

Editorial

An Entry for the Irish Sporting Pages: Remember Susan O'Hara

Megan A. Conway, PhD
RDS Editor-In-Chief

I sat down to coffee with one of my students the other day, started dishing out advice, and realized that I was her mentor. And the scary thing was, she was actually listening to me. Throughout my life I have had the good fortune to know other people with disabilities who I have looked up to and who have given me the strength to persevere when things seemed impossible. Realizing that I have come of an age where I can and should do the same for others is sobering.

Photo below is of Megan and Susan at the DSP Graduation in 1992.



One of my dearest mentors and friends, Susan O'Hara, just passed away this summer at the age of 80. I first got to know Susan thirty years ago when she was Director of the Disabled Students Program (DSP) at UC Berkeley and I was an enthusiastic and overwhelmed Freshman. Susan, a polio survivor, gathered a group of disabled students together on a regular basis to discuss

disability issues on campus and offer advice on how to address them. The advice I remember most is, "What are YOU going to do about it?" She encouraged us to identify specific problems that we all shared, think through solutions, and act collectively on those solutions. It seems cheezey to say this, but Susan "empowered" us. She made us feel like whatever life dished up, we *could* do something about it.

Susan saw the funny side of things that were also unfair or exasperating. A favorite story of mine was her description of first coming to UC Berkeley and visiting the "dorm" for students with severe physical disabilities. Instead of being housed with other students, their dorm was literally a wing of the campus hospital. "When I rolled in there I expected to see a bunch of sick people," said Susan, "But the first thing that happened was somebody handed me a paper cup of Scotch and I thought to myself, 'hmmmm, these folks are definitely not sick!'" She was soon to direct Berkeley's first residential program for disabled students,

which moved out of the hospital and into an actual dorm, but she recognized the wonderful irony of the sense of autonomy that students felt from having their own space even if it was in a hospital wing.

I last saw Susan a year before she died after she had been confined to her bed for several years due to illness. I will be honest, when I walked into her room I did expect to see a sick person. “Guess what?” she bubbled conspiratorially as I poured tea and selected from an assortment of cookies on the table next to her bed, “Word has it that Queen Elizabeth is going to step down and pass over Charles to make William King!” “Umm, are you sure about that?” I scrolled through the internet looking for a reputable source for this information. “Yes, my attendant told me so this morning. Can you imagine? What does Charles think about THAT?” “I’m sorry Susan but I can’t find anything that confirms that story is true.” “Oh no,” she crowed, “It looks like I have been the victim of fake news!”

Susan, of unabashed nosy Irish stock, used to call the obituaries the “Irish Sporting Pages.” She loved to read the stories of other people’s lives, or rather what their friends and loved ones thought were the stories of their lives. She was always modest about her own accomplishments; her leadership in establishing one of the first supported living university residential programs for students with severe disabilities, her years working to advocate for (and exemplifying) independent living, her travels abroad, her volunteer work for a Bay Area philanthropic Foundation, her passion for and contribution to the UC Berkeley [Disability Rights and Independent Living Movement Oral History Project](#), and of course the many dozens of young (and old) people like me who she mentored and encouraged.

I bid you “adieu” Susan. If any one of us can contribute half as much material to the Irish Sporting Pages as you did, we will have accomplished much. But we still have time to work on our entry.



An Entry for the Irish Sporting Pages: Remember Susan O’Hara by [Irish Sporting Pages: Remember Susan O’Hara Megan A. Conway](#) is licensed under a [Creative Commons Attribution 4.0 International License](#). Based on a work at <http://rdsjournal.org>. Permissions beyond the scope of this license may be available at <https://www.rds.hawaii.edu>.

Research Article

Disability Policy and Wheelchair Users' Accessibility in Jordan

Mohammad Ali Mulazadeh, PhD & Talal Soliman Alharbi, PhD
University of Kwazulu-Natal
Coventry University & Al-Areen Engineering Consultants

Abstract: The main purpose of this article was to evaluate wheelchair users' access to public buildings in Jordan. The key assumption was that accessibility to public buildings in Jordan did not meet the needs of wheelchair users. Field observation method was applied using the accessibility checklist of Americans with Disabilities Act Accessibility Guidelines (ADAAG) as a tool to collect data from a randomly selected sample of 30 buildings in Amman city. Quantitative analysis was used and results show that the average level of accessibility compliance of the surveyed buildings was too low (23%) to meet the needs of wheelchair users. The study concluded that little progress has actually been achieved in terms of environmental accessibility, which implies that Jordan's disability policy was not successful in creating accessible environments in which wheelchair users' equal rights of access to education, employment and basic services is guaranteed. The conclusion also sends a clear message to professionals and decision makers that despite the existence of disability legislation, wheelchair users are still facing physical and social barriers that prohibit their access to public buildings. In other words, law without recognition of the rights of people with disabilities tends to become ineffective.

Keywords: Disability; Accessibility; Wheelchair User; Social Inclusion

Literature suggests that social exclusion is more apparent for those with mobility limitations as long as their equal rights of opportunities are not recognized by the wider society (Barnes, Mercer, & Shakespeare, 1999; Giddens, 1993). Creating an accessible built environment as such, cannot be achieved without societal recognition of the equal rights of people with disabilities to that of their peers. If this were achieved it would lead to their inclusion into mainstream society. This was also asserted by Napolitano (1996) who believed that securing access for people with disabilities to the built environment and their presence in the social sphere will enviably contribute to the acceptance and appreciation of their problems by the wider community. He added that:

“Being able to use the environment is about more than being able to 'get about'. At a deeper level it is about a sense of belonging. Until the environment supports mobility impaired people's participation with dignity and pride intact, this sense will continue to evade them” (Napolitano, 1996, p. 34).

This quotation sustains the theory behind the social model of disability which advocates that attitudes towards inclusion should go hand in hand with the design and construction of the built environment in order to give equal rights of accessibility to people with disabilities. Hisser (1995) who himself is a wheelchair user, emphasizes that the inaccessibility of public

facilities “may cause disabled people to be alienated, ill, poor and marginalized” (p. 56). He recommended that wheelchair users’ accessibility of basic needs, services, basic education, and employment would guarantee their integration into mainstream society.

Disability Policy in Jordan

Following the proclamation of the 1981 International Year of Disabled Persons (IYDP) by the United Nations, large numbers of countries in the developed and developing world including Jordan, have initiated Acts to reduce the negative attitude of society towards people with disabilities and to assure their rights of equal opportunity with peers (Eleweke, 1999).

According to Article 9 Convention on the Rights of Persons with Disabilities, accessibility (CRPD) means:

“To enable persons with disabilities to live independently and participate fully in all aspects of life, States Parties shall take appropriate measures to ensure to persons with disabilities access, on an equal basis with others” (CRPD, 2006, p. 8).

Although the Convention came into force on 3 May 2008, and has 160 signatories and 175 parties which includes 172 states the vast majority of people with disabilities who live in developing countries including Jordan are still waiting to practice their full rights of accessibility.

Within the context of this societal negative attitudes towards people with disabilities in Jordan, the poor accessibility of built environments was not far from expectation. As such, it is too difficult if not impossible, for disability law to change the attitudes of society and actually guarantee the equal rights of participation or equalization of opportunities for people with disabilities in developing countries.

The change of societal concepts according to Vasey (1989) can have a direct impact on the creation of built environments while negative perception can adversely affect environments and render them inaccessible. He asserts that “the attitudes of a given society must change if a disabled person is to realize his/her dream of being ... integrated into mainstream culture” (Vasey, 1989, p. 6). The change must begin within the home as early education of a child with a disability is an influential factor in shaping the future reactions of the child.

Jordan, which is officially called ‘The Hashemite Kingdom of Jordan’ is a Muslim Arab country in the Middle East with a population of more than 9 million in 2016 that has a high rate of disability. It was estimated that the population of people with disabilities in Jordan would reach 600,000 people by 2016, half of whom are living in the capital city of Amman (Nabawy, 2012). Nearly one third (27%) of people with disabilities are physically disabled and have no access to basic services, and are destined to be either isolated or more reliant on others (HCD, 2011). In response to this up surging number of people with

disabilities, outcomes of Jordan's government has initiated a policy in 1993 which was later advanced into Law No. 31 in 2007. This policy calls for the recognition of equal rights of people with disabilities and made public and private sectors liable by the law to create accessible built environments. Assessing the outcomes of Jordan's disability policy and its outcomes in terms of creating accessible public buildings in which wheelchair users can use public spaces and live independently is important and is the focus of this study.

Purpose of the Study

This study was undertaken in order to define the degree of accessibility compliance of public buildings in Jordan, and the implication for wheelchair users' access to education, employment and basic services. The findings of this study can be used as a reliable index against which the effectiveness of Jordan's disability policy can be evaluated.

Method

Field observation method based on the checklist of the Americans with Disabilities Act Accessibility Guidelines (ADAAG) were applied to collect data from a randomly selected sample of 30 buildings in the city of Amman. The collected data was analyzed quantitatively from auditing the accessibility of public buildings. The access audit technique proved to be an essential technique by which accessibility of public buildings are measured and recorded (Ormerod, 2005). Buildings from all categories, public or private, that are involved in providing public services were categorized as public buildings. Government's published and unpublished materials were also used to link the findings of this study with the actual condition of wheelchair users' access to education, employment and basic services.

Procedures

The checklist of ADAAG is amended to fit this study and be used as the standard tool for measuring the accessibility compliance of buildings in Jordan. The checklist was modified in order to cover six accessibility areas including: parking, ramps, entrances, accessible routes, toilets and lifts. For two reasons the ADAAG was used for auditing the sample buildings and facilities. First, its suitability, reliability and applicability were approved by a number of published studies (McClain, Beringer, Kuhnert, Priest, Wilkes, Wilkinson, Wyrick, 1993; McLain, 2000; Useh, Moyo, & Munyonga, 2001; Rivono-Fisher, 2004). Secondly, Jordan's disability law and its associated National Building Code (NBC) were short of providing any quantified accessibility standards to guide or assist constructors for implementation, and research for measuring the degree of accessibility compliance of buildings.

The buildings' managers were approached before beginning the survey and informed about the purpose of the research, confidentiality of the data to be collected, and the caution that would be taken not to hinder or impede the activity of the building in query during surveying. After getting the buildings managers consent, data was collected through direct observations and measurements.

The authors were assisted by four volunteer students who were briefed and provided with measurement tools to carry out the survey. The compliance of an 'area of accessibility' in or about a building is measured in terms of its accessibility and closeness to the ADAAG standards. If the properties of an area of accessibility for instance, a ramp matches Section 4.8.2 of the ADAAG standards then its compliance degree would be satisfactory. The same procedures were used to calculate other 'areas of accessibility' based on the ADAAG guideline.

Calculating the degree of accessibility compliance of each building was however, obtained by dividing the number of available facilities complying with ADAAG standards over the total number of required accessible facilities in each building. For example, if ADAAG standards require five accessible parking places in a particular building but there was only one available, then the compliance of the building in terms of accessible parking is 20%. Accordingly, accessibility compliance of a building lacking any particular service area would be zero or non-compliant.

Findings of the Study

To begin with parking spaces, nearly 70% of the 30 buildings lacked accessible parking or zero accessibility and only 6 buildings had parking spaces with more than 50% accessibility compliance that matched the ADAAG standards. The same condition was found regarding accessible routes or footpaths connecting the parking to the entrances. The average compliance of the routes was almost absent (0.8%). For example, the width of the route connecting the parking and the newly constructed headquarter of the Court of Justice in Amman was too narrow to accommodate two pedestrians or allow wheelchair users to negotiate the path safely - let alone two wheelchair users meeting each other (Figure 1). The findings imply that construction regulations of buildings suggested by the Jordan's disability law and its relevant NBC were either neglected or ill-defined with regard to accessibility for people with disabilities.



Figure 1. Photo of narrow path entering the Court of Justice.

Nearly 80% of the buildings (23 out of the 30) had either substandard or no ramp installed for wheelchair access. For example, in some cases, an unsafe iron sheet with a steep slope was installed as a temporary ramp which was far from being within the required standard (Figure 2). Only 23% of the buildings have provided ramps which were close to the required standards reaching 50-100% compliance.



Figure 2. Photo of Iron sheet used as a ramp in a hospital in Amman.

The majority (80%) of doors entrances in all buildings had clear opening width (815mm) and a high level of accessibility compliance between 50%-70% but none of the buildings were 100% compliant with the applied standards. On the contrary, except for one accessible toilet in the HCD building, the rest of the buildings' toilets were either substandard or no toilet was designed to be accessible for wheelchair users. Most of the toilets were found without a grab bar mounted on the wall and no washbasin at a suitable height. Doors opened outward and had no standard space for turning a wheelchair. Lifts in half of the buildings were either absent or substandard and in the remaining buildings the lifts satisfied the required standards for compliance.

Findings of Education Buildings

Secondary data revealed that the illiteracy level of people with disabilities is significantly higher (30.5%) than that of the national illiteracy rate of 9.3% (DOS, 2004; HCD, 2011). This big difference can be attributed to the inaccessible educational buildings that prohibit students with disabilities from entering them. The lack of/ or unsafe ramps low compliance of lifts (11.6%), toilets (6%) parking (21.6%), and routes (25%) have all acted as barriers to enter educational buildings, which makes it more difficult for students with physical disabilities to enter and navigate the buildings.

Findings of the Workplace

The facilities for people with disabilities in the workplace were found to be worse than that of educational buildings. For example, Jordan's NBC obligates constructors to install ramps in all buildings and lifts for buildings of more than four floors. However, accessibility compliance of ramps and lifts in most workplace buildings were found to be very low.

According to the ADAAG standards, accessible areas such as parking should be close and connected by accessible paths to the main building. However, the average accessibility of parking areas in workplaces including hospitals were rather low (21.5%) and located far from the main buildings. The distance of parking areas however, in the majority of observed buildings was much greater than the defined standard of 50m and lacking accessible paths. A number of accessible parking spaces had no symbol or sign to indicate that the parking is designated for people with disabilities though existence of such a sign cannot prevent the non-disabled from occupying the designated spaces.

A report by Malkawi (2015) in Jordan, confirms that the employment rates of people with disabilities in both public and private sectors showed little improvement and remained between 0.5% and 1%. Azzeh (2015) has also reported a high rate (48%) of unemployment among physically impaired people in Jordan which can be attributed to the low accessibility compliance of both educational (22%) and workplace (25.5%) buildings. Inaccessibility of workplaces has caused wheelchair users to remain jobless for longer periods of time than the rest of the working age groups.

Findings of Cultural and Recreational Buildings

A number of the recreational centers, such as parks, public libraries, mosques, and cinema halls had no ramp at the entry gate, which renders them inaccessible. The Grand Mosque and its toilets and ablution area were inaccessible (Figure 3). An ablution area is considered as the prerequisite step before entering a mosque for praying. Nevertheless, the condition of internal doors and corridors and their components such as width and handrails were in a satisfactory condition.



Image 3. Photo of grand mosque with no ramp.

The stadium was the only recreational area which seems to have an accessible ramp inside the building. However, there was no ramp to connect the main road to the inside ramp beyond the gate that seems to be permanently locked for unknown reasons (Figure 4).



Figure 4: Photo of no ramp to connect the main road to the gate of the stadium.

The findings demonstrate that in spite of the implementation of disability laws in Jordan, the inaccessibility of public buildings and relevant services remain unchanged leading to under education, unemployment, and social exclusion of a majority of people with disabilities.

Discussion

Middle East Arab countries, regardless of their multifaceted economic position, are prohibiting wheelchair users from accessing public buildings despite the existence of disability legislations (Hall & Imrie, 1999). With no exception, the overall results of the accessibility auditing of public buildings in Jordan show that the average accessibility compliance of all buildings was only 23%. This low average implies that not much has actually been accomplished in the field of wheelchair users' accessibility to the public buildings in Jordan.

Clause 1, Section E, Article 4, of the disability Law of Jordan for example, emphatically stresses on "inclusive environment that provide the freedom of movement and equal rights of accessibility for all" (Jordan Disability Law, 2007, p. 5). Article No. 32 of the National Building Code has also obliged public and private constructors to apply the building regulations concerning people with disabilities in 'all new buildings and old buildings wherever possible (World Bank, 2005, p. 16).

Nevertheless, the HCD which was given power by the law in order to enforce the standards and tackle the inaccessibility problems by follow-up observation and evaluation has failed in enforcing the standards even in its own headquarter building. The gradient of a ramp which was installed in the entrance of the HCD main building was too steep for a wheelchair user to negotiate without a companion or people help (Figure: 5).



Figure 5. Photo of a substandard ramp in the entrance of HCD main office.

The results are not surprising when it comes to developing countries. The findings of a comparative study carried out by Welage & Liu (2011) for example, show a meaningful difference in the level of accessibility compliance of public buildings among developed and developing countries. The study by Welage & Liu (2011) indicated that the average accessibility compliance of buildings in developing countries including Zimbabwe, UAE, Turkey, Nigeria, and Jordan (added by the authors) is far less than the average accessibility compliance of buildings in the USA (Figure 6).

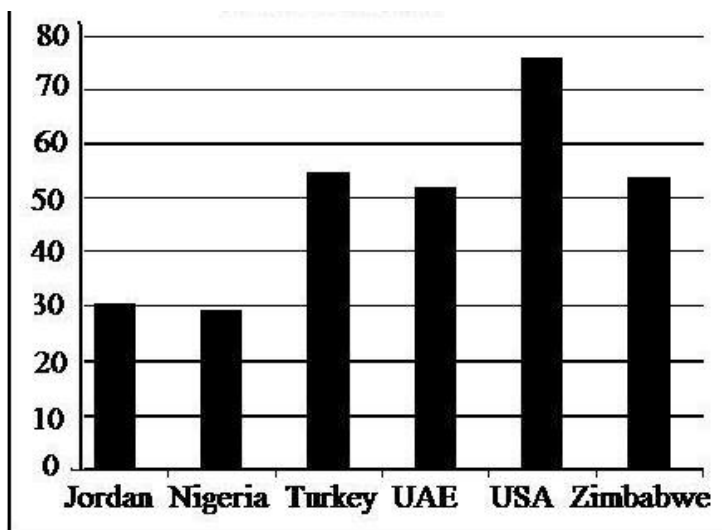


Figure 6. Accessibility compliance percent of buildings by country – Jordan (30%), Nigeria (29%), Turkey (55%), UAE (52%), USA (78%), Zimbabwe (54%)
Source: Welage & Liu (2011) and field survey in Jordan.

Without exception, the level of accessibility compliance of most buildings and their relevant services were too low to provide wheelchair users’ equal rights of access to education, employment, and basic services.

The consequence does not seem to be limited to Jordan’s legislation as Gleeson (2001) stated that “achieving the goals of human rights is still hampered by ineffective legislation

inaccessible design regardless of political concern” (Gleeson, 2001, p. 259). In line with Gleeson (2001), and Kitchin & Law (2001, p. 288) also consider that the absence of accessible toilets “not just undermine social justice and disabled people’s rights of citizenship rather disregards their health and dignity problems as well”. Anderson and Kitchin (2000, p. 167) have also found it “vital for designers and architects, during the building processes, to take into account the difficulties experienced by disabled individuals throughout the course of their daily activities. This is true because environmental design is “the legal driver for curbing discriminatory situations by removing barriers” (Casserley & Ormerod, 2003, p. 153).

Accessibility of public buildings was found to be extremely limited in a manner that no one of the 30 surveyed buildings had a higher level of accessibility compliance than 58%. This means that Jordan’s disability legislation has failed in achieving its set target of creating an accessible built environment. Consequently, wheelchair users have no option but suffering more isolation and social exclusion.

In summary, a change in the living condition of people with disabilities, requires initial changes to the culture as a prerequisite for the change of societal attitudes. Change of culture and attitudes of a society is a long-term process that may take generations before people with disabilities are accepted and truly integrated into mainstream society. In other words, attitudinal changes cannot happen overnight or be dictated by legislation alone. Rather, re-education and greater understanding of the diversity of people's lives is the key to removing the discrimination and oppression of people with disabilities. In order to understand the people they are designing for, and appreciate the frustration of people with disabilities, designers, decision makers, and architects should have sufficient awareness of the societal attitudes toward disability. The designer should involve end-users in determining the design and contributing some of the expertise needed (Imrie & Hall, 2001).

Conclusion

In conclusion, the results of this study show that not much has actually been done in the field of wheelchair users’ accessibility of public buildings in Jordan. A key finding of the research indicates that overall low (23.8%) accessibility compliance of public buildings has created considerable difficulties for wheelchair users in reaching their daily needs. Based on this finding, it can be concluded that the Jordanian disability policy was not successful in providing wheelchair users with equal opportunities in accessing education, employment and basic services.

The results confirm that the environmental standard recommended by the ADAAG was not enforced by Jordan’s disability law. This is because the prevailing social negative attitude towards disability has curtailed the creation of an accessible environment. The problem of an inaccessible built environments goes far beyond physical barriers leaving wheelchair users with no option but to be socially isolated.

It is right to conclude that policy formulation cannot achieve its goals unless the wider society becomes aware of and recognizes the equal rights of opportunities for people with

disabilities with their peers. In other words, law or regulation cannot be a success or make a difference on the ground unless they are accompanied by changes in societal attitude towards people with disabilities.

The findings of this research send a clear message to the planners, designers and decision makers that they were unsuccessful in bringing about what they have promised. Their efforts instead should focus on the inclusivity method in order to pave the way for wheelchair users' social integration and their fullest participation in socio-economic activities.

This conclusion may also alert professionals and officials to the fact that effective implementation of a law in a society where negative attitudes towards people with disabilities is dominant is deemed to be difficult if not impossible. Accordingly, imposing a set of rules and standards which have no credentials in the belief and culture of a society, undoubtedly cannot achieve the expected results.

Message for Policy Makers and People with Disabilities

Creating a barrier-free built environment is a prerequisite step towards the ultimate goal of social inclusion which can preserve human dignity and contribute to the socio-economic advancement of society. In order to avoid discrimination against people with disabilities, designers should consider the participation of end users (wheelchair users) during the design process in order to create a 'wheelchair friendly' environment. The findings of this research might also be helpful in broadening the vision of legislators and building designers in Jordan and other similar countries in the region and stimulating them to strive for equal opportunities and adequate service provision.

Mohammad Ali Mulazadeh, PhD is an Associate Professor in Urban Planning focusing on Urban land-use, housing development and disability and Environmental Accessibility. As a multidisciplinary researcher and a lecturer he worked with Chamran University in Iran, London South Bank University in UK and University of Kwazulu-Natal in South Africa where he was retired. email: mmulazadeh@yahoo.co.uk, Tel: 00447716429252

Talal Soliman Alharbi, PhD is the CEO of Al-Areen Engineering Consultants and research fellow in Coventry University focusing on Urban Planning, disability, accessibility and adaptability of Built Environment. As an experienced researcher and environmental Developer he has participated in many KSA's national projects to create a suitable environment for all.

References

- Anderson, P., & Kitchin, R. (2000) Disability, space and sexuality: Access to family planning services. *Social Science & Medicine*, 51(8), 1163–1173.
- Azzeh, L. (2015 April 02) 7.7% of people with disabilities are employed — report. Retrieved from: <http://www.jordantimes.com/news/local/77-people-disabilities-are-employed-%E2%80%94-report>.

- Barnes, C., Mercer, G., & Shakespeare, T. (1999). *Exploring disability a sociological introduction*. Oxford: Blackwell Publisher.
- Casserley, C., & Ormerod, M. (2003). The legal argument for inclusive design. In J. Clarkson, R Coleman, S Keates, & C Lebbon, (Eds). *Inclusive design: Design for the whole population*, London: Springer.
- Convention on the Rights of Persons with Disabilities (CRPD). (2006). UN Convention on the Rights of Persons with Disabilities, Article 9. Retrieved from <https://www.un.org/esa/socdev/enable/rights/convtexte.htm>
- Department of Statistics DOS. (2004). Distribution of disability by province in Jordan, Department of Statistics, govt. Publication, Jordan.
- Eleweke, C. J. (1999). Special needs professional preparation and development in Nigeria: The challenges ahead. *African Journal of Special Education*, 4(2), 41–49.
- Giddens, A. (1993). *Sociology*. 2nd ed. Cambridge: Polity Press.
- Gleeson, B. (2001). Disability and the open city. *Urban Studies*, 38(2).
- Hall, P, & Imrie, R. (1999). Architectural practices and disabling design in the built environment: *Environ plan B*, 26, 409–425.
- Higher Council for Affairs of persons with Disabilities (HCD). (2011). Annual report on disability in Jordan.
- Hisser, B. (1995). *The nature and causes of transport disability in Barriers*, G Zarb (Ed.). London: Policy Studies Institute.
- Imrie, R., & Hall, P. (2001). An exploration of disability and the development process. *Urban Studies Journal*, 38, 333–350.
- Jordan Disability Law, No 31. (2007). On the rights of people with disabilities.
- Kitchin, R., & Law, R. (2001). The socio-spatial construction and accessible public toilets. *Urban Studies Journal*, 38, 287–298.
- Malkawi, K. (2015). Laws on employment of people with disabilities not fully implemented. Retrieved from <http://www.jordantimes.com/news/local/laws-employment-people-disabilities-not-fully-implemented%E2%80%99>.
- McClain, L., Beringer, D., Kuhnert, H., Priest, J., Wilkes, E., Wilkinson, S., & Wyrick, L. (1993). Restaurant and wheelchair accessibility. *The American Journal of Occupational Therapy*, 47, 619–623.
- McLain L. (2000). Shopping center wheelchair accessibility: ongoing advocacy to implement the Americans with Disabilities Act of 1990. *Public Health Nursing*, 17(3), 178–186.
- Nabawy, A. A. (2012). Perspective of parents and teachers about appropriate jobs for some categories of disabilities and the obstacles of getting a job. *Life Science Journal*, 10(2).
- Napolitano, S. (1996). Mobility impairment. In G. Hales (Ed.). *Beyond Disability Towards an Enabling Society* (pp.30–35). London: Sage.

- National Building Code. (2009). Specifications and standards recommended for the Jordanian construction code, govt. Publication.
- Ormerod, M. (2005). Undertaking access audits and appraisals: an inclusive design approach. *Journal of Building Appraisal*, 1, 140–152.
- Rivono- Fisher, D. (2004). Wheelchair accessibility of public buildings in Al Ain, United Arab Emirates. *Disability and Rehabilitation*, 26, 1150–1157.
- Useh, U., Moyo, A.M., & Munyonga, E. (2001). Wheelchair accessibility of public buildings in the CBD of Harare, Zimbabwe. *Disability and Rehabilitation*, 23, 490–496.
- Vasey, S. (1989). Disability culture: It's a way of life. *Feminist Arts News*, 2(10), 5–6.
- Welage, N., & Liu K. P. Y. (2011). Wheelchair accessibility of public buildings: A review of the literature. *Disability and Rehabilitation: Assistive Technology*, 6(1), 1–9.
- World Bank. (2005). Legal framework suggested best practice, Jordanian National Building Law No. 7/93, Ministry of Tourism and Antiquities, Amman, Jordan. Retrieved from: https://www.mota.gov.jo/Documents/Legal_framework.pdf.



Disability Policy and Wheelchair Users' Accessibility in Jordan by [Mohammad Ali Mulazadeh & Talal Soliman Alharbi](#) is licensed under a [Creative Commons Attribution 4.0 International License](#). Based on a work at <http://rdsjournal.org>. Permissions beyond the scope of this license may be available at <https://www.rds.hawaii.edu>.

Research Article

Can We Say They are also Beautiful? Disability is not a Curse

Mahtab Ahmad, PhD

Bahauddin Zakariya University, Population Welfare Department

Abstract: Throughout the world negative connotations and scapegoating of individuals with disabilities is far too common. The purpose of this article is to examine the history that shows how persons with disabilities are viewed, and ends with suggestions on how to improve this perception in countries where these productive citizens may not be fully valued. A critical review was conducted by dividing the definition of disability into five different perspectives (historical, religious and theological, legal, socio-cultural, and developmental), and concludes that when viewed through an international lens, traditional dogmas continue to exist. The belief that disabilities are '*divine punishments*', and any subsequent miseries related to the disability are attributed to misdeeds from a past life. Beliefs that foster this negative perception support mistreatment and allow for the continuation of unfounded negative stereotypes. Understanding and exploring these beliefs is considered the first step in changing these negative perceptions.

Keywords: Body; Beauty; Disabilities; Religion; Stigma; Negative Connotations

Introduction

Most people would agree that we live in a world where beauty is often measured by a person's physical characteristics. The emphasis on physical attributes are often highlighted in the media where portrayals include the picture of 'perfect body' and belief, starting in childhood, that those who do not meet this expectation can be ignored or degraded. According to the phenomenology of perception, an intimate connection between body, experience, and image is pre-requisite faith for looking 'perfect' as loss of a body part can be devastating for self-identity (Landes, 2012; Merleau-Ponty, 1945). Some individuals have defined 'perfect' as a state of being where all of the facets of the individual are portrayed without flaws, blemishes or defects (Fontaine, 2003). This intense focus on the physical appearance of a person points out flaws and develops a 'belief' in the gap between 'ability and disability.' If first impressions guide any future interactions, individuals with disabilities could be viewed negatively and treated harshly stopping others from wanting to seek further contact thereby blocking the ability to see the inner qualities and intellectual giftedness of the person.

Seeing these limited portrayals of beauty can also lead people with or without physical disabilities to believe that they too need to have the perfect body and will strive to achieve it. Working hard to meet this standard of having the perfect body can leave people feeling inadequate and frustrated. It can also help to determine the type of person that is sought for a mate or life partner as well as those active socially and in community. When a selected partner does not meet this expectation, they may be rejected or treated with disdain (Fontaine, 2003; Mekoosha, 2006). As society developed from an agrarian one to more industrialized, the

social and community exposure has increased and with these changes so has the potential to stigmatize someone for their physical attributes. The connection with such stereotyping was assigned to women in particular, recognizing them with the faith and desirability based on their beauty (Goffman, 1963).

Due to the intense pressure of industrialization and mass performance those individuals that were not able to keep-up were perceived as different and were segregated. This type of segregation was described as *aesthetic anxiety* and highlighted the tendency of 'public morality' to reject deviations from normal physical appearances (Hahn as cited in Oliver, 1989, p. 8). This meant that presenting as aesthetically pleasing was somehow connected to the assumption that the individual was also efficient and effective in his/or her capabilities (Goffman, 1979). Supporting this belief countries adopted Galton-led approaches that mainly focused on creation and use of intelligence tests designed to screen-out those who were more intelligent from those who were not (Lewis, 1989).

Furthermore, the negative perception of individuals with disabilities was further fostered through medical science with the assumption that any form of diversity in the human body was undesirable. This assumption, sanctioned by the medical field, offered a means to get rid of such 'anarchic bodies' (Peters, 1994). This left such people to be viewed negatively and constructed socially as carrying an unusual genetic character; allowing these individuals to become primary targets for discrimination. Historically, women in particular were targeted and scrutinized with the belief that these women should refrain from the reproduction of imperfect bodies (Fontaine, 2003; Frohmader, Storr, Cooper & Fontaine, 2000). Unfortunately, this type of negative thinking that '*disability breeds disability*' resulted in various discriminatory practices. And it highlighted the popularity of genetic testing, abortion, and sterilization to avoid the possible reproduction of 'faulty' bodies (Kaplan, 1994; Pastina, 1981; Peters, 1994). This assumption was later supported further by the discovery of DNA in the 1950s which opened new ways to access for understanding about the workings of a body, and to justify the creation of a physically-perfect human. However, given advances in medical science, either unintentionally or not, about how perfection can be identified has supported myths of disability being viewed negatively in many societies (Peters, 1996).

Images of the ideal body supported by portrayals and expectations of modern society often exclude individuals with what is perceived to be a 'non-perfect' body. This exclusion involves social situations and ties that do not match with the ideal body stereotype. These occurrences of exclusion can affect the person's physiological, sociological and emotional aspects, which can lead to what some have termed as a syndrome of mental rejection (Ganai, 1994; Gardner, 2002). This over-valuation of what is considered the physical ideal has left those with what are considered 'non-normative' bodies treated with the stigma of being viewed as unproductive, imperfect and useless. Since they can become the target of social rejection these persons with 'non-normative' bodies may be ignored and avoided by others (Ferreira & Guimarães, 2003; Furnham, Badmin & Sneade, 2002). If not supported by close relationships and family the social rejection could in turn end in their 'social death' and it is witnessed more or less everywhere in the world (Humphrey, 1999).

Beyond the question of impairment and functional limitations, critical disability theory views disability as an issue of social values and institutional priorities that who and what gets valued, and who and what gets marginalized (Pothier & Devlin, 2006). The theory asks to interrogate a system of justice that is based on a politics of faith “just us” (the so called abled-bodied). The World Health Organization (WHO, 2011) stressed this concern by reporting that 15% of the world’s population was being discriminated against purely based on the fact that they had ‘non-normative’ bodies. This physically present body-wise bias has led to the scapegoating of individuals with non-normative bodies. The purpose of this article is to examine the literature to explain how perceptions and beliefs about the body image have influenced what is considered physically and emotionally ‘non-perfect’, and how it relates to helping all individuals to maintain accepted and productive roles in society.

Methodology

This topic was researched based on secondary data retrieved from a variety of sources: websites, books, doctorate dissertations, and articles on history and attitudes towards disability. Body; Beauty; Disabilities; History; Religion; Negative Connotations; Social Stigma; Disability Rights; Discrimination; and Development were used as “keywords” for searching literature on various aspects related to this study.

In order to better understand the distinction between normal and abnormal; pure and impure; and healthy and unhealthy; Stiker (1997/2005) argues to look at religious and supernatural and moral and medical worldviews. The disability studies theory is a synthesis of social constructionism and critical theory that places disability in resisting notions of stigma and gives a way to examine barriers by applying social, cultural, religious, historical, and philosophical perspectives to study disability in a society (Cory, White & Stuckey, 2010). So, the literature retrieved from various sources was examined to gain insight on the subject matter and information from less-authentic sources was discarded. The literature then by sorting out into five different perspectives: historical, religious, legal, socio-cultural, and developmental was critically reviewed and analyzed to conclude the situation.

Review and Discussion

Historical Perspective

It is believed that a critical part of the foundation of western civilization can be better understood by examining the beliefs of the ancient Greeks. Their philosophical, architectural feats and artistic endeavors have had a profound effect on the culture of the entire world (Devonport, 1995, as cited in Barnes, 1997; Risebero, 1979). It is often overlooked, however, that the Greek economy had a history of violence that flourished on slavery and was based on an overtly patriarchal and hierarchical foundation. Early Greek society has been universally renowned for asserting personal rights and ensuring that people were treated with dignity. However, these courtesies were only extended to Greek males, which generally ignored the rights of women and non-Greeks and thus enabled this civilized society to justify oppression and exploitation. Since the Greeks lived in turbulent times and were often prone to war,

military service for Greek men was obligatory. Greek society was composed of semi-autonomous city states and these areas often remained engaged in war against each other as well as with other neighboring areas. To some extent this was assumed necessary in order to maintain a constant supply of able-bodied slaves (Cahn, 1990; Russell, 1981). Hence, infanticide of sickly, weak or disabled infants was widespread and to avoid the loss of physical prowess and productivity in some states it was mandatory (Tooley, 1983). A reflection of the expectation of male supremacy and concentration on physical attributes is outlined in detail in a section entitled *'How to recognise a child that is worth raising'* from a gynecology manuscript written by a Greek physician, Soranos, in the second century AD.

Unfortunately, recognizing individuals with disabilities as a personal flaw is not limited to early Greek societies. Perhaps, ancient Greek society profoundly affected others to continue to shape western society in the same manner (Stiker, 1997/2005). In Roman societies for example individuals with physical disabilities were portrayed as jesters serving at the pleasure of nobility in the Roman Empire (medieval courts). This was also followed by the acts of their infanticide during the Renaissance. Infants and those with physical abnormalities were drowned and burned during the Spanish Inquisition, or kept in cellars in correctional institutions. Another notable area in history was the Nazi German era with quotes such as *'exterminated disabled and impaired persons first'* providing another example of how these perceptions have been supported over time (Greenwood, 1996). The philosophy in Nazi Germany that supported the extermination of the disabled was the perception that impaired bodies were unproductive and caused an extra burden on society (Imrie, 2001). Thus, for Nazi Germany the punishment and ostracism of disabled individuals was considered as a solution suitable for the society. During the Holocaust in Europe, nearly 100,000 children and adults with disabilities were killed as they were considered morally bad or genetically flawed. Many other examples of unfair treatments can be found throughout the history (PACER Center, 2004; Wray, 2002).

Though, it was beyond the scope of this article to explore all historical trends many countries and societies supported this belief of inferiority. For example, in America, this was evident in the 1800s where in colonial America an 'Institution for Idiots' was founded in Massachusetts in 1848 along with the dehumanization in the orphanages of the nineteenth-century.

To summarize, it can be argued that there are breaks in how we have historically viewed disability but the older worldviews continue to shape our present view, so it is important to use history to illuminate the present (Stiker, 1997/2005).

Religious and Theological Perspective

Religion and religious beliefs provide the foundation for many of our societal beliefs. Using religious dogma and power to explain the unknown means the teachings can have the power to control behavior. Religious lessons guide what people believe to be true, and how they should act in accordance with these beliefs (Goldberg, 2006). Thus, the public and private behaviors are often governed by these codes of conduct described in religious law. For

example, in biblical prophecies such as *'The Jesus healed the lame and blind'* (New Testament Stories, 2005, pp.100–101), if these religious teachings are examined it can provide an understanding about disability, and how images of deformed bodies have been displayed. In fact, religion has been entangled with *secular power* and *polity* to exploit its relationship with the establishment to effect well.

The religion in discussion here is limited to the three versions of Abrahamic traditions: Judaism, Christianity, and Islam, and Hinduism based on Hindu theology. Judaism, Christianity, and Islam fall under the umbrella of the Abrahamic traditions as all three recognize the historical figure Abraham and his descendants as central figures in their faith and beliefs. There is significant overlap in the sacred texts of each faith and in each of them evidence can be found related to the treatment of people with what are often considered non-normative bodies.

The *Yahweh* stories are considered central in Hebrew tradition. In the *Yahweh* stories, disabilities are generally documented as negative degradations of the 'perfect' body. These disabilities are perceived as divine punishments. People with physical impairments were considered impure and a potential threat for bringing pollution to their surroundings and other people (Hentrich, 2007). Jewish law describing the need for perfection in both the sacrificial object and the preparer of the sacrifice is well discussed in this regard (Miles, 2002a, 2002b).

The David stories also communicate negative images and roles for people with disabilities in society. Meribaal, one of the sons of Saul, was spared from being killed with the notion that he was no threat to David because he had a physical disability (lame/or crippled) that would legally exclude him from assuming the throne (Schipper, 2006). Meribaal's inability to rule is unclear. Yet it seems that purity law associated with the religious practice was responsible for his disqualification, and his disability lead to beliefs related to the status of reduced manhood.

In addition, after assuming power in Jerusalem, David banned persons with disabilities from the temple (Hentrich, 2007). Whether it was due to revenge from those who opposed him or because of the issues of 'purity and pollution', the writings of this nature continued to provide a foundation for marginalizing persons with disabilities in multiple aspects of social life (Bishop, 1995).

Christianity is believed to get its roots from the Hebrew bible as the Old Testament became a separate religion with the birth of Jesus. The New Testament contains stories of what happened during and after the birth of Jesus and the themes outlined are rooted in social expectations (Miles, 2001). Disability carried a markedly different meaning and function in the New Testament. Rather than simply considering disability as a punishment, people with impairments became a medium for God to communicate messages of mercy and power. As explained in the book of John people are born with impairments in order to provide opportunities for God to demonstrate his power. They are not manifestations of the sins of their parents (Miles, 2001, 2002b). Moreover, there is long history of showing both negative and positive attitudes towards disability with the interpretation and reinterpretation of the New

Testament on a regular basis for centuries.

For instance, it has been widely misapprehended and caricatured that in sixteenth century a renowned reformer Martin Luther made remarks about babies with impairments based on his belief that they were not actually human babies but rather incarnations of devil (Miles, 2001). Indeed many disabled persons were receiving humble attention and a kind treatment from the services of Church but for curing and healing purposes, in which the goal was ‘normalization’ of the bodies of persons with disabilities (Eiesland, 2009). No doubt the most famous and sacred saying that Jesus heals the wounds by forgiving sins served as basis of social reforms for improving the lives of individuals with non-normative bodies. Yet, the overwhelming interpretations of the Jesus narratives contributed to set disabled people apart from society by creating an implicit message that those who are not healed or cannot be healed are not like us.

The word Islam means submission to the will of God. Muslims believe that one is born in the body that the God bestows on one to have, otherwise they all are equal. Only God is perfect. Physique matters less in Islamic lessons. Therefore, to dishonor or exclude people based on their non-normative bodies from life is an act against the will of God (Miles, 2002b). Impairments are considered normal aspects of the human experience. Although health is benevolence from God, disease, disability, pain and suffering are not divine punishments or wrath. These happen only to test patience and commitment of believers with the faith as well as with God. Those who observe patience here in this life will receive a great reward in the Hereafter (Islam, 2009). The Quran not only calls for inclusion of such people in social life but also gives them concessions in various obligations and commands for their social protection in several ways. The Holy prophet Muhammad (peace be upon him) behaved decently with disabled people by showing his humbleness to their particular circumstances, and commanded not to consider such things which should stand in their way of leading to live a normal life (Pervez, 2014).

Besides such provisions in religion, the symbolic use of various types of infirmities in the interpretations of religious lessons provides a justification for people (to some extent) to turn their back on the disabled individuals. And in Muslim societies they are disregarded in various walks of life for one or the other reasons and often treated pathetically. Several demeaning titles are used to undermine them. For instance, in a Muslim society like in Pakistan although a compatible faith- and intellect-oriented reflection is well documented (Khan, Watson & Chen, 2017) instead of calling the actual names, the disabled are often called by demeaning titles at public places. A glimpse of those titles used as a routine matter with regard to a disability is as follows:

- *Langra* – (a person with mobility impairment)
- *Kana* – (a person with visual impairment of one eye)
- *Andha* – (a person with visual impairment of both eyes)
- *Tounda* – (a person with hand or arm impairment)
- *Gounga* – [a person unable to speak (Dumb)]

- *Behra/Dora* – [a person with hearing impairment (Deaf)]
- *Pagal/Kamla* – (a person with mental retardation/ intellectual disability)

As a result, disabled people often fear coming out at public places and mingle with social as well as religious gatherings. In addition, the concept of *Jinns* behind intellectual disabilities largely prevails in rural belts (Alam, 2014). In some other Muslim majority areas in West Africa, harmful practices of infanticide and trading in body parts of children with disabilities rooted in local traditional beliefs have also been documented (see Kumar, 2013).

Hindu mythology connects physical differences in appearance to the actions performed in a past life. For instance, mental and physical sufferings are considered as consequences of past inappropriate actions (Whitman, 2007). The stories in Hinduism portrayed disabilities negatively by showing people with disabilities as cruel and evil. The stories of a blind king Dritarashtra and the lame *Shakuni* are documented evidences in this regard. Lord *Vishnu* refused to wed a woman because of her being dark and disfigured by saying that disabled people have no place in Heaven. He preferred to marry off the woman to a tree (Bhambani, 2003; World Bank, 2007).

In a World Bank survey (2007), half of the respondents believed that disability was a curse of God; and thus, disabled people were being denied their entry to temples in extremist parts of India (T.A.A, 2013). An identical situation appears in Buddhism as well where disabled persons are considered as those who “*berated and laughed at those bowing to Buddha’s*” (Buddhist Text Translation Society, n.d.). These individuals are being punished now for those misdeeds within a past life. The idea of ‘*karma*’ has created a further deception in this regard with the super-added suffering of disabled individuals beyond their physical sufferings. They are demeaned by giving a title as ‘*Mongol*’ (Bualar & Ahmad, 2009). The Confucius and Zoroaster theologies also regarded them as ‘children of a caring God’ – the underlying meaning that they have abnormal bodies with ‘weak minds’ (PACER Center, 2004).

There is no single founder in Taoism and Shinto mythology. Taoists believe in harmony among nature and humans in an uncertain world with changing ambiguities. For Taoists, a main goal of healing is harmony and balance of the *yin* and *yang* which can reinforce prejudice against disability. According to Taoism, disability results from a ‘*disharmonious fusion of nature and man*’ (Lam, Tsang, Chan, & Corrigan, 2006). Hence, an individual with a disability can expose an imbalance, and a problem that needs to be fixed and realigned. We can uncover the social meanings of disability in ancient Japan by looking at the representative tales of Shinto mythology. According to the ancient tales of the *Kojiki* and *Nihonshoki*, *Hiruko* is the first child of Japan's creation god and goddess and is born with a physical disability. He is deemed ‘*a no-good child*’ by his own parents and therefore, is cast away into the ocean (Goto, 2004; Yokota, 2015).

Sikhism asks for truthful living, contentment, humility and compassion, attainable through meditative practice and selfless charitable service. Those who choose to be initiated into the Sikh way of life are known as ‘*Khalsa*’: meaning ‘pure ones’. While talking about

their spirituality, the first Sikh Guru Nanak (1708) is reported as saying “I am blind, mute, crippled and totally lacking in understanding; O God, Preserver of all, please preserve me!” (Guru Nanak p. 530, line 1 cited in Disability Forum, 2005). It seems referring disability to an inability (Hussian, 2005; Sandhu, 2005).

In other words, the cause of impairment in spirituality is concerned with spiritual power. Hence, it develops a pathetic fallacy to address the issue with spiritual maneuvers, such as exorcism and faith-healing (Kristiansen, Vehmas, & Shakespeare, 2009).

Legal Perspective

The word disability was coined approximately 500 years ago in the legal field (Hasnain, Shaikh, & Shanawani, 2008). In legal systems, social inequality and rule of law are closely related, and the court of law is an arena that is known both to produce and reproduce social inequality (Lundberg & Simonsen, 2015). The core concept of intersectionality is the entanglement of various differentiating social categories and their impact on individuals, social practices, institutions, and cultural beliefs of power relations (Gullikstad, 2013).

The early laws in ancient societies: Greek, Roman, Arab, and Chinese provided sets of compensation schemes with precise payments for the loss of a body part but without taking into account *the loss of ability to perform specific tasks or jobs*. For instance, in Arab law, the price of compensation for loss of a body part was fixed according to the worth and value of the part. For instance, the loss of a penis was compensated by the amount of length lost, and the value of an ear was based on its surface area. In the same manner, all other early compensation schemes were also consisted of injury-specific compensation schedules (Guyton, 1999).

Later in more modern times, secular charity took part in addressing disabled people, and as a result, disability started gaining legal status to some extent. Greenwood (1996) revealed that development and placement of the English Poor Law 1601, the German social legislation in 1880, the workers' compensation laws in 1920s, and the Social Security Disability Insurance Program in the United States were the first partial legitimizations of the inevitable impairment and disability.

The English Poor Law of 1601 was the first legal response to disability which secularized the protection of persons with ‘special needs’, and scrutinized vagrants getting charity together with the people of ‘special needs’, and categorized needy people on a work-based system which helped to define disability but narrowly. In actuality, with this law, Queen Elizabeth's government only divided the needy into three groups. The disabled persons were placed in the group labeled ‘helpless poor’. However, the words chosen for labeling the group and their tones themselves are indicative of demeaning stereotypic notions against disability.

Although the German social legislation of Bismarck in the 1880s was not so much to control vagrancy, its state-sponsored welfare notion based on social hierarchy and hierarchy and labor mobility bureaucratized disability with the essence of invalidity and compensatory

insurance. Social security laws and old-age benefits followed with the medicalization of disability *i.e.* the physician certification of the severity of impairment (Greenwood, 1996). Three laws were passed: the Health Insurance of Workers Law of 1883 which provided protection against the temporary loss of income as a result of illness; the Accident Insurance Law of 1884 that aided workers injured and impaired during job; and the Old Age and Invalidity Insurance Law of 1889 to provide a pension annuity for workers who attained 70 years of age for retirement. However, these laws remained focused only on covering the top segments of the blue-collar working class. They were not addressing impairments and loss of “abilities” other than in the result of injury. In the United States, in 1930s, the Social Security Disability Insurance was adopted to insure those who could not work due to infirmities that were not related to work. It was the first initiative to recognize and address disability - *the loss of ability to perform specific tasks or jobs*, yet half-heartedly (Guyton, 1999).

Guiding principles, in review of the ancient literature, were whether and eventually in what ways, ancient systems provided legal protection and secured rule of law for disabled people. The development of social policies and ‘democratization’ in western societies at that time only led to increased awareness of the relation between disability and social justice (Kermit, Mjøen, & Olsen, 2011; Petersilia, 2001).

Later in the newly emerging economies, these laws gave new direction and now attention was given to finding a better definition of what actually constituted a disability and who would qualify as a disabled person. In 1981, the United Nations (UN) declared the International Year of Disabled Persons with the aim of promoting recognition and acceptance thereby declaring a time-frame in which a series of “Decades for Disabled Persons” were identified, and several agencies such as the International Labour Organization (ILO), and World Health Organization (WHO) came forward to act on this.

Initially, the WHO provided a threefold model for Classification of Impairments, Disabilities, and Handicaps (ICIDH) and referred to “impairment” as a defect, “disability” as a functional limitation, and a “handicap” as an inability to fulfill social roles. Twenty-years later, the WHO (2001) presented a revised model for classification of functioning, disability, and health - the *International Classification of Functioning* (ICF) trying to differentiate between “body function and structures” and “activities and participation.” Both the models provided medical experts as the authority based on the fact that they dominated the categorization of a disability.

In addition to models defining disability, laws protect fundamental rights and justice in which theoretically, no citizen is above the law. There are several principles pertaining to legal protection for individuals with disabilities. Likewise, one should be able to defend one’s rights and not be deprived of any opportunity in public domain. In a wider sense, legal protection is laws whose enactment should be in line with human rights (Kjønstad & Syse, 2005), such as proclamation of the Convention on Rights for People with Disabilities (UNCRPD) in 2006 to reaffirm their rights, respect, and dignity. And states both in the North and South by ratifying have made their national policies for disabled people.

However, these legislations have served more as agencies to control disability as a social problem rather to fulfill the real notion of its successful integration and acceptance in society. For instance, every state has a 'lip-servicing' national policy for protecting the rights and dignity of disabled people. But the so called 'court of law' has left disabled people pity for an unending struggle for their dignity and rights. Deaf and people with intellectual disability are vulnerable with regard to have a meaningful access to 'legal system' for claim of their rights (Pravda, 2011).

Socio-Cultural Perspective

The socio-cultural theories emphasize that citizenship is not just an issue of individual status; it is also a practice that positions individuals in the larger community. This substantive approach raises questions of exclusion, obligations, liberty, equality, belonging, agency, identity, personhood, social recognition, and self and others (Kabeer, 2002).

By analyzing the literature in this perspective it is easy to see people with a disability can be viewed negatively within a society. One revealing statement was made by the founding Father St. Hopkins, who had cerebral palsy, 'My hands may tremble; my heart does not' (see NCLD/Y, 2016). It is true; assumptions about any group of people can lead to stereotyping or stigmatization in human society (Kleinman, 2006). The traits and values of a certain group can be subject to predominant stereotypical reproductions that are based on class, caste, belief, and racism stemming from the belief that to be accepted the person must present as physically -fit. Stereotypical impressions and beliefs such as this lead to people with disabilities being considered a burden rather being capable of a productive existence.

When the dubious 'aesthetic sense' of the able-bodied person is considered not only ideal but also necessary for social acceptance and productivity the confidence of the person with a disability can be affected. Ellis (2000) pointed out that "modern society is averse to risky bodies and anxieties about the corporeality of the body revolve around concerns of preserve independent bodies, of health, fitness, and youth" (p. 17). As a result, cultural expectations that confirm Ellis's argument reinforce efficacy of what is normal and creates barriers to those who are facially disfigured and not able to present an expected body-wise aesthetic appearance.

Imrie (2001) by quoting Hawkesworth denoted such persons as 'dirty', 'disordered', and 'object of disdain' and this lack of desirability pushes them back into the shadows and away from mainstream society. Nothing could be further from the truth, however, and this devaluation upon looks alone takes away for an individual's ability to present how he/or she actually feels and what can be contributed.

Habitus of disabled people is termed as 'dys-appearing bodies' a deviation from biomedical norms (Leder, 1990); and, is rarely believed to be included in policies and plans (Mitchell, 1996). Thus, the physically disabled are often believed to be out of place and regarded only as a figure of fun and ridicule (Imrie, 2001). Marks (1999) by drawing attention to "the particular habitual way of relating to environment the body adopts" argued that impaired bodies are symbolically marked out that deprives life opportunities and in turn

influences their social standing. Likewise, Miles (2007) pointed out that people with non-normative bodies in rural Punjab were facing a stigma of labeling them as ‘untouchables’. It indicates that disability is still a taboo in societies with unsteady progress made towards disability rights.

In short, meshing of these socio-cultural values, attitudes, and political practices of the able-bodied have differentiated persons with a disability as abnormal human beings. As a result, this perception of inferiority or punishment as brought about purposefully by the divine, has left no space for such persons in a community as well as in the hearts of masses.

Developmental Perspective

No doubt, social theories and theories of justice have contributed to addressing the issues of disability and have evolved with a range of frameworks and models to deal with disability either medically or socially that are designed to ameliorate its effects on individuals with a disability. These different understandings of the relationship of impairment to limitation inform two contrasting approaches to disability and development. When the contributions of these two approaches are summarized, a picture is presented that has tried to address disabled persons by considering them either more or less as permanently dependent on society rather than ensuring their free will and fair access and success.

Throughout history, the pioneer medical model has viewed disability and impairment as an intrinsic ‘problem’ that belongs to the individual. When viewed as a personal problem - means societal support is not needed. The model ignores or underestimates the contribution of social and other environmental factors to the limitations faced by people with disabilities (Davis, 2002; Shakespeare, 2006). For instance, if not being able to work is a personal issue or a result of divine choice when a wheelchair user is unable to get into a building because of steps or a stair it is viewed as the problem of the individual not that of the stair or steps. Hence, the rehabilitation approach is followed with such arrangements that leave people with disabilities in isolation from treatment to education such as recommending them to stay at home and receive separate schooling. The premises postulated in these rehabilitation approaches particularly in developing societies, have adversely affected and led persons with disabilities to become passive recipients or beggars.

In contrast, the social model of disability developed in the 1970s by activists in the Union of the Physically Impaired Against Segregation (UPIAS) understands disability as a relation between an individual and his/or her social environment: the exclusion of person with certain physical characteristics from major domains of social life. Such exclusion is manifested not only in deliberate segregation, but in a built environment and organized social activity that restricts the participation of individuals labeled as disabled. For instance, the social model sees the stair or steps as a disabling barrier and hence, considers society as the factor that disables the people (Oliver, 1996).

More moderate versions of the social model maintain their emphasis more on social causes while insisting on the interactive character of disability (Altman, 2001; Bickenbach, 1993). It draws an idea of ‘inclusive’ society by advocating for adjustments focusing on

maintaining a disabled-friendly physical environment in the homes or in helping with transportation as well as the various destinations. Besides being a dominant paradigm for understanding disability, the social model is however, less concerned with the innate desirability of disabled persons. Several critics argued that extreme versions of the social model implausibly deny or undermine the role of impairment itself as a source of disadvantage (Anastasiou & Kauffman, 2013; Shakespeare, 2006; Terzi 2009).

To summarize, the medical as well as the social model both rest on a false dichotomy of biological impairments and social limitations where biological impairment and social exclusion are deeply interwoven and difficult to tease and deal apart (Martiny, 2015). Hence, the disabled people particularly in developing world are living invisibly in their community besides with the possession of some sort of compensatory resources.

Conclusion

From the literature critically reviewed from various perspectives, it becomes evident that historically, the powerful effect of physical appearance on how individuals were evaluated remains prominent in how they were identified and subsequently treated. This is highlighted by the widespread belief that physical-attractiveness stereotypes have largely prevailed where attractive humans are believed to possess various desirable qualities, whereas those whose appearance was less pleasing were viewed negatively.

It is clear that spirituality and religious beliefs create the foundation for interpretation of events and the meaningful experiences that are attributed to individuals with or without disabilities (Mathewes, 1995). Starting with the belief that human beings are created in the image of God, it postulates that every human being is sacred and should be treated with dignity (Pyne, 1999). Yet, the brief and incomplete interpretations of the sacred texts and theological religions (some of them presented above) make it more complex for believers. Some believers struggle and when interpretations are ambivalent and contradictory, myths about inferiority can be propagated. Through misinterpretation these lessons and readings can foster the dogma that disabilities are 'divine punishments' that could mislead people to hate and turn their back on people with disabilities except lip-servicing. As a result, this negative connotation leads impaired bodies to be ridiculed (Imrie, 2001).

Similarly, stressing socio-cultural ideals seeking and praising body-wise perfection and achievements, creates a fear of people with a disability that ultimately leads to stigmatizing those with body-wise deficiencies as 'deviants' by the culture. The purpose of this article was to highlight some of the perspectives that can help people to better understand the foundations of the pre-conceived notions that they may hold and how these beliefs can be to the determinant of disabled people. It is clear that many of these negative stereotypes are deeply ingrained in a culture and will not easily be transformed. Proper education and awareness, however, may be the first step to starting to change some of these negative perceptions. Getting a better understanding as to why people feel and act as they do is the second step, then allowing all people to recognize the inner beauty of people with non-

normative bodies, which in-turn will free them from the 'cult of normalcy' (Reynolds, 2005). Once a proper religious education and awareness is extended, it will help to bolster a religiously defensible sound: "God loves people regardless of their physical appearances and genetic makeup, and we should do likewise" (Peters, 1996). Thus, people can come to acknowledge the belief that disabled people are also beautiful and disability is not a curse; an environment ripe for practice and policy change will result.

Mahtab Ahmad, Ph.D., after completing his PhD in the Regional and Rural Development Planning Field of Study at the Asian Institute of Technology, Thailand, has served as an Assistant Professor/Coordinator of the Department of Sociology at *Bahauddin Zakriya University Bahadur Campus, Layyah*, Pakistan, and is currently serving in Population Welfare Department/visiting faculty at BZU Campus, *Layyah*. His research interests include Community Development; NGOs & Development; Education & Development; Aging & Disability; Population & Health; and Conflict & Development. <mahtabdgk@gmail.com>

References

- Alam, A. (2014). *Muslim Ignorance about Intellectual Disabilities*. Retrieved from <http://www.5pillarz.com/2014/04/03/muslim-ignorance-to-intellectual-disabilities>.
- Altman, B. (2001). Disability Definitions, Models, Classification Schemes, and Applications. In G.L. Albrecht, K.D. Seelman & M. Bury (Eds.), *Handbook of disability studies* (pp. 97–122). Thousand Oaks, CA: Sage Publications.
- Anastasiou, D., & Kauffman, J. M. (2013). The social model of disability: Dichotomy between impairment and disability. *Journal of Medicine and Philosophy*, 38(4), 441–459.
- Barnes, C. (1997). A legacy of oppression: A history of disability in Western culture. In L. Barton & M. Oliver (Eds.), *Disability Studies: Past Present and Future* (pp. 3–24). Leeds: The Disability Press.
- Bhambani, M. (2003). Societal responses to women with disabilities in India. In A. Hans & A. Patri (Eds.), *Women, disability and identity* (pp.76–88). New Delhi: Sage Publications.
- Bickenbach, J. (1993). *Physical disability and social policy*. Toronto and London: University of Toronto Press.
- Bishop, M. E. (1995). Foreword. In M. Bishop (Eds.), *Religion and disability: Essays in scripture, theology, and ethics* (pp. v-x). Kansas City, MO: Sheed & Ward.
- Buddhist Text Translation Society. (n.d.) *The Buddha Speaks the Sutra on Cause and Effect in the Three Periods of Time*. Retrieved from http://www.cttbusa.org/cause_effect/cause_and_effect.htm#rt
- Bualar, T., & Ahmad, M. M. (2009). Why does community-based rehabilitation fail physically disabled women in northern Thailand?. *Development in Practice*, 19(1), 28–38. doi:10.1080/09614520802576351

- Cahn, M. (1990). *Classics of Western philosophy: 3rd edition*. Indianapolis: Cambridge.
- Cory, R. C., White, J. M., & Stuckey, Z. (2010). Using disability studies theory to change disability services: A case study in student activism. *Journal of Postsecondary Education and Disability*, 23(1), 28–37.
- Davis, L. J. (2002). *Bending over backwards: Disability, dismodernism & other difficult positions*. New York: New York University Press.
- Devonport, J. (1995). Part M, access and disabled people. Paper presented at the *Disability Research Unit in the School of Sociology and Social Policy*, University of Leeds, 10 February.
- Disability Forum. (2005). *Gurbani on Disease and Disability*. (1999-2005) SikhWomen.com. Retrieved from <http://sikhwomen.com/equality/social/challenged/quotes.htm>
- Eiesland, N. (2009). Sacramental bodies. *Journal of Religion, Disability & Health*, 13(3/4), 236–246.
- Ellis, K. (2000). Welfare and bodily order: theorising transitions in corporeal discourse. In K. Ellis & H. Dean (Eds.). *Social policy and the body: Transitions in corporeal discourse* (pp. 1–22). Basingstoke: Macmillan.
- Ferreira, M. E. C., & Guimarães, M. (2003). *Dducação inclusiva*. Rio de Janeiro: DP & A.
- Fontaine, M. L. (2003). Perfect? An analysis of the global human genetics Fix. In A. Hans & A. Patri (Eds.). *Women, disability and identity* (pp. 43–55). New Delhi: Sage Publications.
- Frohman, C., Storr, A., Cooper, M., & Fontaine, M. L. (2000). *Leadership & mentoring resources kit for women with disabilities*. Australia: WWDA, Canberra.
- Furnham, A., Badmin, N., & Sneade, I. (2002). Body image dissatisfaction: Gender differences in eating attitudes, self-esteem, and reasons for exercise. *The Journal of Psychology*, 136(6), 581–596.
- Ganai, N. A. (1994). Child Abuse: The etiology and prevention. In S. Sood & J. N. Choudhary (Eds.). *Marriage, family and socialization: in developed and developing countries*. Jaipur, India: Arihant Publishing House.
- Gardner, R. M. (2002). body image assessment of children. In T. F. Cash & T. Pruzinsky (Eds.), *Body image: A handbook of theory, research & clinical practice* (pp. 127–134). New York: Guilford.
- Goffman, E. (1963). Stigma: Notes on the management of spoiled identities. In G. Ritzer & J. M. Ryan (Eds.). *The concise encyclopedia of sociology* (pp. 617–618). Wiley-Blackwell: A John Wiley & Sons, Ltd., Publications.
- Goffman, E. (1979). *Gender advertisement*. London: Macmillan.
- Goldberg, M. (2006). *Kingdom coming: The rise of Christian nationalism*. New York: W.W. Norton and Company.

- Goto, Y. (2004). *People with disabilities (the for beginners series)*. Tokyo, Japan: Gendai Shokan.
- Greenwood, G. J. (1996). Chapter 2: History of disability as a legal construct. In L. Stephen, I. Demeter et al. (Eds.). *Disability evaluation 5,5*. American Medical Association, Missouri: Mosby Publishers.
- Gullikstad, B. (2013). Intersectionality – a fruitful term?. [interseksjonalitet – et fruktbart begrep] *Tidsskrift for kjønnsforskning. Nr. 1. Årg, 37*, 68–75.
- Guyton, P. G. (1999). A brief history of workers' compensation. *The IOWA orthopaedic Journal, 19*, 106–110.
- Hasnain, R., Shaikh, L. C., & Shanawani, H. (2008). *Disability and the Muslim perspective: An introduction for rehabilitation and health care providers*. Centerfor International Rehabilitation Research Information and Exchange (CIRRIE) Monograph Series. New York: University at Buffalo; The State University
- Hentrich, T. (2007). Masculinity and disability in the Bible. In H. Avalos, S.J. Melcher & J. Schipper (Eds.). *This abled body: Rethinking disabilities in biblical studies* (pp. 73–88). Atlanta, GA: Society of Biblical Literature.
- Humphrey, J. (1999). Disabled people and the politics of difference. *Disability and Society, 14*(2), 173–188.
- Hussain, Y. (2005). South Asian disabled women: Negotiating identities. *Sociological Review, 53*(3), 522–538.
- Imrie, R. (2001). Barriered and bounded places and the spatialities of disability. *Urban Studies, 38*(2), 231–237.
- Islam, W. (2009). *Rights of Disabled in Islam*. Retrieved from <http://sifoundation.webs.com/islamicrights.htm>
- Kabeer, N. (2002). *Citizenship and the boundaries of the acknowledged community: Identity, affiliation and exclusion*. Working Paper 171. Brighton: Institute of Development Studies.
- Kaplan, D. (1994). Prenatal screening and diagnosis: The impact on persons with disabilities. In K. H. Rotterberg & E. J. Thompson (Eds.). *Women and prenatal testing: Facing the challenges of genetic technology* (pp. 49–61). Ohio: Ohio State University Press.
- Kermit, P.O., Mjøen, M., & Olsen, T. (2011). Safe in the hands of the interpreter? A qualitative study investigating the legal protection of deaf people facing the criminal justice system in Norway. *Disability Studies Quarterly, 31*(4). <http://dsq-sds.org/article/view/1714/1762>.
- Khan, Z. H., Watson, P. J., & Chen, Z. J. (2017). Religious reflection in Pakistan: Further evidence of integration between Muslim faith and intellect. *Journal of Beliefs & Values, 1–5*. doi: 10.1080/13617672.2017.1292725
- Kjønstad, A., & Syse, A. (2005). *Velferdsrett I. Law of welfare 1*. Oslo: Gyldendal akademisk.

- Kleinman, A. (2006). Anthropology in the clinic: The problem of cultural competency and how to fix it. *PLOS Medicine*, 3(10), 1673–1676.
- Kristiansen, K., Vehmas, S., & Shakespeare, T. (2009). *Arguing about disability: Philosophical perspectives*. NY: Routledge.
- Kumar, D. (2013). Africa's Disabled Cursed by Apathy and Abuse. Retrieved from <http://www.aljazeera.com/indepth/features/2013/09/2013922121017135639.html>
- Lam, C., Tsang, H., Chan, F., & Corrigan, P. (2006). Chinese and American perspectives on stigma. *Rehabilitation Education*, 20(4), 269–279.
- Landes, D.A. (2012). *Phenomenology of perception, 1945* [translated in English in 2012]. New York, NY: Routledge.
- Leder, D. (1990). *The absent body*. Chicago, IL: University of Chicago Press.
- Lewis, J. (1989). *Removing the grit: The development of special education in Victoria, 1887-1947*. Bundoora: La Trobe University.
- Lundberg, C., & Simonsen, E. (2015). Disability in court: Intersectionality and rule of law. *Scandinavian Journal of Disability Research*, 17(1), 7–22.
doi:10.1080/15017419.2015.1069048
- Marks, D. (1999). *Disability: Controversial debates and psychosocial perspectives*. London: Routledge.
- Martiny, K. M. (2015). How to develop a phenomenological model of disability. *Medicine, Health Care and Philosophy*, 18(4), 553–565.
- Mathewes-Green, F. (1995). A ramp is not enough. *Christianity Today*, 39(12), 68.
- Mekoosha, H. (2006). What the hell are you? An intercategory analysis of race, ethnicity, gender and disability in Australian body politic. *Scandinavian Journal of Disability Research*, 8(2–3), 161–176.
- Merleau-Ponty, M. (1945). *Phénoménologie de la perception*. Paris: Éditions GALLIMARD.
- Miles, C. (2007). *Imran's djinn, and theories of epilepsy*. Sweden: Independent Living Institute.
- Miles, M. (2001). Martin Luther and childhood disability in 16th century Germany: What did he write? What did he say?. *Journal of Religion, Disability, & Health*, 5(4), 5–36.
- Miles, M. (2002a). Disability in an eastern religions context: Historical perspectives. *Journal of Religion, Disability & Health*, 6(2/3), 53–76.
- Miles, M. (2002b). Some influences of religions on attitudes towards disabilities and people with disabilities. *Journal of Religion, Disability & Health*, 6(2/3), 117–129.
- Mitchell, W. (1996). *City of bits: Space, place, and the infobahn*. Cambridge, MA: MIT Press.
- National Consortium on Leadership and Disability for Youth (NCLD/Y). (2016). *Disability*

- History: Timeline: 1700s*. NCLD-Youth.info. Institute for Educational Leadership. Retrieved from <http://www.nclld-youth.info/index.php?id=61>
- New Testament Stories.(2005). Chapter 39: *Jesus heals a blind man* (pp.100–101). The Church of Jesus Christ of Latter-Day Saints.
- Oliver, M. (1989). Disability and dependency: A creation of industrial societies. In L. Barton (Eds.). *Disability and dependency* (pp. 6–22). London: Falmer Press.
- Oliver, M. (1996). *Understanding disability: From theory to practice*. Basingstoke: Macmillan.
- PACER Center. (2004). *History of disability in brief*. PECER Center, Inc. Building Program Capacity to Serve Youth with Disabilities #1: Disability Awareness. Retrieved from familieslead.org/files/1414/1296/0207/history_in_brief.pdf
- Pastina, L. (1981). The impact of genetic disability. *Sexuality and physical disability personal perspectives* (pp. 32–34). St. Louis: C.V. Mosby Co.
- Pervez, S. (2014). The Treatment of Handicapped People in Islam. *Why Islam?* Retrieved from <http://www.whyislam.org/social-values-in-islam/social-ties/disability-in-islam>
- Peters, T. (1994). Designer children: The market world of reproductive choice. *The Christian century*, 111(36), 1193–1196.
- Peters, T. (1996). In search of the *perfect* child: Genetic testing and selective abortion. *The Christian Century*, 113(31), 1034–1037.
- Petersilia, J. (2001). Crime victims with developmental disabilities. *Criminal Justice and Behavior*, 28(6), 655–694.
- Pothier, D., & Devlin, R. (Eds.). (2006). *Critical disability theory: Essays in philosophy, politics, policy, and law*. Vancouver, Toronto: UBC Press.
- Pravda, D. (2011). Understanding the rights of deaf and hard of hearing individuals to meaningful participation in court proceedings. *Valparaiso University Law Review*, 45(3), 927–965.
- Pyne, R. A. (1999). *Humanity and sin: The creation, fall, and redemption of man*. Nashville, TN: Word Publishing.
- Reynolds, T. E. (2005). Love without boundaries: Theological reflections on parenting a child with disabilities. *Theology Today*, 62, 193–209.
- Risebero, B. (1979). *The story of Western architecture*. London: Herbert.
- Russell, B. (1981). *History of Western philosophy*. London: Unwin.
- Sandhu, J. S. (2005). A Sikh perspective on life-stress: implications for counselling. *Canadian Journal of Counselling*, 39(1), 40–51.
- Schipper, J. (2006). *Disability studies and the Hebrew Bible: Figuring mephibosheth in the David story*. New York: T & T Clark.

- Shakespeare, T. (2006). *Disability rights and wrongs*. London: Routledge.
- Stiker, H. J. (1997/2005). *Corps infirmes et sociétés/a history of disability*. Ann Arbor: University of Michigan Press.
- [T.A.A]. (2013 July 3). *Hindu temples deny disabled people entry* [Video File]. Retrieved from www.youtube.com/watch?v=cCGN1KwniQ0
- Terzi, L. (2009). Vagaries of the natural lottery? Human diversity, disability, and justice: A capability perspective. In K. Brownlee & A. Cureton (Eds.), *Disability and disadvantage* (pp. 86–111). New York: Oxford University Press.
- Tooley, M. (1983). *Abortion and infanticide*. New York: Oxford University Press.
- Whitman, S. M. (2007). Pain and suffering as viewed by the Hindu religion. *Journal of Pain*, 8(8), 607–1613.
- World Bank. (2007). *People with disabilities in India: From commitments to outcomes*. New Delhi: World Bank.
- World Health Organization. (2001). *International classification of functioning, disability, and health: ICF*. Geneva: World Health Organization (WHO).
- World Health Organization. (2011). *World report on disability*. Malta: World Health Organization (WHO).
- Wray, M. (2002). DEMOS Project: *Improving provision for disabled students 1999 - 2002*. (Funded by the Higher Education Funding Council for England) Manchester: Metropolitan University.
- Yokota, H. (2015). *Ideology of killing people with disabilities*. Tokyo, Japan: Gendai Shokan.



Can We Say They are also Beautiful? Disability is not a Curse by [Mahtab Ahmad](#) is licensed under a [Creative Commons Attribution 4.0 International License](#). Based on a work at <http://rdsjournal.org/index.php/journal/article/view/796>. Permissions beyond the scope of this license may be available at <https://www.rds.hawaii.edu>.

Research Article

Aversive Ableism: Modern Prejudice Towards Disabled People

Carli Friedman, PhD

Council on Quality and Leadership

Abstract: The aim of this study was to examine the patterns of explicit (conscious) and implicit (unconscious) disability prejudice. The majority of participants were implicitly prejudiced against disabled people despite having low explicit prejudice. This pattern is in alignment with aversive ableism — disability prejudice was present among those who meant well.

Keywords: aversive ableism; prejudice; ableism

Unlike the historically prominent medical model of disability that frames disability as an individualized problem one “suffers” from and needs treatment for (Linton, 1998), the ideological shift to the social model conceptualizes disability as something that is socially constructed—a form of social oppression. Under this model, Barnes and Mercer (2003) “conceptualize disability as a form of social oppression akin to sexism and racism, although it exhibits a distinctive form, with its own dynamics...as a historically and culturally specific form of social oppression” (p. 18). Abberley (1987) also argues that the social model or social theory of disability is strongest when it is based on the concept of oppression. Abberley discusses oppression as socially created disadvantages that are placed upon disabled people. This includes the recognition of the social origins of impairment, and opposition to the economic, social, environmental, and psychological disadvantages imposed on disabled people.

Systemic discrimination, which is rooted in history, constitutes a significant amount of the oppression disabled people face. Barnes (1997) suggests, “To appreciate fully the extent and significance of the oppression of disabled people an understanding of history and its relationship to western culture: the central value system around which western society is clustered, is vital” (p. 4). According to Barnes, one of the important tenets of ancient Greek and Roman society was citizenship. The creation of the civilized man justified oppression because the creation of this category (civilized) also created an opposite; it made others, such as disabled people, uncivilized and justified their unequal treatment as such (Barnes, 1997). In early Christian and Jewish culture impairments were viewed as God’s punishment for wrongdoing (Barnes, 1997). In the 16th century, plagues, poor harvests, and reduced church wealth pressured the State to intervene in poverty (Barnes, 1997). In doing so, the first poor laws created a distinction between deserving and undeserving poor. Industrialization, which began in the 18th century, brought a period of enlightenment that emphasized science and reason (Barnes, 1997). Barnes argues this is where disability in its current form emerged as a result of productivity, medicalization, and the creation of normality.

In more recent history, disabled people were first addressed as a class by United States

policy that defined them as sickly, such as ugly laws or “unsightly beggar ordinances” (Schweik, 2009, p. 140). Developed out of fear, these policies suggested purpose was to prevent people from getting disease by making sure they did not gaze upon those who were “ugly;” they also served to keep disabled people out of sight (Schweik, 2009). Another example of disability discrimination is when disability was used to justify the oppression and unequal treatment of women and other social minority groups in America (Baynton, 2001). According to Baynton, in the past Black people were seen as a disabled race in terms of biology because they were thought to have weaker organs and “suffered” from conditions such as Drapetomania, which caused enslaved people to run away. Moreover, suffragettes argued, “They were not disabled...and therefore were not proper subjects for discrimination” in order to win the right to vote (Baynton, 2001, p. 34). The linking of Black people and women with disability revealed not only an attempt to portray these groups as weak but also served to reinforce stereotypes of disability as unfit and therefore deserving of “less than.”

Although these historical examples may seem like ignorant decisions of the past, disabled people still face pervasive discrimination. For example, about 50% of disabled people experience poverty (Fremstad, 2009). The unemployment rate for disabled people has never been below its pre-civil war rate of 70% in the United States (Russell, 2000). To this day, disabled people are still forcibly sterilized for eugenic reasons (Alexander & Gomez, 2017; Garland-Thomson, 2017; Tilley, Walmsley, Earlea, & Atkinson, 2012). [Similarly, women of color are still forcibly sterilized for eugenic motivations (Johnson, 2013; Krase, 2014; Nittle, 2017) that parallel Baynton’s (2001) discussion of a portrayal of a ‘disabled race’ above, indicating traditional forms of prejudice and discrimination are far from resolved.] These are just a few examples of how disabled people are commonly discriminated against on both individual and systemic levels. Indeed, ableism, which Linton (1998) defines as “discrimination in favor of the able-bodied,” including “the idea that a person’s abilities or characteristics are determined by disability or that disabled people as a group are inferior to nondisabled people” (p. 9), still occurs today, although perhaps less often in the form of extremely overt policies such as ugly laws. Instead, many disabled people face subtle discrimination which is embedded in structures and social systems (Chen, Ma, & Zhang, 2011; Doyle, 2002; Keller & Galgay, 2010; Proctor, 2011; Rojahn, Komelasky, & Man, 2008). Ableism manifests itself through institutional, systemic, and subtle discrimination, however research has tended to focus less on subtle and implicit (unconscious) prejudice – everyday prejudice (Harpur, 2011; Keller & Galgay, 2010; Linton, 1998; Thompson, Bryson, & de Castell, 2001). Fortunately, disability’s theoretical and policy designation as a social minority, analogous in some ways to race, allows for other theories about discrimination to be investigated for relevance to disability.

Social Psychology Research on Modern Racism

The field of social psychology has examined different forms of modern implicit racism at length. Beginning in the 1950s the field changed to view prejudice as a normative process thereby shifting the focus away from pathology. As a result, this wave of study saw prejudice as existing in a large majority of people rather than a small subset of the deviant population

(Dovidio, 2001; Gamst, Liang, & Der-Karabetian, 2011). Doing so birthed major research theories on unintentional and subtle modern biases such as those examined by symbolic¹ racism and aversive racism theories.

Unlike old-fashioned racism that looked at overt and dominant prejudice, symbolic racists believe racial discrimination is no longer a serious problem, disadvantaged Black people are just unwilling to take responsibility for their lives, Black people are demanding too much too quickly and thus going beyond what is “fair,” and the special treatment of Black people is not justified (Henry & Sears, 2002; McConahay & Hough, 1976; Sears & Henry, 2003, 2005; Sears, Henry, & Kosterman, 2000). Symbolic racism is rooted in abstract beliefs about socialized values, which Black people supposedly violate (Henry & Sears, 2002, 2008; McConahay & Hough, 1976; Sears et al., 2000). In order to be subtle and not overt, symbolic racism is typically expressed through symbols such as opposition to busing for integration. Symbolic racism is related to racial antipathy and conservative values, especially because “it is based on the belief that Blacks violate key American values, particularly the idea of individualism, the belief in working hard to get ahead in life” (Henry & Sears, 2008, p. 111). As a result, it is not uncommon for symbolic racism to influence political attitudes (Henry & Sears, 2008). However, symbolic racism operates separately with conservatism:

“General conservatism and traditional racial prejudice are psychologically separable and distinctive, but symbolic racism is grounded about equally in both. That is, symbolic racism is the glue that links political conservatism to racial prejudice” (Sears & Henry, 2003, p. 264).

Unlike symbolic racism that looks at subtle discrimination that exists among conservatives, aversive racism theory specifically focuses on those people who are progressive and well-meaning yet still participate in biased actions or thought (Dovidio, Pagotto, & Hebl, 2011; Gaertner & Dovidio, 1986; Gaertner, Dovidio, Nier, & Hodson, 2005). Aversive racists are those who believe they are not prejudiced—in fact, egalitarian values are important to their self-image—yet feel discomfort around Black people. When situations are not ambiguous and norms for behavior are well defined they will not participate in prejudiced acts or hold prejudiced beliefs; in fact, they may go out of their way to appear non-prejudiced in these situations (Dovidio & Gaertner, 2008; Gaertner & Dovidio, 1986, 2005). However, aversive racists act in prejudiced ways in ambiguous situations where it is harder to be “caught” being racist (Dovidio & Gaertner, 2008; Gaertner & Dovidio, 1986, 2005; Gaertner et al., 2005; Murrell et al., 1994). Thus, this form of racism theory examines aversive racists’ anxiety and discomfort around Black people, how this prejudice is inconsistent with their self-concepts, and the rationalized disassociated products of these inconsistencies.

Modern Disability Prejudice

Mainstream narratives portray disabled people in many harmful ways. For example, disabled people are commonly portrayed as pitiful, helpless, and bitter. These portrayals stress

that disability is inherently negative and problematic and accordingly assumes disabled people are incapable and resentful. These portrayals of disability also inform nondisabled people's attitudes towards disabled people. Although they may hold these problematic and negative views about disability, nondisabled people often simultaneously associate positive socially desirable traits to disabled people. These positively held beliefs are problematic not only because they create unfair expectations but also because they tend to impact how nondisabled people interact with disabled people. Thus, disability is located at an intersection unique to most social minority groups in that disabled people are both viewed negatively and often treated with particular care. These layers of attitudes are why it is particularly important to examine the complexities of disability attitudes and ableism.

Disability attitudes may appear positive thus making disability prejudice more hidden in its modern form. As disability prejudice can be confusing because it is almost always exclusively implicit rather than explicit (conscious), aversive racism theory may be a great window to examine it. I theorize that nondisabled people's interaction with disabled people is more likely to be prejudiced in an aversive rather than symbolic fashion because social norms dictate it is not acceptable to discriminate (at least overtly) against disabled people – people would look 'bad' doing so. Social norms also dictate helping those in inferior and pitiable positions; people see disabled people as more deserving of help and positive treatment (Appelbaum, 2001; Garthwaite, 2011; Imrie & Wells, 1993; Stewart, Harris, & Sapey, 1999). Thus, the aim of this study was to establish a construct of aversive ableism by examining the patterns of explicit and implicit disability prejudice. To do so, this study operated under the following hypothesis: the majority of participants will be prejudiced in the aversive ableism pattern. This hypothesis was examined by comparing scores of participants on the explicit Symbolic Ableism Scale (SAS) and the Disability Attitudes Implicit Association Test (DA-IAT). A regression of explicit and implicit prejudice was conducted with linear, quadratic, and cubic components in order to explore the best-fit form of the relationship. Then, participants' scores were categorized into prejudice styles using an adapted version of Son Hing, Chung-Yan, Hamilton, and Zanna's (2008) two-dimensional model of prejudice.

Methods

Participants

Since it was expected that disability prejudice most commonly operates implicitly, different groups of participants were used to maximize the presence of different types of implicit prejudice. That is, to try to get the widest range of implicit prejudice instead of those who are all very prejudiced. Participants were graduate and undergraduate students recruited through a large diverse urban university. Graduate students were working towards a doctorate or master's degree in a disability related field, while the undergraduate students came from a wide variety of disciplines across the university but were taking an undergraduate level course related to disability. It was theorized that these participant groups would produce a spectrum of implicit prejudice because of their varying relationships with disability. It was expected that the graduate students would serve as the 'low norm' as they would have lower implicit levels of prejudice or favor disabled people because of their interaction with disability studies

and the disability community. Students in undergraduate level classes self-selected to take disability courses so it was expected they would have somewhat less implicit prejudice than the general population but it is likely they still have implicit prejudice because they are less likely to have the depth of understanding of disability studies graduate students.

To determine the minimum necessary sample size, an a priori G*Power analysis was completed using G*Power 3.1 (Erdfelder, Faul, & Buchner, 1996; Faul, Erdfelder, Buchner, & Lang, 2009; Faul, Erdfelder, Lang, & Buchner, 2007). As the aim was to have large variation in *D* scores (DA-IAT), for the G*Power calculation the group means used were from -.65 to .65; $M = 0$, $SD = .44$; power $(1 - \beta) = .95$; $\alpha = .05$. The analysis indicated that a total sample of 35 people would be needed for the large effect size ($\eta^2 = .93$). To strengthen the research, the goal was to have about 100 people complete the study. However, size was dependent on who volunteered for the study, thus we had 84 participants. Participant demographics can be seen in Table 1.

Table 1: Demographic of Sample

<i>Demographics of Sample</i>		
Characteristic	<i>n</i>	%
Gender		
Woman	71	84.5
Man	12	14.3
Neither	1	1.2
Age range		
18-25	66	78.6
26-33	14	16.7
34-40	2	2.4
41-48	1	1.2
49-56	1	1.2
Disability		
No	67	79.8
Yes	14	16.7
Prefer not to say	3	3.6
Race		
White	32	38.1
Asian or Pacific islander	22	26.2
Hispanic or Latino/a	16	19
Black	6	7.1
Middle Eastern	4	4.8
Interracial	3	3.6
Other	1	1.2
Education level		
Undergraduate	68	81.0
Graduate	16	19.0
Political orientation		
Liberal	48	57.1
Conservative	8	9.5
Other	28	33.3

Instruments

Disability Attitudes Implicit Association Test

One of the most prominent implicit methods is the Implicit Associations Test (IAT), a projective method (Greenwald, McGee, & Schwartz, 1998). The IAT presents participants with two target-concept discriminations (e.g., Black and White) and two attribute dimensions (e.g., pleasant and unpleasant). Participants must categorize stimuli as belonging to the categories in different stereotype congruent and incongruent combinations. By measuring reaction time the IAT is able to examine associations – the quicker the reaction time, the stronger the association between groups and traits (Karpinski & Hilton, 2001).

The DA-IAT (Greenwald et al., 1998) is the most prominent disability related IAT. The DA-IAT is similar to the standard IAT, except it uses symbols to represent ‘disabled-persons’ and ‘abled-persons’ target-concept discriminations and word stimuli for ‘good’ and ‘bad’ attribute dimensions. For example, the wheelchair symbol represents disabled people while someone skiing represents a nondisabled person. Several studies have shown the DA-IAT’s construct validity (Aaberg, 2012; Pruett, 2004; Pruett & Chan, 2006), discriminant validity (White et al., 2006), and reliability (Pruett, 2004; Pruett & Chan, 2006; Thomas et al., 2014). Moreover, research has shown that even when participants try to fake an IAT, faking is evident (Cvencek et al., 2010). The IAT has built in safeguards against participants selecting at random or trying to fake. The updated scoring algorithm includes eliminating any trials with response latencies of greater than 10,000 milliseconds (Greenwald et al., 2003). Moreover, any subjects who have 10% or more trials less than 300 milliseconds will be removed (Greenwald et al., 2003).

Symbolic Ableism Scale

The Symbolic Ableism Scale (SAS) (Friedman & Awsumb, in press) was used to measure participants’ explicit bias. The SAS presents participants with thirteen statements about disability on a seven-point Likert scale (from strongly disagree to strongly agree). For example, one item is: “disabled people are demanding too much from the rest of society.” The SAS has been found to have good construct validity (Friedman & Awsumb, in press).

Procedure

After approval from the university’s Institutional Review Board, this study was administered to participants on a unique website. After being presented with the informed consent, participants received instructions about the DA-IAT; they were told to push the ‘E’ key if the stimuli belonged in the categories listed on the left and the ‘I’ on the right. They were told to do this as quickly as possible but with the least amount of errors. If participants placed stimuli to the wrong side a red X appeared in the middle of the screen until they made the correct choice.

The DA-IAT involves seven blocks (rounds) of categorization tasks. In the first DA-IAT practice block the screen shows only the target-concept discriminations with ‘abled-persons’ on the left of the screen and ‘disabled persons’ on the right. Participants were presented with 20 trials of randomized disabled and abled-persons stimuli in the middle of the screen and were asked to sort them accordingly. The second practice block is similar; ‘good’ is on the left of the screen and ‘bad’ is on the right and participants sort the related good and bad stimuli for 20 trials. For block three both ‘abled-persons’ and ‘good’ are on the left and ‘disabled persons’ and ‘bad’ are on the right. They were then presented with all the stimuli options for 20 trials. Block four is exactly the same except it lasts for 40 trials. Block five, which lasts 40 trials, is also a practice block where only ‘bad’ is listed on the left and ‘good’ on the right and they were only presented with good and bad stimuli. This gives participants the opportunity to get used to the switched location of these two attribute dimensions. Block six begins the stereotype inconsistent items. For both block six and seven ‘disabled persons’

and ‘good’ are on the left and ‘abled-persons’ and ‘bad’ are on the right. They are presented with all of the stimuli again. Block six includes 20 trials while block seven includes 40. Participants were randomized to receive either this order of blocks or stereotype inconsistent items in block three and four (disabled persons and good and abled-persons and bad) and then consistent in blocks six and seven (disabled persons and bad and abled-persons and good).

After completing the DA-IAT, participants completed the SAS. The IAT was administered before the SAS to avoid any possible priming. Finally, participants answered questions about their demographics.

Analysis

SPSS 21 was used for all analysis. The implicit *D* scores from the DA-IAT were analyzed using the updated IAT scoring procedure (Greenwald et al., 2003). *D* scores were produced for each participant based on their response latencies in stereotype consistent and stereotype inconsistent blocks. Scores of implicit prejudice (DA-IAT) reported the strength of preference for nondisabled or disabled people. *D* scores larger than .14 reveal a preference for nondisabled people over disabled ones (Aaberg, 2012; Greenwald et al., 2003). Scores of .15 to .34 reveal a slight preference for nondisabled people, .35 to .64 a moderate preference, and .65 and greater a strong preference (Aaberg, 2012; Greenwald et al., 2003). Negative values of the same values above reveal preferences for disabled people, and scores from -.14 to .14 reveal no prejudice (Aaberg, 2012; Greenwald et al., 2003).

Explicit measures of the symbolic ableism seven-point Likert scale were first reverse scored when applicable and then recoded from one to seven to zero to one in accordance with the SAS. An explicit disability prejudice SAS score was calculated for each participant using the mean score of these Likert items.

The relationship between implicit and explicit prejudice was examined using linear, quadratic, and cubic regressions to determine the best-fit form of the relationship. Then, in order to determine types of prejudice present in alignment with Son Hing et al.’s (2008) two-dimensional model of prejudice participants’ explicit and implicit scores were categorized as high and low. There are no standardized cut-offs for high and low for explicit and implicit prejudice levels; Son Hing et al. (2008) comment, “a potential problem with this approach [of classifying as explicit and implicit scores as high and low] is that cut-off scores are sample specific and malleable” (p. 983). For this reason, implicit scores were cut-off based on the moderate prejudice level (.35) according to IAT standards. The SAS cut-off used was the mid-point equivalent on the Likert scale (.50). After the explicit and implicit scores were categorized as high and low, profiles from Son Hing et al.’s (2008) two-dimensional model of prejudice were used to categorize types of prejudice: high explicit and high implicit are symbolic prejudiced; high explicit and low implicit are principled conservatives²; low explicit and high implicit are aversive prejudiced; and, low explicit and low implicit are truly low prejudiced.

Results

The mean of all participants' ($n = 84$) explicit scores was .31 ($SD = .13$) (moderate explicit prejudice). Figure 1 details the density and distribution of the explicit prejudice results. The results on the Shapiro-Wilk's test were not significant suggesting the scores were normally distributed.

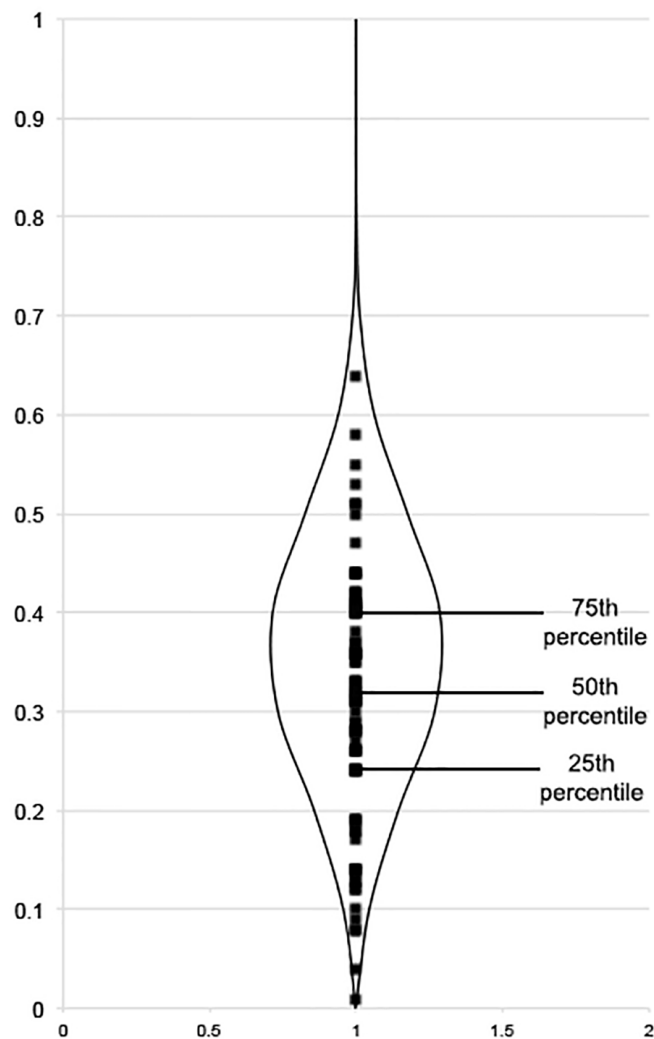


Figure 1. Beanplot of explicit prejudice. The beanplot's shape details explicit prejudice's density while the beans mark the distribution of scores. The beanplot indicates most people scored within .2 and .4 on the SAS.

On the DA-IAT, the participants had a mean D score of .45 ($SD = .44$) (moderate preference for nondisabled people). This score was significantly different from zero according to a one-tailed t -test ($t(81) = 9.28, p < .001$), indicating an implicit preference for nondisabled people. In this study 79.3% ($n = 65$) of participants preferred nondisabled people, 9.8% ($n = 8$) preferred disabled people, and 11% ($n = 9$) had no preference. The majority of participants *strongly* preferred nondisabled people; see Figure 2 for the distribution of scores. It should be noted two participants' D scores were excluded from the analysis. One participant's D score

was excluded because it was an extreme outlier that affected the normality and caused a failed Shapiro-Wilk test. The other participant's D score was excluded because of an error rate greater than 30%³, suggesting they were not following instructions or did not understand the task.

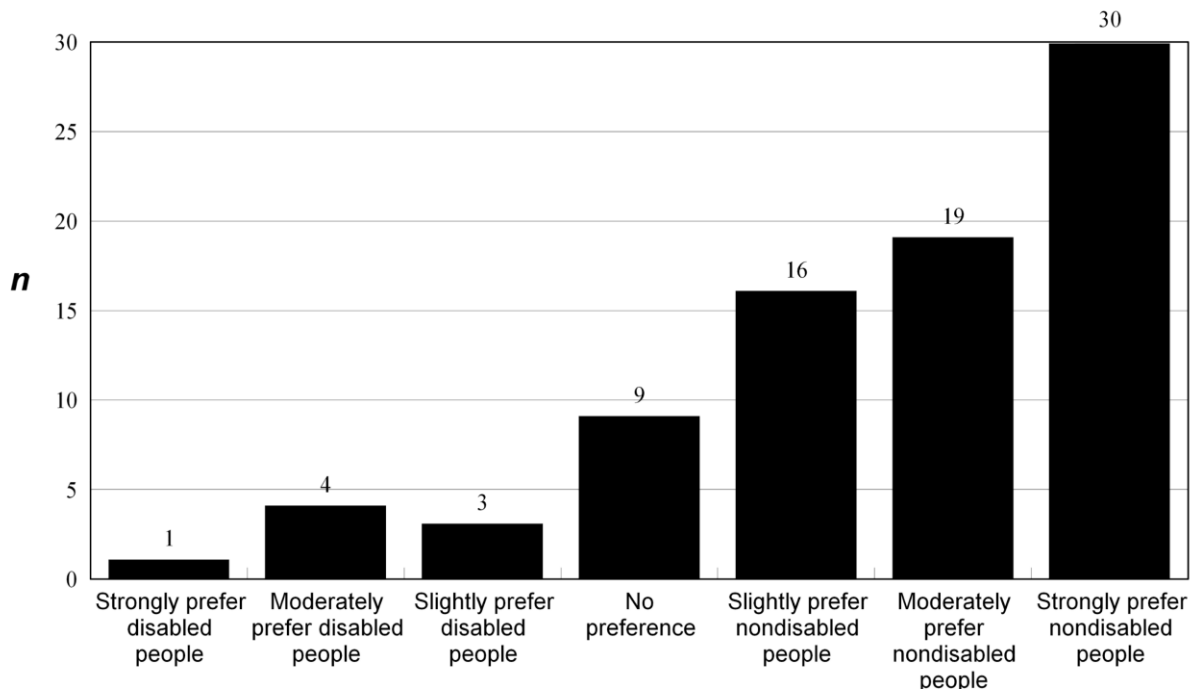


Figure 2. Implicit preferences for nondisabled and disabled people. The figure indicates the majority of people preferred nondisabled people, with fewer people scoring as having no preference, or preferring disabled people.

A centered regression analysis was conducted to evaluate the relationship between explicit and implicit scores and the prediction of the implicit scores from the explicit scores. The variables have a quadratic relationship, which was significant $F(2, 79) = 5.31, p = .007$. The regression equation for predicting the implicit scores from the explicit scores is

$$\text{Implicit Score} = .52 + .98(\text{Explicit Score} - .31) - 4.41(\text{Explicit Score} - .31)^2$$

For example, according to the model, a person with an explicit score of 0 would be expected to have an implicit score of -.21 (slightly prefer disabled people), an explicit score of .25 would indicate an implicit score of .45 (moderately prefer nondisabled people), and an explicit score of .50 would suggest an implicit score of .55 (moderately prefer nondisabled people). Both the explicit mean deviation score and the quadratic term were significant at $t = 2.46, p = .016$ and $t = -2.00, p = .049$ respectively. Although statistically significant, this model only predicts 12% of the implicit scores so it is still a fairly weak relationship.

In order to determine types of prejudice present in alignment with an adapted version of Son Hing et al.'s (2008) two-dimensional model of prejudice participants' explicit and implicit scores were categorized as high and low. Using these criteria participants' scores

were then grouped into symbolic ableist (high explicit, high implicit), principled conservatives (high explicit, low implicit), aversive ableist (low explicit, high implicit), and truly low prejudiced (low explicit, low implicit). Participants were classified as 5 symbolic ableists, 44 aversive ableists, 2 principled conservatives, and 31 truly lowly prejudiced (Figure 3).

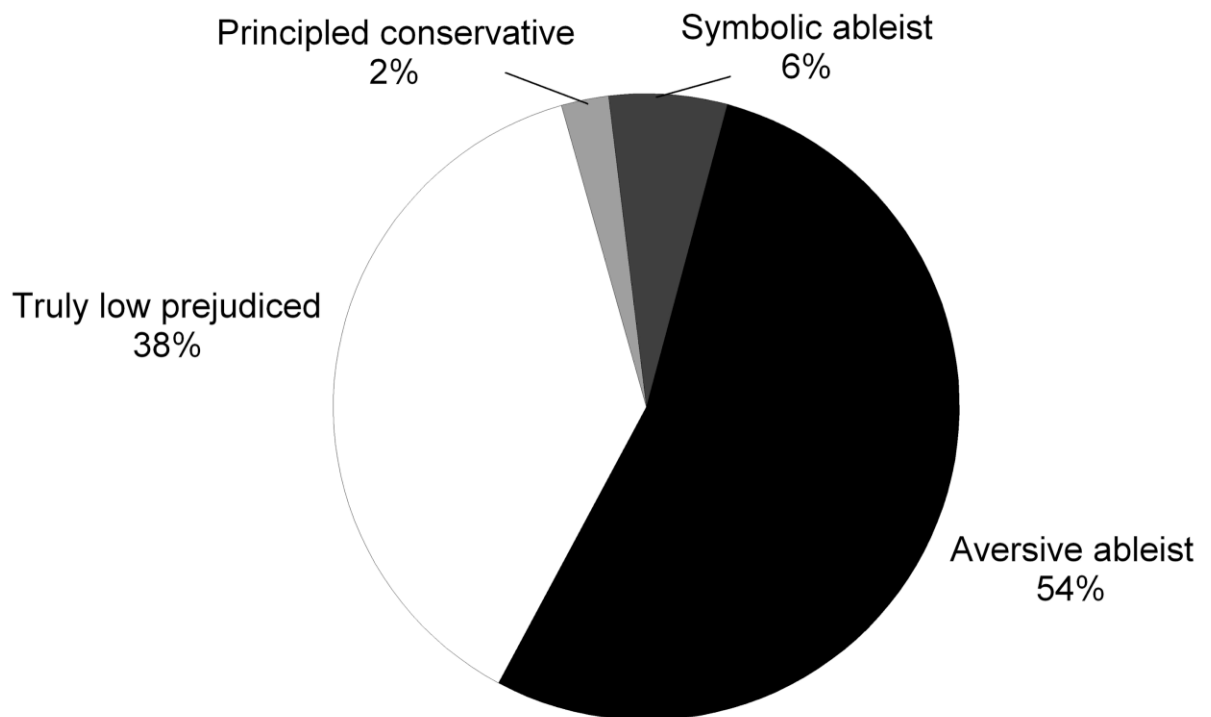


Figure 3. Styles of prejudice ($n = 82$). This figure shows the breakdown of participants' ableism types; the majority of participants fell into the aversive ableist category with fewer truly low prejudiced, symbolic ableist, or principled conservative.

Discussion

Reconceptualizing ableism in a less dichotomous nature can help us reframe ableism to better capture, and in the future change, the complexities of everyday unconscious microaggressions that are so detrimental to disabled people. In order to help complicate current understandings of ableism – to interrupt a dichotomous understanding of ableism in which one is prejudiced or not – this study established the construct of aversive ableism by examining the patterns of explicit and implicit prejudice using an adapted version of Son Hing et al.'s (2008) two-dimensional model of prejudice. Doing so was a necessary first step so that the intricacies of these complex and multidimensional forms of prejudice can be mapped and, ultimately, reduced.

It was theorized that nondisabled people's interaction with disabled people is more likely to be prejudiced in an aversive (low explicit, high implicit) rather than symbolic fashion

(high explicit, high implicit) because social norms dictate it is not acceptable to discriminate (at least overtly) against disabled people. In alignment with the study's hypothesis, findings revealed although explicit scores were fairly low, suggesting people consciously held (or recognized holding) little prejudice, the majority of the participants preferred nondisabled people implicitly, indicating they were indeed prejudiced. This pattern is in alignment with aversive ableism. Using this model, the majority of participants were aversive ableists (54% aversive ableists, 38% truly low prejudiced, 6% symbolic ableists, and 2% principled conservative). Our findings indicate many people are more prejudiced against disabled people than they understand or recognize; in fact, our findings suggest that this may be the most common type of modern prejudice – those who feel positively but hold negative attitudes about disabled people.

Now that the two-dimensional concept of aversive ableism has been documented, all aspects of how this prejudice operates must be understood. A necessary next step to build upon and map this concept is for research to now explore the differentiations between aversive ableism and aversive racism. The subtle experiences of discrimination disabled people face are particular to them because of both their unique history and their present-day experiences as a discriminated against social minority. On the basis of common disability narratives and stereotypes, there will be some differences between aversive racism and aversive ableism both in context and expression; aversive racism cannot just be “applied” to disability. These disability narratives are not only harmful but also differentiate disabled people from other social minority groups. For example, the inspiration narrative that dictates that everything disabled people do is inspirational because they must ‘overcome’ their disability is harmful for disabled people because it implies either that they are not normal or that they achieve monumental tasks ‘despite’ their disability. Not only does this not reflect the lived reality of most people, it also creates unattainable expectations for disabled people by perpetuating the myth that their true disability is a bad attitude instead of institutional barriers (Tighe, 2001). Another disability narrative that most likely interacts with aversive ableism is pity. Although having pity for someone is not inherently negative, the pity narrative is harmful for disabled people because it assumes that they are inherently tragic because of their disabilities, that they are incapable, or that they are victims (Reid, Stoughton, & Smith, 2006). These factors, among others, separate disabled people and the discrimination they face from other social minorities. For this reason, their experiences will be unique. Aversive ableism is not likely just to be aversive racism by another name applied to another group; rather, it likely builds on an understanding of prejudice often too subtle to articulate in rapid social interaction but which affects the group immensely. These layers of attitudes are why it is particularly important to examine nondisabled peoples’ explicit and implicit attitudes about disability, especially how they may differ from similar forms of racism. Aversive racism has useful lessons for disability; however, it also raises many points of difference between race and disability that suggest a need for a unique concept of aversive ableism that is ultimately unique from aversive racism.

This study's evidence of aversive ableism is one of the first steps in developing the

construct of aversive ableism. However, aversive ableism, like aversive racism, is a complex concept that is beyond the scope of just one study. Future research can “examine prejudice as it relates to unambiguously meaningful behaviors and among relevant populations... to make progress in this debate” (Payne, Krosnick, Pasek, Lelkes, Akhtar, & Tompson, 2010, p. 368; von Hippel, Brener, & von Hippel, 2008). This includes examining how it may differ from aversive racism theory as suggested above but also future aversive ableism studies could benefit from expanding to larger groups of participants from wider backgrounds. For example, one possibility for future study of aversive ableism is to focus on different groups such as direct support professionals or families of disabled people that interact with disabled people yet may hold aversive attitudes.

Another avenue for the future to explore is the relationship between political orientation and symbolic and aversive ableism. The differentiation between conservatives and liberals’ disability prejudice may be less clear-cut than with racism because of complex attitudes towards disabled people and social norms that portray disabled people as deserving of positive and favorable treatment. Conservative ‘pull yourself up by your bootstrap’ individualism and dislike for welfare systems may certainly interfere with their views of disabled people; however:

“Unlike the experience of many minorities, opposition to disability rights seldom has been marked by overt displays of bigotry or hostility; and politicians have often been included to provide sympathetic endorsements for the goals of disabled persons, even when they have shown strong resistance to the claims of other disadvantaged groups” (Hahn, 2005, p. 42).

Moreover, as Berdein (2007) found principles are not consistent across people, and some conservatives apply and abandon their principles differently depending on race, the differentiation between principled conservatism and symbolic ableism needs to be explored more in depth.

Although this study has uncovered many aspects of aversive ableism, it is not without its limitations. One major limitation of this study was related to the subject pool. Because of financial restrictions this study’s participants were all students. Although there is a precedent for using university students as participants, especially in social sciences research, students are young and more often from middle class backgrounds (Peterson, 2001; Peterson & Merunka, 2014; Walpole, 2003). Despite recruitment occurring at a very diverse urban university, it is possible the results would be different if it had been possible to have random subjects from the general population. Similarly, although the study aimed for an even gender breakdown, the majority of participants were women. This may have implications as women in Hirschberger, Florian, & Mikulincer’s (2005) study had more favorable attitudes towards disabled people than men. This study took place in an university environment; it is possible aversive ableism is enacted differently in these settings than in the real world. This subject pool is also limited by the volunteer basis of its participants. There is a chance of self-selection bias as a result. Similarly, another limitation of this study was that participants were

more educated about disability than the general population. This is tied to a potential selection bias because all participants are in disability related courses. It is likely that the general population of disabled people would have more implicit prejudice (Nosek, Smyth, Hansen, Devos, Lindner, Ranganath, & Banaji, 2007) and therefore significantly less people would fall into the ‘truly low prejudice category.’

Once research has shown a more in depth understanding of aversive ableism, work can begin to reduce this subtle yet common form of disability prejudice. Aversive forms of prejudice are not so easily reduced because people already believe they are being egalitarian – they are not motivated to change because they do not realize they are prejudiced (Gaertner & Dovidio, 1986, 2005). Gaertner et al. (2005) explains, “Like a virus that has mutated, racism may have evolved into different forms that are more difficult not only to recognize but also to combat” (p. 385). While its inevitability is often assumed, the social devaluation of disabled people is not inevitable and can be reduced, although not easily (Gill, 2000; Susman, 1994). Although according to literature on aversive racism simply telling people they are prejudiced is not an effective intervention, in terms of reducing aversive racism, the most prominent intervention is the common ingroup identity model, which in recognizing the role of social categorization, uses the positive consequences of ingroup membership and recategorization instead of trying to reduce the negatives of outgroup membership (Dovidio & Gaertner, 2004; Dovidio, Gaertner, Anastasio, & Sanitioso, 1992; Gaertner & Dovidio, 2005; Murrell et al., 1994). Future research should examine if the common ingroup identity model is also a useful intervention to reduce aversive ableism. In the meantime, at the very least, it may be more fruitful for people to critically examine ones’ own privileges and prejudices than to do nothing. Certainly, no harm is going to come from figuring out how one is committing microaggressions and consciously trying to change ones’ behavior.

Many participants in this study believed they viewed disabled people positively. Yet, the types of discrimination and prejudice that have been evidenced for so long in literature were still present among people who meant well. This pattern of prejudice – aversive ableism – may be one of the most prominent forms of ableism today. In order to combat it, we must first understand it. This study took one of the first steps by establishing aversive ableism as a two-dimensional construct, and reconceptualizing ableism as a spectrum. Next, the hard work of disrupting these unconscious processes can begin. Doing so is necessary to end the social oppression of disabled people.

Carli Friedman, PhD. is the Director of Research at The Council on Quality and Leadership (CQL). She received her PhD in Disability Studies from the University of Illinois of Chicago. Her research focuses on ableism, meaningful community inclusion, and quality of life.

References

- Aaberg, V. A. (2012). A path to greater inclusivity through understanding implicit attitudes toward disability. *The Journal of Nursing Education, 51*(9), 505-510.
doi:10.3928/01484834-20120706-02

- Abberley, P. (1987). The concept of oppression and the development of a social theory of disability. *Disability, Handicap & Society*, 2(1), 5-19. doi:10.1080/02674648766780021
- Alexander, N., & Taylor Gomez, M. (2017). Pleasure, sex, prohibition, intellectual disability and dangerous ideas. *Reproductive Health Matters*, 25(50), 114-120, doi: 10.1080/09688080.2017.1331690
- Appelbaum, L. D. (2001). The influence of perceived deservingness on policy decisions regarding aid to the poor. *Political Psychology*, 22(3), 419-442. doi:10.2307/3792421
- Barnes, C. (1997). A legacy of oppression: A history of disability in Western culture. In L. Baron & M. Oliver (Eds.), *Disability studies: Past, present and future* (pp. 3-24). Leeds: The Disability Press.
- Baynton, D. C. (2001). Disability and the justification of inequality in American history. In P. Longmore & L. Umansky (Eds.), *The new disability history: American perspectives* (pp. 33-57). New York: University Press.
- Berdein, I. (2007). *Principled conservatives or covert racists: Disentangling racism and ideology through implicit measures (Doctoral dissertation)*. Stony Brook University, Stony Brook, NY.
- Chen, S., Ma, L., & Zhang, J.-X. (2011). Chinese undergraduates' explicit and implicit attitudes toward persons with disabilities. *Rehabilitation Counseling Bulletin*, 55(1), 38-45. doi:10.1177/0034355211410705
- Cvencek, D., Greenwald, A. G., Brown, A. S., Gray, N. S., & Snowden, R. J. (2010). Faking of the implicit association test is statistically detectable and partly correctable. *Basic & Applied Social Psychology*, 32, 302-314. doi:10.1080/01973533.2010.519236
- Cvencek, D., Greenwald, A. G., & Meltzoff, A. N. (2011). Measuring implicit attitudes of 4-year-olds: The Preschool Implicit Association Test. *Journal of Experimental Child Psychology*, 109, 187-200. doi:10.1016/j.jecp.2010.11.002
- Cvencek, D., Meltzoff, A. N., & Greenwald, A. G. (2011). Math-gender stereotypes in elementary school children. *Child Development*, 82(3), 766-779. doi:10.1111/j.1467-8624.2010.01529.x
- Dionne, C. D., Gainforth, H. L., O'Malley, D. A., & Latimer-Cheung, A. E. (2013). Examining implicit attitudes towards exercisers with a physical disability. *The Scientific World Journal*, 2013. doi:10.1155/2013/621596
- Dovidio, J. F. (2001). On the nature of contemporary prejudice: The third wave. *Journal of Social Issues*, 57(4), 829-849. doi:10.1111/0022-4537.00244
- Dovidio, J. F., & Gaertner, S. L. (2004). Aversive racism. *Advances in Experimental Social Psychology*, 36(1), 1-52. doi:10.1016/S0065-2601(04)36001-6
- Dovidio, J. F., & Gaertner, S. L. (2008). New directions in aversive racism research: Persistence and pervasiveness. In C. Willis-Esqueda (Ed.), *Motivational aspects of prejudice and racism* (pp. 43-67): Springer New York.

- Dovidio, J. F., Gaertner, S. L., Anastasio, P. A., & Sanitioso, R. K. (1992). Cognitive and motivational bases of bias: Implications of aversive racism for attitudes toward Hispanics. In S. B. Knouse, P. Rosenfeld, & A. Culbertson (Eds.), *Hispanics in the workplace* (pp. 75-106). Newbury Park, California: Sage Publications.
- Dovidio, J. F., Pagotto, L., & Hebl, M. R. (2011). Implicit attitudes and discrimination against people with physical disabilities. In R. L. Wiener & S. L. Willborn (Eds.), *Disability and Aging Discrimination* (pp. 157-183). New York: Springer.
- Doyle, A. (2002). *The viability of the implicit association test applied to attitudes toward individuals with disabilities and measurement of coworker attitudes toward individuals with a disability*. (Master of Arts), Western Kentucky University, Bowling Green, Kentucky. Retrieved from <http://digitalcommons.wku.edu/theses/654> (654)
- Enea-Drapeau, C., Carlier, M., & Huguet, P. (2012). Tracking subtle stereotypes of children with trisomy 21: From facial-feature-based to implicit stereotyping. *PloS one*, 7(4), e34369. doi:10.1371/journal.pone.0034369
- Erdfelder, E., Faul, F., & Buchner, A. (1996). GPOWER: A general power analysis program. *Behavior Research Methods, Instruments, & Computers*, 28(1), 1-11. doi:10.3758/BF03203630
- Faul, F., Erdfelder, E., Buchner, A., & Lang, A.-G. (2009). Statistical power analyses using G* Power 3.1: Tests for correlation and regression analyses. *Behavior research methods*, 41(4), 1149-1160. doi:10.3758/BRM.41.4.1149
- Faul, F., Erdfelder, E., Lang, A.-G., & Buchner, A. (2007). G* Power 3: A flexible statistical power analysis program for the social, behavioral, and biomedical sciences. *Behavior research methods*, 39(2), 175-191. doi:10.3758/BF03193146
- Fremstad, S. (2009). *Half in ten: Why taking disability into account is essential to reducing income poverty and expanding economic inclusion*. Washington, DC: Center for Economic and Policy Research.
- Friedman, C. & Awsumb, J. (in press). The Symbolic Ableism Scale. *Review of Disability Studies: An International Journal*.
- Gaertner, S. L., & Dovidio, J. F. (1986). The aversive form of racism. In S. L. Gaertner & J. F. Dovidio (Eds.), *Prejudice, discrimination, and racism: Theory and research* (pp. 61-89). Orlando: Academic Press.
- Gaertner, S. L., & Dovidio, J. F. (2005). Understanding and addressing contemporary racism: From aversive racism to the common ingroup identity model. *Journal of Social Issues*, 61(3), 615-639. doi:10.1111/j.1540-4560.2005.00424.x
- Gaertner, S. L., Dovidio, J. F., Nier, J., & Hodson, G. (2005). Aversive racism: Bias without intention. In L. B. Nielsen & R. L. Nelson (Eds.), *Handbook of employment discrimination research* (pp. 377-395). Netherlands: Springer.
- Gamst, G. C., Liang, C. T. H., & Der-Karabetian, A. (2011). Racism- and Prejudice-Related Measures *Handbook of Multicultural Measures* (pp. 251-335): SAGE Publications, Inc.

- Garland-Thomson, R. (2017). Eugenic world building and disability: The strange world of Kazuo Ishiguro's *Never Let Me Go*. *Journal of Medical Humanities*, 38(2), 133-145. doi: 10.1007/s10912-015-9368-y
- Garthwaite, K. (2011). 'The language of shirkers and scroungers?' Talking about illness, disability and coalition welfare reform. *Disability & Society*, 26(3), 369-372. doi:10.1080/09687599.2011.560420
- Gill, C. (2000). Divided understandings: The social experience of disability. In G. L. Albrecht, K. D. Seelman, & M. Bury (Eds.), *Handbook of Disability Studies* (pp. 351-372). Thousand Oaks: Sage.
- Greenwald, A. G., & Farnham, S. D. (2000). Using the implicit association test to measure self-esteem and self-concept. *Journal of Personality and Social Psychology*, 79(6), 1022-1038. doi:10.1037/0022-3514.79.6.1022
- Greenwald, A. G., McGhee, D. E., & Schwartz, J. L. K. (1998). Measuring individual differences in implicit cognition: The implicit association test. *Journal of Personality and Social Psychology*, 74(6), 1464-1480. doi:10.1037/0022-3514.74.6.1464
- Greenwald, A. G., Nosek, B. A., & Banaji, M. R. (2003). Understanding and using the Implicit Association Test: I. An improved scoring algorithm. *Journal of Personality and Social Psychology*, 85(2), 197-216. doi:10.1037/0022-3514.85.2.197
- Hahn, H. (2005). Antidiscrimination laws and social research on disability: the minority group perspective. In P. Blanck (Ed.), *Disability Rights* (pp. 343-361). Burlington, VT: Ashgate.
- Harpur, P. (2011). Embracing the new disability rights paradigm: The importance of the Convention on the Rights of Persons with Disabilities. *Disability & Society*, 27(1), 1-14. doi:10.1080/09687599.2012.631794
- Harris, R. M., & Harris, A. C. (1977). Devaluation of the disabled in fund raising appeals. *Rehabilitation Psychology*, 24(2), 69-78. doi:10.1037/h0090915
- Henry, P. J., & Sears, D. O. (2002). The Symbolic Racism 2000 Scale. *Political Psychology*, 23(2), 253-283. doi:10.1111/0162-895x.00281
- Henry, P. J., & Sears, D. O. (2008). Symbolic and modern racism. In J. H. Moore (Ed.), *Encyclopedia of race and racism* (pp. 111-117). Farmington Hills, MI: Macmillan Reference.
- Hirschberger, G., Florian, V., & Mikulincer, M. (2005). Fear and compassion: A terror management analysis of emotional reactions to physical disability. *Rehabilitation Psychology*, 50(3), 246-257. doi:10.1037/0090-5550.50.3.246
- Huang, Y., Wang, L., & Shi, J. (2009). When do objects become more attractive? The individual and interactive effects of choice and ownership on object evaluation. *Personality and Social Psychology Bulletin*, 35(6), 713-722. doi:10.1177/0146167209333046
- Ilavarasu, J. V., Rajesh, S. K., & Hankey, A. (2014). Implicit measure for yoga research: Yoga implicit association test. *International journal of yoga*, 7(2), 120.

doi:10.4103/0973-6131.133889

- Imrie, R. F., & Wells, P. (1993). Disablism, planning, and the built environment. *Environment and Planning C*, *11*, 213-213. doi:10.1068/c110213
- Johnson, C. G. (2013). Female inmates sterilized in California prisons without approval. Retrieved from <https://www.revealnews.org/article-legacy/female-inmates-sterilized-in-california-prisons-without-approval/>
- Karpinski, A., & Hilton, J. L. (2001). Attitudes and the Implicit Association Test. *Journal of Personality and Social Psychology*, *81*(5), 774-788. doi:10.1037/0022-3514.81.5.774
- Karpinski, A., Steinman, R. B., & Hilton, J. L. (2005). Attitude importance as a moderator of the relationship between implicit and explicit attitude measures. *Personality and Social Psychology Bulletin*, *31*(7), 949-962. doi:10.1177/0146167204273007
- Keller, R. M., & Galgay, C. (2010). Microaggressive experiences of people with disabilities. In D. W. Sue (Ed.), *Microaggressions and marginality: Manifestation, dynamics and impact* (pp. 241-267). Hoboken, NJ: John Wiley & Sons, Inc.
- Krase, K. (2014). History of forced sterilization and current U.S. abuses. Retrieved from <https://www.ourbodiesourselves.org/health-info/forced-sterilization/>
- Linton, S. (1998). *Claiming disability, knowledge and identity*. New York: New York University Press.
- Ma, L., Chen, S., Zhou, M., & Zhang, J. (2012). Social axioms and implicit attitudes about people with disabilities. *Social Behavior and Personality: an international journal*, *40*(2), 251-258. doi:10.2224/sbp.2012.40.2.251
- Maison, D., Greenwald, A. G., & Bruin, R. (2001). The Implicit Association Test as a measure of implicit consumer attitudes. *Polish Psychological Bulletin*, *32*(1), 61-69.
- McConahay, J. B., & Hough, J. C. (1976). Symbolic Racism. *Journal of Social Issues*, *32*(2), 23-45. doi:10.1111/j.1540-4560.1976.tb02493.x
- Murrell, A. J., Dietz-Uhler, B. L., Dovidio, J. F., Gaertner, S. L., & Drout, C. (1994). Aversive racism and resistance to affirmative action: Perception of justice are not necessarily color blind. *Basic and Applied Social Psychology*, *15*(1-2), 71-86. doi:10.1080/01973533.1994.9646073
- Nittle, N. K. (2017). The U.S. government's role in sterilizing women of color. Retrieved from <https://www.thoughtco.com/u-s-governments-role-sterilizing-women-of-color-2834600>
- Nosek, B. A., Banaji, M. R., & Greenwald, A. G. (2002). Harvesting implicit group attitudes and beliefs from a demonstration web site. *Group Dynamics: Theory, Research, and Practice*, *6*(1), 101-115. doi:10.1037//1089-2699.6.1.101
- Nosek, B. A., Smyth, F. L., Hansen, J. J., Devos, T., Lindner, N. M., Ranganath, K. A., . . . Banaji, M. R. (2007). Pervasiveness and correlates of implicit attitudes and stereotypes. *European Review of Social Psychology*, *1*(1), 1-53. doi:10.1080/10463280701489053

- Payne, B. K., Krosnick, J. A., Pasek, J., Lelkes, Y., Akhtar, O., & Tompson, T. (2010). Implicit and explicit prejudice in the 2008 American presidential election. *Journal of Experimental Social Psychology, 46*(2), 367-374. doi:<http://dx.doi.org/10.1016/j.jesp.2009.11.001>
- Peterson, Robert A. (2001). On the use of college students in social science research: Insights from a second-order meta-analysis. *Journal of Consumer Research, 28*(3), 450-461. doi:10.1086/323732
- Peterson, R. A., & Merunka, D. R. (2014). Convenience samples of college students and research reproducibility. *Journal of Business Research, 67*(5), 1035-1041. doi:10.1016/j.jbusres.2013.08.010
- Proctor, S. N. (2011). *Implicit bias, attributions, and emotions in decisions about parents with intellectual disabilities by child protection workers*. (Doctor of Philosophy), Pennsylvania State University, University Park, PA.
- Pruett, S. R. (2004). *A psychometric validation of a disability attitude implicit association test*: University of Wisconsin--Madison.
- Pruett, S. R., & Chan, F. (2006). The development and psychometric validation of the Disability Attitude Implicit Association Test. *Rehabilitation Psychology, 51*(3), 202-213. doi:10.1037/0090-5550.51.3.202
- Ratliff, K. A., & Nosek, B. A. (2010). Creating distinct implicit and explicit attitudes with an illusory correlation paradigm. *Journal of Experimental Social Psychology, 46*(5), 721-728. doi:10.1016/j.jesp.2010.04.011
- Reid, K., Stoughton, E. H., & Smith, R. M. (2006). The humorous construction of disability: 'Stand-up' comedians in the United States. *Disability & Society, 21*(6), 629-643.
- Robey, K. L., Beckley, L., & Kirschner, M. (2006). Implicit infantilizing attitudes about disability. *Journal of Developmental & Physical Disabilities, 18*(4), 441-453. doi:10.1007/s10882-006-9027-3
- Rojahn, J., Komelasky, K. G., & Man, M. (2008). Implicit attitudes and explicit ratings of romantic attraction of college students toward opposite-sex peers with physical disabilities. *Journal of Developmental and Physical Disabilities, 20*(4), 389-397. doi:10.1007/s10882-008-9108-6
- Russell, M. (2000). The political economy of disablement. *Dollars & Sense, 231*, 13-15.
- Sabin, J. A., Marini, M., & Nosek, B. A. (2012). Implicit and explicit anti-fat bias among a large sample of medical doctors by BMI, race/ethnicity and gender. *PloS one, 7*(11), e48448.
- Schweik, S. (2009). *The ugly laws: Disability in public*. New York: University Press.
- Sears, D. O., & Henry, P. J. (2003). The origins of symbolic racism. *Journal of Personality and Social Psychology, 85*(2), 259-275. doi:10.1037/0022-3514.85.2.259
- Sears, D. O., & Henry, P. J. (2005). Over thirty years later: A contemporary look at symbolic racism *Advances in experimental social psychology*, (Vol. 37, pp. 95-150): Elsevier

Academic Press, San Diego, CA.

- Sears, D. O., Henry, P. J., & Kosterman, R. (2000). Egalitarian values and the origins of contemporary American racism. In D. O. Sears, J. Sidanius, & L. Bobo (Eds.), *Racialized politics: The debate about racism in America* (pp. 75-117). Chicago: University of Chicago Press.
- Shakespeare, T. (1996). Disability, identity, difference. In C. Barnes & G. Mercer (Eds.), *Exploring the divide: Illness and disability* (pp. 11-16). Leeds: Disability Press.
- Son Hing, L., Chung-Yan, G., Hamilton, L., & Zanna, M. (2008). A two-dimensional model that employs explicit and implicit attitudes to characterize prejudice. *Journal of Personality and Social Psychology*, 94(6), 971-987. doi:10.1037/0022-3514.94.6.971
- Stewart, J., Harris, J., & Sapey, B. O. B. (1999). Disability and dependency: Origins and futures of 'special needs' housing for disabled people. *Disability & Society*, 14(1), 5-20. doi:10.1080/09687599926343
- Susman, J. (1994). Disability, stigma and deviance. *Social Science & Medicine*, 38(1), 15-22.
- Teachman, B. A., Gapinski, K. D., Brownell, K. D., Rawlins, M., & Jeyaram, S. (2003). Demonstrations of implicit anti-fat bias: the impact of providing causal information and evoking empathy. *Health Psychology*, 22(1), 68. doi:10.1037/0278-6133.22.1.68
- Thomas, A., Doyle, A., & Daly, V. (2007). Implementation of a computer based Implicit Association Test as a measure of attitudes toward individuals with disabilities. *Journal of Rehabilitation*, 73(2), 3-14.
- Thompson, S. A., Bryson, M., & de Castell, S. (2001). Prospects for identity formation for lesbian, gay, or bisexual persons with developmental disabilities. *International Journal of Disability, Development and Education*, 48(1), 53-65.
- Tighe, C. A. (2001). 'Working at disability': A qualitative study of the meaning of health and disability for women with physical impairments. *Disability & Society*, 16(4), 511-529.
- Tilley, E., Walmsley, J., Earle, S., & Atkinson, D. (2012). 'The silence is roaring': sterilization, reproductive rights and women with intellectual disabilities. *Disability & Society*, 27(3), 413-426. doi:10.1080/09687599.2012.654991
- Tringo, J. L. (1970). The hierarchy of preference toward disability groups. *The Journal of Special Education*, 4(3), 295-306. doi:10.1177/002246697000400306
- von Hippel, W., Brener, L., & von Hippel, C. (2008). Implicit prejudice toward injecting drug users predicts intentions to change jobs among drug and alcohol nurses. *Psychological Science*, 19(1), 7-11.
- Walpole, M. (2003). Socioeconomic status and college: How SES affects college experiences and outcomes. *The review of higher education*, 27(1), 45-73. doi:10.1353/rhe.2003.0044
- White, M. J., Jackson, V., & Gordon, P. (2006). Implicit and explicit attitudes toward athletes with disabilities. *Journal of Rehabilitation*, 72(3), 33-40.

Young, S. (2014). I'm not your inspiration, thank you very much. Retrieved from http://www.ted.com/talks/stella_young_i_m_not_your_inspiration_thank_you_very_much/

Zola, I. K. (1985). Depictions of disability - metaphor, message, and medium in the media: A research and political agenda. *Social Science Journal*, 22(4), 5-17.

Endnotes

1. This category includes both the concepts of symbolic and modern prejudice. While at one time they were considered separate, the significant bulk of the literature now considers them the same thing (Henry & Sears, 2008). Thus, it is referred to as symbolic prejudice throughout this manuscript for clarity.

2. Son Hing et al. (2008) describe principled conservatives as those who truly value the abstract conservative ideas, which causes them to dislike policies that stray from tradition. Principled conservatives score high on explicit racial prejudice because “they cherish the values confounded with the content of the MRS [modern racism scale]” and low on implicit racial prejudice because they discriminate against both racial groups equally implicitly (Son Hing et al. 2008, p. 973). However, Son Hing et al. (2008) note “principled conservatism might not be a race-neutral ideology; rather racism and conservatism could be linked because both are used to legitimize hegemony” (pp. 972-973).

3. Although there is no standardized overall error rate for removal, 30% was selected because it was the most frequent cut-off point found among IAT literature. Of the 20 IAT manuscripts found that discussed their exact overall error rates the cut-off points ranged from error rates greater than 15% to greater than 40%; the median was 30%, the mode was 35%, and the mean was 28.4% (Chen et al., 2011; Cvencek, Greenwald, & Meltzoff, 2011; Cvencek, Meltzoff, & Greenwald, 2011; Dionne, Gainforth, O'Malley, & Latimer-Cheung, 2013; Enea-drapeau, Carlier, & Huguet, 2012; Greenwald & Farnham, 2000; Huang, Wang, & Shi, 2009; Ilavarasu, Rajesh, & Hankey 2014; Karpinski & Hilton 2001; Karpinski, Steinman, & Hilton, 2005; Ma, Chen, Zhou, & Zhang 2012; Maison, Greenwald, & Bruin 2001; Nosek et al., 2007; Nosek, Banaji, & Greenwald 2002; Ratliff & Nosek 2010; Sabin, Marini, & Nosek, 2012; Teachman, Gapinski, Brownell, Rawlins, & Jeyaramet al., 2003; Thomas, Doyle, & Vaughn, 2007).



Aversive Ableism: Modern Prejudice Towards Disabled People by [Carli Friedman](#) is licensed under a [Creative Commons Attribution 4.0 International License](#). Based on a work at <http://rdsjournal.org/index.php/journal/article/view/811>. Permissions beyond the scope of this license may be available at <https://www.rds.hawaii.edu>.

Research Article

Parents With and Without Disabilities: Demographics, Material Hardship, and Program Participation

Rajan Anthony Sonik, PhD, JD, MPH

Health Equity Research Lab, Cambridge Health Alliance, Harvard Medical School

Susan L Parish, PhD, MSW

Bouvé College of Health Sciences, Northeastern University

Monika Mitra, PhD, MSW

Lurie Institute of Disability Policy, Heller School for Social Policy and Management,

Brandeis University

Joanne Nicholson, PhD

Geisel School of Medicine at Dartmouth, Dartmouth-Hitchcock Medical Center

Abstract: To compare demographics, material hardship, and public benefit program participation among parents with and without disabilities, we analyzed data from the 2008 Survey of Income and Program Participation. Households led by parents with disabilities were significantly more likely to experience hardships despite also being more likely to receive public benefits. Policy recommendations include greater outreach regarding these programs to parents with disabilities and more generous benefit levels.

Keywords: Disability; Parents; Economic Hardship

People with disabilities represent between 12.6% and 18.7% of the US population (Brault, 2012; Kraus, 2015) and face significant economic insecurities throughout the lifespan (Ghosh and Parish 2013; Parish et al. 2008; Parish et al. 2010; Parish, Rose and Swaine 2010, 2010; She & Livermore, 2007; Author et al., 2016a). For example, Peiyun She and Gina Livermore (2007) found that having a work-limiting disability for even less than one year is associated with increased odds of not meeting all expenses, not making rent or mortgage payments, not paying utility bills, not seeking needed medical care, not seeking needed dental care, and being food insecure in the United States. Similarly, having a child with a disability is associated with an increased likelihood of lacking a telephone, not being able to pay rent, postponing medical care, postponing dental care, and being food insecure (Parish et al. 2008; Sonik et al. 2016a).

Notably, these findings persist even when families with disabled household members receive public benefits (Sonik et al. 2016a; Sonik, Parish, and Rosenthal 2016b). These findings indicate that the benefits provided by current programs may not be fully sufficient to meet the complex needs of people with disabilities. This conclusion is supported by evidence from programs such as the Supplemental Nutrition Assistance Program, which has been shown to partially but incompletely alleviate food insecurity (Gregory, Rabbit, & Ribar, 2013; Mabli & Ohls, 2015; National Research Council, 2013; Nord & Golla, 2009; Ratcliff et al., 2011[1] [RS2]; Shaefer & Gutierrez, 2013). Families experience sharp increases in food insecurity prior to initial receipt of benefits, followed by modest but incomplete reductions in

food insecurity after benefits are received (Gregory et al., 2013; National Research Council, 2013). As a result, in cross-sectional analyses, receipt of Supplemental Nutrition Assistance Program benefits is counterintuitively associated with greater levels of material hardship, even after adjusting for income (e.g., Alaimo, Briefel, Frongillo, & Olson, 1998; Cohen, Ohls, Andrews, Ponza, Moreno, Zambrowski, & Cohen, 1999; Jensen, 2002; Ribar & Hamrick, 2003; Wilde & Nord, 2005; Gregory et al., 2013; National Research Council, 2013). Similarly, among low-income families that include children with disabilities, those receiving Supplemental Security Income benefits were more likely to experience food insecurity (Rose-Jacobs et al., 2016[3] [RS4]). In another study, a subpopulation of families including individuals with developmental disabilities had both heightened levels of program participation and widespread moderate—but not extreme—forms of material hardships (Sonik et al. 2016b).

Disability and Parenthood

Despite hardships documented among people with disabilities more broadly, parents with disabilities have received minimal study in terms of demographic and economic descriptions. Social and legal barriers to successful parenthood among people with disabilities are, however, well documented. For example, a review of existing child protection laws across the 50 states and the District of Columbia found that 37 contained language indicating that parental disability is a basis for terminating parental rights (Lightfoot, Hill, & LaLiberte, 2010). Almost all of these statutes specifically identify mental illness and intellectual and developmental disabilities (though often with outmoded language), and several statutes focus on physical disabilities as well (Friesen, Nicholson, Kaplan, & Solomon, 2009; Kaplan, Kottsieper, Scott, Salzer, & Solomon, 2009; Lightfoot et al., 2010). A comprehensive report by the National Council on Disability (2012) found multiple formal and informal challenges to parenting for people with disabilities, ranging from a medical provider culture that discourages fertility for women with disabilities (including encouragement of sterilization, especially among women with psychiatric disabilities), to cultural and statutory biases in the family court and child welfare systems against providing parents with disabilities access to the same parental rights afforded to parents without disabilities.

Consequently, parents with disabilities in general have a heightened risk of losing custody of their children (National Council on Disability, 2012). Individuals with particularly stigmatized disabilities such as mental illness have been reported to experience custody loss at even higher rates, with some estimates of removals occurring 80 percent of the time (Joseph, Joshi, Lewin, & Abrams, 1999). Moreover, children removed from parents with disabilities, as compared to children removed from parents without disabilities, stay in foster care longer and receive fewer formal supports for reunification with their parents (Lightfoot & DeZelar, 2016). Related to this phenomenon, parents with mental illness who lose custody of their children have reported confusion with the process and are, at times, even unclear about where their children live (Sands, Koppelman, & Solomon, 2004).

Given the relationship between poverty and interventions by state child welfare

agencies (Eckenrode, Smith, McCarthy, & Dineen, 2014), poverty and material hardship among parents with disabilities are potentially related to the direct challenges to their parental rights just noted (i.e., cultural and statutory biases). However, few studies have examined the economic well-being of individuals with disabilities, let alone public benefit participation among these parents. The most recently reported nationally representative estimates regarding parents with disabilities found that 6 percent (4.1 million) of parents co-residing with their minor children had disabilities (Kaye, 2012). This study reported that 30 percent of parents with disabilities had income below the federal poverty line and 16 percent of these parents received Supplemental Security Income benefits, a federal means-tested program for low-income, low-asset individuals with work-limiting disabilities (Kaye, 2012). No other measures of material hardship—such as food insecurity and unmet expenses for other essential items—or of public assistance utilization—such as benefits from the Supplemental Nutrition Assistance Program (formerly the Food Stamps Program)—were presented (Kaye, 2012). Also, comparisons to parents without disabilities were not made in this report.

Other studies focusing on subsets of the disability community or with smaller samples have found high levels of hardship beyond income poverty. For example, Alison Luciano, Joanne Nicholson, and Ellen Meara (2014) found that, nationwide, parents with serious mental illnesses were almost twice as likely as parents without any mental illness to have income below the federal poverty level (30% versus 17% for mothers and 17% versus 9% for fathers). In a sample of Supplemental Security Income recipients, parents with mental illness were twice as likely as parents with other disabilities to be unable to pay their rent and 76 percent more likely to experience food insecurity (Sogar, 2016). In addition, qualitative studies involving low-income mothers with disabilities reported severe experiences of material deprivation, even when receiving benefits from social safety-net programs (Magaña, Parish, and Cassiman 2008; Parish, Magaña, and Cassiman 2008). Perhaps relatedly, parents with mental illness were more likely to report having fair or poor health when compared to their counterparts without mental illness (Luciano, Nicholson, & Meara, 2014). Overall, the number of parents with disabilities and their degree of vulnerability indicates that the well-being of this population is a serious public health concern.

Broadly, parenthood is a key life event for which people with disabilities lack full inclusion. Understanding the economic vulnerabilities in this population may be critical to understanding the supports needed to achieve more inclusive policies for parents with disabilities.

Research Questions

The patterns of economic deprivation and program participation observed among the general population of people with disabilities suggest that parents with disabilities may face similar challenges. If so, these hardships may, in unique ways, interact with and exacerbate the social and legal challenges to the rights of parents with disabilities more broadly. Therefore, to better understand the material needs of parents with disabilities, we used data from the nationally representative Survey of Income and Program Participation to pursue the

following research questions: (1) how do parents with and without disabilities of varying severities compare on individual characteristics?, (2) how do parent households compare on measures of material hardships and program participation?, and (3) are there any relationships between parental disability status and material hardships?

Methods

Data

The longitudinal Survey of Income and Program Participation is representative of the non-institutionalized population of the United States (US Census Bureau, n.d.). We utilized data from wave 6 of the 2008 panel of the survey, which was collected between May and August of 2010. In addition to core questions relating to income, demographic information, and program participation, wave 6 contained extensive sets of topical module questions regarding disability status and material hardships. The detailed information provided in these modules allow for differentiation of disabilities into severe and non-severe categories and for examination of multiple domains of material hardship (Brault, 2012; Stoddard, 2014).

The Survey of Income and Program Participation provides several weights that allow for estimation of the number of people or households who are represented by each surveyed person and household (Westat, 2001). Person-weights can be used to calculate descriptive statistics for individual-level variables, such as race and gender. For household-level variables, such as the percentage of households experiencing specific material hardships, household-weights can be used. For variance estimations, the Survey of Income and Program Participation recommends using Fay's modified balanced repeat replication method (Westat, 2001). To prevent respondents from small geographic areas from being identifiable, the Survey of Income and Program Participation alters its primary sample units by combining them into larger variance strata and then splitting each stratum into two variance units. Fay's method is therefore recommended for variance estimation because it is able to account for both halves of the strata that are generated. Resulting variance estimates are nominally conservative (Westat, 2001).

Sample

Parent analysis

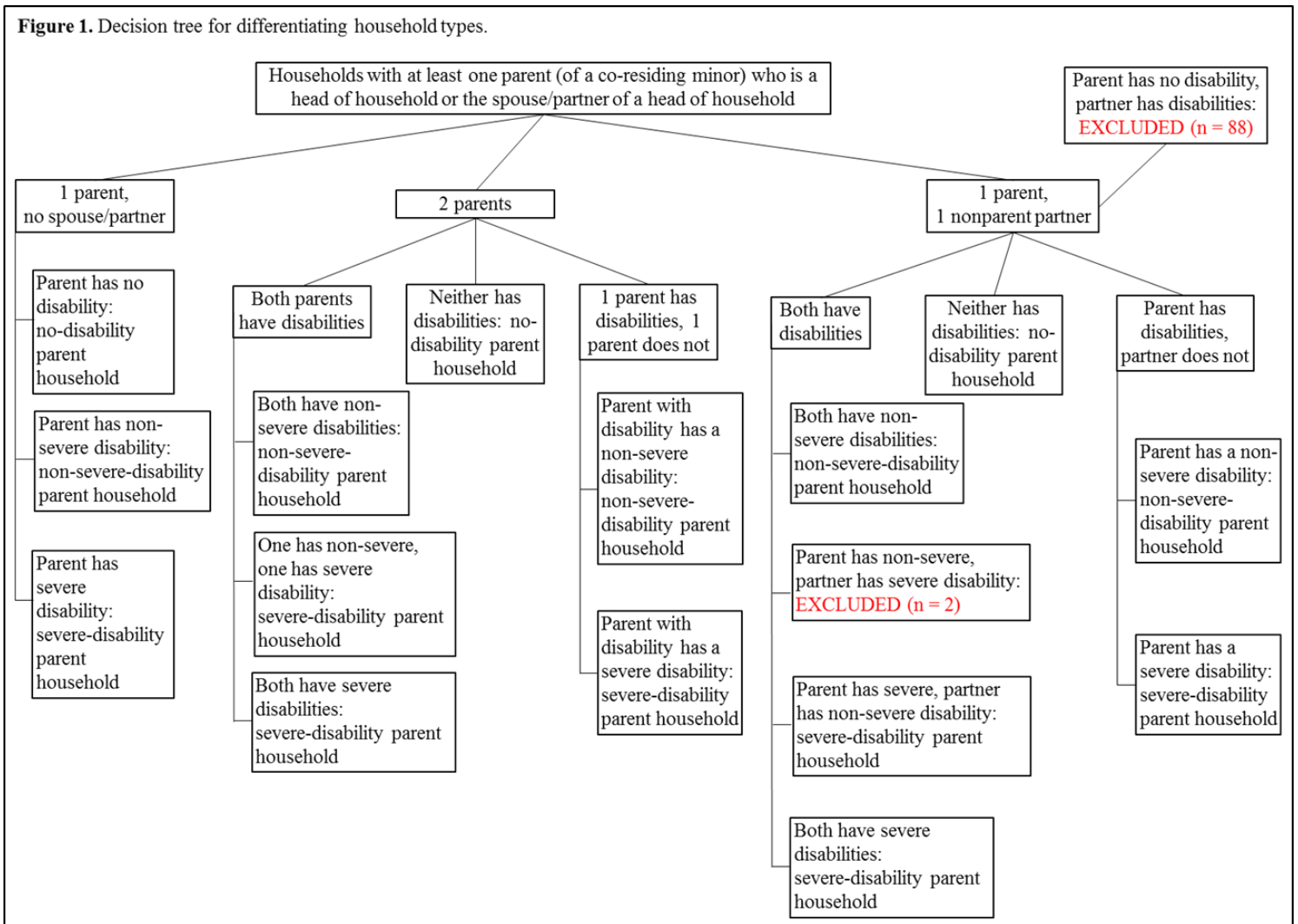
We identified co-residing parents with and without disabilities caring for their minor children (biological, step, or adopted) using several steps. First, we identified individuals who were heads of households or the spouse or partners of heads of households who lived with at least one of their minor children ($n = 17,578$). We limited our sample of parents to those who were heads of households or the spouses or partners of heads of households because of the additional financial responsibilities assumed by individuals in this role and in order to limit data to a maximum of one parent or parenting-pair per household (e.g., if a parent/head of household lived with his or her sibling and sibling's child, the sibling would be excluded). Next, among the parents identified in the first step, we identified those without disabilities ($n = 15,636$), those with non-severe disabilities ($n = 743$), and those with severe disabilities ($n = 1,199$), using criteria described by the US Census Bureau in its estimates of the prevalence of

people with disabilities in the United States (Brault, 2012). The US Census Bureau criteria identifies disabilities relating to various physical tasks, aspects of communication, activities of daily living, instrumental activities of daily living, intellectual and developmental disabilities, mental health conditions, and work-related disabilities (Brault, 2012). The exact definition involves nearly 100 variables, but in general severe disabilities are identified as those involving total functional limitations or leading to a need for assistance from others (Brault, 2012). These initial two steps were used for person-specific estimates, such as demographic information.

Parent-household analysis

Identifying the category of parenting households involved separate steps, depending on whether the identified parent(s) lived (i) without a spouse or partner, (ii) with a spouse or partner who was the biologic, step, or adoptive parent of a child in the household (meaning they were also a parent in the individual analysis), or (iii) with a partner who was not a parent of any kind to any child in the household (meaning they were not a parent in the individual analysis) (Figure 1). In the first scenario, a single parent, the disability status of the parent (none, non-severe, or severe) was also the status for the household. In the second scenario, in which there were two parents, several outcomes were possible: (a) if one parent or both parents had a severe disability, the household was assigned severe disability status; (b) if one parent had a non-severe disability and the other parent had either a non-severe disability or no disability, the household was assigned non-severe disability status; and (c) if neither parent had any disability, the household was assigned a status of no disability. Finally, the third scenario, a parent living with a nonparent partner, had several possible outcomes as well: (a) if the parent had a severe disability, the household was given severe disability status; (b) if the parent had a non-severe disability and the nonparent partner had either a non-severe disability or no disability, the household was given non-severe disability status; (c) if both the parent and the nonparent partner had no disabilities, the household was given a status of no disabilities; (d) if the parent had a non-severe disability and the nonparent partner had a severe disability, the household was excluded ($n = 2$); and (e) if the parent had no disability and the nonparent partner had any type of disability, the household was excluded ($n = 88$). We excluded households in these latter two situations because it was not clear what, if any, caregiving responsibilities the nonparent partners held, making conceivable equally strong arguments for these households to fall into different categories. Ultimately, we identified 8,380 no-disability parent households, 633 non-severe-disability parent households, and 1,116 severe-disability parent households. This approach yielded three mutually exclusive households types, and ensured that there were no duplicated households across categories.

Figure 1. Decision tree for differentiating household types.



Measures

Dependent variables

We explored sociodemographic characteristics, economic and material hardship prevalence, and public benefits program participation. Individual-level sociodemographic factors included, age, gender, race and ethnicity, marital status, health status, and educational attainment, and whether or not any of the children in the parent’s home had any disabilities. As with adult disability, child disability status was also determined based on criteria described by Matthew Brault (2012). Household-level economic factors included income, employment status, food insecurity—identified through methods developed by the United States Department of Agriculture (Nord, 2006), child food insecurity, whether there were any unmet expenses or service needs due to income (including expenses deemed essential, needs to see a doctor, needs to see a dentist, utility expenses, and rent or mortgage payments), whether the telephone or other utility services had been disconnected, whether the family had been evicted because of unpaid rent or mortgage payments, and whether the home had any conditions problems (including malfunctioning plumbing, infestation with pests such as rats or mice, leaking roof or ceiling, broken windows, cracks in walls or ceiling, holes in the floors, or

exposed electrical wires). Finally, we examined household-level receipt of benefits from Supplemental Security Income, the Supplemental Nutrition Assistance Program (both generally and among income-eligible families with income below 185% of the federal poverty level), Temporary Assistance to Needy Families, and unemployment insurance.

Independent variables

For each dependent variable we ran two sets of bivariate analyses: (i) comparing non-disability parents and households to non-severe-disability parents and households, and (ii) comparing non-disability parents and households to severe-disability parents and households. We generated two dummy variables as the independent variables, one for each of these comparisons. For logistic regressions, we used separate dummy variables that were indicators of non-severe-disability household status and severe-disability household status.

Covariates

In logistic regression analyses, we controlled for age, gender, race and ethnicity, marital status, health insurance status, health status, income, education, and employment status. In addition, given the added vulnerability noted in past studies among households including children with disabilities (Parish et al., 2008; Sonik et al., 2016b), we controlled for whether or not any children in the household had a disability. Finally, given evidence that families seek public benefits *after* material hardships arise (Gregory et al., 2013; National Research Council, 2013), we did not adjust for public benefit program receipt as these were likely temporally external to any potential relationships between parental disability status and material hardships. As such, they would be inappropriate to include in cross-sectional models.

Analyses

Stata (Version 14.0) was used to conduct all statistical calculations. We conducted bivariate comparisons on all sociodemographic, economic, and program participation variables. Stata utilizes adjusted Wald tests for weighted mean comparisons and corrected Pearson's χ^2 tests for weighted percentage comparisons, both of which involve F statistics. In addition, we conducted weighted multivariate logistic regressions to examine the relationship between household parental disability status and selected material hardship factors while adjusting for sociodemographic factors.

Results

Parents With and Without Disabilities

We estimated that 10.3 percent (95% CI: 9.8%, 10.9%) of parents co-residing with their minor children had disabilities; 4.0 percent (95% CI: 3.7%, 4.4%) had non-severe disabilities and 6.3 percent (95% CI: 5.8%, 6.7%) had severe disabilities (Table 1). Sociodemographically, the sample of parents with non-severe disabilities had a similar gender and racial and ethnic makeup as the parents without disabilities, but these groups differed on all other variables (Table 1). Compared to parents without disabilities, parents with non-severe disabilities were significantly less likely to have ever married (86% versus 90%, $p < 0.001$) or live with a spouse or partner (79% versus 87%, $p < 0.001$). In addition, parents with non-

severe disabilities were more than seven times as likely to have fair or poor general health than parents without disabilities (23% versus 3%, $p < 0.001$), they were less likely to have a high school (85% versus 89%, $p < 0.001$) or college degree (25% versus 34%, $p < 0.001$), and they were more likely to have children with disabilities (26% versus 11%, $p < 0.001$) (Table 1). Parents with severe disabilities experienced similar differences when compared to parents without disabilities, though with larger effect sizes (Table 1). In addition, parents with severe disabilities were significantly less likely than parents without disabilities to be men (61% versus 54%, $p < 0.001$), non-Hispanic white (59% versus 63%, $p < 0.001$) or Asian (3% versus 5%, $p = 0.01$), and they were significantly more likely to be non-Hispanic black (16% versus 10%, $p < 0.001$) (Table 1).

Table 1. Parent demographics^a

Variable	Parents without disabilities ($n = 15,636$)	Parents with non-severe disabilities ($n = 743$)	F^b (for comparison to parents without disabilities)	Parents with severe disabilities ($n = 1,199$)	F (for comparison to parents without disabilities)
% (SE)	89.7 (0.3)	4.0 (0.2)	n/a	6.3 (0.2)	n/a
Age (mean), years (SE)	38.8 (0.1)	40.0** (0.4)	7.9	41.5*** (0.3)	67.5
Women, % (SE)	54.2 (0.2)	58.3 (2.0)	3.8	61.5*** (1.3)	25.8
Race/ethnicity, % (SE)					
Non-Hispanic white	63.0 (0.7)	62.1 (2.0)	0.2	58.9* (1.7)	5.5
Non-Hispanic black	10.4 (0.4)	11.6 (1.4)	0.9	15.9*** (1.2)	26.4
Non-Hispanic Asian	4.6 (0.2)	4.0 (0.7)	0.5	3.0* (0.5)	6.4
Non-Hispanic, other	2.4 (0.2)	2.9 (0.7)	0.6	5.5*** (0.9)	25.0
Hispanic	19.7 (0.5)	19.1 (1.7)	0.0	16.7* (1.3)	4.0
Family status, % (SE)					
Ever married	90.4 (0.3)	86.3*** (1.3)	14.3	83.9*** (1.2)	35.1
Divorced	6.5 (0.2)	10.7*** (1.3)	16.2	12.7*** (1.1)	51.4
Lives with spouse or partner	86.6 (0.3)	79.0*** (1.7)	27.6	72.1*** (1.5)	139.9
Health status, % (SE)					

Excellent	33.6 (0.5)	13.0*** (1.2)	138.6	4.9*** (0.8)	271.6
Very good	40.7 (0.5)	29.0*** (1.9)	32.0	10.6*** (1.0)	354.4
Good	22.5 (0.5)	34.9*** (1.7)	55.1	27.6*** (1.2)	15.5
Fair	2.9 (0.2)	18.2*** (1.6)	381.6	36.1*** (1.8)	1,451.6
Poor	0.2 (0.0)	5.0*** (0.8)	420.1	20.9*** (1.5)	2,850.7
Educational attainment					
High school/GED or m (SE)	89.3 (0.4)	85.4** (1.4)	9.2	79.8*** (1.4)	71.9
Bachelor's degree or m (SE)	33.7 (0.5)	24.6*** (1.9)	20.4	15.2*** (1.1)	163.2
Any children (<18 years) with disabilities in home, % (SE)	11.3 (0.4)	26.1*** (2.0)	99.7	30.4*** (1.7)	264.1

^a All values weighted; ^b For comparisons of weighted means (e.g., income), STATA conducts adjusted Wald tests, and for comparisons of weighted percentages (e.g., gender), STATA conducts corrected Pearson's χ^2 tests. Both produce *F* statistics; * $p < 0.05$; ** $p < 0.01$; *** $p < 0.001$.

Parent Households With and Without Disabilities

Among households that included parents co-residing with their minor children, we estimated that 16.2 percent (95% CI: 15.4%, 17.0%) met our definition of a parent-disability household; 6.0 percent (95% CI: 5.5%, 6.7%) were non-severe-disability parent households, and 10.2 percent (95% CI: 9.5%, 10.9%) were severe-disability parent households (Table 2). Economically, non-severe-disability parent households had significantly less income on average than non-disability parent households (\$64,762 versus \$73,874, $p < 0.001$) and were more likely to have income below 100 percent of the federal poverty level (22% versus 18%, $p = 0.04$) (Table 2). Non-severe-disability parent households were also approximately twice as likely to experience any measure of food insecurity (any food insecurity: 23% versus 11%, $p < 0.001$; very low food insecurity: 8% versus 3%, $p < 0.001$; child food insecurity: 8% versus 5%, $p < 0.001$) (Table 2). Non-severe-disability parent households were also two to three times as likely than non-disability parent households to be unable to pay for various critical expenses (such as rent or mortgage payments: 20% versus 10%, $p < 0.001$) and to experience problems with their housing conditions (such as having infestations with rats or mice: 17% versus 7%, $p < 0.001$) (Table 2). These households were also significantly more likely to receive Supplemental Security Income and Supplemental Nutrition Assistance Program benefits (Table 2). Severe-disability parent households also had significantly less income than non-disability parent households (e.g., their mean income was \$46,300, $p < 0.001$), in addition

to facing elevated rates of unmet expenses and poor housing conditions (Table 2). Effect sizes were again larger for severe-disability parent households on income, public benefit participation, and most material hardship measures.

Table 2. Material hardship and program participation among households of parents with and without disabilities^a

Variable	Parents without disabilities (<i>n</i> = 8,380)	Parents with non-severe disabilities (<i>n</i> = 633)	<i>F</i> ^b (for comparison to parents without disabilities)	Parents with severe disabilities (<i>n</i> = 1,116)	<i>F</i> (for comparison to parents without disabilities)
% (SE)	83.8 (0.4)	6.0 (0.3)	n/a	10.2 (0.3)	n/a
Mean Income, \$ (SE)	73,264 (931)	64,394*** (2,341)	14.1	46,300*** (1,638)	177.3
FPL ^c category, % (SE)					
< 100% FPL	18.2 (0.4)	21.6* (1.7)	4.2	35.2 *** (1.8)	98.9
100-199% FPL	20.5 (0.5)	22.4 (1.7)	1.2	28.2*** (1.4)	34.0
200-299% FPL	17.7 (0.5)	19.3 (1.8)	0.7	16.7 (1.2)	0.5
≥ 300% FPL	43.5 (0.6)	36.6*** (1.9)	12.7	20.0*** (1.3)	178.4
Employed and working % (SE)	80.8 (0.5)	74.9** (1.9)	10.2	35.1*** (1.6)	873.6
Health insurance status, % (SE)					
Uninsured	20.0 (0.5)	18.4 (1.6)	0.9	20.1 (1.4)	0.0
Medicaid and/or Medicare	10.0 (0.4)	16.9*** (1.6)	24.4	38.5*** (1.7)	505.0
Any private	69.9 (0.6)	64.8** (1.9)	7.8	41.5*** (1.8)	204.1
Food security, % (SE)					
Low or very low food security	11.3 (0.4)	23.0*** (1.9)	66.4	29.3*** (1.5)	196.4
Very low food security	3.4 (0.3)	7.9*** (1.1)	31.4	13.3 (1.1)	166.1

Child food insecurity	4.9 (0.3)	8.2**** (1.1)	12.3	11.2**** (1.1)	47.9
Unmet expenses/needs, % (SE)					
Unmet essential expenses	18.6 (0.5)	34.0**** (1.9)	79.8	43.3**** (1.5)	347.3
Unmet need to see doctor	7.0 (0.3)	14.6**** (1.6)	39.4	186.6**** (1.3)	164.9
Unmet need to see dentist	8.9 (0.4)	18.4**** (1.6)	58.9	23.1**** (1.3)	209.2
Unmet utility expenses	12.8 (0.4)	24.3**** (1.7)	63.0	31.4**** (1.6)	215.8
Utilities shut off	2.2 (0.2)	4.5**** (0.9)	11.6	6.8**** (0.8)	66.8
Telephone disconnected	4.6 (0.3)	9.3**** (1.0)	29.6	13.1**** (1.3)	74.6
Housing security, % (SE)					
Unpaid housing payments	10.4 (0.4)	20.3**** (1.6)	50.2	22.5**** (1.3)	115.8
Evicted from home	0.5 (0.1)	1.2* (0.4)	4.9	0.9 (0.3)	2.0
Housing conditions, % (SE)					
Plumbing not working	1.5 (0.2)	4.0**** (0.8)	20.2	1.5**** (0.2)	32.9
Pests (rats, mice, etc.)	7.1 (0.3)	16.6**** (1.6)	67.2	12.5**** (1.1)	38.2
Leaking roof or ceiling	4.0 (0.2)	8.2**** (1.1)	23.1	8.8**** (0.8)	60.6
Broken windows	2.8 (0.2)	6.0**** (1.0)	22.8	7.8**** (0.9)	61.9
Cracks in walls or ceiling	2.3 (0.2)	7.3**** (0.9)	61.5	5.8**** (0.6)	52.3
Holes in floor	0.5 (0.1)	1.6** (0.6)	11.3	1.6**** (0.4)	18.7
Exposed electrical wires	0.5 (0.1)	1.0 (0.4)	2.5	2.5**** (0.5)	40.8
Public benefits ^d , % (SE)					

SSI	2.2 (0.2)	5.2*** (1.1)	16..9	17.9*** (1.2)	549.3
SNAP	15.8 (0.5)	23.2*** (1.7)	24.0	40.8*** (1.7)	277.9
SNAP (if < 185%FPL) ^e	39.0 (0.9)	48.3** (3.2)	8.2	60.4*** (1.9)	91.8
TANF	1.9 (0.1)	2.6 (0.7)	1.1	8.3*** (1.0)	140.2
Unemployment	6.5 (0.3)	6.4 (1.1)	0.0	9.9*** (0.9)	16.4

^a All values weighted and at household level; ^b For comparisons of weighted means, STATA conducts adjusted Wald tests, and for comparisons of weighted percentages, STATA conducts corrected Pearson's χ^2 tests. Both produce *F* statistics; ^c FPL: Federal Poverty Level ^d SSI: Supplemental Security Income; SNAP: Supplemental Nutrition Assistance Program; TANF: Temporary Assistance to Needy Families; ^e Those below 185% FPL are income eligible for SNAP; * $p < 0.05$; ** $p < 0.01$; *** $p < 0.001$.

Relationships between parental disability status and material and housing hardships

Table 3 and Table 4 present the results of logistic regressions for selected material hardship and housing hardships, respectively. After adjusting for various sociodemographic factors, non-severe and severe-disability household status was significantly associated with each hardship variable except for being evicted. Evictions appeared to be a relatively rare event (0.5% for non-disability households, 1.2% for non-severe-disability households, and 0.9% for severe-disability households). Income was highly associated with all tested hardship variables (Table 3 and Table 4). Counterintuitively, employment status was positively associated with several of the tested hardships, including having an unmet need to see a doctor (adjusted OR = 1.37 [95% CI 1.12, 1.67]), having utility services terminated (adjusted OR = 1.71 [95% CI 1.22, 2.39]), and having unpaid housing rent or mortgage payments (adjusted OR = 1.29 [95% CI 1.08, 1.54]) (Table 3 and Table 4). Finally, the household's child disability status was associated with all outcomes except for child food insecurity and evictions (Table 3 and Table 4).

Table 3. Associations between parent disability status and selected material hardships, adjusting for controls^a

	Child food insecurity	Unmet need to see doctor	Unmet need to see dentist	Utilities (gas, electricity, or oil) shut off
Household parent disability status ^b				
Non-severe parent disability	1.5* (1.09, 2.07)	1.97*** (1.46, 2.66)	1.99*** (1.56, 2.53)	1.64* (1, 2.68)
Severe parent disability	1.68** (1.21, 2.34)	2.21*** (1.74, 2.81)	2.07*** (1.63, 2.65)	2.14** (1.37, 3.33)
At least one child with disability	1.2 (0.91, 1.59)	1.5*** (1.26, 1.79)	1.41*** (1.2, 1.65)	1.89*** (1.37, 2.59)
FPL ^c				
< 100% FPL	3.38*** (2.4, 4.75)	2.19*** (1.65, 2.91)	2.25*** (1.73, 2.92)	2.89*** (1.64, 5.1)
100-199% FPL	2.9*** (2.07, 4.06)	1.92*** (1.42, 2.6)	2.33*** (1.79, 3.02)	1.68 (0.99, 2.85)
200-299% FPL	1.86** (1.25, 2.77)	1.81*** (1.35, 2.44)	2.08*** (1.62, 2.67)	1.62 (0.99, 2.64)
Employed and working	1.16 (0.93, 1.44)	1.37** (1.12, 1.67)	1.15 (0.94, 1.39)	1.71** (1.22, 2.39)

^a Weighted logistic regressions were used; odds ratios (95% confidence interval) reported; if two parents were both associated with a household type, the value for the parent head of household was used (see Figure 1); only select covariates are presented (the other covariates were age, gender, race/ethnicity, divorced status, health status, health insurance status, and educational attainment); ^b Reference: no parent disability; ^c FPL: federal poverty level; reference: \geq 300% FPL; * $p < 0.05$; ** $p < 0.01$; *** $p < 0.001$.

Table 4. Associations between parent disability status and selected housing hardships, adjusting for controls^a

	Unpaid housing payments	Evicted from home	Plumbing not working	Pests (rats, mice, etc.)
Household parent disability status ^b				
Non-severe parent disability	1.86*** (1.46, 2.36)	2.05 (0.93, 4.48)	2.3** (1.38, 3.83)	2.27*** (1.78, 2.89)
Severe parent disability	1.63*** (1.27, 2.08)	1.04 (0.4, 2.74)	1.84* (1.07, 3.18)	1.34* (1.01, 1.77)
At least one child with disability	1.46*** (1.21, 1.77)	1.26 (0.64, 2.51)	1.53* (1.08, 2.16)	1.82*** (1.51, 2.19)
FPL ^d				
< 100% FPL	3.27*** (2.53, 4.23)	9.38*** (3.23, 27.23)	3.29*** (1.9, 5.71)	1.47** (1.16, 1.87)
100-199% FPL	2.43*** (1.99, 2.96)	5.55** (1.96, 15.74)	1.87 (1, 3.52)	1.58*** (1.29, 1.93)
200-299% FPL	1.6*** (1.27, 2.02)	3.12 (0.76, 12.82)	1.53 (0.83, 2.81)	1.15 (0.91, 1.45)
Employed and working	1.29** (1.08, 1.54)	1 (0.52, 1.91)	1.13 (0.78, 1.64)	0.91 (0.73, 1.12)

^a Weighted logistic regressions were used; odds ratios (95% confidence interval) reported; if two parents were both associated with a household type, the value for the parent head of household was used (see Figure 1); only select covariates are presented (the other covariates were age, gender, race/ethnicity, divorced status, health status, health insurance status, and educational attainment); ^b Reference: no parent disability; ^c FPL: federal poverty level; reference: \geq 300% FPL; * $p < 0.05$; ** $p < 0.01$; *** $p < 0.001$.

Discussion

We present new estimates of the sociodemographic characteristics, material hardship experiences, and level of public benefit program participation among parents with and without disabilities of differing severities and their households. Our estimates for parents with disabilities differ somewhat from those presented by H.S. Kaye (2012). For example, we estimate that 82 percent and 19 percent of parents with disabilities had high school and

college degrees, respectively, whereas Kaye (2012) reported these figures to be 77 percent and 13 percent. We also estimated that 10 percent of parents had disabilities, compared to the 6 percent reported by Kaye (2012). One potential explanation for these differences is that Kaye's estimates were derived from analyses of the American Community Survey, which uses a different definition of disabilities than the Survey of Income and Program Participation (Stoddard, 2014). The former defines disability as having serious difficulties in one or more of six areas (hearing, vision, cognitive function, ambulation, self-care, or independent living) (Stoddard, 2014), whereas the latter uses a more complex algorithm to differentiate disabilities into broader domains (communicative, mental, and physical) and includes both what it considers "severe" and "non-severe" functional impairments (Brault, 2012).

Beyond these initial figures, we found that the households of parents with disabilities—either non-severe or severe—experience poorer health and poorer outcomes regarding a host of economic and material hardships when compared to parents without disabilities. This was true even while controlling for many possible confounders. Moreover, given the correlations found between income and disability status (Table 2) and the relationship between income and economic outcomes (Table 3 and Table 4), income may have captured a significant portion of the variation in the outcome variables originating from disability status.

Also, we found this trend of worse outcomes to persist for the subset of parents with severe disabilities despite the relatively elevated use of public benefits in their households. This trend is consistent with previous findings suggesting that public benefit programs may alleviate hardship, but such benefits do not eliminate hardship (Shaefer & Gutierrez, 2013; Sonik et al., 2016b). We found this to be true for parents with non-severe disabilities as well, despite their being a relatively closer match to parents without disabilities in race, ethnicity, employment status, poverty status, and public benefit program receipt. For example, despite the fact that the households of parents with non-severe disabilities experienced below-poverty income only about 20 percent more frequently than the households of parents without disabilities, they experienced twice the prevalence of food insecurity. This indicates that mechanisms beyond traditionally examined socioeconomic factors are driving at least some of the material hardship differences among these families. Similarly, our finding that being employed was positively associated with certain hardships is unexpected. It is possible that, once controlling for income and health insurance status, being employed versus not implies a greater risk for falling into a gap between eligibility for public benefit programs and having sufficient earned income to avoid hardship.

Given the high direct and indirect health care costs experienced by families including members with disabilities (Mitra, Findley, & Sambamoorthi, 2009; Parish, Shattuck, & Rose, 2009), one potential mechanism leading parents with disabilities to experience excess economic difficulties may be increased health care costs that drain otherwise similar resources. Our findings that households led by parents with disabilities are more likely than those led by parents without disabilities to have unmet medical and dental needs supports this theory. An important caveat to this argument, though, is that data for this study were collected

in 2010, before the Affordable Care Act fully came into effect. Future studies should examine whether parents with disabilities—and in particular those with non-severe disabilities—have experienced any reduction in their health care costs in recent years and what effect this may have had on the prevalence of material hardships among these families.

Limitations

The Survey of Income and Program Participation relies on self-reported data. Given biases associated with disability status, and in particular parental disability status (National Council on Disability, 2012), underreporting potentially limited our ability to examine the full population of parents with disabilities. However, because the Survey of Income and Program Participation assesses disability through questions about activity- and function-specific impairments rather than potentially charged labels (Brault, 2012), effects from underreporting are likely to be minimal. In addition, despite moderate to large sample sizes, our analyses may still have lacked adequate power to detect differences between groups in their experiences of low frequency events such as evictions. Finally, we did not explore the potential effects of having one versus two parents with disabilities. Doing so would make identifying appropriate comparisons to single parent households and households with parents without disabilities difficult, and the sample size was insufficient to examine this degree of granularity.

Policy implications

Several public benefit programs are either explicitly provided to people with disabilities, such as the Supplemental Security Income program, or have more flexible program rules for recipients with disabilities, such as the Supplemental Nutrition Assistance Program (SNAP, 2013). Any additional assistance provided by these programs appears insufficient to meet the needs of households that include parents with disabilities. Based on our findings, both uptake levels and the amount of benefits provided appear to be at issue. More than 60 percent of income-eligible households led by parents with severe disabilities receive Supplemental Nutrition Assistance Program benefits. Although uptake for this group was one and half times greater than it was for households led by parents without disabilities, they still experienced two to three times the level of very low food security and child food insecurity. These two factors may be related, as families needing assistance may be less likely to seek benefits that they perceive will only partially alleviate the problem they are trying to solve. A combination of greater outreach to parents with disabilities and more generous benefit levels may be warranted.

Affordable and safe housing policies also appear not to meet the needs of parents with disabilities. We found that parents with disabilities were significantly more likely to experience a host of housing condition problems, such as pest infestations, that are likely detrimental to health and well-being. An associated problem was that one in five of these families—twice the rate for families without parents with disabilities—had unpaid rent or mortgage payments, signifying a likely lack of mobility or options for ensuring improved living conditions. Given the already-vulnerable health status of parents with disabilities, unstable and unsafe living conditions are likely to increase health problems and, ultimately,

health care utilization and costs. For these reasons, more robust sustainable housing policies are needed and should contain special considerations for families that include people with disabilities.

Finally, the excess material and housing hardships experienced by parents with disabilities may interact with already-biased social and legal systems with regard to child custody. For example, court systems following inherently biased family law policies are unlikely to see the harsher living conditions faced by parents with disabilities as anything but confirmation of beliefs that question the appropriateness of parenting with disabilities from the start. Consequently, efforts to reform family policies to make them more accommodating to parents with disability will likely need to be made in concert with efforts to alleviate the hardships experienced by these families if they are to be successful.

Rajan Anthony Sonik, Health Equity Research Lab, Cambridge Health Alliance, Harvard Medical School

Susan L Parish, Bouvé College of Health Sciences, Northeastern University

Monika Mitra, Lurie Institute of Disability Policy, Heller School for Social Policy and Management, Brandeis University

Joanne Nicholson, Geisel School of Medicine at Dartmouth, Dartmouth-Hitchcock Medical Center

References

- Alaimo, K., Briefel, R. R., Frongillo Jr., E. A., & Olson, C. M. (1998). Food insufficiency exists in the United States: Results from the Third National Health and Nutrition Examination Survey (NHANES III). *American Journal of Public Health*, 88(3), 416–426.
- Brault, M. (2012). Americans with disabilities: 2010 (Current Population Reports, P70-131). Washington, DC: United States Department of Commerce. Retrieved from <http://www.census.gov/prod/2012pubs/p70-131.pdf>.
- Cohen, B., Ohls, J., Andrews, M., Ponza, M., Moreno, L., Zambrowski, A., & Cohen, R. (1999). Food Stamp participants' food security and nutrient availability: Final report. Princeton, NJ: Mathematica Policy Research, Inc.
- Eckenrode, J., Smith, E. G., McCarthy, M. E., & Dineen, M. (2014). Income inequality and child maltreatment in the United States. *Pediatrics*, 133(3), 454–461.
- Friesen, B. J., Nicholson, J., Kaplan, K., & Solomon, P. (2009). Parents with a mental illness and implementation of the adoption and safe families act. In Notkin, S., Weber, K., Golden, O., & Macomber, J. (Eds.), *Intentions and results: A look back at the Adoption and Safe Families Act* (102–114). Washington, D.C.: Urban Institute.

- Ghosh, S., & Parish, S. L. (2013). Prevalence and economic well-being of families raising multiple children with disabilities. *Children and Youth Services Review, 35*(9), 1431–1439.
- Gregory, C., Rabbitt, M. P., & Ribar, D. C. (2013). The supplemental nutrition assistance program and food insecurity (Paper 21). Lexington: University of Kentucky Center for Poverty Research. Retrieved from http://uknowledge.uky.edu/ukcpr_papers/21
- Hollingsworth, L. D. (2004). Child custody loss among women with persistent severe mental illness. *Social Work Research, 28*(4), 199–209.
- Jensen, H. H. (2002). Food insecurity and the food stamp program. *American Journal of Agricultural Economics, 84*(5), 1215–1228.
- Joseph, J. G., Joshi, S., Lewin, A. B., & Abrams, M. (1999). Characteristics and perceived needs of mothers with serious mental illness. *Psychiatric Services, 50*(10), 1357–1359.
- Kaplan, K., Kottsieper, P., Scott, J., Salzer, M., & Solomon, P. (2009). Adoption and safe families act state statutes regarding parents with mental illness: A review and targeted intervention. *Psychiatric Rehabilitation Journal, 33*(2), 91–94.
- Kaye, H. S. (2012). Current demographics of parents with disabilities in the U.S. Berkeley, CA: Through the Looking Glass. Retrieved from <http://www.lookingglass.org/pdf/States-Data/TLG-Parents-with-Disabilities-US-Demographics.pdf>
- Kraus, L. (2015). “2015 Disability Statistics Annual Report.” Durham, NH: University of New Hampshire. http://www.disabilitycompendium.org/docs/default-source/2015-compendium/annualreport_2015_final.pdf
- Lightfoot, E., & DeZelar, S. (2016). The experiences and outcomes of children in foster care who were removed because of a parental disability. *Children and Youth Services Review, 62*, 22–28.
- Lightfoot, E., Hill, K., & LaLiberte, T. (2010). The inclusion of disability as a condition for termination of parental rights. *Child Abuse & Neglect, 34*, 927–934.
- Luciano, A., Nicholson, J., & Meara, E. (2014). The economic status of parents with serious mental illness in the United States. *Psychiatric Rehabilitation Journal, 37*(3), 242–250.
- Mabli J., & Ohls J. (2015). Supplemental Nutrition Assistance Program participation is associated with an increase in household food security in a national evaluation. *Journal of Nutrition, 145*(2), 344–351.
- Magaña, S., Parish, S. L., & Cassiman, S. A. (2008). Policy lessons from low-income mothers with disabilities: A primer on inadequate incomes, work disincentives, and

- bureaucratic insensitivity. *Journal of Women, Politics & Policy*, 29,181–206.
- Mitra, S., Findley, P.A., & Sambamoorthi, U. (2009). Health care expenditures of living with a disability: total expenditures, out-of-pocket expenses, and burden, 1996 to 2004. *Archives of Physical Medicine and Rehabilitation*, 90, 1532–1540.
- National Council on Disability. (2012). Rocking the cradle: Ensuring the rights of parents with disabilities and their children. Washington, DC: National Council on Disability. Retrieved from https://www.ncd.gov/sites/default/files/Documents/NCD_Parenting_508_0.pdf
- National Research Council. (2013). Research opportunities concerning the causes and consequences of child food insecurity and hunger: Workshop summary. Washington, DC: National Academy of Sciences. Retrieved from <http://www.nap.edu/catalog/18504/research-opportunities-concerning-the-causes-and-consequences-of-child-foodinsecurity-and-hunger>
- Nord, M. (2006). Survey of income and program participation 2001 wave 8 food security data file technical documentation and user notes. Washington, DC: U.S. Department of Agriculture. Retrieved from http://www.nber.org/sipp/food_security/2001.pdf
- Nord, M., & Golla, A. M. (2009). Does SNAP decrease food insecurity: untangling the self-selection effect. Retrieved February 21, 2016, from https://www.ers.usda.gov/webdocs/publications/err85/10977_err85_1_.pdf?v=42317
- Parish, S. L., Grinstein-Weiss, M., Yeo, Y., Rose, R. A., & Rimmerman, A. (2010). Assets and income: Evidence of disability-based disparities in the U. S. *Social Work Research*, 34, 71–82.
- Parish, S. L., Magaña, S., & Cassiman, S. A. (2008). It's just that much harder: Multilayered hardship experiences of low-income mothers with disabilities raising their children. *The Journal of Women and Social Work*, 23(1), 51–65.
- Parish, S. L., Rose, R. A., Grinstein-Weiss, M., Richman, E. L., & Andrews, M. E. (2008). Material hardship in U.S. families raising children with disabilities. *Exceptional Children*, 75(1), 71–92.
- Parish, S.L., Rose, R.A., & Swaine, J.G. (2010). Financial well-being of US parents caring for co-resident children and adults with developmental disabilities: An age-cohort analysis. *Journal of Intellectual & Developmental Disabilities*, 35, 235–243.
- Parish, S. L., Shattuck, P. T., & Rose, R. A. (2009). Financial burden of raising CSHCN: Association with state policy choices. *Pediatrics*, 124(Supplement 4):S435-S442.
- Park, J. M., Solomon, P., & Mandell, D. S. (2006). Involvement in the child welfare system among mothers with serious mental illness. *Psychiatric Services*, 75(4), 493–497.

- Ratcliffe, C., McKernan, S.-M., & Zhang, S. (2011). How much does the supplemental nutrition assistance program reduce food insecurity?. *American Journal of Agricultural Economics*, 93(4), 1082–1098.
- Ribar, D. C., & Hamrick, K. S. (2003). Dynamics of poverty and food sufficiency. Washington, DC: United States Department of Agriculture, Food and Nutrition Research Report No. 36.
- Rose-Jacobs, R., Fiore, J. G., de Cuba, S. E., Black, M., Cutts, D. B., Coleman, S. M., ... Frank, D. A. (2016). Children with special health care needs, Supplemental Security Income, and food insecurity. *Journal of Developmental and Behavioral Pediatrics*, 37(2), 140–147.
- Sands, R. G, Koppelman, N., & Solomon, P. (2004). Maternal custody status and living arrangements of children of women with severe mental illness. *Health & Social Work*, 29(4), 317–325.
- Shaefer, H. L., & Gutierrez, I. A. (2013). The supplemental nutrition assistance program and material hardships among low-income households with children. *Social Services Review*, 87, 753–779.
- She, P., & Livermore, G. A. (2007). Material hardship, poverty, and disability among working-age adults. *Social Science Quarterly*, 88(4), 970–989.
- Supplemental Nutrition Assistance Program (SNAP). (2013). SNAP special rules for the elderly or disabled. Washington, DC: U.S. Department of Agriculture. Retrieved from <http://www.fns.usda.gov/snap/snap-special-rules-elderly-or-disabled>
- Sogar, C. A. (2016). The relationship between parents' physical and mental health symptoms and parenting and material limitations: Results from interviews with parents who receive Supplemental Security Income. *American International Journal of Humanities and Social Science*, 2(2), 36–44.
- Sonik, R. A., Parish, S. L., Ghosh, S., & Igdalsky, L. (2016a). Food insecurity in U.S. households that include children with disabilities. *Exceptional Children*, 83(1), 42–57.
- Sonik, R. A., Parish, S. L., & Rosenthal, E. S. (2016b). Sibling caregivers of people with intellectual and developmental disabilities: Sociodemographic characteristics and material hardship prevalence. *Intellectual and Developmental Disabilities*, 54(5), 332–341.
- Stoddard, S. (2014). 2014 Disability Statistics Annual Report. Durham, NH: University of New Hampshire. Retrieved from <http://www.disabilitycompendium.org/docs/default-source/2014-compendium/annual-report.pdf>
- US Census Bureau. (n.d.). Survey of Income and Program Participation: Methodology. Retrieved from <http://www.census.gov/programs->

[surveys/sipp/methodology/sampling.html](https://www.census.gov/content/dam/Census/programs-surveys/sipp/methodology/sampling.html)

Westat. (2001). Survey of Income and Program Participation user guide. Washington, DC: U.S. Census Bureau. Retrieved from https://www.census.gov/content/dam/Census/programs-surveys/sipp/methodology/SIPP_USERS_Guide_Third_Edition_2001.pdf

Wilde, P., & Nord, M. (2005). The effect of food stamps on food security: A panel data approach. *Review of Agricultural Economics*, 27(3), 425–432.



Parents With and Without Disabilities: Demographics, Material Hardship, and Program Participation by [Rajan Anthony Sonik](#), [Susan L Parish](#), [Monika Mitra](#), & [Joanne Nicholson](#) is licensed under a [Creative Commons Attribution 4.0 International License](#). Based on a work at <http://rdsjournal.org/index.php/journal/article/view/822>. Permissions beyond the scope of this license may be available at <https://www.rds.hawaii.edu>.

Creative Works

On Dance and Aging: An Interview with Berlin-Based Researcher-Dancer Susanne Martin

(with RDS Multimedia and Creative Works Editor, Raphael Raphael)

Raphael Raphael, PhD

RDS Associate Editor of Creative Works and Multimedia

University of Hawaii at Manoa

Abstract: In this interview with Susanne Martin, she considers ways in which she combines her artistic practice as dancer with her theoretical research to better understand aging and dance.

Editors' note: This interview was created in February and March of 2018 via email. I was first exposed to the work of Susanne Martin in an artist panel organized by Jean Marie Casbarian last summer (2017) during a residency I attended with Transart Institute at Uferstudios in Berlin. I was inspired by Susanne's unique approach to her research on aging and dance. She leverages both the living experience of performing in a body and more traditional forms of research. Her unique path as researcher/artist surely invites us all to think about different ways in which we might tap our whole experiences in our work and research. Where relevant, her responses here occasionally include links to experience some of her research/performance firsthand. –RR

RR: How can dance contribute to our knowledge about the experience of aging?

SM: Contemporary dance has the potential to question or dismantle stereotypical body and age-related values and images that are not only a part of dance but also our everyday culture (Albright 1997, Lipscomb and Marshall 2010, Ross, 2007).

I have been interested in images and narratives of age(ing) as a choreographer since 2003. I was thirty-five then. Since then I have created and performed several characters, male and female, dance amateurs and dance professionals between fifty and seventy-five years of age, as well as less character-based deconstructions of age(ing). One could say that this was a quite young age for making age(ing) the major topic and inspiration for one's artistic work. I argue, however, that a premature age(ing) consciousness and concern is rather symptomatic for the dance world's relationship to age(ing). Imagined as well as actually experienced age limits and exclusions start already in childhood, especially in places where the competition and selection-oriented tradition of ballet, with its strict physical norms, has a strong influence on the educational and professional structures of dance (Schwaiger, 2012; Wainwright and Turner, 2006).

Dance as an art form, as a profession, as a field of knowledge and a field with very particular and specialized bodily practices, has a peculiar relationship to age(ing). Western theatre dance has often focused on youthful physicality and, as such, takes part in an unquestioned marginalization of older bodies. However, dance, and specifically contemporary dance, is also

a site for questioning and inventing new ways of experiencing and presenting human bodies in movement (Benjamin, 2010; Brayshaw and Witts, 2014; Hoghe, 2005). Therefore, contemporary dance also has the potential to question or dismantle stereotypical body and age-related values and images that are not only a part of dance but also our everyday culture (Ann Cooper Albright 1997, Valerie Lipscomb and Leni Marshall 2010, Janice Ross 2007). The ways in which this potential can be realized, and indeed, is already being realized is the subject of my PhD thesis *Dancing Age(ing)* that I published in 2017.

Dance is known to be a field with very short career trajectories. Research on the work realities of professional dancers shows that “although [dancers] thought they could continue until their late thirties, on average they actually stopped dancing professionally in their early to mid-thirties” (Baumol, Jeffri and Throsby 2004, p. 4). *Dancing Age(ing)*, however, reveals that the idea of a natural decline of ability does not hold as reason for the traditionally short career of performing dancers in Western artistic dance. I argue that the dominant understanding of age(ing) in the dance profession naturalizes a supposed youthfulness and reiterates an oversimplified “progress-peak-decline” narrative that glosses over underlying issues of debilitating power structures and the problems of a generally underfinanced professional field. Therefore, in the sense of being confronted with ageist norms and often being involved in “process[es] of implicit aging self-stereotypes” (Levy and Banaji, 2002, p. 62) since childhood, I argue dance artists to be experts of social or cultural age(ing) (Woodward, 2006) already by early midlife.

To bring it back to my personal development: age and questions of being either too young or (more often) of being too old have been an issue in my dance life probably since my first dance classes at the age of six. At the age of thirty-five, when many dancers leave the professional field, I started to engage with age(ing) questions artistically. Then, at the age of forty-two I embarked on the adventurous trip of doing a PhD research in dance on “Rethinking Age(ing) in and through Improvisation Practice and Performance,” so the subtitle of my thesis. [It’s important] that I did not enter a PhD program as a way out of the dance profession. I wanted to continue being a performer. I decided for academic research because I realized that it is possible by now to conduct PhD research as a practicing artist and with a focus on the artistic methods and practices I developed as dance artist. What is called a practice as research methodology in the UK (Nelson, 2013) and artistic research in continental Europe (CARPA 1 2009) allowed me to clarify and deepen my ongoing enquiry into questions of age(ing) while also continuing to clarify and deepen my artistic practice of improvisation and performance making. On the one hand, I researched the working strategies of improvisation experts (including myself) that support them to make dance improvisation their life-long artistic practice. On the other hand, I identified specific performance strategies in current dance making that offer an audience images and narratives of age(ing), which divert from stereotypical youth/age dichotomies. I identified performance works that do not repeat the hierarchical contrasting of strength versus weakness, fresh potential versus tiring stagnation, talented or rampant youth versus either demented or wise old aged. Furthermore, through the two solo performances I created as artistic outcomes of my research (*The Fountain of Youth* and *The Fountain of Age*), I developed myself some specific deconstructive

strategies to stage age(ing) in ways that critically question and complicate dominant concepts and representations of age(ing). (See excerpts of the performances here:

<https://vimeo.com/130871033>; <https://vimeo.com/142264906>)

RR: What can dancing do that writing cannot?

SM: Dance as a stage art form can show us bodies, movements, and physical relationships that remind us of the actual uniqueness, quirkiness, and tenderness of having and being a body. Dance reminds us of how precarious and in process of constant change we are as we go through life, through a day, or from one movement to another. Writing can do that as well, I am doing it right now. However, doing or watching dance activates other receptive channels and allows for other kinds of experiential moments. I have always loved the doing of dance; my pleasure in watching dance is still growing, as well as my satisfaction in reading and writing about it.

RR: What is the role of improvisation in your practice and how does it connect to your understanding of aging?

SM: I define my own dancing and performance-making as improvisation-based, because for me improvisation has always been a major reference point, a training focus, and an intellectual stimulation. It is also at the heart of my teaching. At the beginning of my research on age(ing) there was the obvious observation that many of the renowned improvisation focused dance artists keep developing their practice far beyond their forties and even fifties and sixties (see for example Anna Halprin performing on her ninety-fifth birthday: <https://www.annahalprin.org/recentnews>). The apparent age-friendliness of improvisation led me to dig deeper and ask what it is that makes this practice age-friendly? From interviews and participant observations with improvisers aged between forty-six and sixty-three I filtered a range of shared strategies through which they support their life-long dance practice. On a theoretical level this led me to try to articulate the nomadic subjectivities (Braidotti, 1994) that come to the fore when movement artists continue to engage with the claim of improvisation, namely to work creatively with what is present here and now throughout the changes of the body and the changes of life. In *Dancing Age(ing)* I, therefore, argue that the practice of improvisation offers an implicitly critical position to the traditional youth-orientation of Western dance and to the ageist undercurrents that impact contemporary culture in general.

RR: How would you describe your current practice?

SM: I am a dancer who choreographs, I am a choreographer who improvises, I am an improviser who researches, I am a researcher who enquires age(ing) from the perspective and with the methods I developed as a dancer. During the PhD research I focused my artistic practice quite strictly on soloing. Since I completed my PhD and the book, I could finally open myself again to a range of artistic collaborations. I am involved in a variety of performance projects with improvisers from the fields of dance and music. I co-choreographed a piece for eight young semi-professional performers (*Von der Schönheit und Seltsamkeit des Anlehns*) with my colleague Eliane Hutmacher. After years of being

exclusively interested in people of at least my age and older this was an exciting excursion into foreign territory. Besides all this, I am working on the format of danced lectures, which means to present my research on age(ing) through a mix of speaking and dancing. In other words, at each academic conference I spend at least half of my presentation time dancing. I use my live, always age(ing), always precarious body to create an experiential moment for my audience. I have danced already in university corridors and around enormous desks in tiny lecture rooms. How to make such a danced lecture an intellectually satisfying and experientially relevant moment for my academic colleagues is probably the most exciting challenge I gave myself lately. (See a recording of a danced lecture: <https://vimeo.com/album/3608339/video/242220635>)

RR: Are there particular works by others that inspire your practice?

SM: I am still inspired by the improvisers who informed *Dancing Age(ing)*, Ray Chung, Rosalind Crisp, Katarina Eriksson, Julyen Hamilton, Andrew Morrish, and Kirstie Simson. They are my colleagues, friends, and teachers. They keep finding unique ways to continue their particular artistic practices, to stay inspired, to trust change, and to play with what is available to them at each moment.

RR: What are you most excited about now in your practice?

SM: There is a strong sense of new beginnings, which I enjoy. I will teach a contact improvisation workshop in Ukraine soon. I am excited about teaching at the moment and I have never been to the Ukraine, so that is wonderful. And I am just about to start a post-doctoral research on improvisation and embodied knowledge. This will be my next very exciting journey into and through a continuously changing here and now.

Susanne Martin, PhD is a Berlin-based artist and researcher in the field of contemporary dance and performance. She works internationally as soloist and in collaborative settings. Her artistic practice and research focuses on improvisation, contact improvisation, narrations of the aging body, humor and irony in dance, artistic research methods, and improvisation-based approaches to learning, knowledge production and knowledge dissemination. Her book *Dancing Age(ing): Rethinking Age(ing) in and through Improvisation Practice and Performance* has been published by transcript in 2017. www.susannemartin.de

References

- Albright, A. C. (1997). *Choreographing difference: The body and identity in contemporary dance*. Middletown: Wesleyan University Press.
- Baumol, J. W., Jeffri, J., & Throsby, D. (2004). *Making changes: Facilitating the transition of dancers to post-performance careers. Research Project*. [online]. Available from: <http://www.cpanda.org/data/a00191/changes.pdf> [Accessed 2 January 2013].
- Benjamin, A. (2010). Cabbages and kings: Disability, dance, and some timely considerations. In A. Carter & J. O'Shea (Eds.) *The Routledge Dance Studies Reader*. London: Routledge. pp. 111–121.

- Brayshaw, T., & Witts, N. (2014). *The Twentieth-century performance reader*. Third Edition. Abingdon: Routledge.
- Braidotti, R. (1994). *Nomadic subjects: Embodiment and sexual difference in contemporary feminist theory*. New York: Columbia University Press.
- CARPA 1. (2010). *How does artistic research change us?* Proceedings of a conference, Performing Arts Research Centre, Theatre Academy Helsinki 2009. [online]. Available from: http://www.uniarts.fi/sites/default/files/CARPA_1_proceedings%20%282%29.pdf [Accessed 7 March 2018].
- Hoghe, R. (2005). Den körper in den kampf werfen. In G. Klein & W. Sting (Eds.) *Performance: Positionen zur Zeitgenössischen Szenischen Kunst*. Bielefeld: Transcript. pp. 51–57.
- Levy, B. R., & Banaji, M. R. (2002). Implicit ageism. In T. D. Nelson (Ed.) *Ageism: Stereotyping and Prejudice against Older Persons*. Cambridge: MIT Press. pp. 49–75.
- Lipscomb, V. B., & Marshall, L. (eds.). *Staging age: The performance of age in theatre, dance, and film*. New York: Palgrave Macmillan. pp. 11–26.
- Nelson, R. (Ed.) (2013). *Practice as research in the arts: Principles, protocols, pedagogies, resistances*. Basingstoke: Palgrave Macmillan.
- Ross, J. (2007). *Anna Halprin: Experience as dance*. Berkeley: University of California Press.
- Schwaiger, E. (2012). *Ageing, gender, embodiment and dance: Finding a balance*. New York: Palgrave Macmillan.
- Wainwright, S., & Turner, B. S. (2006a) 'Just crumbling to bits'? An exploration of the body, aging, injury and career in classical ballet Dancers. *Sociology*, 40(2), pp. 237–255.
- Woodward, K. (2006). Performing age, performing gender. *Feminist Formations*, 18(1), pp. 162–189.



On Dance and Aging: An Interview with Berlin-Based Researcher-Dancer Susanne Martin by [Raphael Raphael](#) is licensed under a [Creative Commons Attribution 4.0 International License](#). Based on a work at <http://rdsjournal.org/index.php/journal/article/view/867>. Permissions beyond the scope of this license may be available at <https://www.rds.hawaii.edu>.

Creative Works

Stories Our Bodies Tell: The Phenomenology of Anecdotes, Comings Out, and Embodied Autoethnographies

Slava Greenberg, PhD Candidate
Tel Aviv University

Abstract: The essay seeks to explore body-focused phenomenological writing in disability studies and film theory throughout publicly shared anecdotes, coming-out narratives, and embodied autoethnographies. Through the author's own bodily experiences in academia, particularly writing, attending conferences, and teaching, Greenberg bridges the gaps between the disciplines through an embodied autoethnographic phenomenological methodology inspired by film scholar Vivian Sobchack.

Introduction

In this essay, I explore body-focused phenomenological writing in disability studies and film theory, through publicly shared anecdotes, coming-out narratives¹, and embodied autoethnographies. Through my own experiences in academia, particularly in writing, attending conferences, and teaching, I explore the collaborative contribution of two disciplines, disability and film studies, to the articulation of the corporeal being in the world. In the following two sections, I carry on the important work of introducing film and disability scholarship to each other, through a 'coming out' methodology. As opposed to 'inspiration porn', meant to motivate temporarily able-bodied audiences, embodied 'coming out' narratives offer transformative responses and engagements. I argue that these experiences of the body inter-subjectively touch other bodies beyond cognitive perception, in other words, our bodies communicate with other bodies beyond our awareness. My intention is to gather these scholars around my writing table, while respecting and regarding their own bodily intentionality towards their own desks and chairs.

Sara Ahmed's *Queer Phenomenology* (2006) is resting on my too small desk next to my laptop. The image on its cover, a wooden desk and chair superimposed on a blue sky, is prompting me to write these words. Throughout the book, Ahmed addresses her writing desk as well as those used by other philosophers. Ahmed's desk is experienced through her gendered and socialized body:

"It is here [the writing table] that I will gather my thoughts. It is here that I will write, and even write about writing. This book is written on different writing tables, which orient me in different ways or which come to "matter" as effects of different orientations. On the tables, different objects gather. Making a place feel home, or becoming at home in a space, is for me about being at my table. I think fondly of Virginia Woolf's *A Room of One's Own*. How important it is, especially for women, to claim that space, to take up that space through what one does with one's body. And so when I am at my table, I am also claiming that space, I am becoming a writer by

taking up that space” (p. 11).

Like Holden Caulfield in *Catcher in the Rye*, I, too, think about the authors of my favorite academic and fiction books; unlike Caulfield, however, I do not necessarily seek their ‘real life’ friendship. Rather, I imagine them sitting at their desks writing the words I am now reading. Specifically, I think about them orienting towards their chairs. Sometimes, when given enough clues, I can even sense them stretching their bones or stroking their lower back, like I do.

The politics of feminist and the queer practice of inserting oneself into a narrative was eloquently phrased by disability rights activists in the slogan: “Nothing about us without us.” First person narratives, anecdotes, and ‘coming out’ stories have long been popularized by literature and film, yet have only recently been accepted in academia, particularly by the discipline of anthropology, as autoethnographies. Feminist (Averett, 2009; Boylorn, 2013; Ettore, 2017; Griffin, 2012) and queer (Adams & Holman Jones, 2008, 2011) anthropologists claimed that multiple perspectives subvert the idea of a unified ‘truth’, and advocated for self-examination, due to its potential to describe social contexts from the margins. The vulnerability of the speaker/writer’s body, which is usually neglected in academia, is brought forth in various forms when exposing oneself to readers, conference participants, students, and colleagues. Whether the motivation is to critique, disrupt, reclaim, or rethink social orders, the common phenomenological effect of such writings is to transcend embodied vulnerability through intersubjectivity.

During the past decade, in which I have been engaged in film studies and disability studies, I encountered various uses of personal stories, anecdotes, and memories incorporated into research. The relative acceptance of subjective experiences as evidence in an academic study is more natural to disability studies than to film studies, arts and humanities, excluding some philosophical movements, and primarily phenomenology. Disability studies are rooted both in the social sciences and in the disability rights movement, which, I argue take personal experiences more seriously than do humanities and arts scholars. Disability studies scholars positioned in English and Literature departments, in particular, have long been familiar with the transformative powers of autobiographies and autoethnographies focused on disability.

In their book about autobiographies, Smith and Watson (2010) identify sixty autobiographic sub-genres. They include autosomatography/autopathography, characterized by personal narratives challenging stereotypes about people with disabilities, but describe them as unique form of autobiography. They cite Thomas Couser, who suggested that these narratives may also be referred to as “anti-pathologies”; in his experience, the motivation to write first-person narratives is to de-pathologize the self. Couser defined “autosomatography” as distinct from third-person narratives not written by people with disabilities themselves. First-person narratives critique social constructions of the disabled body and employ counter-narratives of survival and empowerment, thus redefining the individual body outside the social stigma and the medical discourse. Moreover, Couser suggests that there are diseases and disabilities that have inspired more autobiographic writing than others. Most prominent

are narratives about breast cancer, HIV/AIDS, deafness, and paralysis, and most recently, narratives about blindness, depression, and autism (Smith & Watson, 2010, pp. 261–262).

Disability studies scholars affiliated with the humanities have also used personal experiences of disability to various degrees in their research, emphasizing diverse embodiments. Tobin Siebers, for example, used first-person anecdotes as both evidence and as a platform for philosophical and social discussions. In his *Disability as Masquerade* (2004) Siebers shared his experience with airports, as a means to discuss ‘passing’, or in this case failing to ‘pass’ as disabled:

“In December 1999, I had an altercation at the San Francisco airport with a gatekeeper for Northwest Airlines, who demanded that I use a wheelchair if I wanted to claim the early-boarding option. He did not want to accept that I was disabled unless my status was validated by a highly visible prop like a wheelchair. [...] The incident was trivial in many ways, but I have now adopted the habit of exaggerating my limp whenever I board planes. My exaggeration is not always sufficient to render my disability visible gatekeepers still question me on occasion but I continue to use the strategy, despite the fact that it fills me with a sense of anxiety and bad faith, emotions that resonate with previous experiences in which doctors and nurses have accused me of false complaints, oversensitivity, and malingering” (p. 1).

‘Passing’ and non-passing, and other responses to ableist stares were also addressed by Rosemarie Garland-Thomson, Carrie Sandahl, and other prominent disability studies scholars. In her book *Staring: How We Look* (2009), Garland-Thomson shared her own and others’ bodily experiences of being stared at by children, and being asked about missing limbs. Sandahl (1991) used her memory of posing for a medical textbook as a child in her critique of the performativity of disability: “I submitted to being photographed, running my mother’s words over and over in my head, fighting the urge to lower my arms and cover my nakedness. I remember the male photographer’s silhouette behind the camera and how I was praised (‘good girl’) for my compliant performance. I was also told that my face would be concealed when the photos appeared in the textbook, so no one would know it was me. I came to understand that my defective body could be separated from ‘me,’ that my body was not really ‘me’” (p. 11). In recent writing, embodied experiences are even more apparent in disability studies scholars’ research such as Janet Price and Margrit Shildrick (2002), Alison Kafer (2013), Ellen Samuels (2017), and others. In these works, the body becomes a compass for understanding diverse beings in the world.

In film theory, as in the humanities, it is unusual to write about a subjective experience, unless you are analyzing an aesthetic representation in a text. Prominent exclusions are phenomenological and affect film theories, which seek to explore spectatorship and spectators’ bodies, and thus involve personal perception. Linda Williams, for example, opens her seminal “Film Bodies” essay by explaining the motivation for the study through an anecdote about her son’s perception of horror films: “When my seven-year-old son and I go to the movies we often select from among categories of films that promise to be sensational, to

give our bodies an actual physical jolt. He calls these movies ‘gross’. My son and I agree that the fun of ‘gross’ movies is in their display of sensations that are on the edge of respectable. Where we disagree and where we as a culture often disagree, along lines of gender, age, or sexual orientation is in which movies are over the edge, too ‘gross’” (Williams, 1991, p. 2). Williams then uses the insight she gained from watching films with her son in the study of their possible effects on their differently gendered and aged bodies. Such anecdotes are rare in film theory; generally, film scholars address subjective experiences, self-representation, and bodily sensations only when describing their representation on screen, and not as self-experienced.

A prominent exception to this generalization is film scholar and phenomenologist Vivian Sobchack. Over decades of writing, Sobchack established a methodology of embodied autoethnographies. Her book, *The Address of the Eye* (1992) “...is often cited as the most rigorous of the film-phenomenology books, and indeed she does meticulously explore Merleau-Ponty’s work in particular...” (Branigan & Buckland, 2015, p. 354). In *What My Fingers Knew* (2004c) Sobchack explains the motivation for inscribing one’s body into the text: “Nearly every time I read a movie review in a newspaper or popular magazine, I am struck once again by the gap that exists between our actual *experience* of the cinema and the *theory* that we academic film scholars write to explain it - or, perhaps more aptly, to explain it away [...] Contemporary film theory, however, has generally elided both cinema’s sensual address and our own ‘corporeal-material being’ as film viewers until quite recently.” Sobchack’s body is an integral part of her experience of the film and her analysis of Jane Campion’s 1993 *The Piano*:

“Despite my ‘almost blindness,’ the ‘unrecognizable blur,’ the resistance of the image to my eyes, *my fingers knew what I was looking at* – and this in advance of the objective ‘reverse’ shot that followed and put those fingers in their ‘proper’ place (that is, where they could be objectively seen rather than subjectively looked through). [...] From the first (although I didn’t ‘know’ it until the second), my fingers *comprehended* that image, *grasped* it with a nearly imperceptible tingle of attention and anticipation and, off-screen, “felt themselves” as a potentiality in the subjective situation figured on-screen. And this before I *re-cognized* my carnal comprehension into the conscious thought: ‘Ah, those are fingers I am looking at’” (Sobchack, 2004c, p. 53).

As I will show in the second part of this paper, Sobchack teaches us that our bodies possess knowledge beyond our cognitive or intellectual comprehension. This concept is further explicated in her most autobiographic/autoethnographic writing, which focuses on living with a prosthetic leg. In her “Living a ‘Phantom Limb’: On the Phenomenology of Bodily Integrity” (2010); “A Leg to Stand On: Prosthetics, Metaphor, and Materiality” (2004); and “Choreography for One, Two, and Three Legs: A Phenomenological Meditation in Movements” (2017); Sobchack offers a phenomenological autobiography of living with a disability, through which she articulates the corporeal and bodily experience of being in the world.

Bodies, Tables, and Podiums, or: What Film Scholars Need to Learn from Disability Studies

In anthropology, autoethnographies are openly social and political. Reed-Danahay (1997) defines autoethnography as a form of self-narrative that places the self within a social context. Autoethnography is both a method and a text, as is ethnography. Autoethnography is also more accessible and can be done by either an anthropologist who is doing ‘home’ or ‘native’ ethnography, or by a non-anthropologist/ethnographer. It can also be done by an autobiographer who places the story of his or her life within a story of the social context in which it occurs (p. 9). In their *Autoethnography: Understanding Qualitative Research* (2015) Tony E. Adams, Stacy Holman Jones, and Carolyn Ellis provide four main motivations to write an autoethnography: the first is to critique, make contributions to, and/or extend existing research and theory. The second is to embrace vulnerability as a way to understand emotions and improve social life. The third is to disrupt taboos, break silences, and reclaim lost and disregarded voices. The fourth is to make research accessible to multiple audiences (p. 36). While anthropology’s ethnographies use personal narratives to mobilize readers, the anecdotes and coming-out narratives seek to touch audiences and evoke reflexivity, a renewed awareness.

However unpopular personal narratives are in film studies research, they are in fact all around us in varying degrees: at national conferences, in classrooms, toilets, and in faculty lounges. We interact, share, and disclose subjective and sometimes intimate aspects of our lives. Moreover, we often use personal stories to convey complex messages, to declare our positions, publicly acknowledge what had been personal, and take responsibility for our actions. Mostly, we choose to do so willingly, as a means of communicating intimately, despite any possible negative effects or vulnerability. Last summer, a colleague organized a film conference that was open to the public, and invited me to present my research on short avant-garde animations about disability. Shortly after the premiere of a new web series, *Spectrums* (Ezra & Launer, 2017), about the Israeli trans* community, he asked me to present my analysis of a few episodes instead, which would give him a chance to screen the series at a large cinemateque theater. This rather common interaction put me in a difficult position; at the time, I had not yet publicly ‘come out’ as trans*. While it had always been my choice as to when, where, and to whom I came out, this situation meant that I had to choose between closeting myself or come out very publicly, at a time and place set by someone else. Also, refusing the offer would have meant excluding an important series from a conference wherein it deserved to be screened, discussed, and dare I say honored. Furthermore, refraining from presenting on trans* issues when given the chance was something I perceived as not standing behind my community. This was an opportunity to educate; I simply could not have said no. I enjoyed watching and researching the series and its unique cinematic style, and its infinite possibilities of trans* temporalities, and I enjoyed thinking about how it draws from both queer and crip (quip) themes. However, I was very anxious (mainly dysphoric) while writing; my thoughts were often scattered, and I was stressed about the deadline. When I presented, I was more nervous than I was the first time I ever presented at a conference. My voice and legs

were shaking, my palms were sweating, and I was not sure that anything I was saying was even coherent. However, only now that I am narrativizing this experience do I realize that it had become a ‘coming out’ story, one of many.

Coming out narratives appear in personal stories and anecdotes and are infrequently incorporated in academic publishing, and presented in classrooms and conferences. Although our subjective ways of being in the world find themselves in our theories, only a few people willingly and publicly acknowledge that fact, and what that way of being means for them. Public acknowledgements are performative, not only in the sense that they rely on former comings out, but also in provoking responses. Acknowledgements, direct declarations, as well as personal stories are noticed. And they are political tools, forcing visibility on what is otherwise erased. Coming out narratives are a part of the broader autoethnographic methodology. Anthropologist Tony E. Adams (2011) writes about his experiences with coming out: “There was the student who, the week after I came out to the class, wrote in a course paper that she likes women but refuses to talk about it with anyone, and the student who told me that his mother and father said he was “no longer their son” and kicked him out of their house. [...] In classrooms and my office, on the street, in restaurants and bars, and at festivals and church, I never know when I will hear struggles with the closet, coming out, and same-sex attraction” (p. 28). Adams focuses on what this performative declaration does to the ‘audience’, particularly their effects on people who share his identity. As these public acknowledgments provoke response, ethical questions of responsibility surface. Adams addresses privacy issues: “...these experiences require me to use great care: ethically, I must protect the privacy of these persons by masking or altering identifying characteristics such as circumstance, topics discussed, and/or race, gender, and name. Persons with same-sex attraction encounter many personal and social pressures; consequently their identities need to be protected, especially if their experiences are being used in ways they never may want or know” (ibid). However, in this essay, I attempt to explore the transformative effects of disclosures, and the responses that they invoke.

After attending several annual meetings of the Society for Cinema and Media Studies (SCMS), and sensing the lack of a conversation about disability studies’ place in it, I organized a panel to address this under-representation. Seeking to engage the more philosophy-inclined film scholars, I invited Prof. Laura U. Marks, well-known for her profound work on embodied aesthetics, phenomenology, and postcolonial theory, to respond to the panel and offer possible connections between film philosophy and crip theory. The panel, entitled *Crippling Film Theory: What Can We Learn about Spectatorship from Disability Studies?* sought to offer new theoretical approaches to cinematic spectatorship using disability studies and crip theory. Film theory has tended to privilege the seen over the heard and other bodily senses, although, as experienced spectators we know that “When we watch a film, all our senses are mobilized, and often, depending upon the particular solicitations of the film, ... our naturalized sensory hierarchy and habitual sensual economy are altered and rearranged” (Sobchack, 2000). The panel suggested that disability studies may offer new perspectives on rethinking spectatorship, and expand vision-centric film theories.

Kathleen McHugh's presentation focused on touching and tasting and further complicated cinema studies' theories of the gaze through Rosemarie Garland-Thomson's articulation of the stare. Allison R. G. Ross presented a queer and crip analysis of visual and mainstream visuality techniques. Specifically, she focused on how discourses which seek to "erase" or "correct" disabled or non-normative bodies or non-heteronormative sexual identities by rendering them "legible," "functional" or "cured," are challenged by works which problematize these discourses. (Rebecca Sanchez was supposed to make a presentation about the embodied language of Chaplin's work through critical deafness, but unfortunately could not attend.) I presented three short animated films that offer an antidote to the social organization of vision, and above all, to the supremacy attributed to vision in the experience of spectatorship. I suggested that what crip theory may teach film scholars, especially through accommodative forms, is that our differently-abled bodies go beyond traditional 'watching' and 'listening' in cinema.

This was also the first SCMS conference to include a land acknowledgement in the program, which the chairs were asked to read before presenting the panel. For those familiar with disability studies conferences, this is a standard presentation, followed by a disability statement. This new addition called attention to the absence of the disability statement. While it is now common knowledge that accessibility means ramps and toilets, even when everything is seemingly made accessible, the potential users of these are imagined to be solely attendees; no one seems to envision that speakers might be disabled. In a recent Feminist Film conference I presented, for example, the building, hall, and toilets were wheelchair accessible. However, the stage was an elevated structure with a podium, a table and five chairs with several steps leading to it. No presenters at that conference used wheelchairs, so the organizer and participants did not have to address this potential issue. Another feminist conference that I attended celebrating a feminist nongovernment organization's thirty years of activism resolved this problem creatively. Although the organizers called ahead to ensure that the building had accessible halls and toilets, the theater's representatives neglected to mention, or it simply did not occur to them as necessary to say, that the stage was not accessible. Only when the first presenter who uses a wheelchair was about to get to the stage did the organizer realize that it was inaccessible. In an activist context and nonacademic setting, the organizers asked everyone to leave the hall and move into the lobby where they reset the microphone, and brought out some chairs. What I imagine would have happened at the aforementioned academic feminist film conference given the same set of circumstances, is that they might have seated the presenter below the stage, thus rendering the speaker partially visible or entirely invisible to the audience. However, this disembodiment of the disabled body is but a radical case of disregard of the body. If we examine the podium, a central artifact in the conference stage design, for example, we find that it functions as an eraser or concealer of the body; it is meant to illuminate and enhance cognitive/intellectual perception. Designed to make it easier for the speaker to read notes, hold a glass of water, etc. and amplify the speaker's voice with and microphones, the modern podium does so effectively only for those who happen to fit standardized bodily norms.

In film studies, the arts, and humanities, we are not supposed to speak about our subjective perceptions nor the corporeal aspects of our bodies. We may use anecdotes, analyze bodies on screen and in narratives; but directly sharing our bodies' histories is not yet legitimate. I often see colleagues and friends sneaking out during fascinating discussions because their bodies physically ache from the sitting position. They each hide their need to stretch, lie down, walk, and move their bodies. Others, myself included, are overloaded by the enhanced sensory, intellectual, or social stimuli, and thus seek quiet dark spaces in which to relax. We meet at the line to the only accessible and gender-neutral toilets, and only there are we free to speak about our bodies. Public coming out narratives, sharing personal experiences, and body histories are more appreciated in disability studies, for the most part, than they are in film, arts and humanities, as noted. Critical examinations of the body, and the self in social contexts are the fundamentals of disability studies' philosophy and methodology.

What happened after the SCMS panel was yet another example of the transcendental effect of embodied coming-out narratives. In Laura U. Marks' very thorough response to the panel, she 'came out' as having mirror-touch synesthesia, a condition of sensual empathy. A week after the conference, I was teaching a class in which I presented Marks' book *The Skin of the Film* (2000). A student interrupted the conversation and described sensations similar to those shared by Marks herself and identified as mirror-touch synesthesia, although I never mentioned it nor was it in the book. Similarly, every time I teach Vivian Sobchack's *What My Fingers Knew* (2004), and screen Samantha Moore's animated documentary, *An Eyeful of Sound* (2010), at least one student comes out as having synesthesia. These experiences are evoked by sensual and body diversity and a conversation about them. Our bodies' knowledge engages with other bodies in ways beyond our intellectual perception.

Following my presentation and coming out at the panel at the Cinemateque that I mentioned, I met a former student who took my Body in Cinema class several years ago, also a trans* person. He shared my part in his coming out narrative, through a memory of my then butch presence. He also remembered me recommending J. Jack Halberstam's *Female Masculinity* (1998), which was my own inspiration. The language in which our bodies spoke to each other's was not yet narrativized; however, it was inter-subjectively perceived beyond language. Sharing our bodies' histories in research, conferences, and classrooms evokes intersubjective responses beyond our awareness, because our bodies bear knowledge of their own. Disability studies' contribution to the disciplines of film, arts and humanities results in a renewed awareness of the different forms and shapes our bodies take in researching, writing, teaching, and interacting with the world. Disability studies forces us to acknowledge our diverse ways of reaching our writing desks, and to defy the admiration of disembodied podiums and the types of bodies that they accommodate.

Phenomenological Autobiography of Living with a Disability, or: What Disability Scholars Need to Learn from Film Scholars

A decade after the conceptualization of the medical and social models in disability theory, Tom Shakespeare and Nicholas Watson (2002) argued that these models created a

dichotomy between impairment, which is perceived as personal and embodied, and disability, which is defined as a social issue. They suggest that we let go of these models, and instead, focus on disability embodiment and disability as an identity. Such emphasis will enable a constant undermining of the dualism of impairment/disability, and proposes the investigation of the body as a new starting point for disability studies (pp. 22–28). Film scholar and phenomenologist Vivian Sobchack theorizes her embodied autobiography and complicates the assumed perception of a ‘fundamental philosophy.’ Sobchack’s writing may also be read within the embodiment model of disability studies, as she examines her body’s intentionality towards the world in various situations: sitting through epic historic films in *Surge and Splendor* (1990), her fingers, skin, nose, lips, tongue, and stomach in *What My Fingers Knew* (2000), and all other parts of her body in *The Address of the Eye* (1992). In her book, *Carnal Thoughts* (2004c), Sobchack thoroughly explores the phenomenology of living with a prosthetic leg.

Sobchack articulates her own concepts, methodology, and style, which derive from her embodied phenomenology. In three of her essays, Sobchack (2004c, 2010, 2017) addresses the phenomenology of living with a disability directly, without it being foreshadowed by film analysis, nor used as metaphor. Her methodology provides theoretic and often poetic frameworks for investigating disability through bodily autobiographies. Sobchack offers an “intimate laboratory” through which she theorizes the phenomenological autobiography of living with a disability. Rather than discuss the articles chronologically, I propose a phenomenological order, illuminating the multiplication of organs. The three essays propose a supposedly counter-intuitive experience of amputation resulting in gaining a phantom limb, a prosthetic, and a cane. Not only is ‘losing’ a leg not narrated as a tragedy in Sobchack’s philosophy, her body’s transformations and shifting intentionalities position the disabled body as closer to the renewed awareness that phenomenological philosophy strives to achieve.

In *Phantom Limb*, Sobchack creates a vocabulary to describe embodied experience through disability. Like many disability scholars, and a few film scholars, Sobchack sets the grounds of her field by means of an anecdote about an encounter with a child, who gazed at her:

Shortly after my amputation, at the supermarket on crutches, I was confronted by the curious gaze of a lone little girl, probably not much older than three. ‘Where’s your arm?’ she asked. ‘You mean leg’, I replied. She stared at the empty space beneath my skirt and persisted: ‘Where’s your arm?’ ‘You mean leg’, I said again, trying to think of an explanation that would be comprehensible to a toddler: ‘My leg got sick. I had to take it to the hospital.’ As she was pondering this, her mother appeared and the child pointed at me and asked, ‘Where’s her arm?’ Clearly embarrassed more by the social situation than by her child’s anatomical mistake, the mother nonetheless dealt with the supposed *gaucherie* of the former by apologizing for the latter. ‘I’m really sorry’, she said, ‘I broke my arm last year. It was in a cast for a while and must have made quite an impression on her.’ (Indeed!) (Sobchack, 2010, p. 55).

This anecdote serves as a springboard to discuss our limited knowledge of our own bodies. A similar anecdote about a child's stare, shared by an interviewee, was used by Rosemarie Garland-Thomson for a different theory: "[I]n the past I have responded quite unfairly to staring people. One tiny child once asked me where my leg was, and I (sort of fed up that day) looked down and FREAKED OUT! 'Oh my God!' I exclaimed, 'I had it this morning!' Now I simply tell them I was sick and the doctor took it off and wait to see if they have any other question" (Gerald-Thomson, 2009, p. 89). For Gerald-Thomson, 'starees' feel responsible for educating a child about tolerating human differences or indulging a child who does not yet know not to stare. For Sobchack, the gazer inter-subjectively orients our awareness of our bodies. The anecdote thus allows for both an embodied and a critical discussion – central to both film and disability scholars – about absence and excess, real and phantom. Furthermore, social movements are discovering that it is no longer possible to think in Cartesian/Kantian ways about the body and society. Social interaction is intercorporeal, as well as intersubjective (Merleau-Ponty, 1962, as cited in Hughes & Paterson, 1997, p. 340).

Phantom Limb focuses the phenomenon of the transforming body, or a phenomenology of becoming disabled. Sobchack's articulation of the corporeality of the phantom limb echoes disability studies scholar Ellen Samuels' embodied autoethnography in *Six Ways of Looking at Crip Time* (2017). Samuels uses her bodily history to explain crip time as broken time: "It requires us to break in our bodies and minds to new rhythms, new patterns of thinking and feeling and moving through the world. [...] It insists that we listen to our bodyminds *so* closely, *so* attentively, in a culture that tells us to divide the two and push the body away from us while also pushing it beyond its limits. Crip time means listening to the broken languages of our bodies, translating them, honoring their words" (Samuels, 2017, np). Samuels and Sobchack seek new words to describe the body. Although striving to articulate a physical disability, Sobchack focuses on its invisible aspects the phantom/real sensations. Such narratives, concepts, and acknowledgements reinforce the claims made by people with invisible disabilities, most prominently the Mad Studies movement, but also people dealing with chronic pain and fatigue, who struggle to provide evidence of their experiences. These "intimate laboratories," as defined by Sobchack, further undermine present/absent, real/imaginary dichotomies that film and humanities scholars seek to challenge.

In "A Leg to Stand On" (2006), Sobchack addresses the materiality of disability and its lived aspects involving gender and class. The essay may be interpreted as aligned with feminist criticism of universal phenomenology, such as that posited by Simone de Beauvoir, Luce Irigaray, Judith Butler, and Sara Ahmed. They criticized the universalistic position and the basis of "the fundamental philosophy" presented by phenomenologists like Edmond Husserl and Maurice Merleau-Ponty. Examining Merleau-Ponty's supposedly gender neutral and generalizing position in his later work about the body, Beata Strawaska (2006) argues that the problem in the universalistic approach is that it aims to present a wholesome theory of bodily experience based on the (male) norm or (male) standard (pp. 92–93). The relations between the disabled body and the social aspects of gender, class, and race have been thoroughly discussed by disability studies scholar Alison Kafer (2013). Kafer analyzes

various studies which suggest that people of color (POC) and underprivileged populations are treated more aggressively due to the inaccessibility of quality treatment for chronic illness. Kafer concludes, that ‘some futures (and some bodies) are more protected than others’ (p. 34).

However, Sobchack’s works dig to the base or root of embodiment, and focus on the corporeality of the flesh. Sobchack shares the ‘unsexy’ details of her prosthetic leg: “... my full (and rather ordinary) ‘AK’ leg cost no less than US \$10,000–\$15,000, since a top-of-the-line carbon fiber ‘BK’ prosthesis used for sports competition (with a special Flex-Foot its inventor also calls the “Cheetah Foot”) costs at least US \$20,000 per leg. Should I wish it (which I don’t), I could request that my HMO approve the purchase and fitting of the latest Bock ‘C-leg’ one in which microprocessors, strain gauges, angle detectors, hydraulics, and electronic valves ‘recreate the stability and step of a normal leg.’ [...] On the other hand (or leg?), the health maintenance organization (HMO) might refuse me not only because the “C-leg” costs US \$40,000–\$50,000 but also because I’m a woman of a certain age who is generally perceived as not needing to be so ‘well equipped’ as someone who is younger (and male)” (Sobchack, 2004b, p. 219). These details are meant to ground the material of a prosthetic, its mundane reality, and relations with her body. However, the phenomenological, social, and institutional relations discussed by Sobchack are also transformative: “...my consciousness, for example, altered at times by a heightened awareness not only of such things as the availability of ‘handicapped’ access and parking but also of the way in which city streets, although still the same objective size, have subjectively expanded in space and contracted in time so that responding to traffic lights now as I cross the street creates a heightened sense of peril and anxiety I never felt before my amputation” (pp. 219–220).

Sobchack describes prosthetics materially, and argues against using it [only] metaphorically or figuratively. “...somehow, somewhere, in all this far-reaching and interdisciplinary cultural work (and with the exception of disability studies), the literal and material ground of the metaphor has been largely forgotten, if not disavowed. That is, the primary context in which ‘the prosthetic’ functions literally rather than figuratively has been left behind as has the experience and agency of those who, like myself, actually use prostheses without feeling “posthuman” and who, moreover, are often startled to read of all the hidden powers their prostheses apparently exercise both in the world and in the imaginations of cultural theorists” (p. 208). However, even in disability studies, prosthetics may sometimes be used as metaphors, albeit with well-intended purposes such as in *Narrative Prosthesis: Disability and the Dependencies of Discourse* (Mitchell & Snyder, 2000).

In “Choreography for One, Two, and Three Legs,” Sobchack further rejects the boundaries of the body parts and re-organizes concepts of embodiment through prosthetics, canes, and intersubjective relations with other bodies:

When the music slowed, my prosthetist came to my table and asked me to dance. My first reaction was, in no small part, terror. Not only was my body suffused with memories of dancing badly in public even before I had a prosthetic leg, but it was also stiffened by the fear of falling – or was it flying? ‘I can’t’, I said. But Steve would not

take 'no' for an answer. 'You can', he said. (Candoco, indeed!) And he pulled me up from the table, took my cane from my hand and hung it on my chair, and, putting my hand on his shoulder and his around my waist, he moved me into a space on the dance floor. 'Listen to the music and trust me', he said – and I realized that, unlike all those teenage boys whose lead I refused to follow, I could – and I felt myself relax, yield to the music and the rhythm and the improvisational give and take of the bodily movement we made together. I forgot to look at my feet. I forgot to think choreographically – that is, in specific terms of my individual steps and also ahead of them. And although, unlike Catherine Cole, I did not end this dance with a pirouette on one leg, for the moment I did displace focus on my bodily immanence to the transcendent ensemble of our movement and I really began to waltz (2007, p. 196).

Sobchack's multiple legs – flesh and prosthetic, 'real' and phantom, canes and other people's shoulders extend the body in a corporeal sense. This inherent intentionality towards other bodies conjures the feminist co-dependence with a crip 'touch ethics.'

Also applying Merleau-Ponty's writing about the intersections between senses and intersubjectivity, Janet Price and Margaritt Shildrick (2006) explore these concepts regarding a possible 'touch ethics'. Merleau-Ponty's famous example of the intertwining of senses was touching hands; the hand touches and is touched simultaneously. The touching hands model has already been thoroughly re-interpreted by feminist scholars, yet further exploration of the concept through disability studies offers an additional layer of meaning to corporeal experience. Price and Shildrick examine the touching hands anecdote by placing a person with a movement disability on the receiving end of the touch and a complete stranger on its giving end, or a person with a hearing or visual disability who uses touch to get attention, orientation, or recognition. Moreover, the clinical encounter between doctors and people with disabilities invokes intimate touch within an unequal power relationship (Price & Shildrick, 2002, p. 70). Despite the power relations invested in bodies touching, what phenomenological philosophy offers through the intersectionality of senses is that absolute mastery is not possible. Price and Shildrick ask further, "What does it mean to hold a hand that has temporarily lost sensation that cannot press back in return? Why does your own hand suddenly feel clumsy in its gestures?" (p. 72). Through the reversibility of touch, "...we are in a continual process of mutual reconstruction of our embodied selves." Thus, the instability of the disabled body is an extreme instance of all bodies (ibid). Finally, Price and Shildrick conclude, "...if we fully accept both the phenomenological notion of the inseparability of bodyliness and being-in-the-world, and the postmodernist contention that not only the subject but the body itself is discursively constituted and maintained, then it is necessary to rethink what would actually make a difference to those with physical disabilities. The disintegrity and permeability of bodies, the fluctuations and reversibility of touch, the inconsistency of spatial and morphological awareness, the uncertainty of the future, are all features that may be experienced with particular force in the disabled body, but are by no means unique to it" (pp. 73–74). They suggest an ethics that acknowledges "...the constitutive relationship between the embodied subject and the world, the notion that our subjectivity consists in a becoming in

a world of others” (p. 63). What we can learn from feminist critics, they argue, is to replace exclusionary models with ideas of embodied subjectivity, “...which is actively and continuously produced through social interactions with other body-subjects.” However, these interactions are also enacted through our “bodies and their mutually constitutive effects one on another [...] the post-conventional perspective demands recognition that our sense of self, and how we orient ourselves to the world, is irrevocably tied up with the bodies of those around us” (Price & Shildrick, 2002, p. 63).

Film theoretician Vivian Sobchack’s phenomenology further complicates concepts and methods of investigating the human body, which are essential to both film theory and disability studies. Sharing her vocabulary, perception, and articulation of embodied autobiographies with disability studies’ scholars and students may provide a philosophical methodology stretching the limits of anthropologist autoethnographies. Moreover, by conceptualizing diverse embodiments, the universal premises of “the fundamental philosophy,” Sobchack’s embodied autoethnography offers a seat at a desk once imagined as accommodating only able-bodied-white-cis-men.

Toward Possible Conclusions

Disability Studies scholar and anthropologist Amy Shuman (2012) talked in an interview about the democratic participation brought forth by the Americans with Disabilities Act (ADA), and questions about access that were consequently raised: “If we believe that a democracy brings everyone to the table, then literally how do you bring everyone to the table? Sometimes it’s a question of access to the table, being able to see, hear or understand what’s going on at the table. So people with intellectual disability are at the last frontier, because we don’t expect them to be at the table.” She concluded that it would be interesting for people to ask themselves “why they wouldn’t be interested in disability studies. What’s not relevant about it?” Seeking to raise these questions, I have brought film and disability scholars around my own table, hoping it accommodates their perceptions and allows room for their insights of being in the world.

Embodied autoethnographies offer both film and disability scholars a methodology to examine their bodies more intimately, and get reacquainted with the ways in which it surfaces in our writing. By focusing on our differently abled bodies while we read and write, teach, listen and speak, take to a podium at a conference, or what toilets we use on breaks, universalistic perceptions of being in the world are further challenged. These disability autoethnographies offer new means of rethinking our bodies, beyond socially constructed and policed dichotomies of mind/body, lack/excess, real/phantom, etc.. Embodied autobiographies remind us that our bodies do not merely orient our being in the world, but also determine our understanding of ‘being’ and the ‘world.’

Finally, practices of sharing our bodies’ histories, through anecdotes, coming out narratives, autobiographies, or autoethnographies, do not only expose an emotional vulnerability; rather they speak to other bodies in an intersubjective language beyond

cognitive comprehension. And while we still find limits in pursuing our intentionalities and orientations towards chairs, desks, podiums, stages, or simply toilets – the anecdotes, comings out, statements, and acknowledgements – stretch out to bodies in undermined, uncharted, and inexplicable ways.

Slava Greenberg is a Ph.D. candidate in the Steve Tisch School of Film at Tel Aviv University, where he teaches film theory, media, and disability studies. Slava wrote his master thesis on *Body in Conflict: The Disintegrated Body in Israeli Post-Second- Intifada Films*. His dissertation research focused on short avant-garde animation, disability, and spectatorship. He has presented chapters from the dissertation in film and disability studies conferences and publications (Animation, Frames, Jewish Film and New Media, and contributed a chapter to Documentary and Disability). Slava's current research conjures Trans* Studies and Crip Theory in documentary film.

References

- Adams, T. E. (2011). *Narrating the closet: An autoethnography of same-sex attraction*. Walnut Creek, California: Left Coast P.
- Adams, T. E., & Holman Jones, S. (2008). *Autoethnography is queer. Handbook of critical and indigenous methodology*. In N. K. Denzin, Y. S. Lincoln, L. T. Smith (Eds.), Thousand Oaks, CA: Sage, 373-390.
- Adams, T. E., & Holman Jones, S. (2011). Telling stories: Reflexivity, queer theory, and autoethnography. *Cultural Studies: Critical Methodologies*, 11(2), 108–116.
- Adams, T. E., Holman Jones, S., & Ellis, C. (2015). *Autoethnography: Understanding qualitative research*. Oxford and New York: Oxford UP.
- Ahmed, S. (2006). *Queer phenomenology: Orientations, objects, others*. Durham and London: Duke UP.
- Amy Shuman Interview [Ohio State English]. (2012). [Video File]. Retrieved from www.youtube.com/watch?v=yJYs4H9xvXI/. Accessed 13 May 2018.
- Averett, P. (2009). The search for wonder women: An autoethnography of feminist identity. *Affilia*, 24(4), 360–368.
- Boylorn, R. M. (2013). Blackgirl blogs, auto/ethnography, and crunk feminism. *Liminalities: A Journal of Performance Studies*, 9(2), 73–82.
- Branigan, E., & Buckland, W. (2015). *The routledge encyclopedia of film theory*. New York: Routledge.
- Ettorre, E. (2017). *Autoethnography as feminist method: Sensitising the feminist 'I'*. London & New York: Routledge.
- Ezra, A. M., (Director) & Launer, A. T (Director). (2017). *Spectrums*. [Video]. Israel.
- Gerald-Thomson, R. (2009). *Staring: How we look*. Oxford and New York: Oxford UP.

- Griffin, R. A. (2012). I AM an angry Black Woman: Black feminist autoethnography, voice, and resistance. *Women Studies in Communication*, 32, 138–157.
- Halberstam, J. (1998). *Female masculinity*. Durham and London: Duke UP.
- Hughes, B., & Paterson, K. (1997). The social model of disability and the disappearing body: Towards a sociology of impairment. *Disability & Society*, 12(3), 325–340.
- Kafer, A. (2013). *Feminist, queer, crip*. Bloomington and Indianapolis: Indiana UP.
- Marks, L. U. (2000). *The memory of the senses. The skin of the film: Intercultural cinema, embodiment, and the senses*. Durham and London: Duke UP, pp. 194–242.
- Mitchell, T. D., & Snyder L. S. (2001). *Narrative prosthesis: Disability and the dependencies of discourse*. Ann Arbor: Michigan UP.
- Moore, S. (Director). (2010) *An Eyeful of Sound*. [Video File]. Canada, Holland, UK.
- Price, J., & Shildrick, M. (2002). Bodies together: Touch, ethics and disability theory. In M. Corker and T. Shakespeare (Eds.) *Disability/Postmodernity: Embodying Disability Theory* London: Continuum, 62–75.
- Reed-Danahay, D. E. (1997). *Auto/ethnography: Rewriting the self and the social (explorations in anthropology)*. Oxford and New York: Berg.
- Salinger, J. D. (1951). *The Catcher in the Rye*. Boston: Little, Brown and Company.
- Samuels, E. (2017). Six ways of looking at crip time. *Disability Studies Quarterly*, 37(3).
- Sandahl, C. (1999). Ahhhh freak out! Metaphors of disability and femaleness in performance. *Theatre Topics*, 9(1), 11–30.
- Shakespeare, T., & Watson, N. (2002). The social model of disability: An outdated ideology?. *Research in Social Science and Disability*, 2, 9–28.
- Siebers, T. (2004). Disability as masquerade. *Literature and Medicine*, 23(1), 1–22.
- Smith, S., & Watson, J. (2010). Appendix A. sixty genres of life narrative. *Reading Autobiography: A Guide for Interpreting Life Narratives*. London and Minneapolis: University of Minnesota, 253–286.
- Sobchack, V. (1990). ‘Surge and splendor’: A phenomenology of the Hollywood historical epic. *Representation*, 29, 24–49.
- Sobchack, V. (1992). *The address of the eye: A phenomenology of film experience*. New Jersey: Princeton UP.
- Sobchack, V. (2004a). A leg to stand on: Prosthetics, metaphor, and materiality. In *Carnal Thoughts: Embodiment and Moving Image Culture* (pp. 203–225). Berkeley, Los Angeles, and London: University California.
- Sobchack, V. (2004b). *Carnal thoughts: Embodiment and moving image culture*. Berkeley, Los Angeles, and London: University California P.

- Sobchack, V. (2004c). What my fingers knew: The cinesthetic subject, or vision in the flesh. In *Carnal Thoughts: Embodiment and Moving Image Culture* (pp. 53–84). Berkeley, Los Angeles, and London: University of California
- Sobchack, V. (2010). Living a ‘phantom limb’: On the phenomenology of bodily integrity. *Body and Society*, 16(3), 51–67.
- Sobchack, V. (2017). Choreography for one, two, and three legs: A phenomenological meditation in movements. *International Journal of Performance Arts and Digital Media*, 13(2), 183–198.
- Strawaska, B. (2006). From the Body Proper to Flesh: Merleau-Ponty on Intersubjectivity. *Feminist Interpretations of Maurice Merleau-Ponty*. In D. Olkowski & G. Weiss (Eds.), University Park: The Pennsylvania State UP, 92-106.
- The Americans with Disabilities Act of 1990. (nd) Retrieved from www.ada.gov. Accessed 23 April 2017.
- Campion, J. (Director) (1993). *The Piano* [Video]. New Zealand, Australia, France: Jan Chapman Productions
- Williams, L. (1991). Film Bodies: Gender, Genre and Excess. *Film Quarterly*, 44(4), 2–13.

Endnotes

1. I use ‘coming out’ narratives, borrowed from queer theory, to describe any form of declarations of one’s invisible identity (LGBTQI or invisible disabilities).



Stories Our Bodies Tell: The Phenomenology of Anecdotes, Comings Out, and Embodied Autoethnographies by [Slava Greenberg](#) is licensed under a [Creative Commons Attribution 4.0 International License](#). Based on a work at <http://rdsjournal.org/index.php/journal/article/view/883>. Permissions beyond the scope of this license may be available at <https://www.rds.hawaii.edu>.

Best Practices

Inclusive Economic Strategy For People With Disabilities: Proactive Management, Organizational Change: A Reasoned Approach to Disability

Bachir Kerroumi, PhD
Laboratory LIRSA

Abstract: The answers to the problem of employment of people with a disability in businesses have often focused on social issues. However, the context which determines the inclusion process mainly depends on project management within organizations. Our purpose is the analysis of favorable factors in management strategies and approaches to people with disabilities.

Keywords: effective management, managing inclusion, social model

Introduction

For any organization, managing people with disabilities involves the setting up of a strategy to manage the diversity of the productive potential of every individual (Allen, 1994). First, this requires the development of a reasoned approach to disability, by understanding its nature and identifying its possible consequences, both positive and negative, in order to implement appropriate techniques and expertise to compensate for the disability in the context of any given job. Secondly, it is important to analyze the set of tasks entailed in a job, both to measure the compatibility of a person's skills with these activities, and to highlight ways in which the employee with a disability may cooperate with his/her able-bodied colleagues. An example of this process would be identifying exchanges of work tasks to allow the person with a disability to reach the same level of productivity as other members of the team. A deliberate effort is needed within the team to develop strategies aimed at the inclusion of people with disabilities, avoiding their isolation. For this purpose, the measures needed to ensure accessibility and inclusion within an organization require the involvement of managers, since they must be put at the center of inclusive processes for people with disabilities. Disabled people's skills and potential productivity must make up the core of any action plan to reach the goal of genuine inclusion.

The advent of new technologies (Burgstahler, Comden, Lee, Arnold, & Brown, 2011), namely the ergonomic adaptation of working tools (assistive ware, ergonomic desks, computing braille display) allows specific tasks to be carried out by workers with disabilities. For example, the fact that people with disabilities in management positions bring added value, both for productivity and innovation, is already well established (Mitra, 2006). Colleagues with a disability in managerial positions have proved their worth in many organizations. They work at all levels, develop their own strategies for compensation, with or without technical support. Their disability often forces them to develop additional skills to balance the disability, whether physical or sensory. Hence physically colleagues with disabilities might

dynamically optimize their concentration and acquisition of new skills in relation to their work. Similarly, visually impaired colleagues might reorganize work methods with perhaps more emphasis on abstract concepts. In the workplace, people with a disability, backed with their differences, directly or indirectly bring richness in methodology across organizations.

In-Work Training and Promotion

In-work training is seldom used as a leverage tool to promote the inclusion of employees with disabilities in managing strategies (Allen, 1994). There are many obstacles to this possible path to promotion. For example, the burden of legal and administrative regulations creates a micro-market of training specially designed for people with disabilities, in which choices become far too limited (Schur, Kruse, Blasi, & Blank, 2009). Failure to develop continuing education or training is a hindrance to career development. The lack of strategy with respect to recruitment of persons with disabilities in typical work situations (conventional labor market) is obvious. The vast majority of people with disabilities who have higher education qualifications come late to a full-time professional work, whether in the private or public sector (Schur et al., 2009). According to the European Union Eurostat statistics published in 2011, 47% of people with disabilities are working, compared with 66% of people without disabilities. In most countries of the European Union, 24 out of 28, (see Eurostats) the lack of fundamental equal rights such as the disability discrimination legislation for education and employment (Mitra, 2006) is a key explanatory variable.

Analysis and Suggestions

In the context of policies based on voluntary choices rather than legal enforcement, it would be wise to carry out an audit on the management of human resources with respect to the inclusion of employees with disabilities. It is worth analyzing organizational procedures in relation to the application of legal regulations (Mintzberg, 2013). This evaluation must take into account the following points:

- Recruitment mechanisms which consider the specific needs of the person with a disability;
- The approach of management towards disability (differentiated management or management integrated into the global strategy);
- Involvement of employees with a disability at the heart of all services;
- The benefits of dynamic management strategy of people with disabilities for all employees (Riddell, Edward, Weedon, & Ahlgren, 2010);
- Ergonomic approaches to work settings and equipment (defined by productivity or limited to the adaptation of equipment);
- The role of the workplace doctor (compulsory in France although optional for most European countries), its involvement in recruitment processes and redeployment must

only focused on health aspects;

- The redeployment process (based on medical diagnosis or skills assessment);
- The impact of perceptions of employees with a disability on the behavior of their peers.

The findings from this evaluation will be used to identify the strands of work needed to achieve the goal of employing people with disabilities at the heart of organizations in the best possible way: to meet labor needs effectively and to develop an efficient managerial strategy in relation to abilities (Mintzberg, Lampel, Quinn, & Ghosha, 2003). The framework for carrying out such an audit must take into account, the elements making up a global strategy for managing human resources, as well as, changes of approach that will help integrate employees with disabilities and avoid any possible isolation. In this way, the inclusion initiative can effectively pay off, and bring genuine progress to a global strategy. The central leverage points on which the project must rest upon are:

- Methods used to recruit employees with disabilities;
- Know-how with regard to redeployment and re-training of employees;
- Systems to support in-work training;
- Ergonomics that are truly integrated into the work organization;
- A policy consisting in predicting needs before they arise;
- Subcontracting to the specialized disability sector (associations, cooperatives, specialized companies).

Objectives of the Management Initiative

The targets in this dynamic management process are multiple and convergent:

- Setup a policy based on voluntary rather than legal action, whilst making an effort for the short-term to meet national legal requirements and, consequently, to comply with those regulations which promote positive action for the employment of people with disabilities (Jones, 1997).
- Balance recruitment and redeployment to introduce real equity in career development and establish the principle of non-discrimination inside organizations, to avoid all discrimination on grounds of disability (Shakespeare & Watson, 2002). So managers must achieve a greater presence of employees with a disability in each social and professional categories (Barel & Fremeau, 2013).
- Change behaviors towards people with disabilities by bringing appropriate know-how to bear in the fields of management systems for disabled employees (Burkhauser, Schmeiser, & Weathers, 2012).

- Consequently, by being of fundamental importance, these organizational techniques should hold a high priority in job retention initiatives.
- Create active cooperation between all the players to allow each one to participate effectively: Human resources management, direction and services, social partners and external specialized organizations involved in systems for inclusion in training: associations of rehabilitation, training centers, universities, job-seeking organizations...

Critical Factors

Recruitment, in-work training and career development.

It is important to restore the balance of representation of social and professional categories "workers, technicians, management" (Sen, 2002, pp. 659-666) within work organizations by recruiting employees with a disability.

In-work training, known as an employees' right, is one essential tool for improving promotion of workers with disabilities. Whether specialized or mainstream, in-work training is also a tool for integration that will benefit all aspects of an employee's career progress. It is one of the success factors of integration.

Redeployment

Qualitative and ethical redeployment requires a job-retention procedure which takes into account the employee's status and previous career. In order to facilitate the roles redesign, an Integration and Redeployment Unit must be created in the Human Resources Department. This unit must have a high priority in accessing the budgets controlling the resourcing of workplace design and equipment, in-work training and skills assessment.

Workplace Design and Accessibility

Workplace design is a new specialization which arose from a study of ergonomics. It has gradually grown to include other disciplines such as computing, technical support, human assistance, etc. Working interfaces adaptation for employees with disabilities is necessary to achieve an autonomy similar to that of their colleagues without disabilities (Feldman, 2004).

Experts have agreed on a definition of needs for workplace design (Florey & Harrison, 2000) based on an analysis of the tasks to be carried out, leading to a set of specifications for a given role (Klimoski & Donahue, 1997). The practical strategy, experimentally developed by these experts, resolves technical problems and has led to a positive evolution of technical, mechanical, electronic and computer-based supports. It requires a mutual agreement and a sharing of experiences, through a formalized procedure using an organization's intranet, particularly between employees with a disability and internal technical support staff.

In short, the success of the managers' undertaking, depends on the ability of improving technical accessibilities but also on the capability of keeping employees with

disabilities regularly informed about technical assistance in relation to their work tasks. Accessibility, and the mobility of employees with disabilities at the heart of the work environment requires two complementary approaches: one based on the respect of regulations on building and workplace design, the other linked to an organization. The convergence of these two approaches meets the global needs of freedom of movement, security and comfort of all employees.

Education of employees in work environments and the role of Health and Safety committees.

The success of disabled people inclusion and integration depends on the perceptions of all the players in the working environment. Human Resources Departments must inform and raise awareness among operational services and trade unions to contribute to the development of a positive culture (Schur et al., 2009) about the social representation of people's differences. Training modules and education about the best ways of creating welcoming environments for employees with disabilities must be in place across an organization. In the same way, information and education of those in charge of apprentices must be ensured.

Conclusion

There are several categories of factors that further integrate people with disabilities into work organizations integration into work organizations. First, there is a need for establishment of a strategic management policy on employment and abilities, which would take into account the specificities of each employee category (women, men, young people, experienced and over 50 ...). Without this proposal, i.e. the creation of a management principle linking overall human resources and their potential, the management initiative for integration of people with a disability is at risk of falling into social welfare or even into charity.

It is crucial to establish education and information targeting all groups with responsibility within the organizational structure. This education must emphasize the abilities and potential of disabled people. Similarly, information about disability must be rationalized, to avoid any confusion with sickness or stages of illness. The players in this mission could be a member of the Human Resources department, a service director or somebody in charge of maximizing productivity. These stakeholders are more likely to create an inclusion initiative based on a productive capabilities system. In addition, the role of the workplace doctor (where applicable) must be strictly limited to diagnosis and identification of incompatibilities linked to impairments (for instance making decisions on behalf of people with disabilities or the managers). Counseling not decision-making. So if the organizational structure is well defined, regarding those who are involved in the process, then the inclusion initiative will be anchored into the culture and central concerns of the organization.

The obstacles to this process are often psychological, and linked to fear of the unknown. They can easily be overcome if those in power show a genuine will to change. Depending on what strategy is adopted, i.e. social, charitable or managerial, able-bodied

colleagues will react either one way or the other. Often, people facing ignorance tend towards imitation (Shakespeare & Watson, 2002). So when we come face to face with employees with a disability we must above all avoid falling into a special behavior, often based on pity. In the long-term, we would run the risk of causing them to lose their dignity. It should be obvious that this type of relation is not natural, and long experience, study and observation on the ground, have confirmed its damaging effects (Colella, 2001). It has been especially well demonstrated (Kuznetsova, 2012), in English-speaking countries and Northern Europe, that behaviors, inherently linked to competence, mutually benefit employees with a disability and those working with them. Good practice begins with a successful implementation of the in-house integration initiative, even if all the necessary know-how is not yet in place. Initially, cooperation may work only in one direction, that is, from the specialized partners to the organization, and not the other way. This way, the work organization will acquire all the necessary techniques to apply the initiative. It is worth noting that this initiative must be turned into dynamic action in order to achieve a real evolution either social, economic or technical. Above all, a fundamental mistake to avoid is not to create a parallel system for recruitment or redeployment. That will isolate employees with disabilities and keep them tied into medical or social models whose effectiveness has never been proven. Advice to managers would be the following: remember that the inclusion of employees with disabilities is part of the global strategy for any organization. It must be part of any framework for high quality organizational management. From a process perspective, in terms of productivity, this approach will improve the performance of systems such as formal management, as a lever for change and proactive strategy. Consequently, both recruitment and job-retention plans for people with disabilities must be embedded in social and economic framework.

Bachir Kerroumi, PhD Researcher-Associate of laboratory LIRSA in CNAM Paris, France.

References

- Allen, J. (1994). *Successful job search strategies for the disabled: Understanding the ADA*. New York: John Wiley & Sons.
- Barel, Y., & Frémeaux, s. (2013). Le management du travail condition de réussite du management de la diversité. *Management & avenir*, 66(8), 85–102. DOI: 103917/mav.066.0085
- Burgstahler, S., Comden, D., Lee, S., Arnold, A., & Brown, K. (2011). Computer and cell phone access for individuals with mobility impairments: An overview and case studies. *NeuroRehabilitation*, 28(3), 183–197. doi: 10.3233/NRE-2011-0648
- Burkhauser, R. V., Schmeiser, M. D. & Weathers, R. R. (2012). The Importance of Anti-Discrimination and Workers' Compensation Laws on the Provision of Workplace Accommodations Following the Onset of a Disability. *Industrial & Labor Relations Review*, 65(1), 161–180.
- Colella, A. (2001). Coworker distributive fairness judgments of the workplace accommodation of employees with disabilities. *Academy of Management Review*, 26(1), 100–116.

- Feldman, D. C. (2004). The role of physical disabilities in early career: Vocational choice, the school-to-work transition, and becoming established. *Human Resource Management Review, 14*(3), 247–274.
- Florey, A. T. & Harrison, D. A. (2000). Response to informal accommodation requests from employees with disabilities; multistudy evidence on willingness to comply. *Academy of Management Journal, 43*(2), 224–233.
- Jones, G. E. (1997). Advancement opportunity issues for persons with disabilities. *Human Resource Management Review, 7*(1), 55–76.
- Klimoski, R. & Donahue, L. (1997). HR strategies for integrating individuals with disabilities into the work place. *Human Resource Management Review, 7*(1), 109–138.
- Kuznetsova, Y. (2012). *Inclusive corporate and employment of persons with disabilities: analysis of CSR strategies of multinational enterprises in Norway and UK*. Retrieved from <https://www.ufhrd.co.uk/wordpress/kuznetsova-y-inclusive-corporate-culture-and-employment-of-persons-with-disabilities-analysis-of-csr-strategies-of-multinational-enterprises-in-norway-and-the-uk/>
- Mintzberg, H. (2013). *Simply managing: What managers do and can do better*. Oakland: Berrett-Koehler Publishers.
- Mintzberg, H., Lampel, J., Quinn, G. B., & Ghosha, S. (2003). *The strategy process: Concepts, contexts, cases*. London: Pearson Education.
- Mitra, S. (2006). The capability approach and disability. *Journal of Disability Policy Studies, 16*(4), 236–246.
- Riddell, S., Edward, S., Weedon E., & Ahlgren, L. (2010). Disability, skills and employment: a review of recent statistics and literature on policy and initiatives (Research report 59).
- Schur, L. A. (2003). Barriers or opportunities? The causes of contingent and part-time work among people with disabilities. *Industrial Relations, 42*(4), 589–622.
- Schur, L., Kruse, D., Blasi, J., & Blanck, P. (2009). Is disability disabling in all workplaces? Workplace disparities and corporate culture. *Industrial Relations, 48*(3), 381–410.
- Sen, A. (2002). Why health equity? *Health Economics, 11*(8), 659–666. DOI:10.1002/hec.762
- Shakespeare, T., & Watson, N. (2002). The social model of disability: an outdated ideology?. In *Exploring theories and expanding methodologies: Where we are and where we need to go* (pp. 9-28). Emerald Group Publishing Limited.



Inclusive Economic Strategy For People With Disabilities: Proactive Management, Organizational Change: A Reasoned Approach to Disability by [Bachir Kerroumi](#) is licensed under a [Creative Commons Attribution 4.0 International License](#). Based on a work at <http://rdsjournal.org/index.php/journal/article/view/829>. Permissions beyond the scope of this license may be available at <https://www.rds.hawaii.edu>.

Dissertation Abstracts

Dissertation & Abstracts v14i4

Compiled by Jonathon Erlen, University of Pittsburgh

Edited by Megan Conway

A Phenomenological Study of Mentoring Policies and Practices on Special Education Teachers. Smith-Washington, V. A. ProQuest Dissertations & Theses, 2017. [EDD/CI Dissertation] United States: Arizona. University of Phoenix. Publication Number: 10265876

Being a Man With an Invisible Disability: College Men's Experiences. Korn, M. ProQuest Dissertations & Theses, 2017. [Ph.D. Dissertation] United States: Rhode Island: University of Rhode Island. Publication Number: 10263711

Stigmas associated with having depression among African American older adults. Adigun, O. J. ProQuest Dissertations & Theses, 2017. [EDD/CI Dissertation] United States: Arizona. University of Phoenix. Publication Number: 10262777

Disability Studies, Multiculturalism and Urban Science Education: A Mixed-Methods Phenomenography of Graduate Student Learning. Boda, P. A. ProQuest Dissertations & Theses, 2017. [Ph.D. Dissertation] United States: New York. Columbia University. Publication Number: 10265995

Teachers' and Parents' Perceptions of Special Education Referral for African American Students. Smith-McClelland, D. ProQuest Dissertations & Theses, 2017. [Ed.D. Dissertation] United States: Minnesota. Walden University. Publication Number: 10272708

An Examination of Home, School, and Community Experiences of High-Achieving Deaf Adults. Tanner, K. K. ProQuest Dissertations & Theses, 2017. [Ed.D. Dissertation] United States: Connecticut: Western Connecticut State University. Publication Number: 10277520

Expert Consensus on Barriers to College and University Online Education for Students with Blindness and Low Vision. Pavithran, Sachin D. ProQuest Dissertations & Theses, 2017. [Ed.D. Dissertation] United States: Utah. Utah State University. Publication Number: 10278575

Perceived Discrimination and Depression Symptoms Among Hispanic Students: Biculturalism as a Moderator Variable. Cruz, J. M. ProQuest Dissertations & Theses, 2017. [Ed.S. Dissertation] United States: California. California State University, Fresno. Publication Number: 10265725

Accessibility of music experiences for individuals with age-related hearing loss. Wilhelm, L. A. ProQuest Dissertations & Theses, 2016. [Ph.D. Dissertation] United States: Iowa. The University of Iowa. Publication Number: 10240478

Postcolonial Encounters with Disability: Exploring Disability and Ways Forward Together with Persons with Disabilities in Western Zambia. Cleaver, S. R. ProQuest Dissertations & Theses, 2016. [Ph.D. Dissertation] Canada: Toronto. University of Toronto. Publication Number: 10194206

The disability-diversity disconnect: Redefining the role of student disability within the postsecondary environment. Aquino, K. C. ProQuest Dissertations & Theses, 2016. [Ph.D. Dissertation] United States: New Jersey. Seton Hall University. Publication Number: 10243991

"I Wouldn't Want to Be Anyone Else": Disabled Girlhood and Post-ADA Structures of Feeling. Todd, A. ProQuest Dissertations & Theses, 2016. [Ph.D. Dissertation] United States: Arizona. Arizona State University. Publication Number: 10246019

Student veterans with disabilities in higher education: The lived experiences of transition and engagement. Bryan, A. ProQuest Dissertations & Theses, 2016. [Ed.D. Dissertation] United States: Massachusetts. Northeastern University. Publication Number: 10194461

Perceptions of Mental Illness in the African Caribbean Culture: The Spiritual Experiences. Clement, C. S. ProQuest Dissertations & Theses, 2016. [Ph.D. Dissertation] United States: Illinois. The Chicago School of Professional Psychology. Publication Number: 10253823

The lived experience of adults with hearing loss as they acculturate into deaf communities. Officer, C. E. ProQuest Dissertations & Theses, 2016. [Ph.D. Dissertation] United States: Minnesota. Capella University. Publication Number: 10243946

Understanding faculty members living with disabilities in higher education. Weiss, L. ProQuest Dissertations & Theses, 2016. [Ed.D. Dissertation] United States: Indiana. Ball State University. Publication Number: 10251801

Voiceless in Medical School: Students with Physical Disabilities. Donlan, M. J. ProQuest Dissertations & Theses, 2017. [Ph.D. Dissertation] United States: Virginia. The College of William and Mary. Publication Number: 10248183

On Our Blindness: Disability Cultures of the Americas. Goldstein, K. D. ProQuest Dissertations & Theses, 2017. [Ph.D. Dissertation] United States: New York. New York University. Publication Number: 10247592

Representations of monstrosity, metamorphoses and physical deformity in Italian Renaissance literature. Bandurski, K. A. ProQuest Dissertations & Theses, 2017. [Ph.D. Dissertation] United States: Illinois. The University of Chicago. Publication Number: 10253755

