individuals change together" (Gurung, 2006, p. 4).

As members of a community, the lives of individuals with ASD are generally determined by the culture in which they are immersed. Families and communities do the best they can to help individuals with ASD function as productive members of society and live as normally as possible, guided by their cultural beliefs and level of understanding. The beliefs held by members of a community regarding the potential and treatment of individuals with autism differ from one culture to another and can change over time (Ravindran & Myers, 2012). Culture influences key aspects of the diagnosis and treatment process, and affects the likelihood that individuals seek help, what treatments to use, available resources, and the relationships between families and professionals. Daley (2002) suggests treatment approaches that work and are culturally accepted in the West may not be the same approaches accepted and used to treat individuals with ASD in other parts of the world. For instance, in the West, known causes of autism are increasingly attributed to science and various treatments that are available which include behavioral, cognitive, pharmaceutical, sensory, relational, vitamins, and diet therapy. However, in other cultures, the causes of autism might be regarded as

“‘Karma,’ ‘Allah’s will,’ or ‘the will of God’” and may be treated with non-scientific remedies such as acupuncture and/or herbal medicine (Ravindran & Myers, 2012, p. 311).

ASD and Stigma

Within the scientific community, autism is viewed as a disorder marked by abnormal social skills stemming from an incurable medical condition (Martin, 2012). Over the years, the negative stigmatization and social perceptions associated with ASD have grown due to the individualized nature of the syndrome and a lack of understanding of the symptoms (Martin, 2012). Historically, one of the most common social challenges faced by individuals with autism is a feeling of isolation as they grow older, due to increased segregation and rejection from peers, combined with an increase in self-awareness (Martin, 2012). An individual’s level of isolation is dependent on key factors such as environment, personality, and intensity of impairment, all being impacted by the level of stigmatization received from others in the surrounding environment. Isolation and rejection are further exacerbated by the fact that the social behaviors of individuals with autism are perceived as different from the norm, or deviant. As such, since the behaviors of those with autism do not meet the expectations of what is appropriate, they are often ignored and avoided by the normative groups.

Goffman’s Theory of Stigma

Goffman’s (1963) framework is useful for examining Saudi mother’s perceptions of their experiences with stigma associated with their children’s autism. Particularly when discussing the societal stigma associated with having certain characteristics, Goffman sheds light on how communities stigmatize individuals that display certain traits that are deemed undesirable. This is true for individuals with autism in Saudi Arabia, where the culture still stigmatizes such individuals.

In *Stigma: Notes on the Management of Spoiled Identity*, Goffman (1963) describes the different types of stigma and how they impact the identity of those who are labeled undesirable by society. Goffman refers to those who are not forced to live under a perceived stigma, or “do not depart negatively from the particular expressions at issue” as “*normals*” (p. 5). This perspective is in line with how society views individuals who have been stigmatized, as well as, behaving the opposite of how normal society should act, despite how damaging these thought processes are to the relationships between the stigmatized and the general population.

Goffman (1963) identifies three separate forms of social stigma that are essential to conceptualizing how stigma impacts members of a society, whether individuals are, or may be perceived through this ever-present lens. The first form of social stigma involves physical abnormalities that are referred to with harsh, unsympathetic words. Goffman writes these “abominations of the body -- the various physical deformities” are enveloped with harsh judgment and are prevalent despite the physical differences occurring without the person’s will or desire (p. 4).

The second form of social stigma is associated with characteristics or behavioral traits

that bring negative connotations despite often being no direct connection between the trait and the negative association. Often, these traits are:

Blemishes of individual character perceived as weak will, domineering, or unnatural passions, treacherous and rigid beliefs, and dishonesty, these being inferred from a known record of, for example, mental disorder, imprisonment, addiction, alcoholism, homosexuality, unemployment, suicidal attempts, and radical political behavior (Goffman, 1963, p. 5).

As seen in this quotation and thousands of other representations of people who express certain traits associated with the stigma, each action or trait can trigger a far worse reaction and behavior in turn.

The last form of social stigma is tribal stigma which is associated with linking different identities and people of a larger group into a singular category. It is created by combining individuals of a specific race, religion, nation, or some form of community into one single group or person, rather than a group of unique individuals. The individualistic needs and components of each person in the stigmatized community are immediately erased and those in the broader outside community are unable to sympathize with those stigmatized. Outsiders, on the other hand, relieve themselves from any responsibility by disassociating themselves from those in the stigmatized community. Therefore, dehumanizing and apathetic responses towards the community become easier and much more frequent (Goffman, 1963).

Goffman (1963) reinforces this statement by continuing to describe what he calls the stigma-theory which allows the community to continuously dehumanize someone with any stigmas and justifies whatever negative issues/perceptions in regard to the stigmatized individuals, as well as, continues to “break the claim that his other attributes have on us” (p. 5). Goffman notes that any other claim or connection that the stigmatized persons have with the general population is put aside in comparison to the overriding stigma, whether from physical, behavioral, or group stereotypes of the stigma.

In the case of autism, social stigma arises from misconceptions, stereotypes, and ignorance of the disorder and those living with it. One can attribute this stigma towards individuals with autism to the fact that research on how to best diagnose and work with autism disorder has only begun to surface relatively recently. Despite research addressing stereotypes, stigmas have unfortunately continued.

Stigmas associated with autism are often based on the three types of stigmas as noted by Goffman (1963), with some stigmas related to how an individual with autism should look, but even more so, the perceived behavioral traits of someone with autism, and the assumed identity grouping of the community of individuals with autism. Educators are often seen as abandoning the needs of children with autism by grouping them as a separate and distinct category from what Goffman would have referred to as normal children. In this way, some educators may excuse themselves from learning and helping children simply because of

stereotypes based on the assumed behaviors that an individual with autism is expected to display. In response, the general population fails children by perpetuating the common stereotypes and resultant stigma in the classroom when a child with autism arrives.

More recently, Bos, Pryor, Reeder, and Stutterheim (2013) highlighted Goffman's contribution concerning stigma. Bos et al. (2013) and Olkin (2002) reiterate that stigma was originally conceived as a physical mark to identify immoral people, but over time, the definition incorporated behavior resulting in social disapproval. According to the authors, stigma varies across social contexts, and from a psychological perspective, stigma serves several functions, which include exploiting and domineering people, enforcing social norms, and avoiding diseases. Additionally, the authors discuss the theoretical views of the concept of stigma and further classify four additional types of stigma, which are public stigma, self-stigma, stigma by association, and structural stigma (Bos et al., 2013), and defined in the next section.

Bos et al. (2013) highlights the interrelationships between the types of stigma. First, public stigma arises from the cognitive representations that are perceived against people with a particularly stigmatized condition, especially if it is fatal or severely disabling. An example of public stigma is the assumptions and the representations a culture has for certain individuals. For example, different cultures have different representations for individuals with a physical impairment based on what they can and can't do. Self-stigma, on the other hand, results from the existence of public stigma, since people experiencing stigma understand the social devaluation attached to their condition. An individual who experiences stigma is likely to associate negative attitudes of others directed at them with their condition. Next, stigma by association affects individuals who have an association with stigmatized people. Mothers of individuals with stigma can experience this type of stigma as well as other relatives of the stigmatized individual. Finally, structural stigma presents the ways in which the society perpetuates a stigmatized condition. Society can perpetuate the feeling of stigma by continuing to associate labels with the condition.

Goffman's (1963) work is crucial for its ability to provide a framework through which stigma could be understood based on its characteristics and causes. Using this framework to understand stigma in a KSA context helps to make sense of mothers' experiences, by highlighting not only the cause of the stigma but how it operates within society.

The Saudi Context

According to Alqahtani (2012), most parents whose children have been diagnosed with ASD argue that cultural, medical, and psychological factors are the main causes of autism. The medical factors perceived to cause autism include vaccination, examination during pregnancy, and vitamin deficiency. Additionally, the cultural factors perceived to cause autism include black magic and the evil eye. Finally, perceived psychological factors are due to the trauma of experiencing the death of parents and associated with causing autism.

Despite the existence of sufficient evidence showing the causes of autism spectrum

disorder, parents blame themselves for their children's condition (Alqahtani, 2012). Since parents do not have adequate information about the causes of autism, they use interventions such as consulting religious leaders and reading Qur'an verses (Alqahtani, 2012). They prefer these treatments because they believe they heal the symptoms of autism. The findings of the study show that no parents used essential therapies focused on developmental, educational, and behavioral interventions (Alqahtani, 2012). Furthermore, it was found that some parents fear seeking help for their children due to the cultural stigma associated with disabilities (Alqahtani, 2012; Zeina, Al-Ayadhi, & Bashir, 2014).

Some individuals applaud women in the KSA for doing a commendable job as caregivers despite the lack of paying jobs (Basaffar, Niehm, & Bosselman, 2016). However, it is crucial to recognize that in Saudi Arabia, women and men play clearly distinct gender roles in the society. As a male-dominated community, men are perceived as the providers for the family while women perform traditional roles even when they are part of the labor force. Similarly, in homes where both parents are working, women are expected to meet the needs of their husbands and take care of their children. This means women have to balance their family and work life in order to be able to satisfy the needs of their children. The men may provide support and help, but they do not play active roles in overseeing the needs of children, including those who require special attention.

The findings are clear that parents in the KSA fear their children will be humiliated due to their autism diagnosis. Children with autism require special attention from parents or caregivers. Therefore, institutions have a responsibility and role to lessen the effects of social stigma that mothers of children with ASD experience. The findings of the current study bring to light the cultural issues associated with raising children with autism and the roles played by institutions in addressing issues of stigma.

Method

This study examined mothers' experiences with stigma associated with their children diagnosed with ASD in the KSA. Using Goffman's (1963) theory of stigma as a theoretical framework, 15 interviews were conducted with mothers in the KSA whose children were diagnosed with autism spectrum disorder. A phenomenological approach was used to explore these mothers' individual, personal experiences, examining the similarities while highlighting the uniqueness of their individual experiences. It allowed a better understanding of their experiences by providing access to their unique perspectives (Creswell, 2007; Marshall & Rossman, 1999; McCaslin & Scott, 2003; Wertz et al., 2011).

A phenomenological approach works from the belief that "there is an essence or essences to shared experience" (Patton, 2015, p. 116). Phenomenologists are interested in shedding light on what individuals experience and more importantly how they experience it. Through its focus on individual experiences, a phenomenological approach works to validate these experiences. In addition, van Manen (1990) posits that a phenomenological approach should strive for collecting stories about the experiences of individuals and validating those

experiences. While it allows for capturing the individual experiences and addressing their uniqueness, a phenomenological approach is described as “the study of the shared meaning of the experience of a phenomenon for several individuals” (McCaslin & Scott, 2003, p. 449). Due to a focus on shared experience, commonalities between the mothers were examined while remaining faithful to the uniqueness of their experiences.

The participants involved in this study included 15 mothers between 22 and 43 years old. They provided information about their experiences with stigma associated with raising children diagnosed with ASD. The study did not focus on the severity of the children’s condition or gender. It included all mothers with children between the ages of 5–12. The mothers provided unique responses to their experiences of stigma. Mash and Wolfe (2010) indicated parents’ reactions depend on their level of education, family setting, and work environment. Parents’ level of education may impact individuals’ reactions to the problems they face based on various forms of social, economic, and cultural stress (Mash & Wolfe, 2010).

Data Collection

Before conducting interviews, mothers involved in the study provided informed consent. The setting for each of the 25–45 minute individual interviews was a local coffee shop. They were audio recorded to ensure accurate capturing of participants' responses. At the end of each interview, a summary of the interview was written, and transcriptions of interviews were created along with additional investigator memos.

Results

The investigation focused on the challenges associated with autism in a male-controlled society, specifically on mothers as they assume the role of primary caretaker for their children diagnosed with autism. Mothers’ responses were organized into themes/sub-themes for the following purposes. First, it represents the association of themes/subthemes. Second, it provides clear insights into mothers’ responses to the important issues that arose in the conversations. Third, it highlights the different issues that mothers chose to emphasize, struggled with, or found useful in their journey of trying to provide the proper services for their children. Finally, others reading this article are able to examine the responses on their own and evaluate the approach followed in analyzing the data.

For the case of data presentation, a numbering system was used. M1 was used to represent the response of mother number 1 as found in the transcript. M1-1 was used to refer to a comment’s position in the conversation containing mother number 1. For example, M1-1 means that mother number 1 provided the comment as the first response in the interview transcript. The numbering system was applied for all the participants. This system allowed easy examination of the transcripts and verification of the conclusions drawn from mothers’ responses.

Mothers’ Responses

The findings represent mothers' responses to their children's situation which are represented in Figure 1. First, the initial emotional responses mothers displayed in reaction to their children's condition are highlighted. Next, following their initial responses, mothers decided to take action to learn about their children's situations, and in addition to the positive steps they took, some relied on their faith to help them cope with the challenges they were facing. The findings conclude with an examination of mothers' perceptions of the negative effects of their children's autism on their social milieu.

Figure 1. Visual Representation of the Components of Mothers' Responses to Shame.

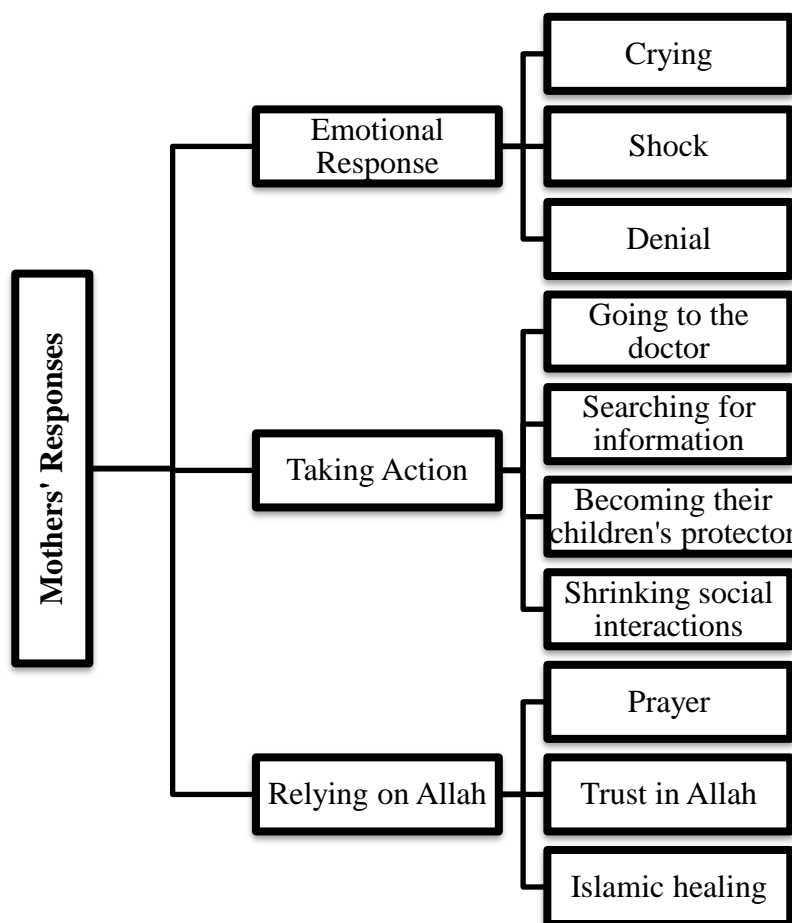


Image Description: Figure 1 provides a representation of the components of mothers' responses to shame. Their responses are divided into three major areas: Emotional Response, Taking Action, and Relying on Allah. Initial emotional responses mentioned by mothers included crying, shock, and denial. After their initial emotional response, some mothers described actions they took or experienced in response to their children's diagnosis. Such actions included going to the doctors, searching for information, becoming their children's protectors, and experiencing shrinking social interactions. Finally, for those mothers who reported relying on Allah, they responded with prayer, put their trust in Allah, or relied on Islamic healing.

Most mothers interviewed noticed the challenges their children were facing at an early

age. Nine of the 15 mothers interviewed, received a diagnosis of autism for their children between the ages of 1 and 2 years old. Of the 15 mothers, four learned of their children's condition when they were 3 years old. One of the mothers reported she learned of her child's condition when the child was 1 year old. Of the 15, only one mother learned of her child's condition at a later age, after the child was 6 years old.

Mothers' emotional responses

The mothers reacted differently to their children's diagnosis. Their initial responses reflected the emotional difficulty associated with receiving a diagnosis. Most of the mothers (M1, 3, 4, 5, 6, 8, 9, 10, 11, 12, 13, and 14) agreed about the emotional challenges they faced shortly after their child's diagnosis. Their responses ranged from surprise to crying. Mother 3 reported that an overwhelming feeling of sadness overcame her. Mother 4 indicated she was in a state of disbelief. She said, "at first, of course, I was in shock, denial, and crying. I tried to deny it in every way possible" (M4-5). She could not do anything to stop the feeling and claimed that "the issue physically drained his father and me" (M4-6).

For some, however, they felt a sense of isolation. Mother 5 asserted that she was in shock and responded with "crying and isolation from everybody for several days. I became hot tempered and cried a lot" (M5-7). Some took this on themselves as Mother 5 explained that she "was in denial and stopped eating and drinking. My brain completely stopped thinking" (M5-8). However, she was not the only one who experienced this feeling. Mother 8 explained, "My husband and I got extremely sad and cried when we figured out that our child has autism. We were definitely shocked because he is our first child" (M8-6).

Isolation sometimes resulted in mothers trying to cover up the issue. Mother 9 said that she and her husband "got scared and did not tell anyone about her disorder" (M9-6). While this was a big problem for the parents, some had a harder time than others. Mother 12 made this point when she described the difficulty her husband had with accepting their child's diagnosis. She indicated, "I was so confused and couldn't believe that my son has autism. My husband and I had a tough time accepting it. I can't forget what my husband said: he can't [be] autistic, he can write, talk, and read. My son cannot be autistic! He is a normal child!" (M12-6). For some, the feelings took longer to deal with. Mother 14 explained that it took her "three months to get rid of that feeling. I felt extremely sad for his situation" (M14-7).

Taking action

Despite initial difficulty in dealing with the diagnosis, eventually some mothers were driven to take positive steps to help their children (M2, 3, 4, 6, 7, 9, 10, 11, 13, 14, and 15). Mother 2 reported, "I tried to take care of him more and visited specialists and experts including counselors and a private tutor specialized in these cases. I also followed up with hospitals and took him to rehabilitation sessions and massage therapy for exercising the affected muscles" (M2-6). This desire to seek help was echoed by others. Mother 7 posited that she "tried to search and read. I wrote the symptoms on the Internet to know what is wrong with him because I had no knowledge about ASD and its symptoms. I asked a counselor. I visited an otolaryngologist. I attended educational workshops. I gained awareness and I

learned about autism and autistic mood and thinking” (M7-6). Not only did mothers seek diagnosis, but some often went beyond that to learn more about their children’s conditions. Mother 10 emphasized this when she said, “I read a lot of articles from Google and I watched a lot of videos on YouTube about this disorder” (M10-7). Some invested money in acquiring more help. Mother 11 indicated that she “asked some speech specialists for some assistance to help my daughter talk” (M11-9).

These mothers also assumed the role of protector for their children. However, sometimes, they became overprotective. Mother 2 said, “I prefer to always be with him when we get out. I don’t like taking him with me to other people’s houses. When I do, I would be close to him the whole time because he does not defend himself” (M2-34).

Being overprotective was often designed to ensure the child’s feelings were not hurt by others. Mother 9 argued that she tried to be with her daughter to “avoid having others hurt her feelings” (M9-38). These protective mothers often worked to stop others from hurting their children. Mother 9 made this point when she described, “a year after my daughter’s diagnosis, I became stronger and I was able to confront them and stop them from making any negative comments because I did not want my daughter to get affected or hate her life when she grows up” (M9-41). Mother 15 agreed that she stopped anyone who tried to mock her child. This strength translated into trying to learn more about others. Mother 3 explained that after becoming overprotective, she felt “much better than before because I learned a lot about his disorder. I also tried to let my friends/relatives to understand/learn about my child’s condition” (M3-39). Mother 15 made the same point when she said, “I learned a lot about his condition, and I want the best for him. I tried to talk to his friends and told them about his disorder” (M15-21). These mothers were not only strong in advocating and standing up for their children, but they also worked hard to learn about the condition and educate others around them.

A shrinking social circle

Some mothers had to deal with a shrinking social circle that resulted from their children’s condition. Six of the 15 mothers (M1, 2, 5, 6, 8, and 9) reported issues with their shrinking social circles. Mother 1 explained that she was unhappy with some of the comments made by people in her circle, which led her to isolate herself. She posited, “I isolated myself and only relied on educated people who supported positively because at first, I swear to Allah, I got really tired of comments made by some people” (M1-42). Mother 5 responded in a similar manner to people in her circle who stigmatized her child. She explained, “I isolated myself and I stayed with my son and I ignored them, and I celebrated my success alone” (M5-47). This type of criticism led many to stay home and keep their children away from the rest of the family. Mother 9 made this point most clearly when she indicated, “sometimes I don’t like to take her with me to any parties or special occasions to avoid criticism and blame or mocking looks that might lead my daughter to have more complications” (M9-29). Mothers’ shrinking social circles were a result of the misconceptions of others and justified by a desire to protect their children from others’ judgmental looks and harsh remarks.

Relying on Allah: Role of religion

Despite the difficulty of their situations, many mothers found comfort in their faith. Mothers 1, 5, 6, and 12 emphasized the role their faith played in helping them become more comfortable with their children's diagnoses. Some reported their faith helped them accept their child's condition. Mother 1 explained, "The first and best resource is Allah's blessing and praying for him only. I was content with what Allah has chosen for me. It made me pleased with my child and I saw improvement. Thanks to Allah" (M1-37). For her, this reliance on Allah "helped and guided/showed me how to behave so I isolated myself indirectly and I felt comfortable" (M1-41). Furthermore, she went on to explain the role the Qur'an can play in helping heal autism. "I ask you and other brothers and sisters who dedicated themselves for this cause to pay attention to my viewpoint/opinion. I think autism can be healed through [the] Qur'an and it is related to satanic/demonic forces. And I have proof for that" (M1-56). For Mother 1, her reliance on Islamic healing helped her child tremendously. She claimed:

To be honest with you, I relied on Islamic healing, and I would recite three times a day and give them honey and ground black seeds and holy water. And the result was my older son improved [by] 80% (M1-58).

Similar to Mother 1, Mother 5 explained that her reliance on Allah made things easier after the initial challenges. She explained, "even his father abandoned him and refused to pay attention, but Allah with his mercy made things easy" (M5-9). Mother 6 found the same comfort in her submission to Allah, relying on prayer to help her child, viewing the condition as "a test from Allah" (M6-37). Because it was perceived as a test, the solution was in trusting God. Mother 12 emphasized that "the effect of trusting God is a miracle. I believe in leaving it to God and to trust him and to pray. Keeping that connection with God is the solution" (M12-41).

Consistent with the reliance on faith was the cultural belief that autism may be a result of an evil eye. Mother 11 explained that members of her family told her that this might be an evil eye. She explained, "two of my sisters-in-law told me that my daughter has an evil eye because she is so beautiful. They told me there are several ways to get rid of it: reading [the] Qur'an and taking her to a Sheikh" (M11-19).

Recommendations

Mothers in this study experienced social stigma similar to that proposed by Goffman (1963) and reiterated by Bos and colleagues (2013) and Olkin (2002). Others in their social circles blamed the mothers or their children for behaviors that deviated from what was perceived as society's norms. Mothers responded in a variety of ways that allowed them to cope with and in some cases, actively confront the stigma they and their children were experiencing.

This study's findings provide many implications for practice and demonstrate the

importance of utilizing and making the most of the mothers' experiences. As the primary caregivers, mothers know more about their children than anyone else. While some specialists tend to ignore mothers' input and experiences, it is clear that a clear diagnosis and the determination of appropriate services should be responsive to mothers' wishes, to ensure services are culturally appropriate and sensitive to families' unique needs.

To overcome the problem of excluding mothers or having them feel as if they cannot bring their children into the community –for fear of stigmatization or negative reactions from others– specialists and other concerned individuals should develop individualized self-management systems to help children develop appropriate social behaviors. Self-management systems are not only useful for helping individuals with disabilities achieve certain behavioral goals but are also inclusive of the parents.

There are four stages when introducing a self-management plan. First, the collaborative team discusses diverse activities for effective and efficient implementation of a plan. The team should include teachers, specialists, and parents who identify and develop target behaviors they want to enhance or curb (Busick & Neitzel, 2009). One way to accomplish this is through goal setting. Goal setting involves coming up with a target for changing behavior (Schulze, 2016) and enables children with ASD to motivate themselves in addressing specific deficits in their abilities related to organizing, planning, and executive functioning.

Next, the self-management system must be effectively introduced to the learner. In this scenario, students should understand vital elements of the system, for instance, they should demonstrate the target behaviors and determine if key aspects of the behavior have taken place or not. The learner is engaged in recording the occurrence or lack of target behaviors. Students should effectively manage the reinforcements related to the achievement of identified goals (Busick & Neitzel, 2009). In this stage, students are encouraged to internalize the steps of the system in their own words to check for understanding. Using a self-instruction strategy is one way to measure comprehension which requires the child to verbalize the steps of a given task to be completed (Schulze, 2016). Self-statements prompt the child to promote a positive behavioral change and gives a student with ASD the ability to perform tasks independently.

The third stage in the process is implementation. Teachers provide the necessary materials for learners to utilize the self-management system as well as enable them to acquire necessary materials independently. Additionally, practitioners may provide different cues such as visual aids and verbal cues as well as teaching them how to self-record target behaviors. Teachers then educate learners on how to acquire access to earned reinforcements (Busick & Neitzel, 2009).

Finally, the fourth stage is to allow students to work independently and measure their development. Practitioners employ periodic check-ups to determine whether the learners are consistent in self-recording and reinforcement. The next step is for teachers to gradually

heighten specified criteria for success while also assessing the success of the students (Busick & Neitzel, 2009).

Another means of measuring outcomes is through self-charting, which empowers students to determine how effective they are in achieving their target goals. Self-charting works hand in hand with goal setting and self-monitoring to increase students' time on activities, academic performance, and accuracy. Furthermore, this strategy enables children with ASD to monitor their progress in behavioral change (Schulze, 2016).

The utility of this strategy lies in its collaborative nature (Busick & Neitzel, 2009). Teachers, parents, and education specialists work together to design plans that help learners achieve individualized behavioral goals, and this collaboration should take mothers' concerns into account. Although all of these steps are used in a school setting, mothers can and should participate in their implementation, learn how to introduce these strategies, and implement them on their own.

Peer support is also required to help both peers and individuals with ASD work in an environment that is inclusive. Studies have shown that peer supports consistently demonstrate increased levels of tolerance, awareness, and acceptance of differences (Bellini, Peters, Benner, & Hopf, 2007; Harper, Symon, & Frea, 2008; Kamps et al., 1992; Kohler, Greteman, Raschke, & Highnam, 2007). Similar support could be provided to family members. Researchers have shown that:

Family therapists are well-suited to help parents stay connected to each other as they create a "new normal." However, family therapists need updated information about autism, and they need to understand how family therapy can help parents of children with autism. Because having a child with autism affects multiple domains of family life...family therapists can utilize an integrative approach with parents, enabling them to flexibly work with the domains of action, meaning, and emotion (Solomon & Chung, 2012, p. 250).

It is also apparent that some mothers deal not only with stigma, but also other cultural beliefs that may inhibit their willingness to trust modern scientific approaches to disability. For specialists who work in this type of environment, the effort that is required is doubled, due to the fact that they must not only help mothers, but also be able to understand the underlying causes behind their fears and lack of trust. As some of these mothers demonstrate, belief in the supernatural as a cause of disability has led some of them to seek traditional methods for dealing with their children's conditions. Professionals should be aware of the need to adapt and to be flexible when working with individuals from different cultural backgrounds. As future specialists are trained, they must be aware of cultural differences. This also includes dealing with people from the same culture, as this study shows, it is important to remember that individuals' responses to disability vary depending on many factors. Al-Aoufi, Al-Zyoud, and Shaminan (2012) eloquently articulated this concern when they argued that:

Despite the fact that Muslims share the same beliefs and principles, people's attitudes and understanding regarding these concepts, and their reactions to individuals with a disability, may vary depending on the intensity of a person's faith, as well as their socio-economic status, level of education, awareness and, more importantly, their cultural context (p. 205).

Such an awareness is necessary in a world that has become incredibly interconnected and diverse in its makeup.

Clearly, much needs to be done to help increase awareness and acceptance of disability. On the institutional level, especially in schools, teachers need to receive proper training to increase their readiness to provide support for students with special needs, including those with ASD. Curricular activities ought to be redesigned to take these needs into account.

Finally, on a societal level, the adoption of a social model of disability is needed which "locates the disablement in the environment and society" (Olkin, 2002, p. 132), as opposed to the moral or medical models which place blame on the individual. One way to support this paradigm change is through the media which can play an instrumental role in helping increase awareness of different impairments, including autism spectrum disorder, and how society and the environment create disabling conditions. This could be achieved through educational programs that teach others about impairments and the subsequent disabling conditions. It also imperative to explore, "the mutual contribution television and disability studies can make to one another, focusing on the role of television and visual media in raising awareness and challenging gaps in understanding" of disabling conditions that are frequently stigmatized (Heward, Palfreman-Kay, & Innes, 2015, p. 229).

Conclusion

As noted above, many of these mothers had negative perceptions of their children's conditions and felt overwhelming sadness upon discovering that their children had ASD. Although these experiences and attitudes improved upon learning more about the disability, many still struggled with the cultural stigma that exists. And while many have found specialized institutions useful, much is needed to help improve people's awareness regarding impairments in an attempt to help the public be more understanding of individuals with ASD and more empathetic toward their experiences. Focusing on developing the knowledge and understanding of members of society in order to impact the present culture, only then might it be possible to address society's perceptions of impairments and eliminate the associated stigma experienced by individuals with impairments and those who love and support them.

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References

- Al-Aoufi, H., Al-Zyoud, N., & Shahminan, N. (2012). Islam and the cultural conceptualization of disability. *International Journal of Adolescence and Youth*, 17(4), 205–219.
- Alqahtani, M. (2012). Understanding autism in Saudi Arabia: A qualitative analysis of the community and cultural context. *Journal of Pediatric Neurology*, 10(1), 15–22. doi:10.3233/JPN-2012-0527
- Basaffar, A., Niehm, L., & Bosselman, R. (2016). Saudi Arabian women in entrepreneurship: Challenges, opportunities, and potential. In *United States Association for Small Business and Entrepreneurship. Conference Proceedings*. United States Association for Small Business and Entrepreneurship.
- Bellini, S., Peters, J. K., Benner, L., & Hopf, A. (2007). A meta-analysis of school-based social skills interventions for children with autism spectrum disorders. *Remedial and Special Education*, 28(3), 153–162.
- Bos, A., Pryor, J., Reeder, G., & Stutterheim, S. (2013). Stigma: Advances in theory and research. *Basic and Applied Social Psychology*, 35(1), 1–9.
- Busick, M., & Neitzel, J. (2009). *Self-management: Steps for implementation*. Chapel Hill, NC: National Professional Development Center on Autism Spectrum Disorders, Frank Porter Graham Child Development Institute, The University of North Carolina.
- Cappe, E., Wolff, M., Bobet, R., & Adrien, J. (2011). Quality of life: A key variable to consider in the evaluation of adjustment in parents of children with autism spectrum disorders and in the development of relevant support and assistance programmes. *Quality of Life Research: An International Journal of Quality of Life Aspects of Treatment, Care & Rehabilitation*, 20(8), 1279–1294.
- Creswell, J. W. (2007). *Qualitative inquiry and research design: Choosing among five approaches*. Thousand Oaks, CA: Sage.
- Daley, T. (2002). The need for cross-cultural research on pervasive developmental disorders. *Transcultural Psychiatry*, 39, 531–550.
- Davis, N. O., & Carter, A. S. (2008). Parenting stress in mothers and fathers of toddlers with autism spectrum disorders: Associations with child characteristics. *Journal of Autism and Developmental Disorders*, 38, 1278–1291.

- Duarte, C. S., Bordin, I. A., Yazigi, L., & Mooney, J. (2005). Factors associated with stress in mothers of children with autism. *Autism*, 9, 416–427.
- Fernandez, M. C., & Arcia, E. (2004). Disruptive behaviors and maternal responsibility: A complex portrait of stigma, self-blame, and other reactions. *Hispanic Journal of Behavioral Sciences*, 26, 356–372.
- Goffman, E. (1963). *Stigma: Notes on the management of spoiled identity*. Englewood Cliffs, NJ: Prentice-Hall.
- Gray, D. (1993). Perceptions of stigma: The parents of autistic children. *Sociology of Health & Illness*, 15(1), 102–120.
- Gurung, R. (2006). *Health psychology: A cultural approach*. Belmont, CA: Wadsworth Publishing.
- Harper, C. B., Symon, J. B., & Frea, W. D. (2008). Recess is time-in: Using peers to improve social skills of children with autism. *Journal of Autism and Developmental Disorders*, 38(5), 815–826.
- Hayes, S. A., & Watson, S. L. (2013). The impact of parenting stress: A meta-analysis of studies comparing the experience of parenting stress in parents of children with and without autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 43(3), 629–642. doi:10.1007/s10803-012-1604-y
- Heward, M., Palfreman-Kay, J., & Innes, A. (2015). In their words: How television and visual media can raise awareness of dementia and other health conditions that carry stigma, including disabilities. *The Journal of Popular Television*, 3(2), 229–242.
- Ingersoll, B., & Hambrick, D. Z. (2011). The relationship between the broader autism phenotype, child severity, and stress and depression in parents of children with autism spectrum disorders. *Research in Autism Spectrum Disorders*, 5(1), 337–344.
- Johnson, N., Frenn, M., Feetham, S., & Simpson, P. (2011). Autism spectrum disorder: Parenting stress, family functioning and health-related quality of life. *Families, Systems and Health*, 29(3), 232–252.
- Kamps, D. M., Leonard, B. R., Vernon, S., Dugan, E. P., Delquadri, J. C., Gershon, B., & Folk, L. (1992). Teaching social skills to students with autism to increase peer interactions in an integrated first-grade classroom. *Journal of Applied Behavior Analysis*, 25(2), 281–288.
- Kohler, F. W., Greteman, C., Raschke, D., & Highnam, C. (2007). Using a buddy skill package to increase the social interactions between a preschooler with autism and her peers. *Topics in Early Childhood Special Education*, 27(3), 155–163.
- Kuhn, J. C., & Carter, A. S. (2006). Maternal self-efficacy and associated parenting cognitions among mothers of children with autism. *American Journal of Orthopsychiatry*, 76(4), 564–575.
- Lyons, A. M., Leon, S. C., Phelps, C. E. R., & Dunleavy, A. M. (2010). The impact of child

- symptom severity on stress among parents of children with ASD: The moderating role of coping styles. *Journal of Child and Family Studies*, 19, 516–524.
- Mak, W., & Kwok, Y. (2010). Internalization of stigma for parents of children with autism spectrum disorder in Hong Kong. *Social Science & Medicine*, 70, 2045–2051.
- Marshall, C., & Rossman, G. B. (1999). *Designing qualitative research*. Thousand Oaks: SAGA Publications.
- Martin, D. M. (2012). The ever-changing social perception of autism spectrum disorders in the United States. *Explorations: Social Sciences*, 160-170. Manuscript submitted for publication.
- Mash, E., & Wolfe, D. (2010). *Abnormal child psychology* (4th ed.). Belmont, CA: Wadsworth.
- McCaslin, M. L., & Scott, L. W. (2003). The five-question method for framing a qualitative research study. *The Qualitative Report*, 8(3), 447–461.
- Miller, V. A., Schreck, K. A., Mulick, J. A., & Butter, E. (2012). Factors related to parents' choices of treatments for their children with autism spectrum disorders. *Research in Autism Spectrum Disorders*, 6(1), 87–95.
- Olkin, R. (2002). Could you hold the door for me? Including disability in diversity. *Cultural Diversity and Ethnic Minority Psychology*, 8(2), 130–137.
- Olkin, R. (2007). Disability-affirmative therapy and case formulation: A template for understanding disability in a clinical context. *Counseling and Human Development*, 39(8), 1–20.
- Patton, M. Q. (2015). *Qualitative research and evaluation methods* (4th ed.). Los Angeles, CA: Sage.
- Ravindran, N., & Myers, B. J. (2012). Cultural influences on perceptions of health, illness, and disability: A review and focus on autism. *Journal of Child and Family Studies*, 21, 311–319. doi:10.1007/s10826-011-9477-9
- Schulze, M. A. (2016). Self-management strategies to support students with ASD. *Teaching Exceptional Children*, 48(5), 225–231. doi:10.1177/0040059916640759
- Solomon, A. H., & Chung, B. (2012). Understanding autism: How family therapists can support parents of children with autism spectrum disorders. *Family Process*, 51(2), 250–264.
- van Manen, M. (1990). *Researching lived experiences*. Albany, NY: State University of New York Press.
- Wertz, F. J., Charmaz, L., McMullen, L. M., Josselson, R., Anderson, R., & McSpadden, E. (2011). Five ways of doing qualitative analysis: Phenomenological psychology, grounded theory, discourse analysis, narrative research, and intuitive inquiry. New York: Guilford Press.

Zeina, R. M., Al-Ayadhi, L., & Bashir, S. (2014). Autism spectrum disorder: Main problem waiting for solution in Kingdom of Saudi Arabia. *Autism*, 8(8), 487–490.



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Disability and Shame Special Issue Forum: Research Article

Mental Health Disabilities, Shame and the Family: The Good, the Bad, the Chosen, and the Imagined

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Abstract: Based on ethnographic research examining the lives of individuals with mental health disabilities in Suffolk County, New York, this paper highlights key aspects of deinstitutionalization, intersectional shame factors impacting disabilities, and community-based mental health care. Findings indicate that individuals' families of origin can promote and maintain shame and psychological distress.

Keywords: Disability; Shame; Family

This paper highlights the phenomenology of individuals with mental health disabilities in Suffolk County, New York. The project considered involuntary commitment, deinstitutionalization, community-based mental health care, family, and transition processes. Findings indicate people's families of origin can create and sustain aspects of shame and psychological distress. As individuals seek compassion and care they had reported that it was lacking during their institutionalization, and they often instead experience shunning and exclusion outside of hospitals or mental health housing. In effect, while large asylums are considered modalities of the past, *total institutions*¹ (Goffman, 1961) remain and are often recreated by systems of care, families, and society effected by expanding historical shame, discrimination, and violence against people with disabilities.

Purpose for Study

The compounded marginalization of people with disabilities²—intersections of racism, sexism, classism, and trauma they endured—motivate this research. Individuals with mental health issues are persistently ignored or invisible (Deutsch, 1949; Fanon, 2004; Neugeboren, 2006). Prior to the late 20th century, most people with persistent mental health needs were institutionalized indefinitely. Later, post-deinstitutionalization, those without financial and emotional support ended up homeless, and were (and still can be) relegated to sub-standard and unsafe housing or in jail (Ben-Moshe, 2011; Jenkins, 2015; Neugeboren, 2006). Others live in contingent—considered as provisional or unchosen—housing sites, often becoming more disabled by systems and people, including, in a majority of cases also by family members, who further subjugate them as they wait for safer housing (Desjarlais, 1994; Frischmuth, 2013; Hatzenbuehler et al., 2013; Jenkins & Carpenter-Song, 2008).

Though modern approaches to provide services in the most barrier-free environments is an improvement over institutions of the past, some theorists argue that community-based

mental health continues to disable people socially, economically and politically, or to the same degree as historic asylums once did (Ben-Moshe, 2011; Luhrmann, 2007; Reaume, 2002, 2006; Whitaker, 2010). Contemporary care spaces—those in the deinstitutionalization era—intend to generate freedom, but often engender shame and greater cycles of anguish (Clapton, Williams, & Jones 2018). Therefore, attending to current care practices and shame is essential in the era of post-deinstitutionalization.

Asylum History on Long Island

Four state-run asylums (referred to in this study as the “Big Four”) all operated within a 30-mile radius of one another in Suffolk County during the late 19th and early 20th century. At one point these four institutions collectively housed the largest number of people with mental disabilities in the world (Kalvin, 2015; Polaski, 2003). Medical opinion of late 19th and early 20th centuries professed that removing people with mental disabilities from the stressors of city life promoted flourishing and mitigated disabling effects of mental differences (Kalvin, 2015). These spaces encouraged families to bring individuals with mental health disabilities in for treatment (Gamwell & Tomes, 1995). The grounds were beautiful and the treatments were touted as state of the art. There was far less guilt to manage for the family members, who were discarding loved ones at the asylums (Gamwell & Tomes). Thus, these new environments served two purposes: they isolated the “sick” individuals by removing them from exacerbating effects of the city, while also protecting the city residents from their embarrassing and menacing deeds. Meanwhile, the pastoral settings, touted as functioning without restraints at that time, would restore health. Participants in this study reported that their families’ desired the same for them—to isolate and rehabilitate them in asylums—in settings away from home where they would not bring attention and disgrace upon the family unit nor disrupt the normal flow of activities.

Methodology and Fieldwork Site

Through in-depth interviews and participant observation in community-based, peer-delivered recovery programs, and in publicly supported mental health housing sites in Suffolk County, New York, findings illuminate how individuals with persistent mental health disabilities describe and feel about their own living environments and occupations. During the following analysis, of a small portion of this data, the consented participants in this study are referred to as individuals. Data was collected from qualitative, semi-structured interviews with individuals in Suffolk County. Individuals were engaged with for nearly 23 months spanning from September 2015 until August 2017. In September 2015, interviews were conducted, peer-based mental health conferences and peer support groups for family and individuals with mental health disabilities were attended, and service providers were consulted. Research flyers were also distributed electronically to 230 people on peer listservs. From that pool and through snowball sampling, 38 individuals volunteered for in-person meetings in order to learn more about the research. Of the 38 volunteers, a total of 26 individuals attended these meetings. The meetings included a verbal and written description of the study, an initial verbal capacity to consent³ screening, and a final written consent if capacity to consent was completed. Individuals who passed the capacity to consent, and were either Suffolk County

residents from the Big Four or residents that used local, community-based public mental health services, were invited to participate. An incentive of a \$25 gift card was given to each participant who completed the initial interview.

Of these 26 individuals, most initial consenting and interviewing meetings lasted 45 minutes to 1.5 hours. Three people chose to meet in private rooms on the Stony Brook University campus. The remainder of people were interviewed in their homes, which were mental health housing sites or privately-owned homes, or if they felt comfortable, at local libraries, mental health agencies where they attended day programs, or at nearby pizza and coffee shops. On three occasions, one individual's meetings occurred in an acute psychiatric ward, although she was medically stable, she was awaiting a community housing assignment. Nine of 26 individuals (34.6%) completed only one meeting. The remaining 17 individuals (65%) completed two to three meetings, as well as, speaking on the phone or emailing back-and-forth. In the case of seven individuals (26.9%), there were four to five meetings that took place in various home and public settings. This includes some travel to Mental Health Clubhouse⁴ activities, other mandatory mental health program sites, having coffee, doing shopping errands or joining them for meals. When individuals agreed, research meetings were conducted with other sites they visited regularly, to get a better feel for their lives and worlds. Additionally, many follow-up interviews took place at community-based mental health housing and day program sites.

The first and second meetings were recorded and transcribed verbatim. Field notes were also conducted during these visits. After the first two meetings, subsequent meetings were recorded but not always transcribed verbatim, only for clarity when necessary. But most of the later meetings, beyond the first and second meetings, where individual's day-to-day occupations were being ascertained, meetings involved more participant-observation in order to understand what daily schedules and routes looked like. Codes or themes found in transcript verbatim and field notes were created and compiled immediately after each interview.

Questions were open-ended but started with requests for individuals' memories of the first time they became aware or were told they may have a mental health disability. They were asked to describe where they grew up and when they first engaged with any form of mental health treatment or lived in a facility dedicated to mental health or psychiatric services. Of note, was the fact that the majority of people interviewed, 25 out of 26, described some form of abuse or trauma in their family of origin, as well as, multiple experiences in and out of mental health housing or hospitalizations. Twenty-three out of 26 also described compounded feelings of stress related to their gender, social class or ethnic background.

It is important to acknowledge and re-emphasize that these ethnographic examples are drawn from a small sample of people in Suffolk County. From the study sample of 26, extremely brief excerpts of seven individuals' interviews are summarized in this paper. Common themes emerged from each of these individuals with regard to shame, family trauma, forced medication and long-term institutionalization or perceived feelings of

containment. None of the study participants' family members were interviewed, so findings were concluded solely from individuals' accounts and research publications relevant to themes that emerged.

Intersectional Mechanisms of Shame

The concept of intersectionality underscores compounded biases and structural inequalities relayed by individuals in this study. For instance, Keisha (a pseudonym)⁵, a Black, bi-sexual female, who participated in the study, feels intersecting pressure points (such as race, class, sexuality and gender) toward her disability. Because of her socioeconomic class, she lives in a space *not chosen by her*, but instead was *available to her* where she must learn to advocate for herself and be compliant in order to stay safe. If she remains compliant, she said, she may be considered for less-restrictive housing in the future. Another participant, Dao, a 40-year-old Vietnamese man, feels alone as an Asian person with multiple disabilities who is estranged from his adoptive and biological family in predominantly white spaces on Long Island. Lamont, a 45-year-old gay Black man, provides an example of these stakes as well. Because of his race, mental health needs, economic class and sexuality, he does not feel he has many options to find community and friends. He further isolates himself, as he tries to maintain compliance requirements with community-based programs and benefits, so that he can access medications and general healthcare. Similar sentiments are recounted by Daniel, José, Helen and Patrice—all of whom described demeaning experiences with family, medications, and involuntary hospitalizations. These seven individuals highlight only a small portion of the multiple layers of shame people in the larger sample described to me.

Trauma: Informing Services Without Further Coercion

The Adverse Child Events (ACE) study (Felitti et al., 1998) teaches us that more than half of people with mental health needs experienced a traumatic experience before the age of 18.⁶ For this reason, the aim to circumvent further traumatic events, such as reducing or eliminating coercive psychiatric care, is gaining acceptance by mental health service providers.⁷ Given that a large majority of psychiatric patients have a past with trauma, caregivers and clinicians are calling for the need to create more safety (SAMHSA, 2014). Sweeney et al. (2018) note that when delivering services, instead of asking "What is wrong with you," providers are moving toward asking, "What happened to you?" (p. 319).⁸

With these questions in mind, it is interesting to consider contemporary theories about identity, shame and family, alongside individuals' lives. An evaluation of individuals' families based on the, admittedly normative, constructs of "good" or "bad," and "chosen" and "imagined" is presented. Drawing from Michele Friedner (2015) and Angela Garcia (2010), include narratives that are indicative of the binds these categories create for individuals who long for 'good' and helpful family, yet ultimately return to sites and relationships that can be further shameful or 'bad' which exacerbate or promote disabling conditions. Individuals repeatedly used the term 'good' to describe family members or supporters who assisted them in some way, and were consistently in their lives or provided them a place to stay. They used the term 'bad' when referring to traumatic events or people in their lives who were physically, sexually and emotionally abusive. Many times, contradictory terms were used, however, when

individuals described a parent as a good person who did bad things. The terms ‘chosen’ and ‘imagined’ represent an ideal that individuals are striving for in close relationships. Many chose new family members to replace biological or legal family members such as guardians and foster parents. Others imagined new family members such as a future spouse, partner or roommate that would make life more complete and fulfilling.

Family Impacts on Disability Shame

While individuals detailed what factors influenced their mental health experiences, family dynamics repeatedly emerged as a factor contributing to how they entered “the system.”⁹ Some mental health experts argue that family involvement aides in recovery (Dixon et al., 2015), while others note that certain family dynamics promote more disabling mental health outcomes (Felitti et al., 1998; Stumbo et al., 2015).¹⁰ Based on individuals’ narratives, it became apparent that experiences with family members can indeed both exacerbate and mitigate disabilities. Using a parallel from anthropologist Angela Garcia (2010), family can be variably productive—helpful and harmful. The same family that negatively impacts psychiatric disabilities might at later points be thought to mitigate it. The family can even be doing both simultaneously. Individuals seeking to reintegrate with family from which they had been estranged thought they were returning (and were even eager to do so) to a family of origin because they were trying to undo or overcome conflicts of the past, only to be further subjugated or shamed.

Sixty-nine percent, 18 out of 26, of these individuals grew up in the vicinity of the Big Four asylums and reported their parents or guardians themselves also struggled with mental health issues:

As young as I could remember, my mom was in Pilgrim State [psychiatric hospital] for mental illness. My foster mom took me to see her in the hospital a lot when I was a kid and it was really sad. My foster mom was okay, but we fought a lot. Even though she knew I had mental illness too, she would just push my buttons. Then my [biological] mom died in Pilgrim. It was hard to understand. My sister and I were also separated; she went with other foster parents far away so I was alone (Lamont).

People like Lamont, quoted above, described phenomena indicative of Garcia’s (2010) summary about heroin addicts sharing the affliction with family. Garcia concludes “there is a complex politics of kin, love and mourning” (Garcia, 2010, p. 149), meaning individuals living with addictions are often fighting and sharing these same struggles with family to the point that they may even have to watch them die doing it. Lamont reported he spent years being resentful toward his biological mother for having abandoned him, and not understanding her disability until he was older and struggled with his own similar symptoms. As a result, after decades of being ashamed, he accepted their shared disabling experiences as possibly genetic and even found empathy toward her. When she died inside the asylum, Lamont said he felt he lost his mother a second time and experienced further abandonment and disgrace because of their disability.

Twenty-four out of 26 study participants (92%), in fact, noted the delicate balance of

negotiating concealed patterns of shame and shaming within their families of origin. Including wanting to find belonging after years of feeling inward shame (from within the family unit), and peripheral shame (from outside the family) which was inflicted on them from society. They worked to overcome abandonment and had tried to cover up physical and emotional abuse to protect the family unit. They found less stigma and judgment in new families they chose.

Daniel, a 56-year-old White male, who spent a number of years in and out of two Big Four asylums and now lives in a single apartment treatment program (ATP), described his family:

My mom and dad kept their drinking and abuse pretty well hidden from the community. They appeared to the neighbors and everyone else as a 'good' Catholic family, but at night when we were home from school there were very scary moments. I just wanted my dad to love me and to fit in, but he could never accept that I wasn't the jock he wanted me to be, even when he tried to beat that into me.

Though he was physically and emotionally "punished for not fitting the mold" as he described, Daniel still ached for his father's acceptance. Daniel and others described what Elizabeth Pleck (2004) refers to as *domestic tyranny* or the historic patterns of covering up physical and emotional abuse in order to protect the perception of the family unit. Daniel stated that tyrannical control was exacerbated by his father's drinking. When Daniel's mental health needs became apparent and his parents were forced to address them, this compounded notions of shamefulness and indignity for Daniel.

Like Daniel, 11 other individuals (42%) described their family 'forcing' them into treatment after enduring abuse and disparagement by that same family. Meanwhile, there is a growing trend in mental health care attempts to reduce coerced treatment and move toward an elimination of restraints and forced medication. In recognition of childhood trauma, Trauma Informed Care (TIC) is considered a more contemporary modality that avoids force as the first go-to intervention (Isobel, 2015; NCTIC, 2013; Watson et al., 2014). Felitti et al. (1998) reported that more than 50 percent of people with mental health issues experienced an adverse childhood experience (ACE) prior to 18. Additional studies (Shonkoff, 2016) suggest ACEs have oppressive physiological effects that can damage a child's developing brain, and this in turn leads to a higher prevalence for later physical and mental health problems.

Eighty-five percent of individuals in this study—22 out of 26—reported memories of at least one ACE, and of these 22, a total of 20 narrated details about two or more ACEs. There were many times some individuals recounted as many as four to five ACEs. They each (every one of the 26) were hospitalized, involuntarily medicated, and in 10 cases, restrained and administered shock therapy.¹¹ One hundred percent of this sample of individuals—each of the 26 individuals—also, at one point or another, was told by their psychiatrists when being treated they would be disabled for the rest of their lives and would not work. Each person explained that these respective diagnoses and prognoses promoted feelings of what they described as shame and despair from at least one member of their family of origin. Two of the

three individuals described that the family was ashamed at the life sentence their respective disability produced. While all three noted that it was the stigma of psychiatric diagnosis itself that also produced a shamefulness—people said they felt the need to hide their diagnoses and the medications prescribed for them. However, when pressed whether families gave reasons of *why* mental health needs were shameful, individuals did not have responses.

Why Family Matters

Pondering accounts of family and kinship may provide singular answers to these questions, but I also caution that I take care *not* to ascribe family roles as one's primary identity. A particular role in the family *can be* one form of identity—a small portion of identity for some, a larger one for others—but it is not necessarily *the only* form of identity. For example, there are stronger and weaker ties—either within family or without family—, where some family is helpful, others are hurtful (Granovetter, 1973), this has caused many individuals to have chosen, ideal, or imagined families (Weston, 1997). Furthermore, many individuals may not have the social capital or privilege to even consider their own roles and identities (Friedner, 2015), making their search for finding chosen families even more difficult. Erevelles and Minear (2010) underscore how intersections like these between disability and class, or gender, can produce “non-citizens and “(no)bodies” (p. 129), or also known as people with disabilities who do not count or who are oppressed.

Further notable, 10 individuals, whose family deemed them “mentally ill” or ‘sick’ (not my terms, but many monikers reported that their family members used to designate these labels to them), had reported feeling uneasy with these labels. These individuals returned to live with those same families of origin for extended periods of time after institutionalization or hospital stays for said illness. Yet, most still attributed a certain degree of disability and shame ensuing from these early caregiver/family guardian relations—whether blood or adoptive family of origin. Therefore, people knowingly returned to the same environment they described as hurtful or harmful, and longing for a change in circumstance. Individuals recognized that re-engaging with disparaging family could start the entire shame cycle all over again—individuals’ symptoms had reappeared at family home sites after their time of hospitalization where they felt ‘relatively stable.’ Once the individual felt ashamed or demeaned and became agitated, then the family member(s) labeled this as a symptom of their ‘disease,’ turning them out once again.

Critical disabilities scholar Clementine Morrigan (2017) offers important propositions about the phenomena I call *shame cycle*, particularly in the case of individuals who have experienced trauma and violence in their past. Morrigan notes that people with psychiatric disabilities are often portrayed as or reduced to ‘acting out.’ This acting out, however, is actually resistance against previous and future violence or an “embodied form of testimony” (Morrigan, 2017, p. 62). Unfortunately, the most common response to this resistance is a desire, on the part of some family and especially psychiatry, to physically or pharmacologically restrain symptoms. Participants in this study, in fact, each noted that family members wanted to protect themselves from harm and avoid family violence by administering more medications. Findings here point to the fact that family of origin—

whether originally helpful or harmful—often works in conjunction with that reactive approach to symptoms, while further perpetuating the myth that people with mental health needs are dangerous or need to be subdued and tranquilized. Rather, as Morigan and others state (Isobel, 2015; Watson et al., 2014), this only serves to further distance and shame people with mental health disabilities from the family and society in general.

Dao, a 38-year-old, Vietnamese male, living in a community residence (CR), noted a similar experience. If there is any disagreement, he told me, his mother's first response is to remind him that he is a disgrace and that he needs more medication. "My mom told me I need more medication when I went to see her. I don't feel like I want more medication though. It makes me feel slow. I just want my family to care about me."

Care in the context of families takes on a distinctive meaning if we think about the dual role of caring and abandonment or even abandonment as care. João Biehl's (2004) ethnographic work on the relinquishment of 'severely mentally ill' people in Brazil provides a useful milieu with which to examine this phenomenon. Biehl interviewed people at *Vida* in Brazil, an institutional site of 'dis-belonging' and exclusion for impoverished disabled people, which originally served as an infirmary, but eventually became what he described as a waiting room for death. Biehl notes that this site serves as one of the many "zones of abandonment" (Biehl, 2004, p. 476) for those considered 'unknowable' or left abandoned, as individuals lacking personhood or not worth knowing, in these zones. Suffolk County residents' narratives like Dao's resonated with these zones of abandonment because, like the United States, Brazil's people have fewer choices for long-term care in a post-deinstitutionalization era. There is less money for funding of community clinics, but ample pharmaceuticals readily obtainable. Therefore, as Biehl's individuals show, "the family is increasingly the medical agent of the state, providing and at times triaging care, and that medication has become a key instrument for such deliberate action" (Biehl, 2004, p. 475). Similarly, Dao said his mother, sister and brother-in-law, began telling Dao years ago precisely when he needs his meds and how much. Dao said he feels his mom thinks "she can boss me around this way." Biehl concludes that individuals with mental health disabilities share this phenomenon when their "families learn to act as proxy psychiatrists," choosing the role of acting doctor or nurse (Biehl, 2004, p. 475). And, because of this, Biehl concludes, "families can dispose of their unwanted and unproductive members, sometimes without sanction, on the basis of individuals' noncompliance with their treatment regimes" (pp. 475–476). This is not to suggest there can be unlimited and non-negotiated care provided by an inexhaustible family, but that there may be a way to include individuals in making decisions about their care as responsible people and/or in concert with the parties in their families.

Beyond that, once a person is relegated to the institution for non-compliance, the goal of managing symptoms or other myriad non-conformity justifies abandonment of the unwanted, and the state vis-à-vis mental health housing sites, such as the community residence (CR), in essence take up the role of family caregiver/proxy psychiatrist. The CR staff will make certain residents are medication compliant and, in this sense, the state or mental health housing construct becomes the new family carer, for better or for worse. With

little to do and few friends and family who visit, an individual has the unchosen replacement of their state-sponsored housing and staff reinforcing old carer or shame-producing roles of the family. As one of the staff in Biehl's (2004) ethnography noted, this leads to a lack of love and that "lack of love leaves these people abandoned" (p. 477). Being 'medication compliant' at CRs in particular was reported as the number one checklist item for individuals wanting reconsideration of some other housing arrangement (sometimes called 'changing levels of care' in Suffolk County or having the ability to move to less restrictive housing), thereby creating "the domestic role of pharmaceuticals as moral technologies" (Biehl, 2004, p. 485). Participants agreed that their care was certainly predicated on this technology.

Domestic Spheres of Influence

Considering kinship and disability, these narratives also underscore what Das and Addlakha (2001) recognize as notions of impairment and disability through "reconfiguration of the domestic sphere" (p. 512). Examining what it was like for parents to accept or reject children that are not normal, they refer to the 'tyranny of the norms of the parents' and consider how children can be shamed as they land outside of domestic citizenship. People's disability muddies their belonging. They are influenced by a role in family but are also often citizens of hospitals and other state institutions. Other times they may be cast out of the citizenship of family and instead fall within the domain of the state, where decisions, even including the right to life, are left to public institutions (Das & Addlakha, 2001). I find this analytic relevant to the individuals in this study, as individuals described confusion from concurrent feelings of both *oppression from* and *longing for* family and parents that had cast them out of the family sphere.

Good and Bad Family

It is interesting to contemplate 'good and bad,' and 'chosen and imagined' families and what makes up kinship as it relates to the family of individuals with mental disabilities and how people must negotiate diminished or expanded kinship networks. By 'family,' those close associations—biological or legal guardian—are considered from early family of origin. This also includes those people who shared a living environment for individuals in their early years and were their primary caretakers. The term 'good family' refers to those people in roles who were reported as loving, safe, consistent role models for individuals. Similarly the notion of 'bad family' describes those people situated as caretakers for individuals who were reported as inconsistent in their care and nurturing. Caretakers may have been psychologically harmful to the children in their care, physically or sexually abused them, were misusing drugs and alcohol, or had been incarcerated during their rearing, before participants turned 18 years of age.

The reference 'chosen family,' designates the associations participants voluntarily selected to be in their family circle—those that they accept and want to maintain relationships with. In some cases, these are the same 'bad' or 'good' family members with whom they grew up with. In other cases, chosen family is completely different individuals all together—a chosen aunt, uncle, neighbor, friend or teacher who becomes a selected kin in an individual's life. Beyond these categorizations, 'imagined family' signifies that tie or relationship an

individual wishes and hopes for. Imagined family may be forthcoming or may never come. Chosen family and imagined family can be in sync, or may never be.

In addition, by using the analytic of domestic citizenship space of family stigma and shame (Das & Addlakha, 2001), individuals' narratives challenge the concept of 'sustaining care.' And more specifically, their experiences underscore how some care is not concerned with optimal thriving in the world—not spiritual or educational work—but is more focused on minimally sustaining people to the very perfunctory point that they simply exist. This further imposes peripheral shame—that shame that individuals experience outside of family as well as from within it. Often when family is the first point of care, the 'bad' can be just barely sustaining. Finally, it is acknowledged here that these categories (*good, bad, chosen, imagined*) are often blurred. These fluctuating groups and roles within individuals' lives may be considered at greater length in future work.

'Good' Family

When individuals talked about their upbringing, eight participants began by reporting that they had a 'good' childhood, then qualified 'good' with some lesser degree of good or an explanation for the less-than-good and shame-filled moments. Thus, 'good' was described as what they want these relationships to be or have been.

Dao, 40-year-old, Vietnamese male, lives in a fully staffed CR or community residence, renamed here, Grace Harbor. He has lived in institutions and in CRs since age 18. He described himself as "mental" and "sick," yet "medication compliant." He said his family was "a good family, but forced me out of the house" because of the former two labels. He said they would tell him he could not stay in the family home because he was "mental" and "sick." He said he now must take his medication and attends a program in the community three days per week as a requirement of his state supported housing. "I don't know why my family won't see me anymore. They tell me I am mental in the head; they tell me I need to be a man and live on my own."

Dao said he enjoyed growing up with his twin brother, mother and father on Long Island. Though he has recollections of his parents fighting considerably, he feels he had a "good family life," yet he adds he was "thrown out" on the streets because of his mental disability and is now not welcome back. Dao said he felt this is 'bad' family behavior, yet he still wants to return to this family. "If I could just go back, I know it would be good."

At another Grace Harbor¹² CR, Keisha lives with nine other people in a two-story Victorian home. Keisha, 31-year-old, describes herself as Black/Puerto Rican. Her residence is run by the same agency as Dao's, and the same name as Dao's CR is used, but is in a different town. CRs such as these in Suffolk County are often about the same size—they usually have eight to 13 residents living in one site—and have full-time staff 24 hours daily.

Keisha recounted what she states was a 'good' relationship with her biological mother, growing up in Harlem, NY. Her mother had nine children to raise, Keisha explained, so she and her twin sister were raised by two different sets of foster parents on Long Island. She said

she wished it could have been different, but Keisha still describes her mother as a ‘good’ mother, and as someone who had to do ‘the right thing’ by sending her to live elsewhere. She said both of her foster mothers are ‘good people, too’ but they had ‘bad people’ living with them. Because of this, she spoke out against abuse and rape the ‘bad people’ perpetrated on her and was taken to several doctors. When she was diagnosed with a learning disability and schizophrenia, Keisha was mandated to take medication. Because they considered her ‘acting out’ and ‘misbehaving,’ she was committed to a smaller community psychiatric hospital. She said she often waits for her mother, foster mother, and sisters to come visit her in her CR but they do not. Thus, while Keisha and Dao long for more time with their family, it appeared they were in the zone of abandonment that Biehl (2004) designates. Their families, long ago, passed over the caring and family work to the State.

As Das and Addlakha (2001) note occurs with subjugated family members with disabilities, both Keisha and Dao’s voices were dismissed due to their inability to conform. “It seems that the tyranny of the norms of appearance threw these children out of domestic citizenship into the domain of the state as the only sphere in which their rights, including the right to life could be claimed” (Das & Addlakha, 2001, p. 513). Both Keisha and Dao were rejected as children who could not be normal, they were shameful to the family and hence expelled from the domestic sphere. Additionally, in Morrigan’s (2017) terms, the resistance Dao and Keisha embodied precipitated a reactive approach to symptoms. The families’ reactive approach to Dao and Keisha’s resistance was to further subdue their ‘symptoms,’ thus landing them in hospitals, then CRs.

José, a 54-year-old Hispanic male, described his parents’ attempt to reconfigure the domestic sphere (Das & Addlakha, 2001) by committing him to two separate asylums. He now lives in a family home only about five miles away from Kings Park, one of the asylums where he lived for a number of years. While José’s later trajectory involved being welcomed back to the family, his painful memories of being rejected, shamed, and ‘not normal’ remain with him:

My dad punished me for not fitting the mold. He would come down the hall after me with a knife. He would tell me I was a loser. The fighting and bickering that was around because of my father’s drinking was finally gone for good once he died. I was glad. I could never understand why my mom put up with it. I hated her for that.

José’s overcoming of his hatred of his mother is notably productive, as Garcia (2010) argues, in the sense that it has created new opportunities for him. He can now spend time with his mother and sister. Prior to that, José said he had trouble respecting his mother because she never left her abusive husband, who continually shamed José. His mother provided just enough care and safety to keep him alive, he said. Yet, she also remained in the same home with this husband who verbally and physically abused her own children, causing what José remembers as a lot of fear and “probably amplified my mental psychosis.” This same father repeatedly chased José with a knife and beat him. Once again, there is a commonality in these trajectories in that ‘good’ family was reported, most people using that exact term, but then

described—albeit variably—as somewhat ambivalent and even shame-filled.

‘Bad’ Family

Similar to the ‘good’ descriptions that bared both commonality and variability, ‘bad’ family theme presented itself and was re-stated consistently through these interviews. Now in her 60s, Helen has lived in and out of state-run asylums, she transitioned to state supported community residences and boarding homes from her teens until the last few recent years of her life. She also lived in what was called a ‘family care’ environment post-release from Central Islip, where she had what she described as her “worst living environment ever.” She reported that her food was withheld by the homeowner and there were often numerous insect and rodent infestations. She now rents a room in a large, private house in a community a few short miles from one of the state asylums she inhabited. She shares this room with a friend she met at a prior state-supported CR. She is also living with two other women with mental health disabilities, who live down the hall on the second floor in their own respective rented bedrooms. Helen ceased attending formal mental health day programs regularly years ago, but now sees a psychiatrist for medications and a separate therapist for talk therapy.

Early in life, Helen reported, she also remembered feeling that her family ignored her and pushed her away because of her mental health disability. “I can remember wanting to commit suicide as early as 6-years-old. They just didn’t understand me. So I looked for other family in other places.”

Helen did not fit the ‘normal’ configuration of her domestic sphere (Das & Addlakha, 2001) and was at the mercy of the tyranny of the norms prescribed by the family. Per Morrigan (2017), Helen’s family had an ashamed and reactive approach to her symptoms from a very early point in her childhood. Though she attempted to report incest and abuse, she was told to keep quiet. As such, they responded to her resistance by subduing or ignoring those symptoms and committing her to hospitals. When discussing those memories of sexual emotional abuse and involuntary commitment, she referred to the family as ‘bad.’

Helen’s inability to place her physical and emotional pain also resulted in a longing for some solace. She said she wanted to become accepted in some form of family. Helen’s need for kinship is reminiscent of the integration and inclusion anthropologist Kath Weston (1997), which argues for the creation of bonds among gay and lesbian individuals when choosing their own family outside of bloodline. When individuals are shunned after coming out about their sexuality, they choose other relationships. “By opening the door to the creation of families different in kind and composition, choice assigned kinship to the realm of free will and inclination” (Weston, 1997, p. 110). For many individuals, acknowledging the presence of a mental health disability—even if it was a label handed down by the family itself—created a shunning or shaming similar to what Weston (1997) described in her study of people coming out of the closet. In which Weston’s findings on the reporting of sexuality that did not jive with standard norms for the family, appears similar to the reporting or labeling of having a mental health disability. For example, Helen and Patrice reported that their families told them they were “sick,” but also told them their illnesses were unacceptable. “You just need to

be treated,” Helen’s parents told her. In other instances where individuals were forced into treatment—Daniel, Dao, Helen, José, Keisha, Lamont, and Patrice were each involuntarily institutionalized—they reported shame followed by a feeling of loss of membership in their family. At the same time, however, by doing so, individuals were later able to open doors to their own new families as well. This ability to choose their own family confers a free will and choice that they never knew existed. The choice for assigned kinship allows people some agency and autonomy, at least with regard to these newly created relationships and bonds.

Helen and her roommates reported having freely chosen their lives together and making plans for the future together. Down the line, Helen said she imagines her next home, living with her roommate, Diane, in a space they create as their very own, with their own family. Helen said she went a long time growing up, not knowing that she could choose new family, or what Weston (1997) calls *replacements for* or “substitutes for blood ties lost through outright rejection or the distance introduced into relationships by remaining in the closet” (p. 116).

Dao’s perceived exclusion or contingent allowance to remain in a family, as he was cast off as ‘ill’ and incapable of maintaining a normal role within the domestic circle of the family, helped perpetuate the domestic description Das and Addlakha (2001) describe as ‘defective.’ Thus, he was denied citizenship within his normal family role in the home, as other adult children are still invited back to stay for long periods of time or spend the night on holidays, Dao is not.

Likewise, Patrice’s compounded experiences of family trauma—physical beatings, significant parental alcohol abuse, along with her own rape outside of the home—were difficult to overcome. She was encouraged by hospital staff to work on talk therapy treatments in addition to medication. When she sought this with her family, to bring them into her healing work, she said they were defensive, ashamed, and called her ‘crazy.’ When she pressed further, her parents encouraged psychiatrists to keep her in hospitals longer and increase her medication. She felt their rejection of her need to work through family trauma, was undermining her ability to move forward. Her attempts were seen as further refusing to comply as Morrigan describes:

No one wanted to believe that trauma was the cause of my conditions. Even though my mom and dad knew I’d been raped, even though they knew they drank excessively and they hit me, they said *I* needed to be hospitalized. It was *my* fault (Morrigan, 2017, p. 87).

In this regard, for Patrice and many other individuals, as Morrigan (2017) characterizes, after being coerced into care, treatment becomes more about shamed compliance rather than wellness for people. Morrigan (2017), a former psychiatric service user himself, describes this as an extension beyond psychiatric care. This was a shared sentiment. Each individual noted that their family accepted their symptoms as resistance that needed to be subdued and overcome, by consigning their bodies to other sites of care, which always involved ‘medication and treatment’ of those shameful symptoms.

‘Chosen’ Family

The predominant theme of ‘chosen’ or ‘my own, new’ family emerged during interviews often. People conveyed how their trajectories ultimately led to other social relationships that served as replacements for ‘not really good’ or ‘less than good’ family who abandoned them socially and physically. In Helen’s case, selected replacement family consists of two very good friends who are roommates in their privately rented house.

Helen’s concepts represent the ‘pursuit of normal’ that Stephanie Lloyd and Nicholas Moreu (2011) underscore as a constant goal for people. Individuals aim for social inclusion as normal people rather than “irregular, disordered” people (Lloyd & Moreu, 2011, p. 593). Even when housing in a community-based site is secure, people do not necessarily feel that social connections automatically fall into place. In this study’s findings, individuals attempt to create new forms of kinship and rekindle old ones, working to overcome earlier experiences of shame.

‘Imagined’ Family

Although individuals described their created or chosen kinships to me, they still had imagined and ideal relationships in mind where the shame of their permanent disabilities was not an issue. For instance, Helen said she imagines a future in which she and only one roommate have their own place and can enjoy nieces and nephews visiting them often. She imagines having parents and siblings that would have accepted her disability and mental health needs more openly.

Dao imagines a time when his twin brother from Florida lived closer, and a time when he could visit his mother and sister whenever he wishes. He imagines what it would be like to have family that would not ignore him. He imagines being married and having children. At times, the visions of imagined family that individuals described to me appeared to help people as they described feelings of ‘hope.’ Other times, individuals chose to end the topic of imagined family, suggesting it could be uncomfortable or an ideal out of reach.

Conclusion

Research supports that individuals with families who are healthy and supportive tend to have better outcomes (Dixon, et al., 2015; Felitti et al., 1998; Shonkoff, 2016). Those individuals who do *not* have helpful or ‘good family’ must work hard to overcome shame. Those who are considered persistently disabled, who do not exhibit socially-imposed, positive outcomes, like return-to-work or school, or imagine and create these new kinships or ‘replacements for.’ As Kath Weston (1997) notes, this task is both exciting and difficult when there is an absence of good family models in people’s early lives.

As Biehl (2004) emphasizes, when people are left in these zones of abandonment, essentially as unwanted and shameful, “they are sure to become unknowables” (p. 477). On the other hand, as individuals move about in the world—with mental disabilities or not—they

come to inhabit public spaces that are modeled after family spaces, or spaces they try to find their bearings in by learning to understand what their public role is. Thus, I deliberately consider the public sense of belonging and worth that my individuals work to have. Some of these are mixed as individuals live in group homes, which provide a chosen family inside their home living space, but are also overlapping a public sphere in the rules, chores, and administrative guidelines that are imposed upon them living there. They endure these recreated domestic sphere spaces while waiting in liminality for an accepting home and family of their choosing and imagination.

Similar to what Weston (1997) argues in her ethnography of lesbians and gays, having a mental disability often constitutes being ashamed or shunned as ‘other,’ which requires renegotiation of family and kinship ties. Weston notes that, “fluid boundaries and varied membership meant no neatly replicable units, no defined cycles of expansion and contraction, no patterns of dispersal” (Weston, 1997, p. 109). This otherness may be likened to that of persons with mental disabilities Das and Addlakha (2001) describe and what Biehl (2004) refers to as negative citizens. Biehl states, “The new role of these abandoned men and women as negative citizens stems precisely from their alleged incapacity to produce anything but bodily infections, parasites, and silent suffering” (p. 485). As Weston optimistically states, however, “the very notion of idiosyncratic choice—originally conceived in opposition to biogenetic givens—lent structural coherence to what people presented as unique renditions of family” (Weston, 1997, p. 109). However, I conclude that people do not end up with glorified chosen families, as chosen families is not an easy category and needs further analysis.

Finally, many of these vignettes have shown, even when family of origin is traumatic, shaming and/or disabling, it is not so easy to leave and stay gone. Sometimes the family is the only form of care available to individuals. However, it can be a dangerous site for care, in which someone returns to the very venue that caused trauma and shame in the first place. Thus, the ambivalent or toxic family can produce another intersection for bias and discrimination.

Given contemporary knowledge about early childhood trauma impacting mental health, this paper aims to show that negotiating family of origins can produce more disabling and shameful experiences. Family ties can continue to complicate and disturb the management of mental health disabilities perpetuating labels of *other*, *deviant*, *sick* or *ill* that contemporary disability scholars seek to negate. Alternative kinships can serve to overcome rejection or unworthiness within families of origin, even if simply for a short duration. When possible, people do choose and imagine alternatives to unhealthy, shaming relationships, and creating new family. Compounding effects of unaffordable housing and limited employment on Long Island, New York do not make this straightforward.

Considering people’s individual and collective stories remains crucial to the culture of change in communities. People with disabilities must be recognized as valid knowledge producers in order for worthiness and positive futures to be possible. Intersecting experiences of oppression from classism, sexism, racism and ableism must be communicated and

addressed: indeed, attending to questions of intersectionality must be foregrounded as it is possible that this study has overly focused on mental health and diagnostic categories.

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References

- Back, L. T., Keys, C. B., McMahon, S. D., & O'Neill, K. O. (2016). How we label students with disabilities: A framework of language use in an urban school district in the United States. *Disability Studies Quarterly*, 36(4). Retrieved from <http://dsq-sds.org/article/view/4387/4481>
- Baladerian, N. J. (2009). Domestic violence and individuals with disabilities: Reflections on research and practice. *Journal of Aggression, Maltreatment and Trauma*, 18, 153–161.
- Ben-Moshe, L. (2011). Disabling incarceration: Connecting disability to divergent confinement in the USA. *Critical Sociology*, 39(3), 385–403. doi: 10.1177/0896920511430864.
- Biehl, J. (2004). Life of the mind: The interface of psychopharmaceuticals, domestic economies, and social abandonment. *American Ethnologist*, 31(4), 475–496.
- Bloom, S. L. (2013). *Creating Sanctuary: Toward the evolution of sane societies*, Second Edition. New York: Routledge.
- Bloom, S. L. (2016). Advancing a national cradle-to-grave public health agenda. *Journal of Trauma & Dissociation*, 17(4), 383–396.
- Bloom, S. L., & Farragher, B. (2010). *Destroying sanctuary: The crisis in human service delivery*. New York: Oxford University Press.
- Carey, A. C., Block, P., & Scoth, R. K. (2019). Sometimes allies: Parent-led disability organizations and social movements. *Disability Studies Quarterly*, 39(1). doi: <http://dx.doi.org/10.18061/dsq.v39i1.6281>
- Clapton, N. E., Williams, J., & Jones, R. S. P. (2018). The role of shame in the development and maintenance of psychological distress in adults with intellectual disabilities: A narrative review and synthesis. *Journal of Applied Research in Intellectual Disabilities*, 31(3), 343–359
- Crenshaw, K. W. (1991). Mapping the margins: Intersectionality, identity politics, and violence against women of color. *Stanford Law Review*, 43(6), 1241–1299.
- Crenshaw, K. W. (2016). *On intersectionality: Essential writings*. New York: New Press.

- Das, V., & Addlakha, R. (2001). Disability and domestic citizenship: Voice, gender, and the making of the subject. *Public Culture*, 13(3), 511–531.
- Desjarlais, R. (1994). Struggling along: The possibilities for experience among the homeless mentally ill. *American Anthropologist*, 96(4), 886–901.
- Deutsch, A. (1949). *The mentally ill in America: A history of their care and treatment from colonial times*. New York: Columbia University Press.
- Dixon, L., Kurek, J., Susin, J., Laitman, A., Guzman, K., & Tabakman, L. (2015, October 8). The family and recovery—what works and what doesn't. In-person panel presentation for *Mental Health Awareness Day* at Pilgrim State Hospital.
- Erevelles, N., & Minear, A. (2010). Unspeakable offenses: Untangling race and disability in discourses of intersectionality. *Journal of Literacy & Cultural Disability Studies*, 4(2), 127–145.
- Fanon, F. (2004). *The Wretched of the Earth*. New York: Grove Press.
- Felitti, V. J., Anda, R. F., Nordenberg, D., Williamson, D. F., Spitz, A. M., Edwards, V., . . . Marks, J. S. (1998). Relationship of childhood abuse and household dysfunction to many of the leading causes of death in adults. The Adverse Childhood Experiences (ACE) Study. *American Journal of Preventive Medicine*. 14: 245–258.
[http://dx.doi.org/10.1016/S0749-3797\(98\)00017-8](http://dx.doi.org/10.1016/S0749-3797(98)00017-8)
- Friedner, M. (2015). *Valuing deaf worlds in urban India*. New Brunswick: New Jersey. Rutgers University Press.
- Frischmuth, S. G. (2013). Keep your sunny side: A street-level look at homelessness. *Culture, Medicine, and Psychiatry*, 38, 312–323.
- Gamwell, L., & Tomes, N. (1995). *Madness in America: Cultural and medical perceptions of mental illness before 1914*. Ithaca: Cornell University Press.
- Garcia, A. (2010). *The pastoral clinic: Addiction and dispossession along the Rio Grande*. Berkeley, CA: University of California Press.
- Goffman, E. (1961). *Asylums; Essays on the social situation of mental patients and other inmates*. Garden City, NY: Anchor Books.
- Granovetter, M. S. (1973). The strength of weak ties. *American Journal of Sociology*. 78(6), 1360–1380.
- Hatzenbuehler, M. L., Phelan, J. C., & Link, B. G. (2013). Stigma as a fundamental cause of population health inequalities. *American Journal of Public Health*, 103(5), 813–821.
doi:10.2105/AJPH.2012.301069
- Isobel, S. (2015). Because that's the way it's always been done: Reviewing the nurse-initiated rules in a mental health unit as a step toward trauma-informed care. *Issues in Mental Health Nursing*, 36(4), 272–278.
- Jenkins, J. H. (2015). *Extraordinary conditions: Culture and experience in mental illness*. Oakland, CA: University of California Press.

- Jenkins, J. H., & Carpenter-Song, E. A. (2008). Stigma despite recovery: Strategies for living in the aftermath of psychosis. *Medical Anthropology Quarterly*, 22(4), 381–409.
- Kalvin, S. (2015, June 3). Volunteer museum tour operator and employee of Pilgrim Psychiatric Center. In-person interview and tour proceedings at Long Island Psychiatric Museum, Brentwood, NY.
- Kessler, R. C. (2000). Posttraumatic stress disorder: The burden to the individual and society. *Journal of Clinical Psychiatry*, 61, 4–12.
- Liebowitz, C. (2015). I am disabled: On identity-first versus people-first language. Retrieved on July 23, 2019, from <https://thebodyisnotanapology.com/magazine/i-am-disabled-on-identity-first-versus-people-first-language/>
- Lloyd, S., & Moreu, N. (2011). Pursuit of a ‘normal life’: Mood, anxiety, and their disordering. *Medical Anthropology*, 30(6), 591–609.
- Luhrmann, T. M. (2007). Social defeat and the culture of chronicity: Or, why schizophrenia does so well over there and so badly here. *Culture, Medicine and Psychiatry*, 31, 135–172.
- Morrigan, C. (2017). Failure to comply: Madness and/as testimony. *Canadian Journal of Disability Studies*, 6(3), 61–91.
- Mauritz, M. W., Goossens, P. J., Draijer, N., & van Achterberg, T. (2013). Prevalence of interpersonal trauma exposure and trauma-related disorders in severe mental illness. *European Journal of Psychotraumatology*, 4, 10.3402/ejpt.v4i0.19985.
- Mock, S. E., & Arai, S. M. (2011). Childhood trauma and chronic illness in adulthood: mental health and socioeconomic status as explanatory factors and buffers. *Frontiers in psychology*, 1, 246. doi:10.3389/fpsyg.2010.00246
- Mueser, K., Rosenberg, S., Goodman, L. A., & Trumbetta, S. L. (2002). Trauma, PTSD and the course of severe mental illness: And interactive model. *Schizophrenia Research*, 253, 123–143. doi:10.1016/S0920-9964(01)00173-6.
- Mueser, K., Trumbetta, S. L., & Rosenberg, S. (1998). Trauma and posttraumatic stress disorder in severe mental illness. *Journal of Consulting and Clinical Psychology*, 66, 493–499.
- National Alliance on Mental Illness. (2019). Mental health facts in America fact sheet. Retrieved August, 5, 2019 from <https://www.nami.org/NAMI/media/NAMI-Media/Infographics/GeneralMHFacts.pdf>.
- National Center for Trauma Informed Care (NCTIC). (2013). Creating a place of healing and forgiveness: The trauma-informed care initiative at the women’s community correctional center of Hawaii. *National Association of State Mental Health Program Directors, Advocates for Human Potential, Inc., Substance Abuse and Mental Health Services Administration*. Retrieved September 24, 2017, from [https://www.nasmhpd.org/sites/default/files/7014_hawaiian_trauma_brief_2013\(1\).pdf](https://www.nasmhpd.org/sites/default/files/7014_hawaiian_trauma_brief_2013(1).pdf)

- National Institutes of Mental Health (NIMH). (2016). Prevalence of serious mental illness among U.S. adults by age, sex, and race. Retrieved December, 27, 2018, from https://www.nimh.nih.gov/health/statistics/mental-illness.shtml#part_154787.
- Neugeboren, J. (2006). *Transforming madness: My brother, madness, and survival*. New Brunswick, NJ: Rutgers University Press.
- Pleck, E. (2004). *Domestic tyranny: The making of American social policy against family violence from colonial times to the present*. Chicago: University of Chicago Press.
- Polaski, L. (2003). *The farm colonies: Caring for New York City's mentally ill in Long Island's state hospitals*. Amityville, NY: Official Offset Printing Corporation.
- Reaume, G. (2002). Lunatic to patient to person: Nomenclature in psychiatric history and the influence of patients' activism in North America. *International Journal of Law and Psychiatry*, 25, 405–426.
- Reaume, G. (2006). Mad people's history. *Radical History Review*, 94, 170–182.
- Seng, J. S., Lopez, W. D., Sperlich, M., Hamama, L., & Meldrum, C. D. R. (2012). Marginalized identities, discrimination burden, and mental health: Empirical exploration of an interpersonal-level approach to modeling intersectionality. *Social Science & Medicine*, 75(12), 2437–2445.
- Sequenzia, A. (2016). Person first language and ableism. Retrieved July 23, 2019, from Ollibean: <https://ollibean.com/person-first-language-and-ableism/>
- Shonkoff, J. P. (2016). Capitalizing on advances in science to reduce the health consequences of early childhood adversity. *Journal of American Medical Association Pediatrics*, 170(10), 1003–1007.
- Stumbo, S. P., Yarbrough, B. J. H., Paulson, R. I., & Green, C. A. (2015). The impact of adverse child and adult experiences on recovery from serious mental illness. *Psychiatric Rehabilitation Journal*, 38(4), 320–327.
- Substance Abuse Mental Health Services Administration (SAMHSA). (2014). SAMHSA's concept of trauma and guidance for a trauma-informed approach. Retrieved on February 7, 2016, from <https://store.samhsa.gov/system/files/sma14-4884.pdf>
- Sweeney, A., Filson, B., Kennedy, A., Collinson, L., & Gillard, S. (2018). A paradigm shift: relationships in trauma-informed mental health services. *BJPsych advances*, 24(5), 319–333. doi:10.1192/bja.2018.29
- Titchkosky, T. (2001). Disability: A rose by any other name? "People-first" language in Canadian society. *Canadian Review of Sociology and Anthropology*, 38(2), 125–140.
- Watson, S., Thorburn, K., Everett, M., Fisher, K. R. (2014). Care without coercion—mental health rights, personal recovery and trauma-informed care. *Australian Journal of Social Issues*, 49(4), 529–549.

Weston, K. (1997). *Families we choose: Lesbians, gays, kinship*. New York: Columbia University Press.

Whitaker, R. (2010). *Anatomy of an epidemic: Magic bullets, psychiatric drugs, and the astonishing rise of mental illness in America*. New York: Crown Publishers.

Endnotes

1. Goffman (1961) defines a *total institution* as, “a place of residence and work where a large number of like-situated individuals cut off from the wider society for an appreciable period of time together lead an enclosed, formally administered round of life” (p. 11).
2. In an effort to support and maintain what Back et al. (2016) notes as a “more positive disability identity,” this paper and its author employ people-first language. However, it is important to recognize that disability first language is also proposed as positive by some scholars and activists (see, for example, Liebowitz, 2015; Sequenzia, 2016; Titchkosky, 2001).
3. Any individual considered to be of impaired decision-making capacity in section 6.9 of the Stony Brook University (SBU) Human Subjects Standard Procedures Manual were to be excluded. This would have included anyone who was unable to provide consent prior to the initial interview. A measure to assess ‘capacity to consent’ was administered to each individual. Any individual who did not answer 10 out of 10 questions correctly on the capacity to consent assessment were to be thanked for their time, but not be included as a participant to enter the study. However, each of the 26 individuals who attended the first meetings passed capacity to consent.
4. Mental Health Clubhouse (MHC) is a pseudonym for a local day program started by former survivors of local asylums in Suffolk County, NY. There are several ‘clubhouse’ type facilities in the area. One clubhouse’s administrators agreed to vet me as a researcher/volunteer for which I underwent fingerprinting and volunteer training. As a volunteer at the MHC, I was invited to attend peer group counseling and therapy sessions as well as make announcements about the research project at peer mental health worker trainings. I sought meetings and similar authorization from three other mental health housing agencies which did not grant me access. I also made announcements at Suffolk County sponsored mental health conferences. Many referrals came from other participants who initially agreed to be in the study, ultimately leading to 12 participants cultivated through snowball sampling.
5. Each person that consented to the study was assigned a pseudonym per Stony Brook University IRB requirements and due to the researcher’s concern for anonymity, though more than half of individuals were willing to divulge their identity. Keisha is one of 15 out of 26 consented individuals who were willing to use her legal name. However, pseudonyms were assigned to all individuals.
6. It is unclear how many people without mental health needs also experienced trauma. It is estimated that as much as 51 to 98 percent of trauma goes undetected and untreated (Kessler, 2000; Mauritz et al., 2013; Mueser et al., 2002, 1998) as does a 51 to 80 percent of mental health needs, depending on age, sex and ethnicity (NIMH, 2016).
7. Solid associations between physical violence or trauma, race, class, gender and disability are well supported (see for example, Crenshaw, 1991, 2016; Lewis, 2017; Seng et al., 2012.).
8. See also Bloom 2013, 2016; Bloom & Farragher, 2010; Mock & Arai, 2011; SAMHSA, 2014, for more work on trauma and mental health.
9. *The system* is a term many participants used to describe their use of mental health services or a feeling of entry into and containment within—everything from having been previously institutionalized in of the Big Four asylums, going to jail or shelters, as well as accessing community programs, or now living in mental health housing and accessing local counseling and/or psychiatry.
10. Previous studies about family mitigating and impacting people with various disabilities reflect a similar mix of helpful allies or harmful abusers (see for instance, Baladerian, 2009; Carey et al., 2019).
11. The National Alliance on Mental Illness (2019) estimates that 20 percent of Americans, experiences a mental illness in [any] given year. Given that the estimated population of Suffolk County was 1.49 million as of 2010, per United States Government Statistics, this would equate to about 298,000 people in the County with mental health needs.
12. All CRs, participants and town names have been changed to retain confidentiality.



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Disability and Shame Special Issue Forum: Research Article

The Cultural and Religious Production of Disability Shame and the Saving Power of Heretical Bodies

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Abstract: This paper explores the cultural and religious production of disability shame, and the ways able-bodied people unknowingly perpetuate that shame—to our own detriment. My analysis suggests that nondisabled people benefit from challenging disability shame by embracing the prophetic perspectives of those who refuse to repent for their somatic heresies.

Keywords: Disability; Shame; Religion

When I asked my friend Hannah—a passionate, brilliant young woman who has cerebral palsy and uses a wheelchair—to tell me about her experiences of shame, she said it is hard to know where to start.¹ This is just one of many stories she shared:

When she was fifteen, Hannah participated in a self-advocacy class with other kids with disabilities. As a ‘problem solving’ exercise, the kids were tasked with imagining what they would do if they were going on a field trip and the teacher forgot to schedule an accessible bus. The answer was easy for Hannah: she’d call her mom, who worked part-time outside the home and who she knew would be able to give her a ride. Hannah’s peers thought this was a sensible plan; but her able-bodied case manager responded disappointedly: “Is that really fair to your mom?” he asked. “Shouldn’t you do things that allow her to live her *own* life—to do her *own* thing?” Hannah recalls that in her own mind, what this man was really saying (without saying it) was: *You should develop more autonomy to compensate for being less-than-whole; you should try to be less of a problem for others.* When Hannah got home later that day, she immediately asked her mom if she was a burden. Her mother insisted that she was not—and that driving her places was not an inconvenience. “This is what you sign up for when you become a parent,” her mother explained reassuringly. Nonetheless, this incident and the feelings of shame it catalyzed marked the beginning of Hannah’s suicidal ideation (H. Papenfuss, personal communication, May 17, 2018).

Several years ago, I probably would have seen the case manager’s shaming response as an indication of his insensitivity or incompetence. From my privileged able-bodied perspective, I might have written it off as an unfortunate incident of ableism that, thankfully, Hannah managed to survive. I may have also felt sorry for Hannah and tried to make her feel better by praising her for being “so strong” despite her case manager’s ignorance. It took my own temporary but debilitating episode of severe osteoarthritis, along with some excursions into the field of disability studies, for me to understand that disability is neither a private

misfortune nor an inherently miserable condition, to paraphrase Rosemarie Garland Thomson (1997), and that ableist oppression is not a series of isolated incidents, but a deeply entrenched sociopolitical system. This system depends on the disability shame it produces—the same shame that made Hannah wonder whether death might be preferable to living with a disability.

This paper explores that shame—both the shaming of people with physical disabilities and the shame they are encouraged to internalize. My analysis suggests that shame is not a natural response to bodies that are physically impaired, but a culturally/religiously conditioned reaction to corporeal diversity that able-bodied people unknowingly perpetuate—to our own detriment.² My discussion begins by highlighting a crucial way nondisabled Americans participate in the systemic production of disability shame, namely, through their yearning and quest for a “better” body—a body defined through a decidedly nondisabled ideal. Though seemingly secular, both the contemporary pursuit of physical improvement and the shame that shadows this quest bear traces of traditional religious narratives that disparage disability. These narratives have been recycled through Cartesian notions of selfhood to produce the illusion that you *should* and *can* control your body—and that failure to do so is shameful. This illusion enables nondisabled people to project our fears of losing control of our bodies/our lives onto the flesh of individuals who are physically impaired. Ultimately, I suggest that nondisabled people benefit from challenging disability shame and embracing the prophetic perspectives of those who refuse to repent for their somatic heresies.³

Where There Is Shame, There Is a System: The Cultural Production of Disability Shame in the U.S. Today

Of the various meanings of “shame” Merriam Webster (2018) offers, the one defining shame as the feeling of “dishonor” or “disgrace” best captures the sense of impropriety, inadequacy, and humiliation that disability shame frequently entails. This definition resembles Brené Brown’s understanding of shame as “*the intensely painful feeling or experience of believing we are flawed and therefore unworthy of love and belonging*” (2012, p. 69). According to Brown, who specializes in shame research, this feeling is often manifest in the sense of never being “good enough” (pp. 24–26).

America’s Culture of Physical Improvement

Shame is often thought of—and experienced as—a private emotion. But to paraphrase anthropologist Mary Douglas, where there is shame, there is a system (Douglas, 1992). As Brown (2012) points out, shame flourishes in cultures that are steeped in comparison and competition—cultures like the U.S., where the relentless pursuit of a better body has become a quasi-religious requirement for virtuous citizens. This obligation is part of a broader culture of physical improvement—a system of beliefs, images, rituals, and moral codes that promise “salvation” (i.e., happiness, health, fulfillment) through a better body. Oriented by commercially-produced fantasies of physical perfection—represented in idealized images of young, mostly white, affluent-looking, cis-gender, slender, nondisabled bodies—this culture teaches us to value some corporeal configurations more than others, even as it encourages

every body to look, feel, and function like the normative ideal (Lelwica, 2017). In contemporary America, the salvation myth of physical improvement plays a central though largely hidden role in the systemic production of disability shame, and in nondisabled people's complicity with this production.

This myth is predicated on the assumption that you can control your body—a foundational belief in the culture of physical improvement that reflects the tenacious influence of Cartesian dualism on Western culture. Descartes's view of a person/soul as a "ghost in a machine"—i.e., a rational, autonomous, sovereign will that inhabits and rules over an unintelligent, involuntary, biodegradable body (Descartes, 1956)—implies that people ought to be able to master their flesh, and that inability to do so constitutes a kind of moral failure. The Cartesian dream of rational self-mastery supports commercial culture's view of bodies not just as objects we can work on and work out, monitor and manipulate, defy, compel, renovate, and fix, but as advertisements for who we are as a person. Paradoxically, the improvable body is believed to be both subject to the will of the sovereign self and a visible manifestation of that self.

In the U.S. today, the presumed correspondence between the sovereign/autonomous self and the well-trained/obedient body is constructed through commercial culture's iconography. Photoshopped images of physical perfection glorify/glamorize bodies whose "owners" (e.g., models, movie stars, athletes, and other celebrities) appear to be in charge of their destiny. Deployed to sell everything from new cars, to hamburgers, to underwear, the idealized body/self is both a linchpin of consumer capitalism and a commodity in itself (Betcher, 2007). In case it is not obvious, the corporeal fantasy that orients the culture of physical improvement gains its authority through its visible association with intersecting forms of social privilege. Thus the "good body" we are conditioned to want is a ticket to the "good life" that is central to the American Dream—a dream characterized by upward mobility and freedom from suffering.

If we zoom in a little closer, however, we will see that the somatic ideal is constructed not only in relation to what's socially *desired*, but also in connection with what's commonly *feared*: the lack of control, inefficiency, dependency, pain, and limits associated with bodies that are physically impaired. Disabling perceptions of such bodies as not-normal, not-healthy, not-beautiful, and not-in-control render them "shameful." Indirectly, these apostate bodies tacitly support the fantasy of somatic perfection that everybody is encouraged to want and become—by providing its quintessential "other": the ultimate "not-me" figure (Betcher, 2007, p. 51).

Nondisabled Americans may not see how the culture of physical improvement trains us to participate in the production of disability shame. We may not recognize the extent to which ableist assumptions about "normalcy" and the imperative to be "in control" shape our ideas about the kind of body we want to have—and the kind of body we *don't* want to have. By defining "improvement" as conformity to an autonomous-looking, nondisabled ideal, dominant cultural body norms encourage everybody to collude with a system of invisible

prejudices and privileges—whether or not we know or intend it. In this system, nondisabled people enjoy the psychic ease that comes from being considered “normal,” along with social access to buildings, jobs, leadership positions, and educational and recreational opportunities that nondisabled status bestows. This same system deprives people with bodily losses or limitations the sense of belonging that perceived normalcy bestows, while encouraging them to feel ashamed of their bodies’ refusal to comply with able-bodied norms, and excluding them from equal participation in society.

The Normalizing/Shaming Gaze and the Somatic Hierarchy/Heresy It Constructs

In a society that places such a high premium on getting “ahead,” looking “good,” being “normal,” and feeling “in control,” the irregularities, vulnerabilities, and/or limits of physically impaired bodies relegate them to the lower ranks of a social/symbolic hierarchy of bodies. This ranking system is constructed through what Michel Foucault called a “normalizing gaze”—a way of seeing and valuing that measures, classifies, compares, and judges physical differences based on a singular standard (Foucault, 1973). This homogenizing optic/ethic gained prominence during the modern period as medical science pathologized bodies that deviated from the Anglo-Saxon, bourgeois ideal, and as capitalist economies delegated inefficient or “unproductive” bodies (e.g., people who were sick, poor, insane, or disabled) to society’s margins (Foucault, 1980, 1988, 1995). According to the moral-scientific-aesthetic taxonomy this gaze constructs, “normal” bodies are good, healthy, and beautiful, while others are degenerate, sick, and ugly (Young, 1990). Despite its supposed “objectivity,” the normalizing gaze is a *shaming gaze*. While it generates awe and admiration of figures at the top of America’s somatic hierarchy, it directs dread, gawking, and pity at those at the bottom. Circulated through commercial, medical, and self-help discourses today, this way of seeing/valuing corporeal diversity teaches us to distinguish between “right” and “wrong” bodies, to internalize this distinction, and to judge and improve ourselves/our physicality accordingly.

However well intended, *improvement* here is code for *controlling* and *conforming* bodies to the normative/nondisabled ideal—an ideal whose authority is constructed through intersecting forms of privilege, e.g., as disproportionately white, affluent-looking, cis-hetero, thin, young, and so on. This translation of “improvement” reveals how the shaming gaze is also a colonial gaze insofar as it circulates an imperial-like imperative to conquer, convert, and ultimately save (i.e., fix or cure) unorthodox flesh from its anatomical heresy. The colonial dimensions of the culture of physical improvement are evident in *rituals* designed to “help” us create a better body (e.g., dieting, working out, anti-aging therapies, cosmetic surgery, prosthetic enhancements) and in commercial and medical discourses’ combative *rhetoric*, which encourages us to triumph over bodily flaws and afflictions (e.g., to fight fat, defy aging, conquer chronic pain, battle cancer)—or to at least camouflage our corporeal mutinies. According to the normalizing optic/ethic that oversees the better body crusade, *everybody* could stand a little improvement, but people with disabilities are particularly good candidates for the salvation that better-body rhetoric and rituals promote. They are encouraged to overcome their physical losses or limits, or, at the very least, to heroically convert them

into inspiring stories—preferably the “supercrip” kind that will impress nondisabled people (Clare, 2009; Kafer, 2013). Failure—or *refusal*—to vanquish disability invites the kind of shaming disappointment directed at Hannah when she solved the problem her case manager presented without buying into the myth of self-sufficiency—i.e., the illusion that individuals should and can be entirely self-reliant, and the corresponding belief that needing help or support from others is a sign of weakness.

Since few bodies live up to the somatic expectations that guide the popular pursuit of physical improvement, the shame that shadows this quest has the potential to infect virtually everybody. Women are especially susceptible to body shame because their worth (or lack thereof) is so often tied to their physicality—a linkage that reflects longstanding views of female flesh as dangerously unruly (remember the story of Eve) or as intrinsically deformed (recall Aristotle’s “misbegotten male”). However, the culture of physical improvement is especially and acutely disabling/shaming for people whose bodies blatantly refuse to obey its mandates for how flesh is supposed to look, function, and feel. And, as Garland Thomson observes (1997), “Corporeal departures from dominant expectations never go uninterpreted or unpunished, and conformities are almost always rewarded” (pp. 7-8). For people with disabilities, punishments for somatic blasphemy come in the form of ostracism, stereotypes, “invisibilization”, dehumanization, isolation, and internalized perceptions of never being “good enough.” Situated in stark contrast to the flawless form at the hierarchy’s apex, representing all that Americans are conditioned to loathe and fear, unorthodox disabled bodies are deemed in dire need of salvation. Though, according to this cultural system, most bodies fall short of perfection, the corporeal “sins” of disabled bodies are seen to desperately need forgiveness.

A Shameful Legacy: Some Biblical Views on Physical Impairment

Because of its deep roots in commercial, medical, and self-help culture, the contemporary quest for physical improvement seems to have little to do with religion. But this is largely because dominant (i.e., white, bourgeois, patriarchal, Protestant) theological traditions have tended to promote an overly narrow, privatized, and disembodied understanding of religion, namely, as comprised primarily of personal beliefs, concerned above all with otherworldly things, and categorically distinct from “nonreligious” cultural phenomena (Schaefer, 2015). This stereotypical understanding ignores the human/embodyed origins of religion, its meaning-making functions, and its ambiguous sociopolitical consequences (i.e., its liberating and oppressive potential) (Lelwica, 2017). A more complex, fluid, and contextual concept of religion that is commonly used among religion scholars today (Asad, 1993; Asani, 2011; Miller, 2012; Schaefer 2015) enables us to see how traditional religious teachings and practices are tacitly embedded in seemingly non-religious attitudes, habits, values, and institutions, including those that shape our notions of “right” and “wrong” bodies, and our corresponding perceptions of disability.

Since Christianity has had the most prominence and thus the most power to influence these perceptions in America, my analysis of religion’s entanglement with the cultural

production of disability shame focuses on this tradition. Three prominent Christian narratives support the disparaging view of disability embedded in the culture of physical improvement: 1) A *moralizing narrative* interprets bodily impairment as a visible manifestation of sin, a kind of blemish on God's perfect creation. In this storyline, the visible body is an index of the state of the invisible soul; 2) An *eschatological narrative* equates salvation/healing with curing or eliminating anatomical abnormalities. In this storyline, "defects" in form or functioning are overcome through God's saving power; and 3) A *spiritualizing narrative* views disability as an opportunity for cultivating virtue. In this storyline, disabled individuals become inspiring role models, while their caretakers are charitable heroes.

I believe that many people, including many Christians, are unaware of the extent to which these ancient narratives have influenced our assumptions about how bodies are supposed to look, function, and feel. Whether or not you are religious, learning to recognize these storylines is a crucial step in challenging their lingering influence.

The Moralizing Narrative: Disability as a Sign of Sin

In her groundbreaking work, *The Disabled God* (1994), Nancy Eiesland identified Christianity's long-standing association between bodily impairment and moral impurity. The sin/disability nexus is exemplified in New Testament texts like John 5:14, in which Jesus heals a man who was unable to walk, then tells him: "Do not sin anymore, so that nothing worse happens to you." Throughout Christian history, this text (and similar miraculous healing stories) fostered a symbolic connection between physicality and morality—and specifically between disability and shame: bodily impairment was a visible punishment for spiritual depravity and unbelief.

The symbolic association between disability and sin supported other demeaning beliefs about somatic impairment that became part of Western culture's DNA. Within the biblical tradition, blind, deaf, or lame bodies are seen to besmirch the image of God, who is envisioned as fully intact and unencumbered. As New Testament scholar John Hull (2013) points out, "God walks in the Garden of Eden; God does not limp (Gen. 3.8)" (pp. 42-43). Given the biblical God's anthropomorphized status as able-bodied, it is not surprising that people with physical impairments have been prohibited from serving as spiritual leaders—both historically and as recently as the 1980s (Eiesland, 1994, Lowe, 2012). Throughout Christian history, visibly flawless bodies were seen to manifest inner states of holiness, while somatic imperfections were seen to express internal states of disgrace (Eiesland, 1994). Thus, a disabling theology constructed impaired bodies as shameful and needing redemption.

The Eschatological Narrative: Healing/Overcoming Disability

If disabled bodies manifest sin, then salvation depends on disability being "cured." Stories of Jesus' miraculous healings were understood to anticipate the final redemption/perfection of the flesh at the end of time (Hull, 2013). A vision of resurrected bodies as flawless is central to classic Christian eschatology (the part of theology that deals with the final judgment and the afterlife). In this storyline, virtuous believers will enjoy the rewards of eternal life in flesh that is fit for paradise. Freed from the corruption of sin, decay,

and death that hamper life on earth, resurrected bodies represent an angelic/imperishable state. Like the photo-shopped fantasies of somatic perfection that proliferate in today's culture of physical improvement, these heavenly forms are relieved of (and redeemed from) the burdens, needs, changes, limits, and vulnerabilities of embodied existence.

Historian Candida Moss (2011) describes how early Christians envisioned bodies in the resurrection as having been “cleansed” or “cured” of their deformities and afflictions. In her analysis, the eradication of bodily “defects” in paradise was part of the narrative of salvation history, whose trajectory moves away from physical diversity/adversity, which signified humanity's fallen/shameful state, toward a celestial future in which the lame walk, the blind see, the crooked are made straight, and all other physical maladies are erased. In this heavenly scenario, “salvation” is synonymous with “healing,” which is interchangeable with “curing,” and God plays the role of cosmic/cosmetic surgeon, “augmenting, extracting, and appending in order to produce aesthetically pleasing, harmonious bodies” (p. 993). By equating bodily redemption with physical perfection, early church leaders systematically eliminated somatic impairments, anomalies, and infirmities from God's kingdom, implicitly reinforcing biblical links between disability, impurity, and punishment (p. 996, 1008-1009). Ultimately, traditional Christian eschatology defines healing as the removal of disability and equates salvation with conformity to an able-bodied ideal (Hull, 2013). This equation leads theologian Sharon Betcher to observe that “Theologies of healing...can be unwitting agents of imperial ideals” (2007, p. 119).

Spiritualizing Narratives: Disability as Opportunity

Narratives depicting disability as a sign of moral fault in need of redemption coexist with the biblical theme of virtuous suffering (Eiesland, 1994). In this storyline, the difficulties surrounding bodily impairment are a kind of divine test through which one is purified: disability is not just a burden but an opportunity to develop spiritually—i.e., to cultivate exceptional faith by enduring somatic losses or limits with saintly grace and courage. Seeing disability as a “cross to bear” suggests that people with disabilities need not (and thus ought not) fall into despair and can even experience impairment as a blessing. Trusting that God can use an undesirable situation for redemptive purposes, this logic suggests, disabled persons can and should obediently accept and adjust to their conditions (Reynolds, 2008).

Within this narrative, the spiritual opportunity that disability presents is also expressed through nondisabled people's charitable acts and attitudes. An ethic of charity orients many contemporary hospitals, nursing homes, rehabilitation centers that serve individuals with “special needs.” Although many have benefited from these institutions, a charitable ethic positions “the disabled” as “objects of pity” on which benevolent caretakers can exercise their virtue (Reynolds, 2008). Somewhat ironically, the charity ethic offers a “suffocating surplus of compassion” to people with disabilities (Hull, 2013, p. 85), even as it distances “the disabled” from those in superior/helping positions, who ostensibly have no need for healing. In the end, this ethic solidifies the separation between “normal” and “not-me” bodies by treating disability as a private tragedy—one that can be managed thanks to the goodwill of the nondisabled—without challenging the social/symbolic systems that view physical deviations

from the normative ideal as dreadful.

Traditional Christian narratives are neither the cause of, nor the sole contributors to, disparaging views of disabled bodies. Nonetheless, these narratives lend conceptual support to the cultural production of disability shame by depicting impairment, in Thomas Reynolds' words: "as something to be healed or gotten rid of—a fault, a lesson in lack of faith, a helpless object of pity for the non-disabled faithful to display their charity, a vehicle of redemptive suffering, a cross to bear, or fuel for the inspiration of others" (2008, p. 28). Becoming familiar with Christianity's shaming narratives enables us to recognize—and resist—their damaging effects beyond the realm of traditional religion.

Recognizing and Resisting Religious/Cultural Conditioning to Perpetuate Disability Shame

These days, shaming perceptions of bodily impairments are not typically couched in explicitly religious terms. Of course, there are exceptions to this general rule. Joan Tollifson, an American Buddhist teacher who was born without a right hand, recalls that when she was a toddler, someone stopped her mother on the street to inform her that God was punishing them (1997). More often, however, theologically-sanctioned disability shame echoes in hushed questions, pointed fingers, gawking stares or averted glances, in "feeling sorry" for "those poor, unfortunate people," turning them into heroes, and/or segregating or striving to "rehabilitate" (as in, *normalize*) their bodies. In *Too Late to Die Young* (2005) the late Harriet McBryde Johnson shares some (perhaps) well-intended but nonetheless shaming reactions to her unconventional body, which she describes as frail and withered as the result of a wasting disease, and which required a wheelchair for mobility:

"I admire you for being out; most people would give up."

"God bless you! I'll pray for you." [note: McBryde Johnson was an atheist]

"You don't let the pain hold you back, do you?"

"If I had to live like you, I think I'd kill myself" (p. 2).

Religiously-supported disability shame also reverberates in the kind of well-intended "be happy" advice that Hannah told me she profusely dislikes. When the topic of her disability comes up in conversation, people regularly encourage Hannah to, "look on the bright side of things," or to, "have a positive attitude"—as if her disability were simply a personal challenge that she could rise above with enough willpower and the proper (i.e., sunny) disposition.

Whether implicit or explicit, contemporary expressions of disability shame recycle Christianity's moralizing, eschatological, and spiritualizing narratives, integrating them with a Cartesian view of the self as a sovereign, autonomous individual. While Christianity's narratives authorize the undesirability/shame of disability, the Cartesian legacy promises that

this undesirability/shame can be overcome *in this life*—if not physically, then by “positive thinking.” This mind-over-matter mentality fuels America’s pull-yourself-up-by-your-bootstraps ideology of individualism; it also supports this country’s creeds of progress, efficiency, and speed—creeds that coalesce in the cultural imperative to create a body that is streamlined, productive, and mobile. The ubiquitous belief that we *should* and *can* control our bodies normalizes disability shame, making it seem (and feel) natural, if not God-given.

And yet, none of us came out of the womb believing that bodies without certain parts or functions are inferior. We learn to see impaired bodies this way. Tollifson observes that when babies approach her arm, “the one that ends just below the elbow...they aren’t frightened or repulsed by it. They don’t feel sorry for me. They don’t think I’m heroic or amazing. They see the actual shape of what’s in front of them without concepts or labels” (1997, p. 22). The same religious/cultural conditioning that teaches us to view disabled bodies as shameful and needing redemption/curing encourages us to perceive nondisabled bodies as normal and therefore better. For nondisabled people, the belief that a better body equals a normal body equals an able-body is difficult to question partly because dominant religious/cultural norms and narratives constantly reinforce these equations and partly because we regularly benefit from them.

Despite such benefits, however, many nondisabled people struggle with body shame. I know this because I have spent the past few decades studying American women’s troubled relationships with their bodies—particularly their obsession with losing weight and their devotion to thinness (Lelwica, 1999, 2009, 2017). My studies reveal that in the U.S. today, the majority of women (and a growing number of men) are unhappy with their bodies. These are mostly nondisabled individuals of varying sizes who feel ashamed of their flesh, which they believe has betrayed them by refusing to get or stay slim. To counteract fears and/or experiences of fat shame, many devote inordinate amounts of time, energy, and money to make their bodies “better,” even when such efforts exacerbate the very shame they are trying to diminish.

I understand the painful feelings of inadequacy that drive this devotion to a better body not just intellectually, but personally. I experienced such feelings both as an adolescent struggling with an eating disorder, and decades later when debilitating arthritis caused me to walk with a noticeable limp (until I had hip replacement surgery). In fact, it was the similarities I recognized between these two experiences that catalyzed my interest in disability studies. In both instances, I was utterly frustrated with my body for not doing what I thought it *should* do. In both situations, I felt not just mad but embarrassed by my inability to control how my body looked, felt, and functioned. In both cases, I saw this inability as a *moral* weakness—a sense that there was something wrong with me—having absorbed cultural/religious narratives that conflate bodily control with virtue. Obviously, the situations were very different. My desire to control the arthritic pain and functioning of my middle-aged body was far removed from my adolescent yearning to be skinny. Yet the feelings of wanting to conquer, fix, or transcend my body were similar, and so were the feelings of shame surrounding this desire.

My point in highlighting the connections between different kinds of body shame is not to minimize the distinctly acute pain of disability shame. Instead, I want to suggest that the same normalizing optic/ethic that produces disability shame also fosters feelings of physical inadequacy among nondisabled people. The pervasive dissatisfaction that many able-bodied people feel toward their flesh suggests that *everybody* has a stake in recognizing and resisting complicity with the shaming gaze projected by a culturally/religiously-sanctioned nondisabled ideal—an ideal that *nobody* can achieve. This resistance is not something able-bodied people should do as a favor to people with disabilities. Rather, it is something we can do to explore our relationship with our own physicality, to examine what “health,” “healing,” or “improvement” might mean for our own one-of-a-kind body.

Resisting the able-bodied “dream of normalcy” requires nondisabled people to wrestle with a question Sharon Betcher poses: “What do we hide from or reject about ourselves in that classification of physiological variations known as disablement?” (2007, p. 19). Investigating the insecurities nondisabled people feel and the judgments we direct toward our own tentatively able-bodies may help us stop projecting them onto the nonconforming anatomies of others, start cultivating a more friendly relationship to our own uniquely vulnerable flesh, and engage in the multifaceted work of creating a world in which diversely configured bodies are respected, nurtured, and loved.

What the World Needs: An Atypical Perspective

As disability scholars and activists point out, disabled bodies are the target of fear and shame because they remind the nondisabled majority of the very things we find disgraceful or intolerable in our lives—e.g., loss of control, suffering, and death. Theologian Mary Lowe suggests that the dread of disability, “can be framed in theological terms as the failure of the temporarily able-bodied to accept their limits as mortal, fragile, embodied and vulnerable creatures of God” (2012, pp. 187-188). Whether or not we envision ourselves as “creatures of God,” anyone who suffers under the pressure to create a better body can benefit from the counter-cultural perspective religions at their best have provided. Religion scholar and rabbi Julia Watts Belser captures this perspective when she marvels at the holy mystery that permeates her disabled flesh: “Muscle, heart, body, and bone testify to the One who made me, to the Source of wind and rain and soil who cobbled my elements into form and breathed soul into my veins. Who had the brilliant audacity to call it good and know it whole” (2014, p. 28).

This affirmation of disability as an expression of humanity’s irreducible diversity—a diversity that is *good*—represents what Simi Linton calls, “the vantage point of the atypical” (2007, p. 81). Able-bodied people need this unorthodox vision to free us and everybody from the imprisoning beliefs that some bodies are better than others and that happiness depends on converting/conforming our flesh to an impossible ideal. In making this suggestion, I don’t mean to romanticize disability. Nor do I wish to turn disabled people into “inspiring heroes,” gloss over the diversity of their somatic conditions and life situations, or downplay the multiple exclusions they experience in an ableist society. Rather, I want to suggest that tentatively nondisabled people like myself have a lot to learn by not averting our gaze from, or

gawking at, or feeling pity for, or assuming the misery or valor of people with disabilities. In what remains of this article, I unpack and endorse McBryde Johnson's suggestion that, "We [people with disabilities] have something the world needs" (2005, p. 208).

Deconstructing Idealized Views of "Body" and "Self"

The world needs people who challenge a religious/cultural optic and ethic that trains us to judge and rank each other based on physical appearances. After years of living with a disability, Alison Kafer (2013) still marvels at the assumptions nondisabled people make about her based on the sight of her body: "my wheelchair, burn scars, and gnarled hands apparently tell them all they need to know" about how miserable, frustrating, and isolated her life supposedly is and will be (pp. 1-2). They do not see a woman whose unconventional thinking and solidarity with other heretical bodies enables her to enjoy life, love passionately, and contribute to a more just society. Similarly, McBryde Johnson says most people she encounters "think they know everything there is to know just by looking at me." (2005, p. 2). Mostly, she says, they see a life of suffering. Were they to read her book, however, they would discover a woman who is quick-witted, sharp-thinking, feisty, assertive, adventurous, audacious, playful, and extremely funny.

The perspectives of people like Kafer and McBryde Johnson interrupt our habitual assumptions about the relationship between our "bodies" and our "selves." On the one hand, their experiences challenge the belief that "who I am" is transparently communicated through "my body;" on the other hand, they resist the notion that "self" and "body" are separate entities. For example, throughout McBryde Johnson's life, nondisabled people encouraged her to view her frail and twisted body as "unimportant" and to focus on her mind instead. But rather than dissociate from her unusually configured flesh, she embraced it as a fundamental aspect of herself: "the body I live in doesn't only affect me. It is me" (2005, p. 255).

The paradox of embodiment McBryde Johnson experiences—her sense of her "self" and "body" as neither identical nor separate—reminds me of Kafer's suggestion that we approach disability as "a site of questions" rather than a self-evident condition (2013, p. 11). As a site of questions, disability invites everyone to ask: what do we really know about a person based on anatomical functioning or appearance? How should we understand the relationship between our blood, bones, organs, cells, and tissues and the thinking/feeling/conscious part of us typically referred to as "self," "soul," or "spirit?" Which cultural and religious norms and narratives shape our thinking about (and experience of) this relationship? Able-bodied people need to spend more time with the questions disability raises in order to remember just how much we *don't* know about the relationship between human physicality, consciousness, and the larger mysteries surrounding our existence.

We also need to critically interrogate our attractions to the fantasy of physical perfection and to the icons and rituals that support this fantasy. Such images and the better body instructions surrounding them flatten the relationship between flesh and spirit into a linear trajectory, with a supposedly sovereign self ritually driving our docile flesh toward the "dream of normalcy"—and the control, happiness, and privilege this dream represents.

Against the grain of this trajectory, disabled bodies expose, “the illusion of autonomy, self-government, and self-determination that underpins the fantasy of absolute able-bodiedness” (Garland Thomson, 1997, p. 46). These bodies’ insubordination reveals the rather obvious flaw in the eschatological narrative: some physical heresies refuse to be eliminated/cured/saved.

Refusing to Be Conformed/Converted

What’s more, many disability activists and scholars are not preoccupied with overcoming their noncompliant bodies. Some, like Kafer, identify as “crip” to express opposition to “compulsory able-bodiedness,” to resist the shame assigned to transgressive flesh, and to eschew the obsession with being “cured” (2013, p. 27). These scholars and activists are not so much rejecting a cure as they are opting not to spend their lives yearning, waiting, and striving for one. This choice opens the door for a different kind of healing—one that involves the agency of acceptance. These days, for example, Hannah responds to the question of whether she hopes to be able to walk in heaven—a question members of her church have been asking her for years—with a rather noncommittal, *maaaaybe*. “It *might* be *kind of* interesting to be able to walk,” she says. “I *might* decide to get up and take a few laps around heaven, just to see what it’s like. But then I think I’d be happy to sit back down in my chair” (H. Papenfuss, personal communication, May 17, 2018). Hannah smiles with amusement as she tells me this—both because she does not believe heaven is a place where dead/resurrected people walk around, and because she knows her nonchalant answer is likely to baffle (and maybe even disappoint) her able-bodied inquisitors.

By refusing to buy into the notion that happiness/salvation hinges on her disability being removed, Hannah reverses the shaming gaze of ableism, directing it back at a society that classifies and judges people based on physical abilities and appearance. In *Exile and Pride* (2009), Eli Clare expresses a similar reversal: “it is ableism that needs the cure, not our bodies.” Instead of a medical cure:

...we want civil rights, equal access, gainful employment, the opportunity to live independently, good and respectful health care, desegregated education. We want to be part of the world, not isolated and shunned. We want a redefinition of values that places disability not on the margins as a dreaded and hated human condition but in the center as a challenge to the dominant culture (pp. 122-123).

Although Clare does not identify as “religious,” his perspective resembles the prophetic critique of systemic injustice within the biblical tradition. This critique relocates the “sin” of disability from individual bodies to social/symbolic systems that punish nonconformity with shame, discrimination, and exclusion. This critique shifts the paradigm from charity towards disabled people, to solidarity among those seeking to transform disabling stereotypes and structures (Lowe, 2012).

The world needs people who recognize that human dignity, pleasure, power, health, and beauty stem not from conforming to a normative ideal, but from the kind of agency that can “make a way out of no way.” Womanist theologian Monica Coleman (2008) uses this

Black folk expression to affirm the creative and ingenious ways African American women have collectively navigated the harsh realities of a racist-sexist-classist society. The spirited agency of the Black women she describes resembles the audacious self-determination of disability activists like McBryde Johnson: “We take constraints that no one would choose and build rich and satisfying lives within them” (2005, p. 208). In a society where some people imagine they would rather die than be disabled, McBryde Johnson’s decision to live “openly and without shame” (p. 256) in/as her unconventional body, her insistence on enjoying the many pleasures of her life, and her commitment to collaborating with others to expose the ignorance of ableist stereotypes suggest a different kind of salvation—not as a future state of perfection when “the lame shall walk and the blind shall see,” but as diversely incarnated wholeness, health, and liberation in the here/now. Salvation, as Eiesland suggests, is the healing and freedom that comes from “the revolutionary act of accepting our bodies” (1994, p. 96). Salvation, as Womanists affirm, involves the capacity to love oneself—“*Regardless*” (Walker, 1983, p. xii).

Isn’t this the kind of salvation most of us want: an unconditionally accepting, shame-free relationship with our bodies and with each other? Isn’t this radical acceptance of our “brilliant imperfection” (Clare, 2017) a fundamental aspect of health, happiness, and healing?

Resisting Eschatological Perfection and Embracing the “Corruption” of Interdependence

Whether we are physically impaired or provisionally nondisabled, Tollifson believes that the various body issues with which we struggle would cease to be problems if we perceived them as babies do: free of preconceptions. From Tollifson’s Buddhist perspective, to experience the body shamelessly is to enjoy, “the perfection of imperfection,” opting to embrace, “life as it actually is from moment to moment. Asymmetrical. Messy. Unresolved. Out of control. Imperfect. Terrible. And miraculous.” (1997, p. 23). Betcher shares Tollifson’s resistance to eschatological purity by replacing idealized notions of “the body” with a view of flesh as “the locus of flux.” For her, flesh represents, “that which we know to be true of lives—pain, difficulty, disease, transience, aging, error, and corporeal limit,” as well as the, “epiphanies and critical insights” that come with those experiences (Betcher, 2010, pp. 106–108). Betcher urges Christians to develop those insights by “renovat[ing] Christian theology’s own commitment to the flesh”—not its conventional obsession with mortifying and controlling the body in the pursuit of virtue, but its affirmation of the interplay of matter and spirit and the ways an incarnation unfolds in diversely configured bodies (2010, pp. 111–112). For Betcher, resisting eschatological perfection and the shame it encourages means “‘keeping trust’ with the Spirit of life” (2007, p. 200).

By trusting the diverse, changing, and imperfectly perfect Spirit of life in the flesh, heretical bodies abandon faith in the illusion of control. Hannah describes this illusion as “a kind of weird lie” to which able-bodied people seem especially drawn (H. Papenfuss, personal communication, May 17, 2018). This strange fallacy is connected to the myth of self-sufficiency. If you are fully able to control your body, you are unlikely to need the help of others. Indeed, you may never have to call your mother for a ride.

McBryde Johnson challenges the myth of self-sufficiency that the illusion of control supports. “Throughout my life,” she says, “I have needed help from other people to bathe, dress, and get out of bed in the morning” (2005, p. 179). While the prospect of having to depend so heavily on caretakers would horrify many nondisabled people, McBryde Johnson ponders, “how strange it would be to do these morning things in solitude as nondisabled people do...it is so natural to feel the touch of washcloth-covered hands on the flesh that is glad to be flesh, to rejoice that other hands are here to do what I’d do for myself if I could” (2005, p. 251). As Betcher points out, for people living with disabilities, “human interdependence names the infrastructure of our freedom” (2010, p. 115). Thus rather than view her life as, “dreadful and unnatural,” as she knows many nondisabled people do, McBryde Johnson welcomes, “the corruption that comes from interconnectedness,” honoring, “the muck and mess and undeniable reality of disabled lives well lived” (2005, p. 228).

The world needs people who unsettle our ableist assumptions not only about how our bodies should be, but also about how our lives are supposed to go. Most Americans are culturally/religiously conditioned to believe that both our bodies and our lives should and could be more perfect. The belief that we should not have to suffer—that every problem has a solution, that we can rise above pain and vulnerability—may well be one of American culture’s most insidious, shame-producing deceptions. Those of us with white, middle-to-upper-class, able-bodied privilege may be especially susceptible to this happy-ever-after chimera, and our privilege may make us prone to projecting the suffering and disappointment we think we are not supposed to have onto the nonconforming flesh of others. By contrast, people with disabilities do not have the luxury of denying life’s difficulties. In Betcher’s words, “the socially abject bodies of the disabled” are, “bodies that admit suffering” (Betcher, 2007, p. 194). Amid a culture dedicated to the denial of finitude, uncertainty, and death, their conspicuous losses and limits bear witness to pain that cannot be overcome, pain that doesn’t, “happen for a reason.” By “reconciling [them]selves with the contours of corporeality” (Betcher, 2007, p. 204), the heretical bodies/perspectives of people with disabilities show nondisabled people how we might begin to alleviate suffering—in ourselves and in the world—by refusing to look away from it.

With the help of the atypical perspective of those who refuse to repent for their somatic heresies, tentatively able-bodied people like myself can begin to own and examine the dread and shame we project onto disability, critically investigate the cultural, religious, and existential sources of our fear and disapproval, and transform insecurities into energy to create a world that respects, embraces, nurtures, and appreciates everybody.

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American Girls and Women (New York: Oxford University Press, 1999), as well as scholarly articles and popular blogs on the topic of women's conflicted relationships with their bodies.

References

- Asad, T. (1993). *Genealogies of religion: Discipline and reasons of power in Christianity and Islam*. Baltimore, MD: Johns Hopkins University Press.
- Asani, A. (2011). "Enhancing religious literacy in a liberal arts education through the study of Islam and Muslim societies." In J. Shephard, S. Kosslyn, and E. Hammonds (Eds.). *The Harvard sampler: Liberal education for the twenty-first century* (pp. 1–31). Cambridge, MA: Harvard University Press.
- Betcher, S. (2007). *Politics and the spirit of disablement*. Minneapolis, MN: Augsburg Fortress.
- Betcher, S. (2010). "Becoming flesh of my flesh: Feminist and disability theologies on the edge of posthumanist discourse." *Journal of Feminist Studies in Religion*, 26(2), 107–118.
- Brown, B. (2012). *Daring greatly: How the courage to be vulnerable transforms the way we live, love, parent, and lead*. New York: Gotham.
- Clare, E. (2009). *Exile and pride: Disability, queerness, and liberation*. Cambridge, MA: South End Press. (Original work published 1999)
- Clare, E. (2017). *Brilliant imperfection: Grappling with cure*. Durham, NC: Duke University Press.
- Coleman, M. (2008). *Making a way out of no way: A womanist theology*. Minneapolis, MN: Fortress.
- Descartes, R. (1956). *Discourse on method* (L. Lafleur, Trans.). Upper Saddle River, NJ: Prentice Hall. (Original work published 1637)
- Douglas, M. (1992). *Purity and danger: An analysis of concepts of pollution and taboo*. New York: Routledge. (Original work published 1966)
- Eiesland, N. (1994). *The disabled god: Toward a liberatory theology of disability*. Nashville: Abingdon.
- Foucault, M. (1973). *The order of things: An archeology of the human sciences*. New York, NY: Vintage. (Original work published 1966)
- Foucault, M. (1980). *Power/Knowledge: Selected interviews and other writings, 1972-1977*. (Colin Gordon, Ed.). New York, NY: Vintage.
- Foucault, M. (1988). *Madness and civilization: A history of insanity in the age of reason*. New

- York: Vintage. (Original work published 1961)
- Foucault, M. (1995). *Discipline and punish: The birth of the prison*. New York: Vintage. (Original work published 1975)
- Garland Thompson, R. (1997). *Extraordinary bodies: Figuring disability in American culture and literature*. New York, NY: Columbia University Press.
- Hull, J. (2013). *The tactile heart: Blindness and faith*. London, UK: SMC Press.
- Kafer, A. (2013). *Feminist, queer, crip*. Bloomington, IN: Indiana University Press.
- Lelwica, M. M. (1999). *Starving for salvation: The spiritual dimensions of eating problems among American girls and women*. New York: Oxford University Press.
- Lelwica, M. M. (2009). *The religion of thinness: Satisfying the spiritual hungers behind women's obsession with food and weight*. Carlsbad, CA: Gürze Books.
- Lelwica, M. M. (2017). *Shameful bodies: Religion and the culture of physical improvement*. London, UK: Bloomsbury Academic.
- Linton, S. (2007). *My body politic: A memoir*. Ann Arbor, MI: University of Michigan Press.
- Lowe, M. (2012) "“Rabbi, who sinned?” Disability theologies and sin.” *Dialog*, 5(2), 185–194.
- McBryde Johnson, H. (2005). *Too late to die young: Nearly true tales from a life*. New York, NY: Picador.
- Miller, M. (2012). *Religion and hip hop*. New York: Routledge.
- Moss, C. R. (2011). “Heavenly healing: Eschatological cleansing and the resurrection of the dead in the early church.” *Journal of the American Academy of Religion*, 79(4), 991–1017.
- Reynolds, T. (2008). *Vulnerable communion: A theology of disability and hospitality*. Grand Rapids, MI: Brazos.
- Parenfuss, H. (2018, May 17). Personal interview with [M. M. Lelwica].
- Schaefer, D. (2015). *Religious affects: Animality, evolution, and power*. Durham, NC: Duke University Press.
- “Shame”. (updated 2018 May 19). *Merriam Webster Dictionary*. Retrieved from <http://www.merriam-webster.com/dictionary/shame>
- Tollifson, J. (1997). “Enjoying the perfection of imperfection.” In L. Friedman and S. Moon, (Eds.). *Being bodies: Buddhist women on the paradox of embodiment* (pp. 18–24). Boston: Shambala Press.

- Walker, A. (1983). *In search of our mother's garden: Womanist prose*. New York, NY: Harcourt Brace Jovanovich.
- Watts Belser, J. (2014). "God on wheels: Disability and jewish feminist theology." *Tikkun*, 29(4), 27–29.
- Young, I. M. (1990). *Justice and the politics of difference*. Princeton, NJ: Princeton University Press.

Endnotes

1. I'm deeply indebted to Hannah Papenfuss for sharing her stories of shame with me. I've known Hannah for several years now. She is currently a junior at Concordia College in Moorhead, Minnesota. She is also a poet and a disability activist.
2. My experience with osteoarthritis (a degenerative joint disease that continues to produce chronic pain in my body) catalyzed my awareness of and interest in disability as an issue that affects everybody; however, for the most part, I inhabit the world as an able-bodied person, with all the privileges associated with that status. Thus throughout this article, I identify with the (tentatively) nondisabled, who, I argue, have a responsibility to better understand and challenge the various ways we may unwittingly perpetuate disability shame.
3. This article draws on and expands material previously published by the author in *Shameful Bodies: Religion and the Culture of Physical Improvement* (London: Bloomsbury Academic, 2017).



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Disability and Shame Special Issue Forum: Research Article

The Intersections of Culture, Disability, and Shame: The Experiences of Emerging Adults with Developmental Disabilities and their Families in South Korea

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Abstract: Every cultural group has its cultural values and beliefs, which influence experiences of their citizens. This study analyzes how culture and shame affect the lives of emerging adults (ages 18–26) with developmental disabilities and their families in South Korea, especially during the transition from early childhood to emerging adulthood.

Keywords: Emerging Adulthood; Transition; Developmental Disabilities; South Korea

South Korea is centrally located in northeastern Asia with a total population of 51.5 million (Ministry of Health and Welfare, 2016). In the late 1800s and early 1900s, Korean education was first made available to children with disabilities (Jung, 2011; Kim, 2012; Kim, Rhee, & Kim, 2009). Special schooling began with children who had visual or hearing impairments. In the 1960s, schooling became available to children with other disabilities (Kim et al., 2009; Park, 2002). Christian missionaries from Western countries were pioneers in providing education to children with visual and hearing impairments (Park, 2002; Ryu, 2009). In 1946, Pastor Y. S. Rhee was the first Korean to establish a Special School while the government was solely focused on developing an education system for children without disabilities (Kim et al., 2009). From then on Pastor Rhee unceasingly advocated for the educational rights of students with disabilities in South Korea.

Special Education in South Korea

The first legislation to support educational rights for children with disabilities, the Special Education Promotion Act (SEPA) of 1977, was enacted in South Korea 32 years after gaining independence from Japanese colonial rule and 24 years after the Korean War (Jung, 2007, 2011; Kim, 2012; Kim et al., 2009; Park, 2002; Ryu, 2009; Yoo & Palley, 2014). This Act promoted free education for children with disabilities during elementary and middle school, which was designated as compulsory for children with disabilities at a time when only elementary education was compulsory for children without disabilities (Jung, 2007; Park, 2002). The original 1977 SEPA was revised several times (for example, in 1987, 1990, 1994, 1997, 2000 and 2007), however, substantive revisions were undertaken in 1994 and 2007.

The 1994 SEPA revision mandated public school districts to provide individualized education plans (IEPs), that established inclusive opportunities and special education services for students with disabilities (Ryu, 2009). In addition, the 1994 SEPA revision played a

significant role in expanding compulsory education for students with disabilities. Compulsory education for students without disabilities was six years of elementary and three years of middle school. For students with disabilities it now included three years of pre-school/kindergarten education, six years of elementary school, three years of middle school, and three years of high school (Jung, 2007, 2011; Park, 2002; Ryu, 2009; Yoo & Palley, 2014).

According to the latest 2007 SEPA amendments, students with disabilities received special education services in various settings, such as inclusive education, self-contained education (special education classes at a public school), and segregated education (classes in special schools). The 1994 revision also made available other related services, such as therapy, speech therapy, vocational training, medical services, and additional necessary therapies, for students with disabilities (Park, 2002; Ryu, 2009; Yoo & Palley, 2014). In addition, an early childhood education program for children with disabilities under age three was made available for free, whereas previously parents had to cover the expenses on their own with occasional support from private organizations (Jung, 2011; Ryu, 2009). After three years of compulsory high school education, the two-year transition education program was also made available to eligible students cost free, however it was not made compulsory (Jung, 2011). The transition program often focused on vocational training that prepared newly completed high school students with disabilities for the next phase of their lives. These revisions also emphasized on increasing professional development opportunities for teachers and encouraged students to actively participate in decision-making processes in their education and future career planning.

Developmental Disabilities in South Korea

Of a total population of 51.5 million in South Korea, approximately 2.5 million people (5 percent of the total population) were reported to have disabilities according to the December 2015 Registration Status for People with Disabilities (Ministry of Health and Welfare, 2016). Of the 2.5 million people with disabilities, 8 percent (210,859 people) were diagnosed as having developmental disabilities. Ninety percent of the population with developmental disabilities (189,752 people) were diagnosed with intellectual disability and 10 percent with autism spectrum disorders (21,103 people). Typically, these two disabilities, intellectual disability and autism spectrum disorder, are considered to be developmental disabilities in South Korea (Choi, Baek, & Yim, 2013).

Under the Welfare of Persons with Disabilities Act (2015), people with an intellectual disability must have significant impairments in cognitive skills which affect their daily lives including their social lives. Those with autism spectrum disorder have significant impairments in communication, social interaction, and/or behavior, which affect their daily lives and social lives, both of which require the support of others. In addition, people with disabilities are often diagnosed as having disabilities of varying severity (Welfare of Persons with Disabilities Act, 2015).

Most disabilities are organized into six severity levels, level 1 is severe and level 6 is

mild; however, developmental disabilities have three severity levels. Twenty-eight percent of 210,855 people with developmental disabilities experience severity level 1, 35% at level 2, and 37% at level 3 (Ministry of Health and Welfare, 2016). Developmental disabilities are considered to be severe impairments in cognitive function, communication, social interaction, and/or behavior that cause developmental delays and/or lack of abilities, which create further limitations in their lives (Choi et al., 2013). Thus, people with developmental disabilities are often perceived as those who would be unable to take care of themselves including managing an occupation and living independently as an adult.

Cultural Values and Beliefs of South Korea

In Korean society, having a disability is associated with negative perceptions, such as shame, inferiority, and worthlessness (Cho, Singer, & Brenner, 2000; Kim & Kang, 2003). Negative perceptions of disability, quite possibly, cause many Korean parents to feel “shame, self-blame, sorrow, denial, and anger” (Cho et al., 2000, p. 241) towards their children with disabilities, especially when their children are first diagnosed. As such, when a child is diagnosed with disabilities, prevailing cultural and societal expectations contribute to Korean parents’ experiences with intense emotional crisis (Lee, 1999). These social perceptions are grounded in Confucian and collectivist values, which have influenced foundational values and beliefs in Korea including culture, traditions, and relationships within Korean society (Hyun, 2001; Kim, 1997; Lee, 1999; Min & Kim, 2012; Paik, 2001; Park & Cho, 1995).

According to Confucianism, society is organized into a hierarchical system with a “vertical structure of superiors and subordinates” (Hyun, 2001, p. 205). In this structure, superiors shared “wisdom, responsibility, and benevolence;” subordinates presented “obedience, loyalty, and respect;” and friends shared “trust and sincerity” (Hyun, 2001, p. 206). Confucianism stresses interpersonal relations between: “ruler and minister, parent and child, older and younger brothers, and husband and wife” (Hyun, 2001, p. 206), thus expecting different behaviors based on each person’s role. This Confucianism structure of society is a large part of the family systems. Thus, “being a loving parent, taking good care of offspring, being a dutiful child, and supporting siblings” (Park, 2012, pp. 2–3) are important values within Confucianism. Another important value that Confucianism emphasizes is collectivism, which places the group “above the individual and the latter’s life is bound to be group oriented” (Lee, 1999, p. 186). In addition, South Korea’s emphasis on collectivistic cultural values were more likely to “support interdependence (rather than independence), complying with social norms (by avoiding socially prohibited behavior), completing socially recognized role transitions (such as marriage), and the capacity for fulfilling family roles (such as providing financially for a family)” (Arnett, 2003, p. 64). Since Confucian and collectivistic cultural values are a large part of the family systems in Korean society; thus, nearly all Koreans place their family at the center of their lives. In other words, greater familism values, which is at a family-level of collectivism (Chun, Knight, & Youn, 2007), are present in Korean families.

Korean society evaluates people based on Confucian and collectivistic cultural values.

In Korean society, “success in individual life was viewed as the highest honor for one’s family” (Lee, 1999, p. 189); therefore, people who have stronger familism values may make decisions that would benefit their family and increase the family’s happiness before their own (Chun et al., 2007; Hu & Palmer, 2012). In addition, parents are defined as good parents when their child reached society’s standard of success (Grinker, 2007). Thus, children’s actions were a reflection on their parents. If anyone violates any of these values, shame is imposed on them as well as on their family (Lee, 1999). Shame is perceived as collective shame. These Confucian and collectivistic cultural values create a face-saving culture (Lee, 1999; Paik, 2001; Park, 2012; You & McGraw, 2011), which is “a kind of a disguised mask characterized by social collectivity in our relationship with others” (Lee, 1999, p. 187). Under the face-saving culture, people are more concerned about perceptions of others; thus, formality and appearance are cornerstones when interacting with others in society.

In Korean society, one of the greatest shames is when the child lacks filial piety toward his or her parents (Lee, 1999; You & McGraw, 2011). Under Confucian and collectivist values, especially familism values, the duty of supporting a family member is a normative part of the family system but negatively perceived as an obligatory duty (Chun et al., 2007). This ideology seemed to influence the National Basic Livelihood Security Act (2012), which mandates that family members continuously and faithfully practice filial piety, as known as unconditional obligation and duty of children to their parents and elderly family members (You & McGraw, 2011), by positioning immediate family members to be family providers. Because of the obligation to support the family members, parents and/or other immediate family members of older children with disabilities are expected to care for their children (Lee, 2016). Thus, the responsibility of caring for family members with disabilities falls squarely on the rest of the family members instead of relying on the government’s service system to guarantee a subsistence level for people with disabilities. In addition, Korean children with disabilities are believed incapable of practicing filial duty, such as financially supporting elderly parents, since many people with disabilities experience difficulties getting and maintaining a well-paid job (Kim & Kang, 2003).

The Study

According to Blumer’s (1969) three premises, people act according to the meanings they attached to things in their world. People’s meanings and perspectives are socially constructed and constantly changing as they are continually influenced by, and on others in specific contexts (Bogdan & Biklen, 2003; Charon, 1992; Taylor & Bogdan, 1998). The overall goal of this study was to understand how culture and shame affect the lives of emerging adults with developmental disabilities and their families in South Korea from one phase of life to the next: early childhood, childhood, adolescence, and emerging adulthood. Using an interpretive methodology grounded in the theoretical perspective of symbolic interactionism, the authors sought to gain a holistic understanding of the experiences of emerging adults with developmental disabilities and their families, including sociocultural contexts. Thus, the study was guided by the following questions:

1. How do family members, especially parents, describe their experiences as their son/daughter with developmental disabilities transition from one phase of life to the next?
2. How does culture and shame affect the lives of both emerging adults with developmental disabilities and their families?

Methods

This study was part of a larger study on understanding the experiences of Korean emerging adults during their transition from emerging adulthood to adulthood (Chun, 2017). In this study, stories of two different South Korean groups of people were included: (1) emerging adults (ages 18–26) with developmental disabilities, and (2) parents of these emerging adults. The criteria for participation were Korean emerging adults (ages 18–26) with developmental disabilities and parents who had not lived outside of South Korea for extended periods, and those who lived in one of 85 cities (designated 77 urban and 8 metropolitan cities) of South Korea.

To be sensitive and appropriate to the high context culture of South Korea—which heavily emphasizes commitment, expectation, and mutual support as important characteristics in the relationships (Kim, Pan, & Park, 1998)—initial recruitments of participants began through social connections of local parent organizations' events. In addition, a snowball sampling approach was employed to recruit additional participants by asking participants to recommend other potential participants who met the above mentioned criteria of the study and who might be interested in participating (Creswell, 2008; Merriam, 2009; Patton, 2015; Schwandt, 2015; Taylor & Bogdan, 1998). Through this process, twelve parent participants agreed to participate; eight parents of emerging adults consented for their children to be observed in different contexts, such as social events and/or home. These eight emerging adults also gave their permission for observations. In addition, when parent participants were initially contacted for the study, they referred to themselves as a mother or father of their child, instead of using their name. They continuously referred to themselves in their parental role as mother or father, which they preferred to be called. Thus, in this study, each parent was referred to as the parent of their child's pseudonym (for example, WooJin's parent).

The most appropriate way to achieve the purpose of this study was to use interpretivist research which relies upon qualitative methods of: (a) semi-structured, in-depth interviews and (b) participant observations. As a primary method, semi-structured, in-depth interviews were conducted with parent participants. Through this method, rich and detailed data were gathered in a flexible, changeable, and informal manner (Merriam, 2009; Rubin & Rubin, 2012). All semi-structured, in-depth interviews and meetings were scheduled at times and locations that were convenient to, and selected by the participants. Each parent participated in one to three interviews with one of the authors who spoke Korean. Each interview lasted approximately two hours and was audio recorded.

In conjunction with the semi-structured, in-depth interviews, participant observation was also incorporated into this study. This data helped “discover complexity in social settings

by being there” (Rossman & Rallis, 2003, p. 194). As the emerging adults interacted with their families and others in their communities, they were observed in various contexts. Field notes were created for each observation by including what one “hears, sees, and thinks in the course of collecting and reflecting on the data” (Bogdan & Biklen, 2003, pp. 110–111). In other words, in-depth and detailed conversations, as well as, complete descriptions of each meeting were included (Geertz, 1973).

Data Analysis and Credibility

As qualitative researchers, the authors used an interactive approach to remain flexible throughout the data analysis process (Maxwell, 2013). First data analysis began when the authors became immersed in the information (Rossman & Rallis, 2003). Then, they created analytic memos, reflections, and ideas that were included as data (Bogdan & Biklen, 2003; Creswell, 2008; Marshall & Rossman, 2006; Rossman & Rallis, 2003). The materials were organized and analyzed by each family group to focus on a particular group’s story in order to understand deeper meanings and perceptions of their experiences.

The initial coding process began with descriptive coding, capturing a summary of the basic topic of a passage, and with in-vivo coding, which contained direct statements that participants used (Saldaña, 2009). Through these coding processes the authors coded groups into common themes and summarized each category. Then, the authors looked across the data under each category and conducted a second cycle of coding across participant families. Since all collected data were coded together, the observation field notes complemented the interview data in the findings, which also helped to contextualize the data more broadly.

Since data were collected in multiple ways—namely through in-depth interviews, participant observations, and document analyses across multiple participants—trustworthiness and credibility were advanced (Creswell, 2008; Maxwell, 2013; Rossman & Rallis, 2003). The authors were able to triangulate information that was gathered through multiple methods and participants, which helped to enhance the quality of the interpretations and findings.

During the process of collecting data, one of the authors verified and confirmed with participants through on-going member checks in order to prevent any misrepresentation of what was shared during the data collection process (Maxwell, 2013). This strategy also identified any of the authors’ personal biases regarding what they shared (Maxwell, 2013). In addition, a Korean-American, who is bilingual and bicultural, reviewed and edited quotes to enhance to fluidity of the contents and contexts, and to ensure participants’ stories were appropriately and accurately captured in English.

Findings

The 12 parents of emerging adults with developmental disabilities shared their experiences as their son/daughter with developmental disabilities transitioned from one phase of life to the next (early childhood, childhood, adolescence, and emerging adulthood) in South Korea. The findings presented how experiences of emerging adults and their parents were affected by cultural values and beliefs of South Korea. The following section discusses four

themes: societal standards, familial responsibility, mothers' roles, and parental emotional burden.

Societal Standards

The parent participants felt ashamed when their children engaged in socially unacceptable behaviors, which were not meeting societal standards and caused an inconvenience for others. When the emerging adults demonstrated some forms of socially unacceptable behaviors, service providers contacted the parents to pick-up their children in the middle of a school or program day. The calls from service providers caused the parents to feel sorry and ashamed for their children's disruptions in the class, so the parents ended up being compliant to service providers' request, though they may not have agreed with it.

WooYoung's parent shared that "WooYoung's teacher did not want him to be in the class due to his behavior so I had to pick him up after two to three hours of attending school." The parents of JooHo said:

JooHo had a crying behavior. . . . If he lost a pencil at school, he would cry until he found that same pencil he lost. . . . Peers also bullied him in school. So every time JooHo had an incident, the school contacted me to pick him up from school.

Similarly, WooJin's parent shared:

One day, I got a call [from the service provider] 15 minutes after I dropped WooJin off at the program at a community rehabilitation center. She asked me to pick him up as WooJin's vocal stimming behavior was interrupting the class . . . when he was supposed to be quietly watching the instructional video.

WooJin's parent shared another incident with one of the female teachers at WooJin's high school:

When WooJin sees [one of the female teachers], he gets very excited and does not know what to do. He does not express himself that way with others, just that teacher. . . . He never touched the teacher, but he walked very close to her. His behavior escalates in warmer months since the teacher wears a short tight skirt with a deep scoop or V-neck top. He engages in the behavior less during colder months when clothes are not as revealing.

WooJin's other teachers in the school were also aware that he responds differently to the female teacher's outfits. However, the school did not suggest to her to consider wearing different attire during work hours. Instead, "the school calls me to pick him up or asks me to address it at home, whenever WooJin shows [socially unacceptable behaviors] at school," WooJin's parent shared. WooJin's mother felt very stressed about his obsessive behavior with the female teacher, because it disturbed her.

When the parents received calls from service providers, the parents just apologized for their children's behaviors and said they would address the behaviors despite not knowing how

to properly help their children. The parents tried everything they knew to ameliorate their children's behaviors.

Familial Responsibility

Under the strong familism values in South Korea, parents are solely responsible for their children with disabilities. For example, WooJin's parent shared incidents that WooJin had, in warmer months, with one of the female high school teachers who wears a tight short skirt with a deep scoop or V-neck top:

I needed to figure out ways to fix things. I needed to think about strategies to manage his behavior. It is my responsibility to support WooJin to reduce his behavioral outbursts so that he won't interrupt the class or group. . . . [For example,] WooJin always looked for and approached one of the female teachers that he liked. Although the way he expresses his emotions is not appropriate, the school does not try to teach him more appropriate ways. I had to come up with an alternative strategy, such as shaking the female teacher's hand.

Additionally, when there are incidents involving emerging adults and other peers, parents of emerging adults often decided they needed to settle the situation by offering a small monetary compensation to the other parents in the school disciplinary committee meeting.

In school disciplinary committee meetings, school personnel acted as mediators between the parents and school personnel, and in some cases, the school also provided support to the students. The parents of YeEun, SungSoo, and MinSoo shared their children's stories as follows. When YeEun was in her senior year in high school:

One of the classmates who also had severe developmental disabilities was touching YeEun's breasts. YeEun began to develop behavior such as refusing to go into the classroom if that student was there or cutting her hair, and taking her clothes off in the restroom. Since the student who harassed YeEun was also a friend and had severe developmental disabilities, I could not follow the policy and seek punishment for the student. When incidences are evoked by a student's behavior, usually the parents of victims and parents of the assaulters would need to settle the case between themselves.

In order to receive any support from the school district, parents needed to report the incident to the school disciplinary committee. YeEun's parent continued, "the school would serve as the mediator for the case. I did not report YeEun's incident to the school disciplinary committee. However, the school offered to provide YeEun with eight counseling sessions."

SungSoo's peers, in the general education classes, bullied him so he had outbursts of indignation, which created a lot of problems during middle and high school. SungSoo engaged in behaviors (for example, screaming, spitting) when he was isolated, or if there were environmental changes. SungSoo's parent explained that, unfortunately:

The school did not address the core of the issue that triggered SungSoo's behavior, nor did they offer any intervention or support to address such behavior. The school wanted

the parents of his peers and I to resolve the incident. I ended up apologizing for SungSoo's behavior and offering monetary compensation to them as a result.

Lastly, when MinSoo experienced a violent assault from three peers during her junior year in high school, MinSoo's parent shared that:

The school relied on the statements of the peers [from the general education class] and did not trust MinSoo's statement. . . . Since the peers harassed a student with disabilities, I could have requested the school expel the peers at the disciplinary committee meeting. However, I am also in a position of raising children so I could not request those children to be expelled. The peers' parents apologized so it was not easy to push for [the peers] to be expelled. . . . The school was willing to pay for the medical bills for treating wounds caused by the incident, but the amount was not that much, so I did not request a reimbursement.

MinSoo's parent went on to explain that because of the trauma that MinSoo experienced from the incident, his parent decided to arrange for counseling therapy. It was the parents' responsibility to arrange resources for MinSoo's therapy sessions. MinSoo's parent said:

Luckily, I knew a counselor, who generously charged only [\$10] an hour for the first couple of months, then [\$35/hr], which was still a discounted rate. Although it was a low rate compared to the standard rate, it was still burdensome to pay [\$35] each week, so MinSoo started attending biweekly sessions . . . MinSoo received counseling for a year and a half, but he could not be freed from the trauma. MinSoo faced limitations with counseling because of his limitations expressing his emotions verbally. . . . In the end, MinSoo continued to suffer from the incident. I did not know that he would have such a hard time being freed from those memories.

As illustrated above, it was mostly the parents who were responsible for addressing any implications of their children's behaviors.

Mothers' Roles

The emerging adult participants with developmental disabilities in this study were born between 1990 and 1998. Eleven of 12 participants' fathers functioned as family breadwinners and provided for the material needs of the family. It was their mothers' jobs to take care of them and manage household-related duties. The parent participants, especially mothers, were solely responsible for finding and supporting the needs of the children.

Before the government-built infrastructures for citizens with disabilities, parents frequently had to move in order to find even minimal services. Interventions (such as speech therapy, physical therapy, occupational therapy, applied behavior analysis therapy, music therapy, academic enrichment tutoring, and play therapy) were expensive, the parents paid out-of-pocket for the supports they hoped would increase their children's development, and eventually ameliorate their child's developmental delays over time by providing intervention from an early age. One parent later realized that intensive intervention schedules during early childhood were not the key to improving developmental delays in all emerging adults.

WooJin's parent shared that:

In 6th grade, WooJin refused to participate in any of the therapy programs [for about a year] . . . looking back, I was not aware of my child's stress from following such an intensive intervention schedule. Since then, WooJin only [agreed to] attend one program per day.

The emerging adults whose parents ensured various interventions and programs during early childhood also had fuller adult schedules. The parents believed that if emerging adults just stayed at home all the time, they would not use time wisely and would feel depressed and lazy, which would not be beneficial for their future development and progress. MinHo's parent believed that "it was necessary and beneficial [for MinHo] to follow and complete an organized and consistent schedule." The parents believed that the children's future depended on how the mothers could organize and plan for their children by using all possible resources they could locate—within the limited options—for emerging adult children with developmental disabilities.

Parental Emotional Burden

Just as the parents searched for various interventions and programs when their children were young, during the transition from schooling to adult life, the parents once again had to search and plan for their children's future by themselves. The parents, especially the mothers, seemed to bear all the responsibility for the quality of their children's life. Eleven participants shared that most of the time fathers did not oppose the mothers' decisions and choices for their children and left decisions regarding the welfare of their children to the mothers. This role led the mothers to be solely responsible for the emotional load of caring for children.

Since the mothers were the main caretakers for the emerging adult, they made the majority of decisions for them. And although the mothers made decisions for the children, the mothers shared the decisions and choices that they planned for their children with their husbands. After seeking and providing various interventions and programs to the emerging adults, when the strategies were not helping them, it was very hard for the parents, especially the mothers, to deal with feelings of helplessness.

Discussion

Social perceptions that are grounded in Confucian and collectivist values (Cho et al., 2000; Hyun, 2001; Kim, 1997; Kim & Kang, 2003; Lee, 1999; Min & Kim, 2012; Paik, 2001; Park, 2012; Park & Cho, 1995; You & McGraw, 2011) influenced the experiences of the families as their children with developmental disabilities transitioned across the lifespan from early childhood to emerging adulthood. While the emerging adult participants were growing up in the 1990s, their parents believed that if their children received various intervention programs (such as speech therapy, physical therapy, occupational therapy, Applied Behavior Analysis therapy, music therapy, academic enrichment tutoring, and play therapy) as early as possible, they would become *normal* like children without disabilities.

During early childhood, there were very few government-supported programs and

support services available to these emerging adults and their parents. There were either no services available to these families or very limited supports in place. Parents had to advocate for their children in their search for support instead of waiting for the government to provide it. Consequently, parents were solely responsible for discovering support services that would potentially address their children's needs. In other words, parents continually explored and planned for their children's future on their own throughout their developmental stages, with limited support from service providers.

In addition, due to strong familism values in South Korea, parents and other family members are obligated to support their family member with disabilities, which reinforces the notion of disability as both an individual and family issue or burden. This ideology seemed to be embraced because of the strong familism values, influenced by Confucianism, that dominated Korean society and led to the legal conclusion that the family was the obligatory provider under the National Basic Livelihood Security Act (2012). This belief frequently caused hardships and distress for parents of emerging adults with developmental disabilities, and even affected the relationships between parents and service providers. For example, due to the cultural values and beliefs of South Korea, especially the strong familism values, when the parents receive calls from service providers, the parents tended to apologize and carry the weight of shame. This often caused them to remove their children from the situation to minimize inconvenience for others, and possibly, their own feelings and experiences of shame. The parents also informed service providers that they would address the behaviors, despite not knowing how to help their children.

In this study, consistent with other studies (Cho et al., 2000; Kim & Kang, 2003; Lee, 1999), the parents who had strong Confucian and collectivist cultural values, felt ashamed by their children's behaviors that caused any inconvenience for others. The parents continued to search for ways to help their children, trying various strategies to help them improve their behavior, as well as, ways to reduce and release the emerging adults' stress, frustration, and/or anxiety. The parents tried various interventions they believed that could help their children reduce and release stress, so that it could potentially increase their children's socially adaptable behaviors. Additionally, the parents, especially mothers, believed that the quality of their children's adult lives was based on how wisely the mother was able to organize and plan for her children.

The South Korean government and policy makers should support pre- and in-service professional development training programs for service providers to develop the necessary skills to effectively support emerging adults and their families during transition to adult life. In South Korea, training programs could enhance service providers' skills in planning goals that would meet the desired outcomes for the next phase of life for the emerging adults; and provide services that better support them to meet their life goals. It is important to remember that having a greater awareness of the cultural values and beliefs of the emerging adults and their families can help service providers gain a more comprehensive understanding of the emerging adults and their families, which would then lead to a more beneficial transition to the next phase of life.

Furthermore, service providers should increase their awareness of, and sensitivity to the values and beliefs of families by understanding the process of how emerging adults with developmental disabilities and their families develop meanings during transition from school to adult life, in other words, from familiar to unfamiliar contexts. Gaining these understandings could enhance the quality of the relationships between service providers and families, which could potentially contribute to both service providers and families having a better understanding of transition expectations, and reduce concerns and stress for parents and families. The authors also encourage service providers to support advocacy and cultural change (Condeluci, 2008), which should be focused on aid and assistance that will result in differences in communities and society. Although, “awareness and attitude shift[s] occur slowly and tediously” (Condeluci, 2008, p. 91), through persevering actions that increase awareness of disability in society would help people with disabilities to have better transition experiences that could result in emerging adults' and their family's quality of life.

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References

- Arnett, J. J. (2003). Conceptions of the transition to adulthood among emerging adults in American ethnic groups. *New Directions for Child and Adolescent Development*, 2003(100), 63–76. doi:10.1002/cd.75
- Blumer, H. (1969). *Symbolic interactionism: Perspective and method*. Englewood Cliffs, NJ: Prentice-Hall.
- Bogdan, R., & Biklen, S. K. (2003). *Qualitative research for education: An introduction to theory and methods*. Boston, MA: Allyn and Bacon.
- Charon, J. M. (1992). *Symbolic interactionism: An introduction, an interpretation, an integration*. Englewood Cliffs, NJ: Prentice Hall.
- Cho, S. J., Singer, G. H. S., & Brenner, M. B. (2000). Adaptation and accommodation to

- young children with disabilities: A comparison of Korean and Korean American parents. *Topics in Early Childhood Special Education*, 20(4), 236–249.
- Choi, B. C., Baek, E. R., & Yim, S. K. (2013). *Baldaljangaeyin gajokesaryae kwanri manual gaebal yungu [A case study on the development manual of the persons with developmental disabilities]*. Seoul, South Korea: Korea Disabled People's Development Institute.
- Chun, M. C. (2017). *Discerning the next steps: Living as Korean emerging adults with developmental disabilities in South Korea* (Doctoral Dissertation). Chapman University, Orange, California.
- Chun, M., Knight, B. G., & Youn, G. (2007). Differences in stress and coping models of emotional distress among Korean, Korean-American and White-American caregivers. *Aging and Mental Health*, 11(1), 20–29. doi:10.1080/13607860600736232
- Condeluci, A. (2008). *The essence of interdependence: Building community for everyone*. Youngsville, NC: Lash & Associates.
- Creswell, J. W. (2008). *Educational research: Planning, conducting, and evaluating quantitative and qualitative research*. Upper Saddle River, NJ: Pearson.
- Geertz, C. (1973). *The interpretation of cultures: Selected essays*. New York, NY: Basic Books.
- Grinker, R. R. (2007). *Unstrange minds: Remapping the world of autism*. Cambridge, MA: Basic Books.
- Hu, X., & Palmer, S. B. (2012). Self-determination within the Chinese culture: Examining cultural values. *Review of Disability Studies: An International Journal*, 8(1), 22–33.
- Hyun, K. J. (2001). Sociocultural change and traditional values: Confucian values among Koreans and Korean Americans. *International Journal of Intercultural Relations*, 25(2), 203–229. doi:10.1016/S0147-1767(01)00009-8
- Jung, D. Y. (2007). South Korean perspective on learning disabilities. *Learning Disabilities Research & Practice*, 22(3), 183–188.
- Jung, D. Y. (2011). Special education in South Korea: Overcoming conflicts for the realization of educational welfare. In M. A. Margret & K. Mazurek (Eds.), *International practices in special education: Debates and challenges* (pp. 264–279). Washington, DC: Gallaudet University Press.
- Kim, S. C. (1997). Korean American families. In E. Lee (Ed.), *Working with Asian Americans: A guide for clinicians* (pp. 125–135). New York, NY: The Guilford Press.
- Kim, Y. W. (2012). Inclusive education in South Korea. *International Journal of Inclusive Education*, 18(10), 979–990. doi:10.1080/13603116.2012.693402
- Kim, B. H., Rhee, K. Y., & Kim, T. Y. (2009). Korean special education and Daegu University: History, phenomenon, and issues. *The Journal of Special Education: Theory and Practice*, 10(1), 323–342.

- Kim, D., Pan, Y., & Park, H. (1998). High-verse low-context culture: A comparison of Chinese, Korean, and American cultures. *Psychology and Marketing*, 15(6), 507–521.
- Kim, S. J., & Kang, K. A. (2003). Meaning of life for adolescents with a physical disability in Korea. *Journal of Advanced Nursing*, 43(2), 145–155. doi:10.1046/j.1365-2648.2003.02689_1.x
- Lee, W. M. (2016). *Buyang uimuje ui bigeuk hyeonjae jinhaenghyeong [The strategy of family obligatory provider system is in progressive]*. Retrieved from <http://www.ablenews.co.kr/News/NewsPrint/Print.aspx?NewsCode=000620160617000241872826>
- Lee, Z. N. (1999). Korean culture and sense of shame. *Transcultural Psychiatry*, 36(2), 181–194. doi:10.1177/136346159903600202
- Marshall, C., & Rossman, G. B. (2006). *Designing qualitative research*. Thousand Oaks, CA: Sage Publications.
- Maxwell, J. A. (2013). *Qualitative research design: An interactive approach*. Thousand Oaks, CA: Sage Publications.
- Merriam, S. B. (2009). *Qualitative research: A guide to design and implementation*. San Francisco, CA: Jossey-Bass.
- Min, P. G., & Kim, C. (2012). The Korean American family. In R. H. Wright Jr., C. H. Mindel, T. V. Tran, & R. W. Habenstein (Eds.), *Ethnic families in America: Patterns and variations* (pp. 174–198). Boston, MA: Pearson.
- Ministry of Health and Welfare. (2016). *Jangaeyin deungroke hyunhwang [Registration status for disabled persons]*. Retrieved from http://www.mohw.go.kr/front_new/jb/sjb030301vw.jsp?PAR_MENU_ID=03&MENU_ID=0321&CONT_SEQ=333547&page=1
- National Basic Livelihood Security Act (2012). *Kookmin gicho sanghwal bojangbub [National Basic Livelihood Security Act]*. Retrieved from [http://www.law.go.kr/법령/국민기초생활보장법/\(11248,20120201\)](http://www.law.go.kr/법령/국민기초생활보장법/(11248,20120201))
- Paik, S. J. (2001). Introduction, background, and international perspectives: Korean history, culture, and education. *International Journal of Educational Research*, 35, 535–607. doi:10.1016/S0883-0355(02)00013-7
- Park, J. (2002). Special education in South Korea. *Teaching Exceptional Children*, 34(5), 28–33.
- Park, M. (2012). Filial piety and parental responsibility: An interpretive phenomenological study of family caregiving for a person with mental illness among Korean immigrants. *BMC Nursing*, 11(1), 1–28. doi:10.1186/1472-6955-11-28
- Park, I. H., & Cho, L. J. (1995). Confucianism and the Korean family. *Journal of Comparative Family Studies*, 26, 117–134.
- Patton, M. Q. (2015). *Qualitative research and evaluation methods: Integrating theory and practice*. Thousand Oaks, CA: Sage Publications.

- Rossman, G. B., & Rallis, S. F. (2003). *Learning in the field: An introduction to qualitative research*. Thousand Oaks, CA: Sage Publications.
- Rubin, H. J., & Rubin, I. (2012). *Qualitative interviewing: The art of hearing data*. Thousand Oaks, CA: Sage Publications.
- Ryu, S. Y. (2009). *Special education and social services in Korea: Past, present, and future*. *International Review of Research in Mental Retardation*, 38, 125–146. doi:10.1016/S0074-7750(08)38005-7
- Saldaña, J. (2009). *The coding manual for qualitative researchers*. Los Angeles, CA: Sage Publications.
- Schwandt, T. A. (2015). *The SAGE dictionary of qualitative inquiry*. Los Angeles, CA: Sage Publications.
- Taylor, S. J., & Bogdan, R. (1998). *Introduction to qualitative research methods: A guidebook and resource*. New York, NY: Wiley.
- Welfare of Persons with Disabilities Act. (2015). *Jangaein bok jibub [Welfare of Persons with Disabilities Act]*. Retrieved from <http://www.law.go.kr/법령/장애인복지법>
- Yoo, J. P., & Palley, E. (2014). The diffusion of disability rights policy: A focus on special education in South Korea. *International Journal of Disability, Development and Education*, 61(4), 362–376. doi:10.1080/1034912X.2014.955790
- You, H. K., & McGraw, L. A. (2011). The intersection of motherhood and disability: Being a “good” Korean mother to an “imperfect” child. *Journal of Comparative Family Studies*, 42(4), 579–598. doi:10.2307/41604469



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Disability and Shame Special Issue Forum: Research Article

Three Dimensions in the Register of Shame

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Abstract: This article highlights the ways in which people with disabilities who have recently been involved in programs set up by the Swiss compulsory Disability Insurance (DI) refer to the register of shame in their discourse. It pinpoints three dimensions of this register: social position, social judgment and mirror-effect and shows that while referrals to shame do not constitute a direct challenge of ableist hierarchies, they do displace the meanings attached to disability.

Keywords: Swiss Disability Insurance; Shame; Vocational Rehabilitation

Introduction

Shame. It does not scream. It brings on a chill

—Henri Michaux, *Difficultés*, 1930

He had joined the brigade of the damned, he told himself, and from now on he would be looked upon as one of those crippled, distorted people who no longer counted as full-fledged members of the human race.

—Paul Auster, *4 3 2 1*, 2017

Persons who receive welfare state benefits often publicly display feelings of shame, unease, guilt or embarrassment (de Gaulejac, 1996; Tabin, Frauenfelder, Togni, & Keller, 2010), such as in the context of dealings with welfare state agents (Driessens, 2010). As researchers in the domain of social sciences, we have regularly heard such discourses during the interviews we conducted with persons having to deal with the Swiss Disability Insurance (DI). This government agency assesses whether an applicant is disabled, partially disabled or able to seek employment, and decides if rehabilitation measures will be proposed.¹

From a sociological point of view, the fact that feelings within the register of shame are displayed by persons whose earning capacity is diminished because of a health impairment—this being the legal definition of disability in Switzerland—is not particularly surprising. On the one hand, contemporary societies are built around a logic that gives value to ability, and that then devalues persons who cannot perform (Stiker, 2005). Ableist ideas

and practices put these people in a position of inferiority (Campbell, 2009; Goodley, 2014), and persons who fail to meet ableist expectations concerning ‘performance’ are systematically described in negative terms as incapable, infirm or as not able-bodied. In prevailing discourses, this vocabulary conveys negative judgments and conjures pejorative narratives of loss and lack, of being broken, less worthy and less human. It is thus hardly surprising that terms such as these have an effect on the persons concerned, people with disabilities.² References to shame, unease, guilt or embarrassment on their part is an expected reaction, all the more so, when they are interacting with people who view themselves as able-bodied.

On the other hand, numerous recent changes in Swiss disability policies, with its litany of pronouncements on the abuse of social benefits by recipients (Ferreira & Frauenfelder, 2007), have emphasized the people accessing social services, are individually responsible for their own recovery, increasing their employability, accessing a greater range of professional opportunities, and/or ceasing to rely on disability benefits (Probst, Tabin, Piecek-Riondel, & Perrin, 2016). Such moral framing of people with disabilities, prevalent in Western liberal democracies’ discourse on social protection, has been pivotal in the implementation of active employment programs aimed at rapidly moving recipients into the labor market (Parker Harris, Owen, Fisher, & Gould, 2014; Yates & Roulstone, 2013). These policy tools, all based on the regulation of individual behavior, are defined as means for “overcoming disability benefit culture” (OECD, 2009, p. 17), and as central drivers for resolving social problems. Applicants for disability benefits are thereby not seen as victims of socio-economic insecurity linked to structural disadvantages, but as financial risks for social insurance schemes. As Skeggs (2004) observes, “[under liberal policy frameworks], those who cannot perform their state-defined ‘duty’ are thus morally suspect” (p. 82). In this context, DI applicants and recipients are pressured to take on the classical posture demanded of the ‘worthy’ poor—that of being ashamed rather than proud (Castel, 2003; Geremek, 1987; Sassier, 1990). Thus, the people we met, unsurprisingly spoke primarily of the negative emotions they had experienced.

A closer analysis reveals, however, that the choice to call upon the register of shame—whether individuals truly felt ashamed or not is not the concern of the present article—is more complex than it might seem. This paper argues that while referrals to shame do not constitute a direct challenge of ableist hierarchies, they do displace the meanings attached to disability. We intend to shed light on this issue through an analysis pinpointing three dimensions of the register of shame: social position, social judgment and mirror-effect. But first, we begin with a brief overview of the scientific literature on shame and present the research methodology we used.

Theoretical Context

During the last decade, the scientific literature pertaining to shame has considerably widened in scope, within the context of what some authors have called the ‘affective turn’ in social sciences (Clough & Halley, 2007; Lordon, 2013). The broad range of work on this topic, inspired by different perspectives, often stands at the crossroads between psychological and sociological theories.

Shame, as an object of categorization within the field of social sciences, may be defined in more or less specific ways. While some authors are intent on distinguishing it specifically from other notions, particularly those of guilt, humiliation and embarrassment (Biddle, 1997; Probyn, 2005), others emphasize the overlapping nature of emotional experiences. These scholars warn against the risk of a reification of categories, due to overly circumscribed definitions (Barrett, 2018). According to the latter, emotions coexist and dynamically blur into one another depending on the context of on-going interactions (Munt, 2008; Sedgwick, 1993). For Scheff (2000), shame is thus, “a large family of emotions that includes many cognates and variants, most notably embarrassment, humiliation, and related feelings such as shyness, that involve reactions to rejection or feelings of failure or inadequacy” (p. 96). We adopt this definition in the present article.

From a sociological standpoint, shame is an affect³ that is linked to individuals’ social position and to the experiences that stem from it (Loveday, 2016; Skeggs, 1997). In Bourdieu’s (2000, 2001, 2014) terms, it’s one of the dimensions of a habitus that becomes embodied in a hexis. It has been fashioned not only by history and culture, but also by dominant norms and values. Thus, as Ahmed (2004) states, it may be understood as “the affective cost of not following the scripts of normative existence” (p. 107). The experience of individuals we met who are dealing with DI falls within this understanding of shame, to such an extent that DI only intervenes for adult workers whose confirmed physical, psychological or mental impairments are liable to compel them to permanently abandon gainful employment. For all recipients, there is thus a deviation from the expected course of existence, such incapacities being socially acceptable only in old age—in 2018, the economic activity rate of the population aged 15 to 64 is 84.2 % in Switzerland (Federal Statistical Office, 2019). We shall analyze later how this deviation is experienced.

Other perspectives can allow us to further nuance our understanding of shame. The interactionist perspective (e.g. Goffman, 1959), for example, emphasizes the reflexive and interpersonal nature of this affect. It highlights that shame is connected both with self-judgment and with the image reflected in the eyes of others, and even with the anticipation of this image; implying not only an awareness of social norms, but also of judgment by others. Therefore, it stems from a moral appreciation, through which the person imagines the disqualifying gaze—real or imagined, present or absent—focused on him or her by people. In other words, social actors respond to the situations they experience, not only in terms of social interactions, but also in terms of anticipation or projections. In a context characterized by recurring political debates about DI, extensively relayed by the media, over the past two decades (six major legislative revisions set in motion, including three actually implemented), applicants and recipients of DI know that their situation is viewed by others in a disqualifying way. Indeed, persons viewed as disabled have been designated since the mid-1990s as responsible for the increase in the costs of DI (Probst, Tabin, & Courvoisier, 2015).

Shame is tied to this designation because the social discourse about individuals considered as disabled, like the discourse about the poor, tends to explain their situation through the notion of personal failings. Within this context, the argument of deservedness gets

conjugated with discourse about parasitism: recipients are defined by the media, the general public, politicians and welfare institutions as ‘shirkers,’ ‘scroungers,’ ‘apathetic’ or ‘wasters.’ This process legitimizes the tightening of controls, for example the introduction of systematic reviews of pension benefits and of the requirement for all insured persons “to take all necessary measures in order to avoid having to resort to insurance benefits” (Despland, 2012, p. 77). As the Swiss government stated, “[since] January 1st 2008, DI has implemented an active battle ... against abuses in this insurance ... that can be divided into four phases: identification of suspicious cases, inquiries and in-depth testing, surveillance ... and finally the recourse to insurance legislation and to the penal code” (Conseil fédéral, 2017, p. 4). Swiss authorities have therefore contributed to spreading the idea that a potentially significant number of people receive, or attempt to obtain, benefits to which they are not entitled, thus discrediting all DI recipients. This goes some way towards explaining the climate within which links are necessarily created between shame and DI, and the context in which our interviewees refer to the register of shame.

Shame is thus not only an affect, it is a ‘moral tool’ (Chase & Walker, 2013). Like ‘politics of resentment’, it “forms an exclusionary emotional and social framework that traps minority identities and people experiencing multiple deprivations in its belief system and practices” (Hughes, 2015, p. 996). In this way, shame, humiliation and disgust maintain the boundary between social constructions of ‘normal’ and ‘abnormal’ and reconstitute the categories of what is acceptable and unacceptable, as Moore (2016) shows using the example of the shaming process of individuals who have transgressed gender norms. These politics of emotions (Ahmed, 2004) confer value on some while denying it to others.

From that standpoint, shame then becomes a pattern of social regulation that reflects and maintains social hierarchies and inequalities. It is a subtle form of power, that promotes the self-regulation of behaviors and the normalization of conducts (Baker, 2013; Creed, Hudson, Okhuysen, & Smith-Crowe, 2014). Thus, Walker (2014) suggests that it “might be better described as cement reinforcing structures of inequality and perpetuating poverty” (p. 191). Shame, in a way, naturalizes social stratification as it leads to “experiencing in the mode of original sin and of essential indignity differences that ... are the product of social conditioning” (Bourdieu & Delsaut, 1975, p. 36). As a result, individuals who experience these processes, “contribute to their own domination by tacitly accepting the limits imposed” (Bourdieu, 2001, p. 38). It is the ‘sense of one’s place’ that is being experienced: the shame of the person who is feeling out of place or the ease associated with the feeling of being in one’s place (Bourdieu, 2000). Being ashamed thus reflects the awareness that individuals have of their social position, shame being “an embodied sense of self-judgment” (Barrett, 2018, p. 39).

In short, shame is one dimension of a habitus, associated with a position in social space. It arises in relation to social judgment, thus requiring a context that views some social positions as inferior. When this judgement is interiorized by the very persons occupying devalued social positions, shame becomes a powerful tool for the reproduction of hierarchies. However, post-structuralist research has shown that because shame also structures the

individual as a subject (Fullagar, 2003; Munt, 2008), it could also lead to the questioning of social roles. Shame, from this standpoint, is not simply a ‘negative’ (Chase & Walker, 2013), or even a ‘debilitating’ (Weiss, 2010) emotion; it affects self-representation in more ambiguous ways.

Methodology

This article is founded upon the discourse of 33 persons who were, or had been, involved in rehabilitation programs run by Swiss DI. This data was collected between February 2016 and January 2017, within the context of the research project “Living under the new paradigm of Swiss disability insurance” supported by the Swiss National Science Foundation.⁴ The goal of the study was to better understand the way in which recipients experienced the recent reforms introduced to DI.

Our project aimed at collecting a wide range of rehabilitation experiences in order to meet the principles set out for the selection of qualitative multiple case samples (Glaser & Strauss, 1967; Pires, 1997). During the process of recruiting participants, we contacted close to a hundred organizations—disease-specific associations, foundations, support groups, unions, psychosocial residential structures, social services—and asked them, respecting all standard ethical criteria, to relay requests for interviews. Despite the number of contacts initiated, we encountered some difficulties in recruiting participants. Refusals stemming from particularly difficult personal situations (in terms of health or of conflict with DI), or from fear that information could get back to DI agents, were reported.

We met 13 women and 20 men aged between 20 and 64 (13 were under 40 years of age, 20 between 40 and 64 years of age). They experienced a broad range of impairments (e.g. hearing impairment, chronic pain, depression, cancer, professional burnout, nervous breakdowns). These persons were at various stages of their contacts with DI: some were involved in rehabilitation measures and others were not; some had returned to employment and others had not. The duration of their involvement with DI ranged from a few months to over 20 years.

A semi-structured interview schedule was designed to focus on the evaluation of the interventions of DI, in order to avoid reproducing the structure of DI questionnaires concerned with health impairments and professional experience. Although none of the questions explicitly focused on emotions, 11 persons explicitly used the term “shame” when describing their experiences and 29 interviewees referred to this affect through the use of words such as “stigmatizing,” “hard,” “difficult,” “painful,” “humiliating” or of metaphorical expressions such as, “It is not something you would shout about from the rooftops.”

All interviews were recorded, transcribed and anonymized. We were able to identify three specific dimensions in the register of shame that we will detail below (social position, social judgment and mirror-effect). At least one of these three dimensions appears in 29 of the 33 interviews we conducted. A majority of interviewees, 17 persons, referred to two of these dimensions, eight persons referred to three, and four interviewees referred to only one. Both

interviewees who gave a positive assessment of DI intervention in their case, as well as those who viewed it as unhelpful or even deleterious to their health, reported experiencing shame. Among those who actually referred to all three dimensions of the register of shame, we found a majority of women, six persons out of eight. Ten out of 11 people who were in work at the time of the interview did not refer to the third dimension of shame, the mirror-effect. Other biographical elements such as age, level of education or type of impairment were not associated with any specific type of discourse about shame.

The First Dimension of Shame: Social Position

The individuals we met describe having been fearful about having dealings with DI because of the social re-positioning that becoming a DI recipient implies. During a typical life course progression, the vast majority of people never come into contact with the DI system—except insofar as they compulsorily pay into it as contributions are deducted from their salaries. To have to be confronted with this institution is an experience we have often heard interviewees describe as “impossible,” “inconceivable” or even “shocking.” That is what Martine (nurse, 47)⁵ explains, “In the beginning, I didn’t want to go because I said to myself: ‘I have nothing to do with disability, I only had a burnout, I just need a bit of time to get over it’.” Ivana (in a retraining program in the administration sector, 34) confirms that having to be confronted with DI put her social worth into question, “It did not sit well with me. I felt useless.... It seemed like I was worth not quite nothing, but almost.” Frequently described through descending spatial metaphors (i.e. falling, tumbling down, falling back, landing), this repositioning, sometimes brutal, to a lower rung on the social ladder carries with it a powerful symbolic charge. As Probyn (2005) emphasized, the shame that is derived from it, “puts one’s self-esteem on the line and questions our value system” (p. x).

But entering into contact with DI is also an encounter with a locus of state power (Bourdieu, 2014). The official instances with its agents acting on behalf of the state hold the monopoly of providing titles, categorizing and judging, and thus consecrating and maintaining the symbolic and social order. People know that they are confronted with an institution, that alone, is endowed with the power of placing them on a disability scale. They also understand that this encounter will have a lasting influence on their social position and may—or may not—give them access to certain social services and financial support without which their basic quality of life would be threatened.

Potential recipients of DI are at a double disadvantage in this confrontation. Firstly, they have no choice, in view of their new position in terms of work capacity, but to turn to DI in order to obtain the means to survive outside the labor market—a pension from DI can enable a person to reach minimum income levels—or to regain an earning capacity through rehabilitation measures. “Now well, I am required to do it ... I just have to,” states Ivana (in a retraining program in the administrative sector, 34). As Brigitte (intern in a secretarial pool, 55) points out, “Nobody wants to be on DI ... it’s part of a treatment, like insulin if [we] have diabetes.” Secondly, DI applicants are systematically made to feel that they are individuals deprived of power facing an institutional system. For instance, the classifications used by DI are not communicated to them, and barely explained. The letters from DI are written in legal

jargon and other obscure language terms. Also agents change, and offices are difficult to get a hold of on the phone. Marie (waiting for a DI decision, 48) describes how her shame has built up, “Since 2012, there’s no one there. Nobody is in charge of my file.... And that’s really terrible. You feel that you don’t exist anymore. You aren’t good for anything.”

Over and above the concrete confrontation with state power, going to the DI office signifies, for our interviewees, the institutional confirmation of their drifting away from standards of normalcy. It means losing the status of an ‘adult involved in productive work,’ and thus no longer being able to consider oneself independent, capable and endowed with the physical and mental capacities that enable one to meet the requirements of the labor market. While being dependent on an employer is perceived as ‘normal,’ financial ‘dependency’ on the state brings with it feelings of shame and a sense of rejection by society as a whole (Fraser & Gordon, 1994; Young, 2003). This difference probably stems from the fact that whilst DI can exempt an individual of working age from the requirement of being employed through the provision of a pension, it simultaneously institutes a status experienced as being of lesser social value. As Jérôme (in training as a salesperson, 46) puts it, it is “a bit difficult to say right, now you’re on DI, that you are ... lowered a bit if you want.” Brigitte (intern in a secretarial pool, 55) points out that, “to find oneself there, on DI, it’s horrible,” while Marie (waiting for a DI decision, 48) explains, “When I see myself now, nobody could imagine I was a nurse.... Can you imagine how low I have fallen? It’s terrible.” Hence, exemption from the requirement to be employed, granted when one is awarded the status of DI pension recipient, is not experienced as freedom from the constraints of the work world, but as a sad fate. Jean, 48, who previously worked as a nurse’s aide and is now a DI pensioner, states it clearly:

I was very upset when they put me on full disability benefit. I was angry.... [The DI agent] explained that it was for my own good ... and ... that there was no shame in it.... He doesn’t realize how it can weigh on my children ... labels, they stick ... labels can be very heavy.

Moreover, this social repositioning is tied to shame because dealing with DI also involves a complex process of exposure. During the course of the DI inquiry, individuals must demonstrate that their health impairments diminish their earning capacity. Having to present oneself through one’s limitations is a source of shame. This is for example the experience that Helmut (waiting for a DI decision, 25) talks about:

I really explained everything to [my DI counselor], everything, all of it, all of it. And even that in order to be at the office at 8 am, I have to get up at 5 am.... I explained to him what I have to do to go the bathroom, when one is half paralyzed you can’t go the toilet in 5 minutes, it takes 40 minutes every morning. It was a bit embarrassing to talk about it ... that I had to massage my abdomen to stimulate my intestinal tract.

Under the scrutiny of the medical gaze, Helmut’s body is measured in terms of efficiency. The disabled body has been socially constructed as monstrous, excessive, contaminated, malign and helpless (Davis, 1995; Mitchell & Snyder, 2000; Shildrick, 2002), and applicants are

forced to identify with that ‘disabled body’ and expose it in order to be eligible for DI benefits. The act of describing and acknowledging the ways in which their activity is constrained by their physical or mental state force people confronted with assessment instruments to objectify their bodies and re-construct themselves as disabled (Reeve, 2012). Moreover, those state redistributive policies contribute to the construction of the body as ‘abnormal,’ deviant and shameful because the disability certification processes are based on a classification of bodies as ‘productive’ on the one hand and ‘unproductive’ and therefore ‘risky’ on the other. A person with disabilities’ work capacity is assessed by the extent to which they diverge from the reference point of the ‘normal’ or ‘ideal’ body defined by social policies. Such processes are an integral part of the conception and implementation of social policies founded upon identifying, categorizing, measuring and eliminating the ‘abnormal.’ However, as eligibility criteria have narrowed over the last fifteen years in the context of austerity narratives, such as in the United Kingdom (Goodley, Lawthom & Runswick-Cole, 2014), participants’ obligation to prove that their bodies are unproductive and diverge from the norm has been exacerbated.

This identification to a dominated status in a system that places value on abilities has multiple consequences because it can affect one’s capacity to play other social roles, for instance those associated with being a parent or conforming to male gender roles. Olivier (special-needs technical instructor, 46) describes what was left of his ability to be a desirable partner:

I was 28 when I started to collect a DI pension ... not married, I thought: ‘But wait, what woman is going to fall in love with me?’ ... I brought myself down right off the bat with ideas like, ‘... You are washed up, you are of no value now.’

In the 27 interviews we conducted, we heard similar references to the first dimension of the register of shame: the assignment to a social position perceived as lower. As we emphasized in the theoretical part of the present article, this perceived social ‘demotion’ also refers to a sense of having deviated from a life course viewed as normal. Beyond this, however, our data shows that this dimension is also connected to the power held by the state to categorize individuals, and to the ways in which state agents carry out this task. It is thus, a reaction to the subordinate position to which individuals are assigned.

The Second Dimension of Shame: Social Judgment

The second dimension of the register of shame, referred to in 20 of the interviews, pertains to the ubiquitous discourse about the abuse of DI benefits we mentioned earlier. Aline (child-care center assistant, 32), for example, says that when she contacted DI, she was “guilt-tripped.” Sonia (DI pensioner, 46) explains “to have this feeling: yes, I am dishonest, I’m taking advantage of the system. Yes, to be a crook,” just like Ivana (in retraining in the administrative sector, 34), who has, “this feeling that people are looking at you in a slightly weird way. You have this feeling that you are, like, a profiteer.” Martine (nurse, 47) brings up a similar experience, “Well now, I arrived in Switzerland in 2013, I found myself having a burn-out, and there, here I am on DI... But what are they going to think about me?” These

experiences result from the state's moral framings of people with disabilities as defrauding the welfare system as mentioned at the beginning of this paper. The conduct on which that rhetoric about abuses focuses is dishonesty, as it pinpoints behaviors such as dissimulation of relevant elements and simulation, in aid of a supposed lifestyle choice of idleness. It is thus, not very surprising that our interviewees express the shame they feel to be suspected of belonging to such a group.

Further, just like the individuals interviewed by Chase and Walker (2013), the persons we met do connect their feelings of shame with the shaming practices they have had to undergo in various social contexts. As Yann (DI pensioner, 24) explains, "Right away we are labelled as profiteers and all that, as leaches on society." For Gabriel (communication manager, 41), "If you say 'DI' ... the suspicion of abuse ... is pretty strong." Antonio (special-needs technical instructor, 36) expresses a similar opinion, "You quickly get to prejudices, it quickly becomes short-cuts: 'Ha, you're on DI? You don't want to do anything then!'" Aline (child-care center assistant, 32) states that she has been "labelled as lazy."

The shaming of DI recipients is largely based on challenging the impact of the health problems they are experiencing on their work capacity. Mario (in training as a building-site manager, 56) talks about what he went through as follows, "People, they don't believe you. Right away, the guy who wants to be on DI, he doesn't want to do anything!... Even my girlfriend ... didn't believe me." Thus, discourses sometimes go as far as questioning the very existence of the illness, particularly in the case of psychological impairment. For some people, this questioning takes the form of attributing responsibility for the illness to the DI recipients themselves, "When you suffer from mental illness, it's almost as if you are responsible for what happened to you" (Dominique, bookstore employee, 43). The DI process itself confronts applicants with a similar attitude, in which individuals have to prove that the health impairments they are experiencing affect their work capacity—even the opinion of their doctor about their illness can be challenged by DI experts. Probably in reaction to this social judgment, our interviewees frequently felt the need to stress the genuine character of the health problems from which they suffer.

The people we encountered also used other strategies of self-presentation during the interviews, which could be seen as attempts to become a subject again. One such strategy we observed involves demonstrating awareness of the social solidarity on which the benefits they are receiving—financial or in the form of programs financed by DI—are founded, since DI is financed by taxes. Individuals say they feel they "owe" (Laurent, in training as a salesperson, 45) or that they have "a debt" (Pierre, social care worker, 50). If this posture—humble and grateful—recalls the historical image of the 'worthy poor' mentioned above, it also provides a way to become a subject who is capable of analyzing and interpreting his or her position in the world. A second strategy is founded upon attempting to distinguish oneself from the group of 'benefit abusers' through one's active participation in feeding the discourse about abuses. Jérôme (in training as a salesperson, 46) best illustrates this situation when he states:

If people need it, if they really can't work anymore ... and they get a DI pension, that's

OK but people who can work and who get on to DI, who are always trying to get on it, to get benefits and then to do nothing afterwards, I don't find that normal.

This distinction strategy entails an enunciation of the truly disabling character of the speaker's own health impairment. Florent (bank employee, 60) explains that, "without trying to profit from it, because that's not at all the kind of thing I would do ... it's a recognition, actually, of my work incapacity that's taking place now."

In daily life, the shame of being labeled as a profiteer leads some of our interviewees to resort to passing by concealing their status (Cooper 2016; Siebers, 2004). They do not mention the fact they are DI applicants or recipients. Carlos (mechanic, 26) explains it as, "[People] often would ask me: 'Yes but what are you up to? What are you looking for?' And most times I would lie, I would say: 'I'm looking for work.'" Gabriel (communication officer, 41) says, "I still had a contract with my employer ... I could use a bit of a ruse, say I still had a contract ... that made it easier to conceal the DI side of things, let's say. At the same time, it's rather hard to say 'to conceal'."

Yet being a DI recipient is not only shameful because of the discourse about abuses of the social security system, it also carries shame because of the ableist social norms (Campbell, 2009; Goodley, 2014) that prevail in contemporary societies. The fear of being judged as disabled or perceived as sick and incapable becomes combined with that of being labeled as a profiteer. For instance, Aline (child-care center assistant, 32) and Martine (nurse, 47) explain that they did not disclose the fact that they had received benefits from DI when they looked for work compatible with their state of health, because they feared they would not be deemed 'competent.'

In this context, interviewees who tell us that they have learned to "accept" their status and that they no longer feel shame are those who are able to successfully justify being a DI recipient. This means that they have accepted—at least for a time—their disability status. Brigitte (intern in a secretarial pool, 55) explains:

I'm not saying I'm happy about it, not at all. But I told myself: 'But actually, it's social insurance, I paid into it.... It's a disability I have, it's a frailty.'... You have to learn to accept you own limitations.

Aline (child-care center assistant, 32) states that, "I tell myself: 'OK, I can't anymore.'... That's what the system is there for." Yet, this acceptance process is fraught with difficulties, as Jean-Michel (quality control agent, 56) states, "In the beginning it was difficult ... I had to work on my own self.... You have to admit that you can be tired, that others won't see you the same way anymore." A few people, like Paul (social worker, 33), take on a more provocative stance, that also reflects that accepting this status requires overcoming some resistance, "Now I say it with pride.'... 'I have just gone through DI, so what?'"

As Despret (2005) suggests, emotions "are a way through which we negotiate our relationship to ourselves, to the world, and to others" (p. 283) and our interviewees' discourse

about shame is a clear illustration of this point. Our data also highlights some of the mechanisms of the social production of inferiority, particularly the fact that being made inferior causes resistance. The ways in which participants in this study referred to the register of shame thus not only reflect a process of internalizing one's own social position, in Pierre Bourdieu's words quoted earlier, but may also constitute an attempt to counter the degradation of one's social status by becoming a subject again.

The Third Dimension of Shame: The Mirror-Effect

When they have been involved in DI rehabilitation programs within the context of professional retraining (i.e. internships, training for a new occupation) or preparing to retrain via work preparedness measures, 15 interviewees brought up a third dimension of the register of shame. This dimension is associated with the concept of vocational rehabilitation implemented by DI, particularly within the context of encounters with other persons taking part in rehabilitation measures. In their interactions, while taking part in such measures, they must confront what we call a mirror-effect, which gives concrete expression to their sense of deviating from ableist norms.

This effect is first of all related to the impression of going back to a previous stage of one's life, as Mario (in training as a building-site manager, 56) explains, he finds it difficult to "go back to sitting in school with 19-year olds." Marie (waiting for a DI decision, 48) states, "Can you imagine? I've had to take written arithmetic tests. Just like the kids, they made me do grammar." Sonia (DI pensioner, 46) also expresses her revolt against these requirements, "You can't ask a person ... 45 years old, with at least 20 years of professional experience, to go back to regular school, to take a leap backwards of 20 years." These persons thus experience not a mere deviation from a norm but a form of regression within their life-course, a step backward in the hierarchy of ages.

Indeed, this "leap backwards" Sonia talks about is not merely temporal; it also pertains to status. It is a return to the status of 'trainee.' We must bear in mind that age is not a natural category or a mere item of classification but a social relationship (Jenny, 1995; Perriard, 2017). Social norms are closely associated with age groups instituted by the State and governing the relationship to employment, i.e. to the dominant norm for individuals between 25 and 64 years of age in Switzerland. Within a standard life-course, comprised of a sequence from childhood, to education or training, to employment and then to retirement:

The dominant position is occupied by the person in employment, ... other social positions being conceptualized on the basis of this dominant position: for children and youth, it is a goal to be attained later; retirement benefits are justified because one has previously occupied it (Tabin & Perriard, 2014).

The dominant position of 'adult worker' confers status, authority, money and (a relative) autonomy. The rehabilitation process brings this position into question, relying as it does on training and education, which people see as corresponding to an earlier phase of the standard life-course.

The inferiority of their new status is confirmed by the description of the interactions with DI. Brigitte (intern in a secretarial pool, 55) explains it this way:

What was a bit difficult as well, was to tell myself I was an intern at 55 after having worked for 38 years. Intern, and not to be able to go to a job interview by myself.... It is a [DI] coach that goes along with us.

Attributes associated with adulthood, such as autonomy, are brought into question in the context of vocational rehabilitation. Julie (commercial employee, 27) describes it as “infantilizing,” with agents assessing activities carried out and saying things like, “‘Right, that’s good. This isn’t quite as good. You should do it like so.’ And that, it didn’t sit well with me.... It’s really this aspect that is a bit infantilizing sometimes. Others are speaking for me.” In her case, an assessment had to be filled out that included a question about “appearance and personal hygiene.” Here, Julie’s feeling of shame is derived from being assessed on competencies that have to do with basic education, and are thus associated with child-rearing.

The mirror-effect is also a function of finding oneself in contact with other individuals defined as needing rehabilitation. Their situations are often seen by our interviewees as impossible to compare to theirs, and they try to distinguish themselves from them. Laurent (in training as a salesperson, 45) thus explains that he spent some time in a structure that was “for drug-addicts and all those kinds. But me, I was there because I had to get myself together and because I was on pretty strong medication after my burn-out ... it wasn’t easy.” Carlos (mechanic, 26) says, “The sheltered workshops they were proposing to me ... people there were having a lot more difficulties than me, they were in wheelchairs.... Why did they want to put me in there?” and Marie (waiting for a DI decision, 48) puts it this way, “I found myself with people, asylum seekers and unemployed people, who did not give a shit about being there.” The mirror-effect causes shame and is a site of resistance for persons trying to counter stigmatic associations with sickness and bodies that deviate from a norm. But the negative views of ‘other’ people are also aimed at distancing oneself from them.

The mirror-effect may also be associated with the activities included in these programs. Our interviewees mentioned tasks such as “sorting used clothing, can you imagine your self-esteem after all that?” (Marie, waiting for a DI decision, 48), or activities viewed as meaningless and without any use, “It was really a waste of time.... The whole week you sat in front of a computer supposedly to learn how to use it a bit.” (Mario, in training as building-site manager, 56).

While they were involved in rehabilitation programs, our interviewees thus experienced various types of deviations from normalcy. Examples ranged from discrepancies in terms of the ‘normal’ age for being in training, to mismatches with other participants in the program and to the—in their view—inappropriate nature of activities proposed within the programs. The way interviewees refer to shame therefore appears, especially when displaying the mirror effect dimension, to be an attempt to regain the status of subject.

Does it challenge classification schemes? When our interviewees express their

criticism of the actions of DI and their resistance to the classifications made by DI agents, we interpreted their discourse as a way of trying to reconstruct themselves as subjects. But it also reflects an internalization of “the ideology of ability”, as Siebers (2011, p. 8) calls it, or internalized ableism (Campbell, 2008), because of the way in which recipients distance themselves from others that they define as “more disabled,” “more sick,” or belonging to other subordinated social groups (i.e. asylum seekers, unemployed people).

Conclusion

Our discourse analysis has shown that persons whose work capacity is challenged by an impairment spontaneously refer to shame, supporting the results of previous scientific studies highlighting the role played by shame in the reproduction of social hierarchies. Our results confirm the central social value of work capacity and show that shame functions as a force that maintains social divisions.

A more detailed analysis brings to light that shame comes in a variety of shades. In some cases, shame is experienced in reference to the new social position to which individuals are assigned; it is thus linked to the way they experience their contacts with DI. Shame stems from the ableist hierarchy that compels persons to interiorize a status defined as inferior, that of disabled person or of person at risk of being labeled disabled, in order to be eligible for benefits. In other cases, shame is associated with the fear of social judgment. Since moral discourse about abuses tends to generalize the suspicious manner in which the disabled people are viewed, shame in this case is also the result of an actual shaming process. Finally, shame may be a consequence of the mirror-effect resulting from involvement in rehabilitation programs. It is then associated with discrepancies with standards of normalcy—be it the ‘normal’ age for being a trainee, the confrontation with other individuals deemed incapable of working, or the type of tasks to be carried out—and it becomes concrete proof of the mismatch they perceive with regard to ableist dominant norm.

However, shame is not merely a negative emotion, the antonym of which would be pride. Our analysis of the ways in which shame is defined, nuanced and referred to in participants’ discourse enables us to bring to light more complex uses of that emotion, and to see them for example as possible strategies for association with the dominant group – i.e. that of persons able to work. Unlike individuals involved in collective action such as *Disability Pride* in the German-speaking regions of Switzerland (see *Disability Pride Zurich*, n.d.), the persons we met do not directly challenge ableist hierarchies when they refer to shame. Rather, they displace meanings attached to disability, and highlight the violent character of identity reassignments stemming from dealings with DI. The way they refer to shame may thus be considered as part of a process in which they realize that no individual should be seen as inferior because s/he is defined as disabled or at risk of becoming disabled. Shame then takes its place in the dual register of emotions described by Despret (2005), “of what we make and of what makes us” (p. 244). Shame, among other emotions, “then actively participates in the creation of the social world” (Despret, 2005, p. 246), and can therefore perhaps be considered a force contributing to a reconfiguration of normalcy.

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References

- Ahmed, S. (2004). *The cultural politics of emotion*. Edinburgh: Edinburgh University Press.
- Baker, H. (2013). The significance of shame in the lives of women who experience male violence. *Liverpool Law Review*, 34, 145–171.
- Barrett, T. (2018). Bourdieu, hysteresis, and shame: Spinal cord injury and the gendered habitus. *Men and Masculinities*, 21(1), 35–55.
- Biddle, J. (1997). Shame. *Australian Feminist Studies*, 12(26), 227–239.
- Bourdieu, P. (2000). *Pascalian meditations*. Stanford: Stanford University Press.
- Bourdieu, P. (2001). *Masculine domination*. Stanford: Stanford University Press.
- Bourdieu, P. (2014). *On the State: Lectures at the Collège de France, 1989–1992*. Cambridge: Polity Press.
- Bourdieu, P., & Delsaut, Y. (1975). Le couturier et sa griffe: Contribution à une théorie de la magie. *Actes de la recherche en sciences sociales*, 1(1), 7–36.

- Campbell, F. K. (2008). Exploring internalised ableism using critical race theory. *Disability & Society*, 23(2), 151–162.
- Campbell, F. K. (2009). *Contours of ableism. The production of disability and abledness*. Basingstoke: Palgrave Macmillan.
- Castel, R. (2003). *From manual workers to wage laborers: Transformation of the social question*. New Brunswick, New Jersey: Transaction.
- Chase, E., & Walker, R. (2013). The co-construction of shame in the context of poverty: Beyond a threat to the social bond. *Sociology*, 47(4), 739–754.
- Clough, P. T., & Halley, J. (Eds.). (2007). *The affective turn: Theorizing the social*. Durham: Duke University Press.
- Conseil fédéral. (2017). Révision de la loi fédérale sur la partie générale du droit des assurances sociales (LPGA). Rapport explicatif relatif à l'ouverture de la procédure de consultation. Retrieved from www.bsv.admin.ch/bsv/fr/home/publications-et-services/gesetzgebung/vernehmlassungen/revision-atsg.html
- Cooper, H. (2016). Passing or trespassing? Unseen disability, containment and the politics of “feeling like a fraud” in a neoliberal bureaucracy. In R. Mallett, C. A. Ogden, & J. Slater (Eds.), *Theorising Normalcy and the Mundane: Precarious Positions* (pp. 120–143). Chester: University of Chester Press.
- Creed, D., Hudson, A., Okhuysen, G. A., & Smith-Crowe, K. (2014). Swimming in a sea of shame: Incorporating emotion into explanations of institutional reproduction and change. *Academy of Management Review*, 39(3), 275–301.
- Davis, L. J. (1995). *Enforcing normalcy: Disability, deafness, and the body*. London: Verso.
- de Gaulejac, V. (1996). *Les sources de la honte*. Paris: Desclée de Brouwer.
- Despland, B. (2012). L'obligation de diminuer le dommage en cas d'atteinte à la santé. Son application aux prestations en espèces dans l'assurance-maladie et l'assurance-invalidité, Analyse sous l'angle du droit d'être entendu. Genève-Zurich-Bâle: Schultess.
- Despret, V. (2005). *Ces émotions qui nous fabriquent. Ethnopsychologie de l'authenticité*. Paris: Les Empêcheurs de penser en rond/Le Seuil.
- Disability Pride Zurich. (n.d.). Retrieved on May 24, 2018 from <http://disability-pride.ch>
- Driessens, K. (2010). La relation entre intervenants sociaux et personnes vivant dans la pauvreté. Affronter l'exclusion et la dépendance. *Pensée plurielle*, 25(3), 91–105.
- Federal Statistical Office. (2019). Retrieved August 7, 2019, from <https://www.bfs.admin.ch/bfs/fr/home/statistiques/travail-remuneration/activite-professionnelle-temps-travail/personnes-actives/taux-activite.assetdetail.8226404.html>
- Ferreira, C., & Frauenfelder, A. (2007). “Y en a qui abusent...”. Identifier, gérer et expertiser

- des ayants droit de la politique sociale. *Carnets de bord en sciences humaines*, 13, 3–6.
- Fraser, N., & Gordon, L. (1994). A Genealogy of dependency: Tracing a keyword of the U.S. welfare state. *Signs*, 19(2), 309–336.
- Fullagar, S. (2003). Wasted lives. The Social dynamics of shame and youth suicide. *Journal of Sociology*, 39(3), 291–307.
- Geremek, B. (1987). La potence ou la pitié. L'Europe et les pauvres du Moyen Âge à nos jours. Paris: Gallimard.
- Glaser, B. G., & Strauss, A. L. (1967). *The discovery of grounded theory: Strategies for qualitative research*. New Brunswick and London: Aldine Transaction.
- Goffman, E. (1959). *The presentation of self in everyday life*. New York: Doubleday.
- Goodley, D. (2014). Dis/ability studies: Theorising disablism and ableism. London: Routledge.
- Goodley, D., Lawthom, R., & Runswick-Cole, K. (2014). Dis/ability and austerity: Beyond work and slow death. *Disability & Society*, 29(6), 980–984.
- Goodley, D., Liddiard, K., & Runswick-Cole, K. (2018). Feeling disability: Theories of affect and critical disability studies. *Disability & Society*, 33(2), 197–217.
- Gorton, K. (2007). Theorizing emotion and affect: Feminist engagements. *Feminist Theory*, 8(3), 333–348.
- Hughes, B. (2015). Disabled people as counterfeit citizens: The politics of resentment past and present. *Disability & Society*, 30(7), 991–1004.
- Jenny, J. (1995). Rapports sociaux de sexe et autres rapports de dominance sociale: pour une intégration conceptuelle des rapports sociaux fondamentaux. *Cahiers du GEDISST*, 13, 109–130.
- Lordon, F. (2013). La société des affects. Pour un structuralisme des passions. Paris: Éditions du Seuil.
- Loveday, V. (2016). Embodying deficiency through “affective practice”: Shame, relationality, and the lived experience of social class and gender in higher education. *Sociology*, 50(6), 1140–1155.
- Mitchell, D. T., & Snyder, S. L. (Eds.) (2000). *The body and physical difference. Discourses of Disability*. Ann Arbor: University of Michigan Press.
- Moore, A. (2016). Shame on you: The role of shame, disgust and humiliation in media representations of “gender-fraud” cases. *Sociological Research Online*, 21(2), 1–18.
- Munt, S. R. (2008). Queer attachments, the cultural politics of shame. Aldershot: Ashgate.

- Organisation for Economic Co-operation and Development (OECD). (2009). *Sickness, Disability and Work. Keeping on Track in the Economic Downturn*. Retrieved from www.oecd.org/els/emp/42699911.pdf
- Parker Harris, S., Owen, R., Fisher, K. R., & Gould, R. (2014). Human rights and neoliberalism in Australian welfare to work policy: Experiences and perceptions of people with disabilities and disability stakeholders. *Disability Studies Quarterly*, 34(4).
- Perriard, A. (2017). Les figures de la dépendance problématique des adultes: analyse intersectionnelle des politiques sociales liées à l'âge et à l'emploi dans le canton de Vaud (Doctoral dissertation). Retrieved from https://serval.unil.ch/notice/serval:BIB_24217351A7FB
- Pires, A. (1997). Échantillonnage et recherche qualitative: essai théorique et méthodologique. In J. Poupart, J.-P. Deslauriers, L.-H. Groulx, A. Laperrière, R. Mayer, & A. Pires (Eds.), *La recherche qualitative. Enjeux épistémologiques et méthodologiques* (pp. 113–169). Montréal: Gaëtan Morin.
- Probst, I., Tabin, J.-P., & Courvoisier, N. (2015). De la réparation à la réversibilité. Un nouveau paradigme dans l'assurance invalidité? *Revue Suisse de Sociologie*, 41(1), 101–117.
- Probst, I., Tabin, J.-P., Piecek-Riondel, M., & Perrin, C. (2016). L'invalidité: une position dominée. *Revue Française des Affaires Sociales*, 4(8), 89–105.
- Probyn, E. (2005). *Blush: Faces of shame*. Minneapolis: University of Minnesota Press.
- Reeve, D. (2012). Psycho-emotional disablism: The missing link? In N. Watson, A. Roulstone, & C. Thomas (Eds.), *Routledge Handbook of Disability Studies* (pp. 78–92). London and New York: Routledge.
- Sassier, P. (1990). Du bon usage des pauvres, histoire d'un thème politique, XVIIe-XXe siècle. Paris: Fayard.
- Scheff, T. (2000). Shame and the social bond: A sociological theory. *Sociological Theory*, 18(1), 84–99.
- Sedgwick, E. K. (1993). Queer performativity: Henry James's the art of the novel. *GLQ: A Journal of Lesbian and Gay Studies*, 1(1), 1–16.
- Shildrick, M. (2002). *Embodying the monster: Encounters with the vulnerable self*. London: Sage.
- Siebers, T. (2004). Disability as masquerade. *Literature and Medicine*, 23(1), 1–22.
- Siebers, T. (2011). *Disability theory*. Ann Harbor: The University of Michigan Press
- Skeggs, B. (1997). *Formations of class & gender: Becoming respectable*. London: Sage.
- Skeggs, B. (2004). *Class, self, culture*. London and New York: Routledge.

- Stiker, H.-J. (2005). *Corps infirmes et sociétés: essais d'anthropologie historique*. Paris: Dunod.
- Tabin, J.-P., Frauenfelder, A., Togni, C., & Keller, V. (2010). *Temps d'assistance. Le gouvernement des pauvres en Suisse romande depuis la fin du XIXe siècle*. Lausanne: Antipodes.
- Tabin, J.-P., & Perriard, A. (2014). Le rapport social d'âge dans les politiques sociales. *Revue Interrogations*, 19.
- Titchkosky, T. (2001). Disability: A Rose by Any Other Name? "People-First" Language in Canadian Society. *Canadian Review of Sociology*, 38/2, 125–140.
- Walker, R. (2014). *The Shame of Poverty*. Oxford: Oxford University Press.
- Weiss, K. G. (2010). Too ashamed to report: Deconstructing the shame of sexual victimization. *Feminist Criminology*, 5(3), 286–310.
- Yates, S., & Roulstone, A. (2013). Social policy and transitions to training and work for disabled young people in the United Kingdom: Neo-liberalism for better and for worse? *Disability & Society*, 28(4), 456–470.
- Young, I. M. (2003). Autonomy, welfare reform and meaningful Work. In E. F. Kittay & E. K. Feder (Eds.), *The Subject of Care. Feminist Perspectives on Dependency* (pp. 40–60). Lanham: Rowman Littlefield.

Endnotes

1. Like the American Social Security Disability Insurance and the Vocational Rehabilitation system.
2. In accordance with the editorial policy, the authors we use the term "people with disabilities," i.e. people-first phraseology (for a discussion, see Titchkosky, 2001). The authors would like to point out that some interviewees emphasize that they do not conceive of themselves as people with disabilities.
3. In this article we use interchangeably the terms affect and emotion (for a discussion see Goodley et al. (2018) and Gorton (2007)).
4. See <http://p3.snf.ch/project-156131>
5. In order to ensure anonymity, fictitious names have been used. The occupations indicated are those the interviewees practiced at the time of interview.



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Disability and Shame Special Issue Forum: Creative Works

An Everyday Situation

Anna Faroqhi

Germany

Abstract: *An Everyday Situation* is a short fictional story about an awkward situation in a subway train.

Keywords: Invisible Disabilities; Embracing Disability; Everyday Situation; Shame

Figure 1. An Everyday Situation, Anna Faroqhi, April 2019



Image Description (left image): An illustration of a crowded subway car. Everyone is occupied with themselves. A woman with a hat is standing in the aisle. Her legs are trembling. Her standing position and shades of red on her coat in the monotone blue-grey of the image mark her as different from the rest of the crowd. Included with the illustration is text, “When to feel more ashamed? When being ignored in a crowded subway train—”

Image Description (right image): An illustration of a crowded subway car. A passenger offers the woman her seat. The entire figure of the woman is drawn in red and now contrasts sharply with her surroundings. A yellow light between the friendly lady and the embarrassed protagonist symbolize that a more significant emotion than shame might develop here. Included with the illustration is text, “---or when you offered a seat?”

Imagine the following situation: you are well into your third week after chemotherapy. The deepest exhaustion is over, the body has already removed a lot of the healing poison and you are on your way to pick up your daughter from school after one of your many medical appointments. As usual, the subway is fully occupied during the after-work hours. There are no free seats left and you have to remain standing in the aisle. The train continues and then you feel it – the weakness that makes your legs tremble with exhaustion. It's been hitting you

more often lately, probably because of the rapid ups and downs of physical processes. You wish for nothing more than for a seat.

Alas! everyone sitting on the benches around you seem to be deep in their own worlds or older in age than yourself. Some of them seem not too stable on their legs themselves, others are packed with bags and groceries. And so you stand there, with your trembling knees and a sinking feeling in your stomach. How desperately would you like to sit down now, indulge the weakness and finally rest? But also, how gladly have you remained invisible among all those people who seem to have a simpler life?

This is what shame feels like. You look like a healthy person, whereas you are not. You want to follow the needs of your body and fear not to do so. Illness, neediness might become visible. You might become visible in a way you do not want to see yourself.

And suddenly there is this woman. She looks tired, maybe from a long day in an office. Friendly and attentively, she offers you her seat.



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Disability and Shame Special Issue Forum: Creative Works

Ann's Scan

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Abstract: The painting, *Ann's Scan*, is a small printed image of one of my brain scans following a Traumatic Brain Injury. The painting includes a plastic glove on the upper right corner and streaks of various colors descending from the glove and on to the brain image.

Figure 1. Ann's Scan, 12 x 12 in., mixed media on canvas, 2018



Image Description: This is a square 12 x 12 in. stretched canvas composed of mixed media. In the upper right-hand corner rests a translucent plastic glove that I scavenged from a box of hair dye. Included is a fragment of scrapbook paper patterned with interlocking butterflies with pale aquamarine and salmon hues nestled or hidden inside this mounted, opaque glove. I angled the paper at 45 degrees with the fingers pointing toward a printed image of one of my post-traumatic brain injury scans, which I highlighted with rose-colored paint on the eyes, nose and smile. Luminescent scarlet and blueberry acrylic-paint bursts and drips diagonally through the fingertips of the glove, descending into the space and gathering to cocoon this rosy, egg-shaped and stylized head. The painting is off-center, adorned, and appears to be buoyantly bouncing.

I want the viewer to imagine the streaks of paint escaping, enacting, and altering the problematic medical gaze. I am a congenital amputee who lives, works, writes, and paints with and about the consequences of surviving a Traumatic Brain Injury (TBI). This canvas

frames the simultaneous visual pleasure, empathy, repulsion and horror that a viewer may experience, once they know the details about my history. Understanding and accepting the shame I often felt during my recovery inspires me to aestheticize my trauma and emotional/corporeal pain. Shaming is a targeted act, yet it reverberates. Shame feels imposing, abstract and indescribable, and in this work, I attempt to confront it. I materialize shame to communicate that it is never to ‘overcome,’ by the mind nor the body, but that shame can inspire transformation.

Ann Millett-Gallant, Ph.D., serves as Senior Lecturer for the University of North Carolina at Greensboro, by designing and teaching online art history, visual culture, and liberal studies courses. Her research bridges the disciplines of Art History and Disability Studies. Her books include *The Disabled Body in Contemporary Art* (2010); *Re-Membering: Putting Mind and Body Back Together Following Traumatic Brain Injury* (2016); and *Disability and Art History*, co-edited with Dr. Elizabeth Howie (2017). She has also published essays and reviews of art and film, and she enjoys painting and composing mixed-media collages.



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Disability and Shame Special Issue Forum: Creative Works

Courage to Write Out my LD ShAMe

David Isaac Hernández-Saca, PhD
University of Northern Iowa
Iowa, United States

Abstract: The poem, *Courage to Write Out my LD shAMe*, is the second of five Learning Disability poems about my Learning Disability shame at my intersections of power and identity in educational contexts as critical autoethnographic texts.

Courage to Write Out my LD ShAMe

Courage to write out my LD shAMe
How can I just write?
How can I just write, when fear holds my throat tight from the shAMe
Courage?
Words
Society
Language
Social interactions
All felt through an ableist lens and I am triggered

No more attachment to LD shAMe
We are not what culture, history, policy, literature, schools, teachers, students or even our
demons, fear says we are
How do I transform? Where is my LDis/ability Pride?

What is LD pride?
What does it feel like?
What does it sound like?
What does it look like?
Where is my LD pride?

David I. Hernández-Saca, PhD, is an assistant professor at the University of Northern Iowa and the nucleus of his research agenda is problematizing the common sense assumptions of what learning disabilities are as it relates to the following lines of research: 1) the emotional impact of learning disability labeling on conceptions of self; 2) the role of emotions and affect in teacher learning about social justice issues, and 3) transition plans and programming for historically marginalized youth with disabilities at their intersections and their families. Lastly, Dr. Hernández-Saca examines violence within the academy against historically multiply marginalized and non-hegemonic scholars at their intersections of power and identities for their wellbeing and healing.



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Disability and Shame Special Issue Forum: Creative Works

Liminality

Lisa Boskovich, MS
Chapman University
California, United States

Abstract: The shame surrounding the construct of disability strikes at the very context of an individual's soul. The overcoming of shame associated with a learning disability diagnosis is a journey. To be free requires the inner looking into the core of self, once viewed and acknowledged healing enters. In this journey the individual is held by hands greater than their own. The path of healing is an individual passage and choice.

Liminality

Wraps the tide,
Passing through my fingertips.
Slowly and gently,
After weeks,
Of rough seas,
Hard fought dreams,
And mixed memories.
Drought filled,
Writing weeks,
And cried tears.
This gray state,
Continues to challenge,
Sweeping past,
Inner victories,
And passed over notions,
Of grace handed,
And grace received.
For the foundation of self,
Ever is it changing.
Invited guests,
Challenge the circumference,
Of an ever- widening circle.
My soul calls,
Home.

Lisa Boskovich, M.S., is a Doctoral Candidate in the Donna Ford Attallah College of Educational Studies at Chapman University in Orange, California with an emphasis in Disability Studies. Her research interests include, fathers who have a child on the autism spectrum, and the phenomenological master narratives of individuals with learning

disabilities. Lisa is currently working as a Research Assistant at the Thompson Policy Institute on Disability and Autism.



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Disability and Shame Special Issue Forum: Creative Works

Out from the Halls

Lisa Boskovich, MS
Chapman University
California, United States

Abstract: The shame surrounding the construct of disability strikes at the very context of an individual's soul. The healing of shame associated with a learning disability diagnosis is a journey. To be free requires the inner looking into the core of self, once viewed and acknowledged healing enters. In this journey the individual is held by hands greater than their own. The path of healing is an individual passage and choice.

Out from the Halls

My voice rises.
Years have passed since,
I heard,
“You have a LD in Perceptual Organization.”
My well-meaning
Community College,
DSPS advisor stated.
My re-entry into education,
After a 12-year absence.
One graph determined,
and too many Tests.
Placed a blanket of Shame around my Soul.
Carried like Chain Mail,
Intertwined,
This new sense of self.
Who I was, prior was Slammed.
Stuck in-between 2 bookends,
Of
Shame and Resolution.
Resolution took another decade,
To heal the brokenness,
I thought I was.
My entrance into:
the rites and rituals,
Of the Academy,
Offered me,
Community,
A sense of belonging.

Hundreds of hours spent with my Mentor,
Over the course of now 7 years,
and continuing.
So many pages of narrative written.
I emerged,
Like the Phoenix,
A Doctoral Candidate.
All My Shame,
IS
GONE

Lisa Boskovich, M.S., is a Doctoral Candidate in the Donna Ford Attallah College of Educational Studies at Chapman University in Orange, California with an emphasis in Disability Studies. Her research interests include, fathers who have a child on the autism spectrum, and the phenomenological master narratives of individuals with learning disabilities. Lisa is currently working as a Research Assistant at the Thompson Policy Institute on Disability and Autism.



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Disability and Shame Special Issue Forum: Creative Works

RELDEASE!

David Isaac Hernández-Saca, PhD
University of Northern Iowa
Iowa, United States

Abstract: The poem, *RELDEASE!*, is the fifth of five Learning Disability poems about my Learning Disability shame at my intersections of power and identity in educational contexts as critical autoethnographic texts.

RELDEASE!

RELDEASE!

RE-EASE!

RE-EASE LD CULTURAL-HISTORICAL AND TRAUMA ENERGY!

RE-**LD**-EASE SHAME!

RELEASE **IT/LD SHAME** BY BEING YOU!

RELEASE **IT/LD SHAME** BY BEING COURAGEOUS!

RELEASE **IT/LD SHAME** BY WRITING YOUR TRUTH, YOUR SPIRIT, YOUR OWN
NARRATIVE ABOUT YOUR ABILITIES AND CAPABILITIES!

RELEASE **IT/LD SHAME** BY REMAKING YOURSELF IN YOUR OWN IMAGE, NOT
THE SOCIAL CONSTRUCTION OF LD, LD EMOTIONS SUCH AS LD SHAME NO
MORE!

FREEDOM!

FREEDOM!

FREEDOM!

FREEDOM FROM LD SHAME OPPRESSION!


RELEASE LD SHAME!

HEAL FROM LD SHAME!

TRANSCEND FROM LD SHAME!

NO MORE LD SHAME = YOU!

David I. Hernández-Saca, PhD, is an assistant professor at the University of Northern Iowa and the nucleus of his research agenda is problematizing the common sense assumptions of what learning disabilities are as it relates to the following lines of research: 1) the emotional impact of learning disability labeling on conceptions of self; 2) the role of emotions and affect in teacher learning about social justice issues, and 3) transition plans and programming for historically marginalized youth with disabilities at their intersections and their families.

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Disability and Shame Special Issue Forum: Creative Works

We Walk Through Corridors

Lisa Boskovich, MS
Chapman University
California, United States

Abstract: The shame surrounding the construct of disability strikes at the very context of an individual's soul. The overcoming of shame associated with a learning disability diagnosis is a journey. To be free requires the inner looking into the core of self, once viewed and acknowledged healing enters. In this journey the individual is held by hands greater than their own. The path of healing is an individual passage and choice.

We Walk Through Corridors

*Passing through Shame,
Only known to self.
Mirrored reflections,
Of who we were,
Of who we are,
and
Who we hope,
We will become.
This Ph.D. Journey,
Lonely is the road,
At times.
Decisions to make,
Fears to face.
It's not the course work,
That's difficult.
It is what the coursework,
Asks of us.
To step outside of our assumptions,
To embrace our fears,
we strive to pass,
and place imposter syndrome,
High upon a shelf,
We can only reach.
Remaining ever hopeful,
The journey will sustain,
Bringing us,
More than the title,
More than the academic hood.*

*That the journey,
Will bring us further,
To the truth of self.
This mirrored reflection,
We call truth.*

Lisa Boskovich, M.S., is a Doctoral Candidate in the Donna Ford Attallah College of Educational Studies at Chapman University in Orange, California with an emphasis in Disability Studies. Her research interests include, fathers who have a child on the autism spectrum, and the phenomenological master narratives of individuals with learning disabilities. Lisa is currently working as a Research Assistant at the Thompson Policy Institute on Disability and Autism.



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Disability and Shame Special Issue Forum: Creative Works

Where is my LD Pride?

David Isaac Hernández-Saca, PhD
University of Northern Iowa
Iowa, United States

Abstract: The poem, *Where is my LD Pride?*, is the third of five Learning Disability poems about my Learning Disability shame at my intersections of power and identity in educational contexts as critical autoethnographic texts.

Keywords: Social Construction of Learning Disabilities; Learning Disability Oppression; LD Emotions; Student Voice; Intersectionality; Critical Autoethnography; Emotionality; LD Shame

Where is my LD Pride?

Where is my LD pride?
Nowhere to be found
Imposed label lead to fear, mistrust, and constant vulnerability
Psycho-emotional disableism constraining my agency

Courage
Courage
Courage
Be courageous to write and let go of LD shAMe

Does writing help me?
Are my poems helping me?
Dark cloud holding me down
Releasing through poems, but seems to come back and feeling the same

Pride = empowerment
Am I empowered?
Why do I not feel empowered with my LD label?
Because my LD label has shattered my sense of self

David I. Hernández-Saca, PhD, is an assistant professor at the University of Northern Iowa and the nucleus of his research agenda is problematizing the common sense assumptions of what learning disabilities are as it relates to the following lines of research: 1) the emotional impact of learning disability labeling on conceptions of self; 2) the role of emotions and affect in teacher learning about social justice issues, and 3) transition plans and programming for historically marginalized youth with disabilities at their intersections and their families. Lastly, Dr. Hernández-Saca examines violence within the academy against historically

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Disability and Shame Special Issue Forum: Creative Works

Who am I as it Relates to LD?

David Isaac Hernández-Saca, PhD
University of Northern Iowa
Iowa, United States

Abstract: The poem, *Who am I as it Relates to LD?*, is the fourth of five Learning Disability poems about my Learning Disability shame at my intersections of power and identity in educational contexts as critical autoethnographic texts.

Who am I as it Relates to LD?

What is my LD knowledge, self, ethics, and origin?
Immigrating to the U.S. crossing the Rio Grande
On top of my brother's shoulder
Cold water, leaving civil war = my family's immigration origin story

Growing up bilingual at home; English only and nation building policy
Erasure of humanity
Erasure of allowing me to be me
LD is nested with our sociology and humanity

However, why this deep seated trauma and LD shAME
LD as double-edged sword
LD emotions experienced as negative
Not considered at my core-a good thing

I am NOT LD
I am NOT LD shAMe
However, broken as if I AM LD SHAME
WHAT A SHAME, NOT ORIGINATED INSIDE ME

David I. Hernández-Saca, PhD, is an assistant professor at the University of Northern Iowa and the nucleus of his research agenda is problematizing the common sense assumptions of what learning disabilities are as it relates to the following lines of research: 1) the emotional impact of learning disability labeling on conceptions of self; 2) the role of emotions and affect in teacher learning about social justice issues, and 3) transition plans and programming for historically marginalized youth with disabilities at their intersections and their families. Lastly, Dr. Hernández-Saca examines violence within the academy against historically multiply marginalized and non-hegemonic scholars at their intersections of power and identities for their wellbeing and healing.



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