

Review of Disability Studies: An International Journal
Volume 11, Issue 1
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Lights. Camera. Disability?

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For ten years, RDS has offered a resource for scholars, students, educators, researchers, and anyone interested in disability studies to tap into the field from a variety of perspectives. We have always found it very important to represent the international community so that we can understand disability studies wholly by way of each and every unique experience chosen for publication. In addition to our global perspective on current research, it has been the intention of RDS to provide an outlet for creative works as well. We believe that creativity can illustrate an idea just as effectively as a research paper, and the emotion it inspires can be far reaching, transcending language and cultural identity.

Over the weekend, while indulging in the overpriced entertainment available at my local movie theater, it was clear why movies are loved the world over. They have captured our souls for over a century. First they were a magical marvel, a display of technology and illusion, only to become completely entrenched in society- we repeat lines of dialogue in everyday conversation, borrow fashion and adopt details of lifestyles we feel compelled to mimic. In short, movies have become a source of direction, a compass, so that we can understand ourselves, where we fit in the world, and what dreams should be held in great esteem. For better or for worse, films serve as a tool, teaching us about our world and the others that inhabit it. This influence is a testament to the power of art. The question I can't help but ask is how do we ensure that everyone is represented in these films? Where are people with disabilities in film and art? Why are they portrayed narrowly and by mainly able-bodied actors? Simply, we can't rely on Hollywood to deliver such diversity just yet, and luckily we don't have to.

Of course people with disabilities are making art and are involved in every step of the various processes. Finally, through the Internet and its many outlets for self-publication, self-producing, and self-promoting, this art is surfacing in the mainstream more than ever before. The disability rights slogan, "Nothing about us without us" certainly applies to art. It has to! How can we understand someone's experience, if he or she isn't the one telling the story? RDS has always accepted creative pieces but as we move forward with the current transition, we hope to increase the number of creative works and multimedia submissions we receive. These sections are motivators for change, encouraging expression and fostering communication.

As this weather-difficult Winter rolls into Spring, and the sun finally shines on your world, perhaps it's time to tap into your own creativity. We want movies, photography, audio pieces, paintings, sculpture, poetry, and short stories. If it's art, we want it, and don't forget to spread the word. There are many stories left untold.

The Mainstream Is Not the Enemy: Maximising Audiences for “Disabled Voices”

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Abstract: The unique, powerful and compelling perspectives of people with disabilities have gone unheard by mainstream audiences for too long. In film and television, this lack has been traditionally blamed on broadcasters, distributors and audiences themselves, who are failing to fulfill their "moral obligation" to watch. But finding an audience for ‘disabled voices’ means a shift in priorities for those who produce disability narratives. Successful film and television producers prioritize ratings and ticket sales, study and analyze what kinds of stories work, and ensure their product has the best possible chance of reaching a wide audience. The producers of disability narratives need to do the same, prioritizing what an audience wants ahead of how people with disabilities are represented, who is making the representation and how it will impact on the “disability community.” I collaborated with three men with intellectual disabilities in the production of my PhD film in Australia in 2010. My aim was to create a comedy film that would appeal to a mainstream audience and give the strongest possible “voice” to my collaborators, a process that required an abandonment of the “us and them” mentality and the forging of a new model of collaborative authorship.

Key Words: comedy, collaboration, authorship

Introduction

Mainstream screen audiences are not easy to reach. They are fussy, highly critical and quick to switch off if they don’t like what they are getting (McNair, 2000; McIntyre, 2003). When it comes to films and television programs about disability, it is even harder to attract -- and maintain -- their attention. If they are not repulsed or jarred by images of people with disabilities eating, having sex and joking (Larsen & Haller, 2002), they are turned off by preaching, cause-driven narratives (Cottle, 1998) or distanced by inaccessible content that “refuses to concede to a non-disabled viewership” (Davies, 1997, p.65).

The result is that the many powerful and compelling voices of people with disabilities, those which offer unique and insightful perspectives on the disabled experience, go unheard. One can blame broadcasters for poor timeslots, distributors for not buying and audiences for not fulfilling their moral obligation to watch; but apportioning blame, and complaining that no one is watching when they really, really “ought” to, is not a practical solution.

Finding an audience for these voices means shifting priorities. It means, first and foremost, that film and program makers listen to their audience. Successful film and television producers prioritise television ratings and movie ticket sales, study and analyse what kinds of stories work, and make sure their product has the best possible chance of reaching their market. The makers of disability narratives need to do the same, prioritising what an audience wants ahead of how people with disabilities are represented in the story, who is making the representation and how it will impact the disability community.

The creative-practice component of my PhD, a comedy film entitled *Down Under Mystery Tour* (Noonan, 2010), took such an approach. As director, producer and co-writer, I used the traditional tools of storytelling – those which have been proven to appeal to mainstream audiences – to try to create a film that would engage and entertain, and still give the strongest possible voice to my collaborators, all of whom have intellectual disabilities. I believe the lessons of my experience can assist the future makers of disability narratives to forge new models of creative collaboration and connect with mainstream audiences.

Overcoming Burdens of Representation

Producers who set out to put disability narratives on screen are burdened with more than the creative, practical and logistical demands of making their product. Whether they have a disability or not, they are immediately weighed down by the baggage of decades of screen representation and the expectations demanded of them by external parties. Sometimes, particularly if the film or program-maker has a disability, this baggage is unintentionally self-imposed.

The burden of representation was initially used to describe the situation of black filmmakers, whose limited opportunities in film brought about a need to make every representation count, pushing minority issues and viewpoints to the forefront whenever possible because they might not get another chance (Hall, 1988; Mercer, 1994; Ross, 1996). This burden was seen as being creatively constraining, placing an inordinate amount of pressure on black filmmakers to create ideologically busy films and weighing down their characters with “issue baggage” (Cottle, 1998, p.306), casting them as spokespersons for a culture in its entirety (Mercer, 1990).

For those constructing and producing disability narratives, the burden of representation can unnecessarily limit and corrupt the storytelling process, putting them in a “tricky bind” – either they will be seen as faithfully representing their culture or “shirking their ethical duty by selling out” (Hyun Park, 2010, p.15). Instead of focusing on the creation of an engaging and entertaining narrative with rich and complex characters, producers (and the writers and directors who work for them) can find themselves constrained by voices, both internal and external, that shout: “You cannot make a disabled character do that!”

This burden is built upon a misguided notion that a particular minority or culture has a “fixed and final property” (Mercer, 1990, p.63). It assumes that certain kinds of screen representations are *positive* and acceptable, and others are not. The *negative* representations, according to many writers, have traditionally had damaging impacts on people’s views of disability, “perpetuat[ing] mainstream society’s regard for people with disabilities” (Norden, 1994, p.1).

This viewpoint relies on deciding which representations are “positive” and which are “negative.” Traditionally, finding such a consensus has been contentious and problematic.

The Search for Positive Representation

Researchers in disability imagery have been consistently unimpressed by mainstream representations of disability. Their lists of recurring disabled characters and narrative arcs can be best summarised under the three broad categories of “victim,” “monster” and “hero” (Shakespeare, 1999, p.164).

The first of these categories, the disabled person as a victim, most often portrays characters as innocent, tragic, pitiable and pathetic; they are embittered individuals who must accept and overcome their disability (Longmore, 1987; Norden, 1994; Nelson, 2003; Cumberbatch & Negrine, 1992; Wolfson & Norden, 2000; Morris, 1996). This depiction relies on the presumption that disability is the diminishment of humanity, a burden on society and a separation and exclusion from the community (Longmore, 1987; Nelson, 2003; Bogdan & Biklen, 1977; Barnes, 1992). It dismisses complex problems of discrimination and social stigma in favor of an individual’s heroic and courageous overcoming (Longmore, 1987; Morris, 1996).

The narrative arcs of victim characters often involve their rescue by the wise, strong, non-disabled person, who helps the afflicted person come to terms with their disability (Morris, 1996), putting the responsibility and problem of the disability “squarely and almost exclusively on the disabled individual” (Longmore, 1987, p.71). When sexuality is addressed, it predominantly characterizes those with disabilities as dangerous sexual deviants, asexual or sexually incapacitated. If they are not physically incapable of a sexual relationship, they are not emotionally capable because of their own insecurities about themselves and their disability. They often require convincing, usually from a non-disabled person, that they can be a sexual being *despite* their disability (p.73). Films featuring characters with learning disabilities such as *Forrest Gump* (Starkey, Tisch & Finerman, 1994), *The Lawnmower Man* (Everett, 1992), and *Of Mice and Men* (Smith, 1992) present their protagonists as asexual, “incorruptible simpletons,” childlike fools whose appearance and naiveté underpin their identities. They are the innocents in a strange and tainted world (Kimpton-Nye, 1997, p.32).

Disabled lives are simply not worth living for many victim characters, as seen in films like *Million Dollar Baby* (Eastwood & Haggis, 2004). Death is often the merciful and necessary outcome, a decision ultimately made by the people with a disability themselves, who realise they are better-off dead than disabled (Longmore, 1987; Nelson, 2003; Morris, 1996).

The second broad category of representation is the disabled person as a monster: an evil, violent, sinister and subhuman creature. This representation has existed in cinema since its early days, with the freakish and deformed characters played by Lon Chaney in horror films of the 1920s (Wolfson & Norden, 2000). Evil villains like Captain Hook, Dr. No and Dr. Strangelove populate a long list of disabled characters that are often feared, loathed, pitied and avoided (Nelson, 2003; Barnes, 1992; Cumberbatch & Negrine, 1992; Sontag, 1978). These and other “warped and threatening villains” (Nelson, 2003, p.178) are generally crippled or deformed by their own doing (through “nefarious experiments”). They despise the world for the way they

have turned out and seek vengeance through crime or destruction against the “normals” who’ve escaped the afflictions they have suffered (Longmore, 1987, p.67). Laughable characters who are objects of ridicule by the nature of their disability -- like Ricky Gervais’ *Derek* (Gervais, 2012) or Jim Carrey’s character in *Me, Myself and Irene* (Farrelly, B., Farrelly, P & Thomas, B., 2000)-- also fit within this category (Barnes, 1992; Wolfson & Norden, 2000).

Disabled characters portrayed as monsters attack beautiful women who would normally reject them while villainous, disabled characters lust after “normal” women with “kinky, leering desires” (Longmore, 1987, p.72). Death, as in the case of the victim character, is ultimately seen as the only possible solution to these narratives. In cases where the monster is despised, it is a death that is just and deserved punishment. When we pity and sympathise with the monster, such as the grotesque human-insect hybrid in *The Fly* (Cornfeld, 1986) or the intellectually-disabled ‘Master-Blaster’ in *Mad Max: Beyond Thunderdome* (Miller, 1987), death is tragic, merciful and inevitable -- but it allows us to escape the associated problems that have led to his social exclusion and what might and can still be done to redress these problems (Longmore, 1987).

The third common category of representation is the disabled person as a hero. The heroic disabled character is a wondrous “supercrip” who triumphs over great odds with special gifts and powers (Nelson, 2003, p.177; Barnes, 1992; Thomson, 2001). These characters are sometimes compensated for their deficiency with extraordinary, superhuman characteristics (Dahl, 1993), either literally as in *The Six Million Dollar Man* (Bennett, 1972) or by way of natural intelligence as in *Ironside* (Chermak, 1967). Special gifts may be physical, spiritual, intellectual, moral, mental or emotional but they often reflect an ability and willingness to cope with their affliction. Bitter, grumpy and self-pitying people with disabilities do not get gifts until they “buck up” and get over themselves (Longmore, 1987, p.71; Nelson, 2003). Civilian superstars, techno marvels and high-tech gurus (Wolfson & Norden, 2000) fall into this category, as do “never-say-die types who accept disability as a physical challenge and go out to conquer the world” (Klobas, 1988, p.1).

These three broad categories of representation are considered by many researchers to be one-dimensional, simplistic, and not representative of reality (Shakespeare, 1999). The dominant screen images show little resemblance to the actual lived experiences of people with disabilities (Wolfson & Norden, 2000) and represent a significant gap between people with disabilities and their screen counterparts (Klobas, 1988; Norden, 1994). Researcher Jenny Morris (1996) claims she could watch television and go to theatres for years without seeing her experience of disability reflected on the screen: “The general culture invalidates me both by ignoring me and by its particular representations of disability” (pp.84-5).

The majority of disability writers want more “realistic” images. They also want more “positive” images. But interchanging the two as if they are the same is problematic. There is considerable disagreement among disability researchers as to whose reality is “positive” and should be represented: unrealistic narratives to some are the lived experience of others (Pointon, 1997). For Meekosha (2000), the protagonist in the film *Hilary and Jackie* (Kent & Paterson, 1998), though criticised by disability imagery writers as a stereotypically-negative portrayal of the victim with a disability, was an accurate and affirming reflection of her own experience: “Her

struggle, her rage, her contempt, her inevitable death... engrossed me... finally, there, indeed, on the silver screen, was a woman like me..." (p. 814).

For many writers on disability imagery, "positive" images are those that treat the disability as a secondary characteristic. The narratives do not seek to define a person by their disability – they just "happen" to have a disability (Morris, 1996, p.113). These portrayals show characters with disabilities that are as close to "normal" as possible: attractive, active, involved and competitive, and experiencing "normal" relationships (Longmore, 1987, p.78; Klobas, 1988; Nelson, 2003). "Positive" images are where people with disabilities show up as "normal people doing things that normal people do" (Nelson, 2003, p.183).

There are two major oppositions to this view. The first comes from writers who challenge the defining of normalcy and question who decides the definition: "If it's hard to deny that something called normalcy exists, it's even harder to pinpoint what that something is" (McRuer, 2006, p.7).

The second argument comes from those who, assuming normalcy can be defined, challenge its validation as the preferred way to live (Darke, 1998; McRuer, 2006). Images that position people with disabilities as needing and desiring normalcy is "the very illusion at the heart of the oppression of disabled people" (Darke, 1998, p.183). Seeking normal, sexually satisfying and attractive characters relegates those that cannot live up to that standard further down the scale of what is acceptable (Darke, 1999). This "fantasy of normality" further marginalizes people with disabilities because they are not able, in most circumstances, to imitate the images of normalcy or gain any benefit from any attempt to "normalize" them (Darke, 1999, p.13). McRuer (2006) criticizes what he calls "the hegemonic mode of representation" that seeks to elicit consent to the dominant economic and political ideologies of the time. This oppression, seen in "compulsory able-bodiedness" (p.198), proposes that able-bodied identities and perspectives are preferable and what we all ultimately seek. Striving for normalcy, he believes, reflects the ability to participate in capitalism: "Being able-bodied means being capable of the normal physical exertions required in a particular system of labor" (p.8).

Rather than focusing on individual struggles for normalcy, some theorists want representations to draw attention to the social structures which problematize disability (Darke, 1999). This argument aligns closely with the social model perspective of disability, which distinguishes between the biological reality of impairment and the notion of disability. The latter is an environment of attitudes and institutional structures that can be acted on, changed and improved: "One may have an impairment but in the right setting and with the right aids and attitudes, one may not be disabled by it" (Pointon, 1997, p.1). This view is in opposition to the medical model, which classifies disability as a biological fact, locating the problem within the individual and their impaired condition: "Lacking part or all of a limb, or having a defective limb or organ or mechanism of the body" (Oliver, 1996, p.22; Ellis, 2007). Disability studies traditionally favors the social model and rejects the medical model as wrong: "It is society which disables physically impaired people. Disability is something imposed on top of our impairments by the way we are unnecessarily isolated and excluded from full participation" (Union of the Physically Impaired Against Segregation, 1976, p.3).

Darke (1998) believes the victim narratives which emphasise an individual's struggle to overcome their impairment can be classified in a genre of their own, which he terms "the normality genre" (p.184). This genre subscribes to the medical model of disability, ignoring social elements of impairment and using traditional genre conventions to define and validate "normality." This is done by emphasising the tragic medical nature of the main character's impairment and building the narrative around their struggle for normalcy, a much superior state of being that is represented by all the other "normal" characters in the drama. Darke (1999) wants representations to focus on society and the realities of social integration (Longmore, 1987).

But other writers sit somewhere between the models: they have a problem with representations that focus solely on society and ignore the impairment altogether, thereby lessening the complexity of a person with a disability's identity and creating a barrier to understanding the immense diversity of the disabled experience and its implications (Meekosha, 2000). Such a view aligns more closely with another approach to disability, one that wants to move away from a medical model versus social model perspective and take into account the distinction between what exists ("ontology") and our ideas about what exists ("epistemology") (Shakespeare, 2006, p.55): "People are disabled by societies and their bodies." Even if all social oppression and discrimination were removed, writers of this view claim people would still suffer with impairments. This model, the critical realist approach, acknowledges that there is a reality outside of language, outside of social construction – "The acceptance of an external reality... there are objects independent of knowledge" (p.54). The critical realist acknowledges that bodies hurt, and are limiting and difficult, regardless of what is thought or said about them.

Other writers want to go further than merely acknowledging the existence of impairment in disabled identities: they want to celebrate it and draw attention to difference. McRuer (2006) likes self-proclaimed "supermasochist" Bob Flanagan, a performer with cystic fibrosis whose aggressive, in-your-face onstage act included nailing his penis to a wall (p.181; Thomson, 2001). Flanagan's extreme imagery gave reassurance to those who were actually like him ("Look at me, I am like you") but added the contingency that he may not be "like you" and, if so, he wanted to imagine a future that "might be something other than, different from, or beyond all of this" (p.183). Flanagan, like McRuer, questioned what normality really is, and if he was deemed to be abnormal, he saw that as a reason for celebration (p.186). The images ascribed to Flanagan as a young poster boy of cystic fibrosis sought pity for the lack of a cure and his implied untimely death, and revelry in the remarkable things he could do because of treatment: "normal" things like painting, sketching and playing drums (p.187). Flanagan's adult reality exploded the poster child mythology and his transgressive representation demonstrated and rejoiced in alternative ways of being and surviving. According to McRuer (2006), Flanagan's counter-hegemonic role "imagined crip existence as atypical and reached for something beyond the world order" (p.194).

Similarly, Irish performance artist Mary Duffy, an armless woman with a hand attached directly to one shoulder, "exposes the body that has always been hidden, both shocking and compelling her viewers" (Thomson, 2000, p.335). Her naked performance on stage, accompanied by a soliloquy that explores the hateful and hurtful words she has encountered throughout her life, upsets the "dynamic of the stare" by "repeating in a kind of testimony the words of those that starers while forcing the audience to look at a classic image of female beauty

bearing witness to its own enfreakment by those words” (Thomson, 2000, p.337). Her representation of self poses any questions of normality, what is appropriate looking, what constitutes beauty and what the truth of the body is (p.338).

There are many other works that confront and challenge notions of positive and realistic representations. Among them is John Callahan’s animated TV series *Quads* (Callahan, 2001), which presents a funny and confronting account of a quadriplegic’s life and ran for two seasons in Canada, Australia and Finland (Cosh, 2001, p.5). Documentary films have also added to the breadth and variety of representations. *Goodbye CP* (Hara, 1972) follows a Japanese man with cerebral palsy on the streets of Japan (Erickson, 2007), *My One Legged Dream Lover* (Olsen & Fowler-Smith, 1998) explores amputee fetish and *Keeping It Real* (Kabillio, 2001) follows gay, disabled comedian Greg Walloch on a concert tour (Carter-Long, 2010).

These opposing views of what represents “realistic”, “positive” and “normal” depictions of disability point to what many researchers have written: it is not possible to agree on what a true representation is because there is “no universally true way anything can be represented” (Darke, 1998, p.183; McKee, 2000; Cumberbatch & Negrine, 1992).

If we acknowledge that it is not possible to have one “positive” or “normal” representation, the most sensible way forward for producers of disability narratives is to create a greater depth and variety of representations (McKee, 2000, p.424), actively building and improving the variety of what has been done to increase the number of different sense-making practices to which people might be exposed. This approach removes the constraints of the past, and prioritises originality and storytelling: “The only thing you can do to give the community a fair representation of itself is to provide a range of programs... it’s about volume and it’s about range... it’s having enough types of programs to really accurately reflect the range of experiences inside a community” (“Executive Producer” in Cottle, 1998, p.305).

This, then, is the first of three core strategies I propose for enabling disabled voices to be heard by mainstream audiences: refuse to carry the burden of representation. Every possible representation fits into one or other stereotype, whether it is the helpless or the hero, the assimilated or the outcast. Producers of representations cannot afford to think in this way as they try to tell original, compelling and honest stories.

Abandoning the “Us and Them” Mentality

The creation of new and original disability narratives is not unproblematic. Many writers insist that the only way to achieve such a range and variety of representations is to give people with disabilities full control of the creative content and how they are represented, enabling content made by them and “not on their behalf” (Beatson, 1996, p.88). This view, particularly in disability arts, advocates and celebrates the notion of a distinct disability culture and echoes Charlton’s concept of “nothing about us without us” (1988, p.4; Shakespeare, 2006, p.185; Jaeger & Bowman, 2005, p.111).

Many writers actively encourage a divide between disabled and non-disabled people on both sides of the camera. For them, it is morally outrageous that the majority of disability

portrayals are played by non-disabled actors (Whittington-Walsh, 2002, Cumberbatch & Negrine, 1992, p.115). This position compares the use of non-disabled actors to white actors getting “blacked up” to play black roles (Harnett, 2000, p.27; Cumberbatch & Negrine, 1992; Lynch 1997).

Opposing this view are those who say acting is about pretence and it is therefore logical that such pretence be extended to non-disabled actors playing wheelchair users, people with cerebral palsy, people with blindness and all manner of disabilities (Cumberbatch & Negrine, 1992, p.115). You don’t have to actually kill someone to play a murderer (Lynch, 1997, p.127). While some say real people with disabilities add authenticity for viewers (Beatson, 1996, p.88), others are not convinced that people with disabilities have an exclusive insight into disability. A non-disabled actor has the ability to connect with individual experiences of marginalisation, disempowerment and prejudice (Shakespeare, 2006, p.196).

The argument from within the film and television industries tends to be an economic one. While most producers and writers would generally prefer that disabled characters are played by actors with disabilities, such decisions are most often limited by access to studios, the availability of suitable actors, and opportunities for training and experience (Cumberbatch & Negrine, 1992; Morris, 1996). Producer David Puttnam (Davies, 1997a, p.54) cites two major difficulties when dealing with actors with disabilities in film: major films seek known actors for the purposes of risk minimization and commercial gain, precluding the severely disabled; film shoots are intense and labored processes that require stamina and it is unlikely that an insurance company would approve an actor with a disability if the risk is too great. Right or wrong, Puttnam believes these realities are the way the industry works: “It’s very doubtful that an industry such as the film business would be likely to adapt itself in any way that would be specifically helpful” (Pointon, 1997a, p.54).

When people with disabilities have played major roles in film and television narratives, they have most often appeared in specialist disability programs and documentaries that rarely reach mainstream audiences – content that even people with disabilities are “tired of seeing” (Mulhern, 1995: 131). My documentary *Unlikely Travellers* (Noonan, 2007), which starred six people with intellectual disabilities, was broadcast to more than 600,000 people over three nights on ABC-TV in Australia in 2007 (OzTAM, 2007). It finished fourth out of the five program choices that night. Millions of mainstream viewers preferred instead to watch *Surf Patrol* (more than double with 1.5 million viewers), *Who Wants to be a Millionaire* and *America’s Next Top Model* (OzTAM, 2007).

When people with disabilities have appeared in fictional narratives on film and television, many of the resulting works have also failed to reach the mainstream. Despite adopting the populist sitcom format, *House Gang* (Mason, 1996), an Australian program featuring three housemates with intellectual disabilities (Anderson, 1997), ran for only two seasons on Australian public broadcaster SBS (Williams, 1997). The critically acclaimed film *Struck By Lightning* (Farrant & Charatsis, 1990), featuring a cast of actors with disabilities, was not a box office success by any means and is among the “least remembered” of Australian films (Williams, 2008).

Nevertheless, there has been some progress, particularly in recent years. Mainstream American programs like *The West Wing* (Wells, 1999) and *Breaking Bad* (Gilligan & Johnson, 2008) have both featured recurring characters played by actors with disabilities. Michael J. Fox, who has Parkinson's disease, has had numerous guest starring roles in *The Good Wife* (King, M., King, R. & Zucker, 2009), *Curb Your Enthusiasm* (David, Garlin & Polone, 2000), *Rescue Me* (Serpico, 2004) and *Boston Legal* (D'Elia, 2004) and recently starred in his own sitcom that deals specifically with his disability, *The Michael J. Fox Show* (Fox, Gluck & Laybourne), in 2013.

The use of more actors with disabilities goes only so far in addressing problems of representation. Many writers believe that only when people with disabilities make the films and programs themselves can we escape the baggage of the misrepresentations of the past and create "real, interesting disabled characters and fresh, exciting stories about disability" (Sutherland, 1997, p.20; Safran, 1998a). Writers in this tradition claim it is possible for filmmakers without disabilities to have insights into disability but they are more likely than not to "warp the images to fit preconceived notions" (Wolfson & Norden, 2000, p.297). For Gill (Shakespeare, 2006, p.185), the trappings of disability grant membership to an exclusive, inescapable club: "Non-disabled people, no matter how much they love us, do not know the inside experience of being disabled. Moreover they are in a position to escape the stigma."

But an approach which relies on improved representations from authors with disabilities presumes that authorial control, whether as director, writer or producer, will necessarily produce a different text. It implies that a person with a disability will have full control of the meaning of the text he creates and the representations he makes within it. This view has long been discredited: "A text's unity lies not in its origin but in its destination" (Barthes, 1996, p.213). The viewer is the interpreter of a film's meaning, not its creator.

For this reason and others, Darke (1997, p.14) rejects the idea that people with disabilities will necessarily do a better job of representing themselves as creators of programs. Firstly, some of the so-called "negative" representations perpetrated by non-disabled film and program makers are a real, lived existence for many people with disabilities. If they were to tell their own stories on screen, it is unlikely their representations would differ significantly from those of non-disabled storytellers (Sutherland, 1997, p.14). Secondly, people with disabilities are as equally socialized as non-disabled people to see disability as a negative, individualized problem which focuses on personal tragedy and triumph. Such narratives, which reduce broader complex social problems to simplistic and easily-solvable personal journeys, already dominate disability narratives (p.20).

Other writers argue that letting people with disabilities make the shows themselves is problematic because they make shows that do not reach wide audiences, they either completely exclude non-disabled people or the content is unappealing to the mainstream because it lacks quality or suffers from the burden of representation (Cottle, 1998, p.306).

The information program *Link* (ATV Central, 1976), which ran for more than five years on the ATV network in Britain, is regarded as being the first dedicated disability program with creators and presenters with disabilities (Davies, 1997, p.65). Davies claims that *Link's* problem,

and ultimate failure, was that it refused to concede to a non-disabled viewership: “They [made] no bones about the fact that it waste[d] no time giving explanations that would make the program more accessible for non-disabled people” (p.65). Davies also wants to assign blame to the broadcaster for the show’s demise and the failure of its successor, *One in Four* (BBC Television, 1986), which tried hard to reach a wider, non-disabled audience. Both shows, he claims, failed to find consistent audiences because they were marginalized in the programming schedules (Davies, 1997). This argument presumes that better placement in the schedule (ie. prime time) by the broadcaster might have attracted audiences (the non-disabled included) and, by extension, enabled the show to succeed. According to McKee (2004), such an argument presumes that the “passive masses” will watch whatever they’re given (p.86). The view of some writers suggests that if programs about disability by people with disabilities were forced on primetime audiences, they would watch them without question. But McKee, referring to empirical research, suggests this is not the case. Popular audiences do not passively accept the programs they are given. The failure of disability programs to reach audiences is not the fault of broadcasters or the scheduling. For McKee and others, audiences are not watching because they don’t like the content.

Whether behind or in front of the camera, the problems of an exclusively-disabled approach are often the same: poor quality content and limited ability based on a lack of opportunity, training and experience. Many argue that societal and institutional barriers, including discrimination, restrict the opportunities for people with disabilities to work only on specialist disability programs; they are disadvantaged by poor training (Mulhern, 1997) and are not given the experience required to tell engaging screen stories for the mainstream (Pointon, 1997a). This argument is similarly used for marginalized, under-qualified actors with disabilities and it is a vicious, closed circle (Cumberbatch & Negrine, 1992; Morris, 1996): actors and program creators with disabilities can only improve with experience but they need experience to be given the opportunities.

A commonsense approach, and a third core strategy for producers of disability narratives of the future, combines the benefits of training and experience with the unique perspective of disability, bringing non-disabled people and people with disabilities together in a constructive and safe collaborative environment.

New Models of Collaboration

A collaborative approach, partnership and alliance between people with disabilities and those without, seeks better quality content without lessening the powerful and unique qualities of the “disabled voice” (Shakespeare, 2006). It envisages situations where experienced, non-disabled filmmakers can use the tools of their craft -- their knowledge of story construction, technical production and audience engagement – to make entertaining screen content in collaboration with actors and filmmakers with disabilities, who may have a voice but not the experience or the tools to make themselves heard.

Principles of emancipatory research, a type of research in which people with disabilities are empowered, have relevance here (Barton, 2005). Although it is broadly defined as research that “should be controlled by disabled people as part of a broader process of empowerment”

(Zarb, 1992, p.51), it is seen by many writers as a process which empowers people with disabilities by “using the knowledge and expertise of the researcher towards this end” (Barton, 2005, p.318) and aims to have people with disabilities and researchers “use their expertise and skills in a common cause” (Oliver, 1996, p.102).

Shakespeare (2006) supports the broad principle of emancipatory approaches and welcomes the notion of putting people with disabilities at the center of analysis but he has problems with what he sees as a “writing out of non-disabled people” (p.186). This is because it presumes people with disabilities exist in a vacuum and diminishes the multi-layered connection between disabled and non-disabled people: (a) disability is permeable in that it can happen to a non-disabled person at any stage of their lives and its severity can lessen or worsen; (b) impairment and disability is only part of the identity of a person and may not be the dominant factor in their lives; they may identify and affiliate with other aspects of their identity (ie. sexuality, religion) above their disability; (c) non-disabled people are a desirable and necessary part of the lives of most people with disabilities, whether they are parents, workmates, friends or siblings. “Only the most separatist disabled activist chooses to socialize or work exclusively with other disabled people” (p.186).

Shakespeare (2006) wants to move beyond the suspicion around non-disabled researchers by recognizing that having a disability does not necessarily equate to an automatic insight into disability. Indeed, one person’s lived experience “may actively mislead them to the nature of disability” (p.195). The diversity of disability types (someone with one impairment may have as little insight into someone else’s impairment as a person without any impairment), the skills and knowledge of experienced researchers, and the ability to connect with individual experiences of marginalization, disempowerment and prejudice means non-disabled researchers have as much to offer and do. Their contribution has helped develop disability studies to the status it currently enjoys (p.196).

Other disability writers support this view, seeking “new traditions of inclusive research” (Dowse, 2009, p.150). They reject the broad assumptions that non-disabled researchers and people with disabilities are oppositional, homogenous and unequal groups and claim that an “us and them” approach has limited both researcher and researched in intellectual disability research (p.150). They emphasise a merging of skills, mutuality and collaboration that promise new forms of co-produced social knowledge, highlighting the importance of listening, acknowledgement and collaboration in the seeking of voice and representation (Goggin, 2009, p.11).

Such collaboration has already occurred in Australian film, most notably with *Dance Me to My Song* (De Heer, 1998), which starred and was co-written by performer Heather Rose, who has a disability. Working with celebrated (and non-disabled) Australian filmmaker Rolf de Heer, Rose played in-front and behind camera roles and had creative input (Duncan, Goggin & Newell, 2005, p.157). The resulting film is confronting and “demystifying,” “systematically dismant[ling]” traditional images of disability (p.156). But such representations and collaborations are not common in Australian cinema.

Although he focuses on biographical narratives, the work of Booth (1996) is particularly relevant here for its discussion of storytelling collaboration between writer/researchers and subjects with intellectual disabilities. He suggests collaboration requires, and often demands, that a skilled storyteller (whether they have a disability or not) uses tools of manipulation and construction to tell the best possible story and reach the widest possible audience. Although he refers to printed texts in the form of biographical accounts, his work has relevance for all narratives, including films and television programs. He sees no problem with a level of manipulation to effectively tell the stories of those who can't, people who have learning difficulties and have difficulties in communicating these stories. Indeed, he believes the narratives of people's lives should be absorbing and readable, drawing readers in on an emotional and intellectual level, and if they're not, they've failed their subjects. Narrative researchers, novelists and filmmakers who "cannot take the reader with them are wasting their time" (p.252).

The Future for Disability Narratives

For too long, the makers of films and television programs about disability have ignored the needs of the audience. Instead, they have focused on the needs of academics, disability imagery experts and members of the disability community who want representations to fit within their definitions of "positive" and "realistic." They have been told they cannot create certain disabled characters, cannot use non-disabled actors to play disabled roles, and cannot tell disabled stories if they are not disabled themselves. In the end, they either give up because it is too hard or make compromised narratives that lack the elements necessary to reach mainstream audiences. Consequently, powerful and engaging stories that speak of the disabled experience either fail to get made or fail to get heard.

Only when the producers of disability narratives put their audience first will things begin to change. It is a road rarely-travelled and it is not without great challenges. In addition to creating an original and engaging product, they must navigate the burden of representation, break down divisive attitudes, balance exploitation and manipulation in a commercialism-driven world and create a space for genuine, constructive collaboration that brings together people of different talents, recognizes and utilizes their strengths, and accepts their limitations.

With patience, experience and co-operation, the road ahead can be forged. Weinberg (Wolfson & Norden, 2000) says the continued intermingling between people with and without disabilities has the effect of minimizing the perceived differences between them and diminishing the stereotype of "disabled as different". Representation, he says, has improved over time as a result of "the increasing level of social interaction among people with disabilities and able-bodied people" (p.299).

If these new models of collaboration take place, people with disabilities will develop the skills and expertise to initiate, perform in, and control screen projects as actors, producers and directors. When this happens, the "disabled voice" will be widely accessible and high-quality narratives about disability will reach and engage audiences. The diversity between "us and them" will be something to be celebrated.

Michael Noonan, PhD's doctoral thesis, which included the production of a feature film, was entitled "Laughing and Disability: Comedy, Collaborative Authorship and 'Down Under Mystery Tour'" and was awarded at Queensland University of Technology in Australia in December, 2010. He previously directed and produced the feature documentary *Unlikely Travellers*, which won the IF Award for Best Documentary in 2007 and screened on ABC-TV (Australia) to a prime-time audience of more than 1.8 million people. He currently teaches film and television at the University of Monterrey in Nuevo León, México.

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Situation Analysis of Disability Resources and Needs of Shantytowns Near Lima, Peru

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Abstract: Individuals in shantytowns of Lima, Peru experience unique challenges due to socioeconomic status and perceived inabilities. A situation analysis using rapid ethnographic procedures was conducted to explore life with disability in shantytowns of Lima, Peru. Participants and their caregivers expressed ideas to improve social inclusion of individuals with disabilities in their communities.

Keywords: disability in the developing world, social/political discrimination, disability analysis

Introduction

Individuals with a disability experience more discrimination from social and political activities, lower levels of education, higher rates of poverty, and decreased levels of employment in comparison to non-disabled populations. Households with an individual with a disability experience extra costs resulting from disability, and these households are more likely to experience food insecurity, poor housing, lack of access to safe water and sanitation, and inadequate access to health care. Poverty is thought to be both a cause and a consequence of disability. Recent studies indicate that over 80 percent of individuals with a disability live in a developing country (Chandran, Hyder, & Peek-Asa, 2010).

In June of 2011, the World Health Organization (WHO) published the World Report on Disability, the first comprehensive global disability analysis in over 30 years. This document identifies areas for further research, in particular qualitative research to better understand the lived experiences of individuals with a disability, as the understanding of disability is limited in many less developed areas. The purpose of this study is to investigate community resources and needs for individuals with disabilities living in the shantytown communities near Lima, Peru.

Literature Review

Currently there are over 650 million adults living with disabilities in the world, and four-fifths live in developing countries (WHO, 2011). According to the World Health Survey (2004), the disability rate in high-income countries averaged 11.8% and 18.0% in lower income countries (WHO, 2011). Disability can be both a cause and a consequence of poverty. Poverty can lead to disability through health conditions including low-birth weight, malnutrition, poor living conditions, unsafe work environments, and injuries (WHO, 2011). More than one-half of disabilities are preventable and can be directly linked to poverty (Parnes et al., 2009). Likewise, disability can lead to poverty: empirical evidence indicates that families of a disabled individual experience both economic and social disadvantages at a higher rate than families without

disabled individuals. Disability often results in lower levels of education, employment, financial earnings, and increased expenditures on health related issues (Parnes et al., 2009; WHO, 2011). The challenges related to disability tend to be greater in developing countries with inadequate health care systems, poor infrastructure, and limited budget for health care needs of their citizens (Maulik & Darmstadt, 2007; Parnes et al., 2009; Spiegel, Gosselin, Coughlin, Kushner, & Bickler, 2008). In developing areas, vulnerable groups, including women and individuals living in the poorest wealth quintile, have higher rates of disability (WHO, 2011).

Quantitative research related to disability in developing areas is limited; however a few socioeconomic trends are indicated. Children who are raised in poverty and have parents with low levels of education have higher rates of mental retardation (Aly, Taj, & Ibrahim, 2010).

Children with disabilities have lower school attendance rates than non-disabled children (WHO, 2011). A study of 15 developing countries indicates that households with disabled members spend more on healthcare than households without disabled members (WHO, 2011). Households with disabled members have fewer assets and worse living conditions than households without disabled members (WHO, 2011). In an analysis of 13 developing countries, disability is associated with greater chance of poverty when poverty is measured as being in the lower two quintiles of wealth (WHO, 2011).

According to the World Health Organization (2010a), community-based rehabilitation (CBR) is an important strategy to meet the needs of people with disabilities, especially in developing countries. Most disabled individuals, especially those in low- and middle-income countries or in rural areas have no access to institutional rehabilitation services. In low income areas, having a disability carries a social stigma that leads to limited access to health care, education, and livelihood opportunities (WHO, 2010b). CBR is implemented through efforts of individuals with disabilities, their families, organizations, communities, and relevant government and non-government organizations (NGOs) with goals of developing strategies for physical rehabilitation, equalizing opportunities, reducing poverty, and including individuals with disability in society (WHO, 2010a). In the late 1970s, WHO developed the first generation of CBR with the attempt to extend rehabilitation and medical care to disabled poor in developing areas. In 1994, the WHO, United Nations Organization for Education, Scientific and Cultural Development (UNESCO), and International Labor Organization (ILO) collaboratively developed the current concept of CBR that extends far beyond simply meeting medical and functional needs of the disabled population (WHO, 2010b). CBR is defined as:

“A strategy within general community development for rehabilitation, equalization of opportunities and social inclusion for all children and adults with disabilities. Available in more than 90 countries worldwide (WHO, 2010b), CBR is implemented through the combined efforts of people with disabilities themselves, their families and communities, and the appropriate health, education, vocational and social services” (WHO, 2002).

In areas with low levels of resources the WHO (2011) recommends that CBR efforts focus on identification of people with disabilities, referring them to appropriate resources, and providing education to health workers and families in strategies to reduce secondary complications related to disability.

Although there is no standardization in studying the effectiveness of CBR, current literature indicates a promising outcome for CBR programs. In an analysis of 29 CBR programs in Asia, Africa and Latin America, Velema, Ebenso, and Fuzikawa (2008) reported that independence and social integration improved in at least 50 percent of CBR clients, roughly half of disabled children were enabled to attend school, and improved self-esteem in clients. Evidence indicates that quality of life for disabled individuals and caregivers of disabled individuals can improve with basic rehabilitation intervention (Velema et al., 2008).

Historically, most disability-related research is conducted in high-income areas like the United States and Western Europe, although it is understood that the disability and poverty relationship differs greatly between developed and developing countries (WHO, 2011). Since few disability research studies have been conducted in developing countries, little is known about the lives of individuals with disability in low-income areas, including shantytowns of Lima, Peru.

Context

Peru is a rapidly developing country in South America with a population of 27.5 million people (Peru National Institute for Statistics and Information, 2007). The capital city of Lima is the most highly populated with approximately 8.5 million people (Peru National Institute for Statistics and Information, 2007). In 2010, the GNI per capita in Peru was US \$4,710 (World Bank, 2010). According to the World Bank (2011), 34.8% of Peruvians live in poverty, or live on less than US \$2 per day, and over 14.7% live in extreme poverty, or live on less than US \$1.25 per day. Peru has a high estimated rate of disability: approximately 31% of Peruvians live with a disability, which is much higher than the global prevalence rate of disability of 15.6% (WHO, 2011). Only 12% of the disabled population has received some rehabilitation services in Peru (Campoverde et al., 2003). Less than 25% of adults with disability in Peru are gainfully employed, and 51.4% of disabled children do not attend school (Campoverde et al., 2003). It is estimated that less than 1% of the buildings in Peru are handicap accessible (National Council for the Integration of People with Disabilities, 2000). Old buildings have not been updated to accommodate the mobility needs of individuals with disabilities; the doors are too narrow and there are no elevators or ramps in place of stairs. Even new buildings with ramps are often not accessible because the incline of the ramp is too steep. Rehabilitation services in Peru are limited and costly, resulting in poor access to rehabilitation for individuals living in poverty. According to the World Bank, in 2009, the average yearly health expenditure per capita in Peru was US \$201, and 75.7% of health care expenditures are out-of-pocket expenses.

Methods

The WHO recommends that the first step before the implementation of CBR is to conduct a situation analysis (WHO, 2010b). CBR programs must be based on information that is unique and specific to each community in order to meet the needs of that specific community. According to the WHO framework for CBR, a situation analysis includes identifying what is known about people with disabilities and their living conditions through data collection of “the environment, social, economic, cultural, and political situation at the national, regional and/or

local level” (WHO, 2010b). Information gathering should also be conducted through in-depth personal interviews and review of current literature and government documentation.

This study is a situation analysis of available and desired resources for individuals with disabilities in shantytowns of Lima, Peru. It was conducted through rapid ethnographic assessment procedures, including participant observation, semi-structured interviews, and focus groups (Scrimshaw & Hurtado, 1987). The WHO recommends that rehabilitation efforts first conduct a situation analysis that includes identifying what is known about people with disabilities and their living conditions through data collection of “the environment, social, economic, cultural, and political situation at the national, regional and/or local level” (WHO, 2010b). The WHO also recommends (2010b) that information gathering should be conducted through in-depth personal interviews and review of current literature and government documentation.

In order to gather diverse information related to disability in these communities, fifteen in-depth qualitative interviews with members of households with disability were conducted and one focus group of caregivers and individuals with disability was conducted. The semi-structured qualitative interviews and focus group provided an opportunity to voice opinions openly in order to provide a deep understanding and rich description of living with a disability. Qualitative interviews elicited personal accounts of barriers and facilitators to individuals with disabilities in these communities. The focus group discussion concentrated on social integration and employment opportunities for disabled individuals. Observation of participants, their environments and home life provided additional insights that did not occur through interviewing. Photography (with consent) was utilized to capture the essence of life with disability in these communities.

The field work was conducted during August, 2011. During this time the first author was familiarized with the socio-cultural and physical environment of the shantytowns of Comas, Huaycan, and Villa el Salvador near Lima, Peru. Visits were made to orphanages, therapy clinics, and a government funded pediatric rehabilitation hospital. Informal discussions occurred with adults with disabilities, caregivers of adults and children with disabilities, community health workers, therapists, social workers, and humanitarian workers. Formal semi-structured interviews and the focus group were conducted with formal consent procedures approved by the Wright State University Institutional Review Board (Dayton, OH) and by the non-government organization (NGO) that the author partnered with in Lima, Peru.

Households with a member with a disability were identified and recruited by utilizing the database of recent recipients of charity wheelchairs from the NGO. Purposeful sampling was used to identify participants representing a variety of disability types and ages. Participant inclusion criteria included residents of Comas, Huaycan, and Villa el Salvador, Peru, age 18 years and older who were familiar with disability through personal experience, familial experience, or community-based knowledge.

One focus group was conducted in the shantytown of Villa el Salvador consisting of five individuals with disabilities and two caregivers. Participants of this focus group were identified during a local government sponsored disability advocacy group meeting. The nature of this

meeting was to discuss employment opportunities for individuals with disabilities. Focus group members were identified through a disability employment advocacy group that works with local government officials. The focus group members were not participants of the individual interviews. Community health workers, therapists, social workers, and humanitarian workers were also interviewed. They were identified through snowball sampling techniques. For instance, one therapist introduced the first author to a social worker who works with the disabled population within that community.

A translator and a community health worker or community social worker was present for each interview. The community health worker has a working relationship with each participant, and their presence helped the interviewer gain access to homes with disabled residents. Additionally, the community health worker helped the interviewer successfully navigate the shantytowns. All participants were asked for oral informed consent prior to the interview or focus group. Additional consent was asked for taking photographs. Individuals with disabilities and their caregivers were interviewed in their homes. Length of the qualitative interview varied from 20 to 75 minutes and consisted of open-ended questions on the following topics:

- 1) Perceptions of and attitudes concerning disability
- 2) Access and barriers to health and education resources, mobility aides, and employment opportunities for individuals with disabilities
- 3) Openness to rehabilitation services for individuals with disabilities
- 4) Perception of resources needed to improve quality of life for individuals with disabilities
- 5) Any other topic that the interviewees wished to share related to life with a disability

The qualitative interviews ended when the interviewee had no additional information to add about life with a disability. Following each interview, the focus group, and informal discussions with community health workers and professionals, field notes were written, providing additional information for qualitative data analysis. All interviews and the focus group were digitally audio-taped and transcribed. Qualitative data was analytically organized through a case study approach, followed by thematic coding (Guest & MacQueen, 2011). Thematic coding was based on themes that emerged from interview narratives and field notes, in addition to common themes related to disability: barriers to rehabilitation, employment, education, and social integration, as well as facilitators of health and social wellness, the availability and use of durable medical equipment (DME), and self-perceptions and attitudes of others towards individuals with disabilities. Names of individuals are fictitious in order to protect the privacy of the interviewees.

Results

Characteristics of Participants

Fifteen homes with a disabled member were visited; there were 17 disabled individuals identified in the 15 homes. Two homes had two disabled family members. Age ranges of the individuals with a disability were 6 to 73 years. Eight of the individuals with disability were

minors under the age of 18. The caregivers (parent or other adult family members) were interviewed when the disabled individual was a minor. The most common diagnosis of disability was cerebral palsy (n=7). Other diagnoses represented included stroke, polio, amputation, Parkinson's disease, deconditioning, encephalitis, and spina bifida. For 15 of 17 of the individuals with disability, family members were identified as the primary caregiver, including parents, children, siblings, and grandparent. Key characteristics of the interviewees with disability are outlined in Table 1.

Through the semi-structured interviews, focus group, and direct observation, several themes emerged about life with disabilities in shantytowns of Lima, Peru. The following discussion provides insight into these themes: poverty, inclusion, education, violence and abuse, family life, and rehabilitation.

(See Chart Below)

Table 1. Characteristics of key participants

Age (yrs)	0-10 [1]	11-20 [7]	21-30 [1]	31-40 [1]	41-50 [2]	51-60 [0]	61+ [5]		
Marital status	Single [11]	Married [3]	Widowed [3]						
Disability type	Cerebral Palsy [7]	Polio [2]	Amputation [2]	Stroke [2]	Encephalitis [2]	Chronic conditions* [1]	Parkinson's disease [1]	Spina bifida [1]	
Age of disability onset (yrs)	Congenital [9]	0-10 [3]	11-20 [0]	21-30 [0]	31-40 [0]	41-50 [0]	51-60 [1]	61+ [4]	
Primary caregiver	Single parent [5]	Married parent [1]	Spouse [1]	Sibling under age 18 [2]	Child under age 18 [1]	Child over age 18 [3]	Grandmother [2]	Non-family member [1]	Does not need caregiver [1]
Provider of household income	Parent [8]	Disabled individual [1]	Sibling under age 18 [1]	Sibling over age 18 [1]	Child under age 18 [1]	Child over age 18 [3]	No income [2]		

[x], x = number of participants with characteristic

* Chronic conditions include heart disease and kidney disease.

Poverty and Disability in Shantytowns of Lima

The connection between disability and poverty in shantytowns of Lima, Peru appears strong. Most of the homes visited in each community were one or two rooms, lacked indoor plumbing, had dirt floors, and gaps in the walls, the roof providing little protection from the outdoor elements. Although most homes had access to electricity used to power one or two lights and a television and/or radio, often the electricity was “borrowed” from power lines by the home owners pulling electricity with a wire into their homes. The houses, furnished with few pieces of furniture were cold, dark and damp. On the walls of a few homes were religious pictures and traditional artwork. Most families cooked over an open fire or propane stove without adequate ventilation.

Although the family structure of the fifteen households that were visited varied greatly, family members were the caregivers for all but one of the houses visited. Single-parent households represented almost 80% of the households with a child with a disability. In two of the houses, the mothers had abandoned their family after their child was identified as having a disability. In these instances, the fathers provided income for the household, and an extended family member assisted with caring for the child with a disability.

Gainful employment opportunities are limited in the shantytown; so many fathers leave the home for weeks at a time for farming and mining work in the highlands east of Lima. Despite employment, these families could not afford daily motorized transportation, and the distance was too far to travel on foot. Although two families did have two parents, those households functioned as a single-parent household due to the absence of working fathers. The burden on the caregiver is great; caregivers and disabled individuals both express feeling like prisoners in their own homes. In most cases, the caregiver stays home 24 hours each day, limiting opportunities for his or her to provide additional income for the family. This is a double disadvantage since the expenses for households with a disabled member are greater than households without disabled members due to special needs for medical supplies, medicines, tests and health care visits. When work is available, average weekly income is 100-150 soles (US\$37-55.50). Caregivers report that diapers for incontinent children and adults cost 2.50 soles each (equivalent of US\$0.90), often totaling 10 soles each day. After the expense of medications (typically costing 5 soles per dose) and diapers, there is little money left over for food, clothing, home maintenance, and other bills.

Caregivers are creative in finding additional means for income. In two households the primary caregiver of a child with a disability earned income completing tasks that they could do in the presence of their disabled child. One mother washed clothes in buckets at home earning a few soles each day. Another single mother collected recyclables from trash piles along the street while carrying her six-year-old son with cerebral palsy. The income she earned selling the recyclables did not meet the needs for her four children; her income was supplemented by money from the father of one of her children.

Parents have to make the difficult decision between providing safety and supervision for their disabled children or additional income for their families. In two households both the father and mother of a disabled child were absent from the home. In one household, siblings cared for

the disabled child, and in the other household the disabled child was left home alone. In the case of “Mariella”, a 15 year old girl with cerebral palsy, her younger sisters, aged 6, 9, and 12 took turns staying home from school to care for their sister. The sisters reported that their father was at work in the mountains outside of town, and he likely would not return until the next week. Their mother was away “travelling” and the girls were uncertain when she would return. For this family, the poverty cycle will continue as the children forfeit education in order to care for their sister while their parents are absent from the home.

In the case of “Juan”, a 14-year-old boy with cerebral palsy, the single mother daily leaves the disabled son home alone while she works at a local store. The home’s only door was padlocked from the outside, providing “Juan” no way to escape in case of fire. The neighbor reported that most days the mother leaves the boy sitting on a chair on his front porch, but today he was inside. No one would be able to enter the home to help him. His mother’s need to provide income for the household compromised the physical needs and a safe environment needed for a child to thrive.

In one single-parent household with six children, two of whom had disabilities, the mother chose not to work in order to provide care for her children. One of her able-bodied sons works in construction and provides a modest income for their family. She reports that at times her family “must go without food so [they] can pay the bills.” She reports difficulty paying the water bill of 7.50 soles/month (approximately US\$2.75/ month) and electric bill of 22 soles/month (approximately US\$8.15/month). Her 11-year-old child with a disability has never seen a physician or been formally diagnosed because they lack the funds to visit the doctor. When asked about the family’s financial situation, the single mother says, “This is life, my life. I am used to this now. Before I cried, but I do not cry anymore. This is my life.” Disability affects not only the individual with the disability, but also their caregivers and the economic livelihood of the household.

Social Inclusion and Disability: Why Are People with Disabilities Hidden in Shantytowns?

As the first author walked through the streets and pathways of Comas, Huaycan, and Villa el Salvador, she wondered why people with disabilities were not visible. Based on a review of literature, it can be expected that more than 15% of the population of poor areas has a disability, but in Huaycan and Comas the author did not see a single person with a disability outside of their home. One caregiver stated that his mother, who had advanced Parkinson’s disease, had not left her home in more than one year because it was too difficult to assist her up and down the steep path that led to their home.

Factors that affect social inclusion in developing areas include infrastructure, terrain, geography, safety and violence in the neighborhood, transportation, self-perception, and attitudinal barriers of others. The roads to the interviewees’ homes often were not navigable by automobile or motortaxi (a motorcycle with a bench on the back for riders). The only way to reach most of the homes visited was on foot. Twice, in order to safely make it to the house, the author used both hands and feet to climb the steep hillsides. Couple the steep hills, rocky terrain, winding pathways with weakness, balance difficulties, and poor safety awareness, and a person with a disability easily becomes a prisoner within his or her own home. In the case of 15-year-

old “Mariella”, who has cerebral palsy, she remains confined in her home nearly every day. The 3 foot wide pathway around her home to the main walkway lies along a 10-15 foot drop-off. Her sisters report that she can only leave her home when her father is available to carry her down the hillside. The wheelchair she received from the charity through which we recruited her for this study is unable to navigate the steep, narrow, and rocky pathway, and her father is rarely available, as he works in the mountains for weeks at a time. Without someone to help her navigate the hillside, Mariella is unable to attend school, church, community events, and socialize with non-family members. Her community has a government sponsored school for children with special needs, but Mariella has never attended school due to the fact that her younger sisters, who are her primary caregivers, are unable to physically assist her to school.

Although each household visited had received a charity wheelchair within the previous two years, seven of the fifteen houses reported that they never use the wheelchair because it is unable to negotiate the terrain. Only one participant reported that he was able to use the chair independently, all other participants reported that they need a helper to navigate the wheelchair outside the home. The style of wheelchair that each interviewee received does not fold, and therefore has limited portability. Even if the family could afford to hire a taxi or motortaxi, the chair would not fit in the taxi or motortaxi, thus limiting the mobility of the individual with a disability once they have reached their destination.

Children and Disability: Why Not School?

Although each community did have a school for children with special needs, seven of the eight children in this study do not attend school. In each case, the caregiver identified transporting the child to school as the main barrier to education. Educational barriers expressed by the caregivers included: the school was too far away, the terrain was too difficult to navigate, and transportation by taxi or motortaxi was too expensive. Additional barriers to education reported by three caregivers were that the special education school was “a bureaucracy,” and the admission and enrollment processes were laborious and unfair. One community health worker reported that the school did not have appropriate equipment to meet the needs of children with disabilities. She stated, “The school does not have proper equipment. The children must sit in regular chairs and they tie them to the chair so they do not fall out of the chair.” One community health worker said she did not trust the special education school because of the lack of proper equipment and the teachers’ inadequate understanding of disabilities. If community health workers cannot recommend that caregivers pursue education for disabled youth, who will advocate for the education of the disabled child? If no one, the child remains uneducated, thus limiting the economic and income potential for the future.

Violence, Crime, and Disability

Shantytowns can be dangerous places, with densely populated areas and people in desperate situations. On several occasions, community members advised caution as we travelled about their communities: “Do not carry anything valuable” and “be aware of your surroundings” were common statements heard. The individual with a disability could be an easy target for crime outside of the home. An individual with a mobility-related disability may have limited ability to physically move out of harm’s way if threatened. The individual with a cognitive-

related disability may have limited ability to make sound judgments in stressful situations. The individual with a communication-related disability may not have the ability to call for assistance when found in a dangerous situation. For this reason and the factors discussed earlier, the individual with a disability often remains isolated at home. But, is a shantytown home safe for individuals with disabilities? At least two interviewees were victims of rape in their own homes. The following narratives give insight into their experiences of violence while living with a disability.

Elena's Story

"Elena" is a vibrant 21-year-old female with cerebral palsy. She is friendly, curious, and social. Her speech is limited, but she communicates in simple sentences when given adequate time. Elena lives with her mother, her 11-year-old brother who also has cerebral palsy, and four healthy siblings. According to her mother, the father is an alcoholic and she does not allow him to visit. She states, "When he comes around, I throw things at him to keep him out of my house." Their home is three small rooms, one of which does not have a roof. The floors are made of dirt. There is no sanitation system or running water.

According to a community health worker, Elena was raped at the age of 16. The rape occurred when her single mother was out of the home working to provide an income for the family. Elena was discovered to be expecting a child when she was seven months pregnant. Once she was identified as pregnant, she was sent to live in a government institution for disabled youth. Elena's son lives in an orphanage for children of disabled and/or mentally ill women. Most of these children were conceived through an act of rape. Once Elena's mother could prove that she was able to provide 24 hour care, her daughter returned home.

Rebecca's Story

"Rebecca" is a 34-year-old female with spastic cerebral palsy who lives with her mother. Rebecca cannot walk, sit up, or roll over on her own. She has spent most of her life lying in bed. Until she started going to therapy in the past year, she had been unable to speak and unable to feed herself. Rebecca's mother works outside the home, and Rebecca is left home alone all day. She has two children under the age of 10, who are both the result of rape. Rebecca's mother cares for her and her children.

In both of these cases, young women with disabilities were raped within their own homes when they were without the supervision of a caregiver. Their mothers made the difficult choice of seeking income over providing 24-hour care for their disabled children. Unfortunately, individuals with disabilities can be victims of violence both inside and outside of their own homes. Women with disabilities are an easy target for sexual violence because they are without a voice to be heard. Their silence can be physical, manifested in the inability to speak, but it also is figurative, as the disabled individual is not respected in the community. According to community health workers, their stories are similar to those of many other women with disabilities in these communities.

Family and Disability

Caregivers' Perception of Disabled Children

When a family is living within a mentality of merely surviving until the next day, a disabled family member is often overlooked and undervalued. Little time is spent investing in the disabled individual and working towards developing their motor, communication and cognitive skills. In several homes, individuals with communication difficulties, especially family members with cerebral palsy, were not viewed by their caregivers as having the ability to think. Caregivers have little education, often only three or four years of formal schooling. Health care providers have not educated the caregivers in techniques to maximize the potential of the disabled individual. Many caregivers knew little, if anything, about the diagnosis of the disabled individual. As a physical therapist, the author saw the potential in the individuals with disabilities; despite their difficulty communicating vocally, it was evident that many understood and desired to socially interact with others. Their eyes were bright, making contact with us. They smiled when they were spoken to, hugged, or touched. The clinical impression is that if given the opportunity to develop their communication skills, many of the non-verbal disabled individuals would be able to communicate with others either through spoken word or assistive technology.¹ The lack of opportunity for individuals with disabilities often begins in the home.

Rebecca's Story(cont.)

For 34 years, Rebecca had little opportunity to interact with other people. Living with severe cerebral palsy, she spent nearly every day bed-ridden, surrounded by newspapers to sop up her waste as her mother went to work. She was unable to speak and did not attempt to communicate or interact with her surroundings. She was unable to feed herself. Several months before my visit, a rehabilitation organization learned of Rebecca's situation and she began attending a rehabilitation clinic once each week. Her mother told the rehabilitation specialists that her daughter did not have the potential to improve, but she was willing to allow the rehabilitation specialists to pick up Rebecca and bring her to their clinic weekly. By the end of the first session, Rebecca verbalized one single word to the rehabilitation specialists: "pee-pee." The rehabilitation specialists assisted her onto the toilet, and she used the restroom. The rehabilitation specialists saw potential in her, and continued to bring her to the clinic weekly. Four months after starting rehabilitation, Rebecca was able to speak in complete sentences: "I want music" and "I don't like that," and she was able to feed herself. It is evident that she has the ability to learn and be more independent; however, this potential was not seen by her caregiver until Rebecca demonstrated her latent abilities.

What happened at the rehabilitation clinic that encouraged Rebecca to speak and be heard for the first time? Someone was willing to give her the opportunity to speak and the extra time required to do so. What would Rebecca be like today if her potential was realized when she was young? What if she had received rehabilitation services starting at a young age? How many children with disabilities are not given the opportunity to develop their skills?

Family Support and Disability

The family unit in Peru is strong and the family is the default caregiver for individuals with disabilities in low-income Peruvian families. Hired caregivers cost 1500 soles/month (approximately US \$555/month), making it a luxury accessible only to the wealthy. “Louisa” is a bed-ridden elderly woman with chronic health issues. Her husband of over 50 years quit his job in order to care for his wife when her health began to deteriorate 10 years ago. Working as a baker, his monthly income was 500 soles (approximately US \$185) and they were able to live a decent life off his salary until his wife became disabled. He said, “I would like to hire help so that I can work as a baker, but it is not possible to pay their wages [1500 Nuevo soles/month]. I miss baking.” Fortunately, Louisa has a spouse who is able to provide care for her, and her adult children provide income for the family. Not all disabled individuals in shantytowns are as fortunate.

Pedro’s Story

“Pedro” is a 73-year-old man who worked as a distributor of potatoes to local markets until the year before my visit. His job required him to carry sacks of potatoes, each weighing 50 pounds or more. According to community members he was one of the strongest and most respected men in the community. However, one day while he was at work, he developed weakness of the left side of his body and fell. Since that day, he has been unable to work, and for several months following the incident he was unable to walk. His mobility has improved, and now he is able to walk with the assistance of a walker.

Soon after suffering the stroke, Pedro’s wife passed away. The stroke that Pedro suffered did not only cause him to lose his job and his income, soon after suffering the stroke he lost his house. Without the ability to work, he was unable to provide income he needed to pay for his wife’s funeral and pay the lease to his house. Without any children or living family, Pedro quickly found himself homeless. He now resides in the back room of a soup kitchen in a shantytown. Volunteers from a local church have provided him with clothes, meals, and physical assistance with bathing and dressing him. According to the community health worker, Pedro has applied to live in a government institution for the elderly without family. However, because he has health issues and requires a caregiver to assist with showering, dressing and meal preparation, he was denied residence. She stated that elderly homes are only for healthy elderly people in Peru. Instead, Pedro stays in the small, dark, dusty room behind the community soup kitchen, wishing people would visit him. He is tearful and lonely.

It is not known how many disabled individuals in Peru are without family and caregivers. Similarly, there are no statistics to indicate how many others with a disability have been forced into homelessness. The family unit can be an asset, when they have the ability to provide adequate care for disabled family members. But, when the family unit is broken or an disabled individual has no family, they will be without adequate care and support. In the shantytown, support is almost exclusively given by families. Neighbors and social programs provide little, if any, assistance to families with members with disabilities.

Rehabilitation, Disability, and Poverty: Why Not Rehabilitation?

Rehabilitation (vocational, mental, physical, and occupational) is a means by which mobility, self-care, communication, and recreation are maximized. Of the fifteen shantytown homes visited, only one household's disabled members were currently receiving rehabilitation services. In this household, there were two individuals with disabilities, the rehabilitation services they received were free of charge, and transportation was provided. In the other homes, lack of money and lack of transportation were identified as the main barriers to rehabilitation. Two other interviewees, one man with a history of stroke and one man with an above-knee amputation, did not know that rehabilitation services could benefit their condition. They reported that health care providers never recommended rehabilitation to them. Eight of the 15 interviewees had received rehabilitation services previously in outpatient clinics, and all of those clinics were several miles from the home of the individual with a disability. All of them cited lack of money for transportation as the reason that they discontinued rehabilitation services.

No rehabilitation for individuals with disabilities leads to decreased levels of independence with mobility, self-care and communication, thus contributing to the social exclusion of individuals with disabilities in shantytowns. Social inclusion affects the quality of life of the individual with a disability. Education, friendships, recreation, and employment opportunities are key areas of life that are limited by social exclusion.

Martin's Story

"Martin" worked in construction as a concrete and plaster expert. He was well-known in the community as one of the best workers in construction. He made a good living, supported his large family, and was "content". One day at work he stepped on a nail, but due to diabetic neuropathy, he did not feel the sharp object in the foot. By the time Martin realized that the nail was in his foot, it had become infected. The infection was severe and antibiotics and wound care did not improve the infection. Eventually, his leg was amputated above-the-knee in order to get rid of the infection.

When I met Martin in his home, he was sitting at the kitchen table and he reported being sad. He said he was sad because he could no longer work at his job, which he loved very much. He said it is impossible to do heavy labor jobs from a wheelchair or while using crutches. When I asked about prosthesis, he reported that he could not afford prosthesis. Without a prosthesis, he would not be able to walk. Without being able to walk, he would not be able to work. He said his family was now poor because he could not work.

For Martin, the barrier to rehabilitation and prosthesis was money. Without money to pay for these services, his independence would not significantly improve. In the shantytowns of Lima, Peru, rehabilitation services are not utilized because there is no money available for such services, despite the fact that all of the interviewees reported that rehabilitation would improve their conditions.

Discussion

Where Do We Go From Here?

Although the United Nations' Millennium Development Goals do not specifically address disability, one of the goals is to reduce poverty by one half by 2015. We propose that social inclusion of individuals with disabilities is an integral component of achieving this goal. The former president of World Bank, John Wolfensohn, stated, "If development is about bringing excluded people into society... then unless disabled people are brought into the development mainstream, it will be impossible to cut poverty in half" (Mji, Maclachlan, Melling-Williams, & Gcaza, 2009). This situation analysis was a preliminary attempt to identify the available resources and needs of individuals with disabilities in the shantytowns near Lima, Peru. We present the following recommendations for local policy makers and community based rehabilitation organizations.

Educating Families About the Potential of Children with Disabilities

The lack of opportunity for the child with a disability often begins within the home. Parents, grandparents, siblings, and other caregivers often do not see the potential of the child with a disability. Caregivers do not see the benefit of sending their child with a disability to school. Community based rehabilitation programs can play a key role in providing education to caregivers to maximize the potential of the disabled child. Education topics can include the following: (1) maximizing communication, mobility and self-care of the disabled child; (2) education for the child with disability, (3) nutrition for the individual with a disability, and (4) psychological, physical and sexual health of the individual with a disability. Support groups for individuals with disabilities and their caregivers could develop partnerships between community members and advocacy groups for the inclusion of disabled individuals into the community. As potential is recognized in individuals with a disability, respect and social inclusion will improve.

Location Matters in Community Based Rehabilitation

Key components to social inclusion for the disabled individual within their community are access to education, rehabilitation and employment. For residents of shantytowns near Lima, Peru, the main barriers to education and rehabilitation are lack of money and lack of transportation. Schools and rehabilitation clinics are typically too far away to walk to, and the household has no money to hire taxi or motor taxi transportation. Thus, it is important to advocate for transportation of disabled children to the public schools. Community based rehabilitation programs should be located in accessible areas by individuals with disabilities. It may not be feasible to utilize one building to serve as a rehabilitation clinic for the entire shantytown. A mobile community based rehabilitation program may be better utilized by individuals with a disability and their caregivers. One may consider renting a room in a community building, like a place of worship or soup kitchen, one day per week, so that individuals with disabilities within a few blocks can more easily access the rehabilitation program. Another day of the week, the clinic could be set up in a different part of the community. Each location can target interventions to meet the specific needs of the individuals with disabilities that attend the rehabilitation program.

Volunteers as Assets to Community-Based Rehabilitation

Non-disabled community members expressed an interest in assisting and working with disabled individuals in their community, but they were unaware of opportunities to do so. Community based rehabilitation can utilize volunteers to supplement rehabilitation and health professionals. Educating volunteers on identifying the needs and assets of the disabled person and basic rehabilitation techniques, like range of motion exercises and self-care techniques, will promote partnerships between the community and the disabled community members. Identification of volunteers can occur at religious organizations, local colleges, and other community organizations. Community based rehabilitation programs should consider partnering with local universities to provide service learning experiences for therapy students. These students would benefit from the hands-on experience while the community based rehabilitation program would benefit from increased labor for minimal cost.

Employment for Individuals with Disabilities

Adults who acquire a disability report difficulty returning to work in the shantytowns. Most employment opportunities in shantytowns are manual labor jobs, and a new disability that affects mobility makes it difficult to return to work. Vocational rehabilitation is a strategy within community based rehabilitation that assists and trains individuals with disability to find meaningful work to provide income for their households. It will be important to partner with businesses in the community and advocate for the employment opportunities for individuals with disabilities. By encouraging business owners to hire individuals with a disability, it would allow individuals with a disability to be seen for their abilities rather than their challenges. In turn, respect and social inclusion of the individual with a disability would probably improve.

Happiness in Life with a Disability in a Shantytown

Although most interviewees with disabilities expressed feelings of helplessness, frustration, and worry, surprisingly, two interviewees expressed that they were content with life. One interviewee who has been unable to walk since contracting polio that affected both of his legs at the age of one said, "My life is good. I cannot complain." The two individuals who said they were happy had these factors in common: (1) positive family support and (2) social integration within their community. Both expressed that they ventured outside the home on a nearly daily basis, had many friends, and had plans for their futures. Despite the economic challenges and physical barriers in the community, it is possible to be happy and have a healthy outlook on living with a disability in a shantytown.

Limitations

This study speaks only from the perspective of individuals with mobility-related disabilities and their caregivers. The needs of those with cognitive, mental health, or sensory related disabilities may differ greatly than those with mobility challenges.

Future Considerations for Research

This study is only a preliminary attempt to understand the barriers to rehabilitation and social integration of individuals with disability in the shantytowns of Lima, Peru. Additional questions arose during interviewing and in the analysis process. Specifically, the issues of sexual health, sexual and domestic violence, rape of disabled females, employment opportunities, the capacity of special education schools, and the differences of life with disability for males and females in shantytowns, needs further investigation.

Conclusion

This study indicates that physical limitations are not the sole reason for social exclusion of disabled individuals in the shantytowns of Lima, Peru. Concern for personal safety limits the individual with a disability's inclusion in society. Limited knowledge and the low perceptions of others, especially caregivers, limit the potential of individuals with a disability. Environmental barriers, including steep and rocky terrain and inaccessible community buildings are indicated as barriers to education and rehabilitation for individuals with a disability. Access to rehabilitation clinics is limited due to a limited number of rehabilitation clinics and no finances for rehabilitation visits and transportation to appointments. It is expected that as accessibility of buildings, education, rehabilitation, and employment opportunities improve, advancements in health, quality of life, social inclusion and the livelihood of these communities will be noted.

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Endnotes

¹Assistive technology includes communication boards and adapted computer software utilized by individuals with disability to increase the possibility to better participate in society and live independently (Eide & Oderud, 2009). The UN Convention on the Rights of Persons with Disabilities (UN, 2006) calls for states to provide disabled individuals with mobility aids, devices, and assistive technology in order for disabled individuals to have equal opportunities and improved independence. However, in low-income countries, it is estimated that only 1-2% of individuals with disability receive such services (Eide & Oderud, 2009).

Enacted Assessment of Disability Support: A “Lived” Method for Assessing Student Life

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Abstract: How does an institution assess the experiences of only one one-thousandth of its overall population? And how does it assess something as non-discrete as “student experience”? In the on-going efforts to assess the quality of life for mobility-impaired students on a mid-sized residential campus, the authors built upon focus group research that identified areas of both success and shared concern by developing a novel form of video-based assessment utilizing split-screen analysis. This analysis was neither especially time-consuming, nor especially expensive, nor particularly difficult to conduct, yet produced immediate, valuable, and useful data.

Key Words: split-screen analysis, post secondary education, mobility impairment

Introduction

Rarely does the average person get to experience life from the perspective of a mobility-impaired person. Perhaps we have the occasional need for a crutch or wheelchair, but it is still difficult for us to understand the lived experience of someone who lives with a physical disability on a daily basis. This study was designed so that universities everywhere can begin to understand the lived experience of a physically disabled person on campus, including the extra amount of time and effort it takes for them to complete everyday tasks such as getting a student identification card or finding a place to sit in class. The investigators tested out a new method of assessment involving video taken from the perspective of both a student using a wheelchair and an ambulatory student, comparing the routes taken and the time spent completing normal student tasks on campus. The method was successful in highlighting the need for more accommodation of the physically disabled students on campus, especially when it comes to physical accessibility in and around campus buildings. The authors believe this method could be used at other universities and similar institutions to assess accessibility.

First we will review the literature on accessibility issues in higher education, and how to assess the accessibility of a university. Then we will discuss possible solutions to accessibility issues in higher education. Next we introduce the new video methodology used in this study and outline our results. Finally, we conclude a discussion of the results, including some of our study’s limitations, along with some suggestions for future research.

Literature Review

Disability Accessibility Issues in Higher Education

Disabled college students face a wide variety of accessibility problems, and among the most fundamental problems are those associated with buildings that were not built within the ADA guidelines. Clearly, if students experience difficulties getting around campus or in and out

of buildings, the quality of their educational experience has been diminished. While this study focuses on these foundational physical accessibility issues, disabled students often face additional challenges on campus.

College students with disabilities are requesting in-class accommodations and many universities have not yet been able to meet the demand for accommodations, as they can be both expensive and logistically difficult. Mandi Hayden, a deaf student at College of the Redwoods in California, sued her university for failing to offer qualified sign language interpreters for all of her classes (Freedman & Freedman, 2007). The judge assigned to her case emphasized that under federal law, universities must allow “individuals with disabilities to request the auxiliary aids and services of their choice” and “honor that choice unless it can demonstrate that another effective means of communication exists or that use of the means chosen would constitute an undue hardship or burden” (p. 4).

It has also become colleges’ responsibility to make sure that recreation programs are accessible to disabled people. As Fujii and Woodard (2006) pointed out, required “accessibility refers not only to architecture but also to the programs provided and the availability of information”(p. 7). In a study of the accessibility of recreation programs on college campuses, Fujii and Woodard found that of those schools that offered fitness/wellness classes and intramural sports, less than 20% offered programs specifically for students with disabilities (p. 7). Additionally, less than 25% of schools surveyed provided training for their staff specifically related to students with disabilities - something that we experienced directly during our own research.

Evaluation of Accessibility in Higher Education

Goode (2007) points out that, “Research about people with disabilities has sometimes alienated them by failing to reflect their own perspectives”(p. 35). Some scholars have attempted to incorporate student perspective in accessibility assessment research through the use of videos and in-depth student interviews (Goode, 2007; Hadjidakou, Polycarpou, & Hadjilia, 2010). These studies were more qualitative in nature, but did attempt to capture the lived experience of the disabled students in a way that quantitative assessment studies could not.

Losinsky, Levi, Saffey, and Jelsma (2003) performed a study on campus accessibility in a more quantitative manner. In their study, they tracked the movement of wheelchair-using students around campus between classes. They measured distance with average speed and time travelled between classes. They determined that the changeover time between classes was not long enough for students using wheelchairs (Losinsky et al., 2003). While our study does compare the time travelled between wheelchair-using students and ambulatory students, our study differs from this study in at least two key ways. First, while Losinsky et al. measured the time it takes to travel between classes, we compared the time it took wheelchair-using and ambulatory students to do mundane tasks as well as to travel to and from classes. For example, we timed how long it took both students to purchase a beverage from an on-campus store, and we compared the time it took both students to get to the office where they can get a student identification card. The second way our study differs from the Losinsky et al. study is that along with the timer, we compared the travel time of the wheelchair-using student and the ambulatory

student by videotaping from their perspectives. We believe this is the most important contribution to the study of evaluation of accessibility, as the use of film adds so much to the assessment process in terms of understanding the lived experience of the student.

Film has proven to be an “effective pedagogical methodology that provide[s] an entertaining and meaningful way to generate discussion and change attitudes about disabilities” (Schwartz, et al., 2010). The use of video in the present study includes both qualitative and quantitative investigative considerations. The split-screen timer tool clearly offers a quantitative comparison between the experiences of the wheelchair-using students and the ambulatory students. At the same time, the nature of video allows the viewer to experience life from the perspective of a wheelchair-using student, and this allows for the emergence of new questions, new theories, and new hypotheses about how those students make meaning from their circumstances. As in other methods of qualitative research, the researchers look for patterns in the experiences captured on video. Triangulation of data is recommended, either by using different participants who use wheelchairs, different methods of data collection, or different investigators reviewing the collected data. In this study, the researchers used focus groups to cross-check the findings of the video observations.

Addressing Accessibility Issues in Higher Education

Many campuses are considering modification of buildings and campus layouts in order to better accommodate students with disabilities. A new system called Remote Accessibility Assessment System (RAAS) has recently been studied and proven to be an efficient and cost effective way to evaluate accessibility of buildings and rooms (Kim & Brienza, 2006). Kim and Brienza are developing an RAAS that uses three-dimensional (3-D) reconstruction technology, which will enable clinicians to evaluate the wheelchair accessibility of users’ built environments from a remote location (p. 257). The RAAS uses standard digital camera photos and 3-D reconstruction computer software to create 3-D models of the users’ environments that can be remotely evaluated by evaluation specialists, architects, or rehabilitation engineers. This sort of technology could allow universities in rural areas or those without on-staff disability support services to evaluate the accessibility of their campus facilities.

Online classes may be one solution for universities that do not currently have the funds to redesign or retrofit their campus or facilities to appropriately accommodate students with disabilities. However, as previous studies have noted, this solution presents its own set of potential pitfalls including separation of students from one another, special audio and visual equipment for students, and also requires the same accommodations from professors that would be necessary in a classroom environment (Fichten, et al., 2009; Seale, Draffan, & Wald, 2010).

Another way to address accessibility issues in higher education is to provide longer transition times between classes. By adding five minutes to the typical fifteen minute class transition time, a university could make the process much easier for students with physical disabilities. Students in this study expressed concern regarding tight class schedules given the additional time it takes them to move from one class to another, so this accommodation will be discussed later in the paper.

A more complex approach to accommodation would be to educate the professors and staff of the university about how they can offer more accommodations to disabled students on an individual basis. As Cory (2011) says, “Together... faculty and DS should be able to create a plan for students that is effective in meeting disability-related needs and the needs of specific academic disciplines” (p. 29). Disability support offices could offer training for faculty and staff about how to best help students with various disabilities, and also train the students how to more clearly explain their individual needs when they find that university staff or faculty are not accommodating them. If faculty invest a minimal amount of time trying to understand how their students learn and in what ways the traditional learning experience needs to be altered to fit their disabled students, students could reap the benefits.

Some medical schools have introduced student support cards, to empower students with disabilities and health issues to request reasonable adjustments (Cook, Griffin, Hayden, Hinson, & Raven, 2012). The credit card-sized laminated card states the nature of the student’s need for support and the adjustments or accommodations required from the instructor. The request for accommodation comes from the Dean for Students, not the student. A study to assess the value of the student support cards found that they were well-received by students, but these programs are still in their infancy. It is possible that they could be more widely adopted, to be used by students throughout universities and not just by medical schools.

Finally, all members of the university community can work together to foster an inclusive culture at universities. As Bessant (2012) points out, “The ‘burden of justice’ continues to rest heavily on students, which indicates that the provision of greater support for students as they negotiate university processes seems warranted”(p. 280). Tools like the aforementioned student support cards provide students with written support from the Dean of Students when discussing their accommodation needs with instructors.

Clearly, there are many approaches to solving accessibility problems. Our own institution has adopted several of them. When institutions adopt any of these, however, it is then incumbent upon them to assess the effectiveness of those approaches. It was with this goal in mind that the following sets of analyses were undertaken.

Methods and Analysis

Focus Group Study

Disability support at Southern Illinois University, Edwardsville (SIUE) has always been good. There has long been a dedicated office, staff and budget all devoted to making sure that students with disabilities have full access to the university experience. That said, this structure pre-dates a significant transition made over the last decade from a commuter to a residential campus. As a result, while it has a clear mandate to focus on academic accessibility, responsibility for the inevitable “student life” issues that come with a residential facility are less clear. One of the authors of this study, who is a student with Cerebral Palsy, wished to access fitness services at the campus fitness center. Such services are available to all students, with costs covered by mandatory student fees. However, the author found that when she attempted to

access those services, she was rebuffed by a staff unsure of how to proceed, concerned about liability issues, and wholly unfamiliar with ADA laws. While all involved worked in good faith and the situation was ultimately worked out to satisfy everyone, there was a great deal of confusion about who was responsible for what, and what to do about it. At about the same time, both this same author and another woman with a mobility impairment became advisees of the other two faculty authors of this study. Embarrassingly, this was the first time either of the non-disabled faculty authors actually noticed the lack of an automatic door opener to the office suite. Once again, this problem was resolved, but again, not without considerable challenge and confusion.



Figure 1 Author attempting to enter her department offices

Motivated by these experiences, a team of graduate students initially undertook a focus-group study in which most of the population of mobility-impaired students on campus were queried directly about their experiences. They were asked about both physical and social challenges they faced, about what was working well on campus, and about ways to improve the things that were deficient (Shaw, McQuiggan & Cox, 2010). Research questions were as follows: RQ 1: What physical challenges have students with disabilities face on the SIUE campus? RQ 2: What social challenges have students with disabilities face on the SIUE campus? RQ3: What suggestion do the students with disabilities have to alleviate the challenges they face on the SIUE campus? RQ 4: What areas have SIUE successfully met the challenges of student with a disability. Results generally fell into 2 overall categories, facilities/maintenance, and people. Under the first of these were issues such as inoperable automatic door openers and elevators, poor communication about those problems, general access to buildings and grounds, and issues with ongoing construction. Under the second were issues such as a lack of planning/consideration of the needs of persons with disabilities, intentional and unintentional

insensitivity, and specific concerns about aspects of Disability Support. They did also note a host of positive experiences. This study was well-received, and many of the issues it raised were acted upon by university administrators. Several of the student participants in this study, however, came away feeling as though much of their story remained untold. Many felt that if a non-disabled person had to spend time in a wheelchair, it would go a long way toward fleshing out the story.

Day-in-the-Life Video

Intrigued by the notion of providing the non-disabled with the experience of life at SIUE in a wheelchair, the authors contacted colleagues in the Mass Communication Department. We met with both a faculty member and a student and pitched them the idea of a “day-in-the-life” video. After filming two of the wheel-chair-using students on campus, interviewing them both, and interviewing two faculty members as well, a short film was produced (Seering, 2012 - <https://vimeo.com/60858582>). The video starts with a narrator posing questions to get people to think about everyday accessibility. It then transitions into a series of one-on-one interviews with professors and disabled students talking about not only their concerns but also their everyday experiences with physical accessibility and academics. On the one hand, the film was so good it ended up winning an Award of Merit at the 2012 Best Shorts competition in La Jolla, California. On the other hand, it ended up still feeling too “pretty” and cinemagraphic to capture the real experience of life in a wheel chair. However, there was a scene in the film in which a disabled student was shown side-by-side with a non-disabled student as both went to the same place to get a bite to eat. This scene came closest to capturing what the authors hoped to capture, and provided the inspiration for developing split-screen analysis

New Methodology: Split-Screen Analysis

To capture the “enacted” experience of life in a wheel chair, we first created a simple, discrete wheelchair mount for a video camera:



Figure 2 Home-made wheel-chair camera mount

This mount was attached to the wheelchair of one of the authors, along with a standard 2 hour “Flip Video” camera. Once installed, it simply blended in with the other electronics on the

chair. The author then went about her normal day while taping until the camera was full. After doing this several times, we had hours of mostly mundane, routine data. While there are some long and complex segments awaiting future analysis, we settled on 10 short and utterly ordinary moments, and selected these segments from the larger videos. Our method was simple. We identified an exact starting point (ie passing through the east door of Alumni Hall), and an exact ending point (ie entering room 1301) and a target behavior (ie taking a seat in the classroom). We then enlisted several non-disabled student confederates to help. We provided each with that same starting point, ending point, and target behavior as found in the existing video segments we'd collected. We then installed the same video camera on our confederate by simply fastening it to his or her shirt. Once they had completed their tasks, we then had matching videos of both the disabled and non-disabled experiences of each of these routine activities, allowing for a true side-by-side comparison.

At this point, we called our film-making colleague and once again threw ourselves on her mercy. By using equipment routinely available in university editing labs and software called Final Cut Pro 7, she was able to create a single frame in which both segments run side by side in real time. Adding text and timers available within the software then became straightforward edits. The end result was what we had all originally envisioned - as "lived" an experience as we could create for readers short of having them spend a day in a wheel chair (to view the film, go here: <http://vimeo.com/59445320>).

Results

We analyzed ten pairs of video segments, ranging from as short as 3 seconds to several minutes in length. All were chosen based on how ordinary they were. Included are simple activities such as getting into a classroom building, finding the classroom, taking a seat, using the restroom, and getting a soft drink. Nothing in this corpus is uncommon or unusual in any way. All represent things all students do on a regular basis. Once we displayed the videos beside one another on the screen, we added only two more elements. First, we made note of when an activity required assistance. For example, in one case, a faculty member had propped open the classroom door with a chair to allow for circulation. The student in the wheelchair could not maneuver around this chair, however, and required assistance from the faculty member to gain access to the room. Second, we compared the total times that it took to complete each activity. For example, if it took the disabled student 30 seconds to do a given activity and it took the non-disabled student 20 seconds to do that same activity, we provided both the difference in real time (10 seconds) and a simple ratio (in this example, 1.5:1). When we had completed an individual analysis of each of the 10 activities – that is, when we had times-to-completion for all disabled and non-disabled activities - we also averaged all the times together.

What we found was that fully half of the utterly ordinary and routine activities our disabled students engaged in, while taking place on a modern, accessible, fully ADA-compliant campus, still required assistance at least once to complete. Further, we found that the difference in time commitment between the disabled and non-disabled student was far greater than anticipated (at least by the non-disabled authors of this study). Activities taking a non-disabled student a total of 6 minutes and 21 seconds took a disabled student 16 minutes and 33 seconds,

for a difference of 10 minutes and 13 seconds, and a ratio of 2.63:1. If we apply that ratio to the rest of the day, we can see how potentially burdensome this difference would become.

Conclusion and Future Research

While the split-screen procedure was well-suited to comparison of like events, there were clearly several limitations. First, this analysis is strictly visual. While watching 2 locomotor events simultaneously was useful, we found that we tended to turn off the sound. Listening to two events simultaneously turns out not to work very well. Thus, this form of analysis would not be useful for events with a significant “audio” component. Second, we found that we were only able to consistently assess times and the need for assistance. Other issues initially identified in the focus group study, such as the differing reactions of passers-by, could not be observed. Third, some of the most interesting segments of video simply do not lend themselves to a side-by-side analysis. For example, in one segment, when asked about the availability of Zumba classes, a staff member at our fitness center replied with what can only be described as a bit of incredulity before providing the requested information. When actually arriving at Zumba for the first time in a wheelchair, our author was ignored entirely. In future, we hope to tape comparable experiences with a non-disabled confederate for comparison, but do not expect split-screen analysis to be especially useful. Finally, we must acknowledge that there are limitations to a time-based assessment. Clearly, the amount of time it takes for a 50 minute class is the same whether sitting in a classroom chair or a wheelchair. Thus, this analysis is useful primarily for considerations of transition times and other times when mobility, or the lack of it, is most salient. And since not all disabilities are mobility-related, further study is needed to determine methods to assess the support levels and environmental quality for students with sensory and cognitive impairments.

While there are obvious limitations to the application of this method, the authors believe that it provides a useful, novel approach to the assessment of student life for the mobility impaired. If just one picture is worth a thousand words, then video, more than either numerical or even narrative data, is worth far more. By showing that the many mundane transitional activities that make up much of a typical college student’s day can take more than two and a half times as long for the mobility-impaired person, and by identifying unexpected places where assistance was required, we believe that we can aid in both identifying areas for improvements and in making accommodations where such improvements are not necessarily feasible. Simple things could be done such as sending regular reminders to faculty to not block doorways, or asking faculty to regularly remind students to not block aisles with their backpacks. More thoughtful things could be done as well, such as having deans take increased transition times into account while building course schedules all flow from this analysis. Above all, this simple analysis makes undeniably “real” differences in the lived experiences of persons with mobility impairments in ways other methodologies simply can do. We are excited to see what others might do with this technique, as it seems as useful tool a for empowering persons with disabilities engaging in self-advocacy as it is for academics.

Knowing how critical time issues can be for the mobility-impaired, consider the following e-mail, recently sent to one of the authors of this study:

Subject: Two Elevators Out Of Service

To: T.E.

The elevator on the west end of Rendleman Hall is undergoing repair and will be out of service until further notice. The central elevator in the Engineering Building is also currently down until further notice. Facilities Management regrets any inconvenience this may have caused.

While such an e-mail is certainly cause for groans to those of us who must now slog up 3 or 4 floors toting a briefcase instead of taking the elevator, this analysis suggests that it represents much more than an “inconvenience” to someone with a mobility impairment. If there is already barely enough time to transition between one class and the next, such an inconvenience could create an unreasonable burden for someone in a wheelchair. It is our hope that this study is a step toward helping to identify and remediate such burdens, and to track our efforts along the way.

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ICT Barriers for People with Disabilities in Namibia: Evidence from the 2011 Namibia Population and Housing Census

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Abstract: Computer technology and the Internet have a tremendous potential to increase the independence of people with disabilities. We investigated the extent to which people with disabilities access information communication technologies (ICT) (focusing on access to computers, internet and mobile phone) and how their ICT access compares with the ICT access of the rest of the Namibian population. More specifically, we investigated factors that affect people with disabilities ICT access in Namibia. The study relied on the 2011 Namibia Population and Housing Census as the main data source for analysis. The results showed people with disabilities are disadvantaged in ICT access. The study reveals that education level, work status, age and place of residence are important factors associated with ICT access among people with disabilities. Results also show that there is less disparity between employed and unemployed individuals with disabilities than without disabilities. Additionally, the results show that those classified as “blind”, “autistic”, “hearing difficulties” and “mentally disabled” fair worse than people with other disabilities in computer, internet and/or cell phone access. There is a need to consider unique issues affecting ICT access for people living with disabilities to achieve Namibia’s goal of equitable access for all as envisioned in its Vision 2030.

Keywords: ICT, Africa, accessibility

Introduction

According to the United Nations (UN), around 10 percent of the world’s population, or 650 million people, live with a disability (UN, 2006). They are the largest minority group. People with disabilities (young and old) face many challenges in an African context. These include abuse, lack of education, illiteracy, and unemployment. They also face challenges around information and communication technologies (ICTs). ICTs can transform the lives of people with disabilities (PWD) in many ways. For example text to speech software enables people with sight problems to hear what others read and people with hearing impairments can access cell phone texts. Similarly, assistive devices have enabled students with severe physical disabilities to follow seminars and classes at many universities and schools. The potential for computer technology and the Internet to increase the independence of people with disabilities cannot be overestimated (Kaye, 2000). Kaye (2000, p.1) pointed to the fact that people with mobility difficulties “can log in and order groceries, shop for appliances, research health questions, participate in online discussions, catch up with friends, or make new ones.” In general ICTs may enable people with disabilities to better integrate socially and economically into communities. Although ICTs hold great promise, it seems the computer revolution has left most people with disabilities in Africa behind. People with disabilities in Africa have an especially low rate of computer and Internet access (Furuholt and Kristiansen, 2007; Samanti et al 2013). Thus, African people with disabilities are at the short end of ICT discourses and discussions.

Recent years have seen much greater interest being paid to the rights of people with disabilities (Palmer, 2012; Eide and Ingstad, 2013). The 2006 United Nations Convention on the Rights of People with Disabilities that came into being in May 2008 (UN Enable, 2008) has particularly been instrumental in championing the rights of people with disabilities. The Convention places considerable emphasis on the accessibility of ICTs, and particularly in Article 9 requires signatories to: “Promote access for persons with disabilities to new ICTs and systems, including the Internet” (UN, 2006) and to “Promote the design, development, production and distribution of accessible ICTs and systems at an early stage, so that these technologies and systems become accessible at minimum cost” (UN, 2006).

The developed world has recognized the benefits of using ICT for socioeconomic development of people with disabilities, however little research has been done in Africa. Over the years, the focus has been on increasing penetration of basic services and meeting underserved demand in rural areas. However, usage of ICTs by people with disabilities has not been addressed specifically. This can be shown by design, environment and location of ICT points of access and facilities like Internet cafes which, for example, lack facilities that ease movement of persons with disabilities like ramps and screen reading software. The main purpose of this paper is therefore to establish a deeper understanding of ICT access by people with disabilities which may provide insight for practitioners and policy makers on how best they should support people with disabilities to access ICT in order for Namibia to achieve the goal of equality. Namibia adopted a Universal Access and Service Policy for Information and Communications Technologies in 2012. While mobile telecommunications access is relatively high, and includes many low-income households, it is not yet universal. Most Namibians over the age of 15 have access to mobile voice telephony, the mobile network having achieved 98% population coverage and most Namibian households listen to the radio, with the level of radio population coverage at 96%. There remains a substantial lack of access to fixed phones, television, the Internet and broadband. Further, analysis of access to all information and communications technology services, from mobile telephony to broadband, reveals that there remains a substantial urban / rural access gap, with considerable disparities in levels of access between urban and rural communities. For example, in 2011, only 46% of Namibians aged 15 and older living in rural areas had a mobile phone, compared to 77% of Namibians in urban areas (Namibia Statistical Agency –NSA- 2012). Only 3% of rural households had a fixed line phone, compared to 26% of urban households. With respect to broadcasting services, the picture is similar, with ownership of a working radio and television set reported by only 66% and 19% respectively of rural households, compared to 81% and 73% of their urban counterparts (NSA, 2012). Only 2% of rural households had Internet access, compared to 27% of urban households. This reflects an urban-rural divide in respect of access to ICTs, which is related to other urban-rural disparities. For example, only 22% of rural households have electricity- which is a key support infrastructure, enabling rollout of telecommunications, broadcasting, Internet and broadband networks - compared to 82% of urban households.

In view of the above, the study utilizes the Namibian Population and Housing Census, a nationally representative data source, to identify:

1. The extent to which people with disabilities access ICT technologies;
2. How their access of ICT compares with the ICT access of the rest of the Namibian population;
3. How having a disability relates to and interacts with other social statuses (e.g. socioeconomic status, age, gender) with regard to ICT access; and
4. An explanation of the observed differences.

These objectives will be achieved by answering the following main research questions:

1. How does access to ICT of people with disabilities compare to access by people without disabilities?
2. How does access to ICT differ by type of disability?
3. What factors predict access to ICT by people with disabilities?

Review of Related Literature

The advent and utilization of computers and the Internet has created unrivalled opportunities for people living with disabilities (Cheatam, 2012). Accordingly, individuals that have limited mobility, sight, speech, or hearing may now aspire and achieve previously unobtainable goals through the use of a computer and the internet. Opportunities include education (e.g. participating in online courses), health (e.g. searching for health information and telemedicine), employment and work (telemarketing), and enhancement of friendships and social participation (networking). ICTs however cannot overcome issues of impairment and disability. Suggestions to that end are exaggerations and will not materialize (Goggin and Newell, 2003). According to Dobransky and Hargittai (2006), despite the increasing use and spread of the Internet and despite its potential for increasing opportunities for people living with disabilities (PWD), there is very little evidence indicating that people with disabilities are benefiting from the spread of the internet and other information and communication technologies (ICT). Similarly, Vicente and Lopez (2010) show that the digital divide in many countries works to exclude elderly, women, the population with lower income, education attainment, those living in rural areas, ethnic minorities and especially those with disabilities. This is even more so in developing countries where people with disabilities face daunting barriers to socioeconomic participation (Samant et al 2013). According to Samant these barriers relate to personal and environmental (infrastructural) resource limitations. They include: high unemployment and poverty, poor attendance at schools, low literacy levels, lack of clean water and sanitation, inadequate access to transport and healthcare. Van Rooy et al (2012) specifically demonstrated that in Namibia people living with disabilities faced a lot of barriers to health care and many experienced bottlenecks in rehabilitation service delivery. The health delivery difficulties people living with disabilities faced in Namibia were compounded by lack of access to income and by generalized poverty. Accessible ICTs can eliminate or mitigate some of the barriers people living with disability face in various fields of endeavor (Samant et al 2013). In particular Samant et al (2013) demonstrate that ICTs can be utilized in low and middle income countries for such economic and social services as banking, health care, education, emergency management, and social participation. In this regard ICTs can help ensure more equal opportunities in social and economic participation and prevent further marginalization and exclusion of people with

disabilities if correctly promoted and implemented. It is also in this regard that the *Convention on the Rights of Persons with Disabilities (CRPD)* recognizes the importance of ICT in promoting the welfare and integration of people with disabilities (UN, 2006). Articles 9, 21, and 26 of this convention state that ICTs can help in the realization of rights of people with disabilities in regard to accessing justice, freedom of expression, political participation, education, health, rehabilitation, and employment. “However, the lack of attention to making ICTs accessible coupled with substantial barriers in accessing AT to use ICTs, continues to exclude persons with disabilities from the mainstream of social and economic development programs and significant ICT-based social opportunities” (Samant et al 2013: 12).

What barriers exist in preventing people with disabilities from accessing ICTs in low income countries? According to Jones (2004) education can present a barrier to accessing ICTs. He found that people that have not had any computer education in school, and as a result are in need of computer skills training to allow them to make use of computers in their work fail to access ICTs more than those that had. Internet café users in Africa are well educated (Furuholt and Kristiansen, 2007). According to Gilbert et al (2008:921) “in overcoming the digital divide, it is important to have access to computers and the Internet, but it is much more important to have knowledge of how to use computers and how to access the Internet”. Therefore education is crucial.

Similarly poverty as represented by lack of resources and/or income can present an obstacle to ICT access. It is in this context that Graham (2011) argues, “The initial material divide concerns a lack of access to the entry points of cyberspace. This divide is almost entirely a question of resources. People need the hardware (computer, modem, router, etc.), software (i.e. browser and email client), and an Internet connection (either hardwired or a wireless access point). Without access to all of the above, there can be no entry into any cyberspaces”. Thus Jones (2004) reported that the most frequently mentioned problem when teachers were asked about obstacles to their use of ICT was the insufficient number of computers available to them. “Wifi access points by their nature discriminate against the poorest members of society by requiring users to own a laptop computer” (Graham, 2011). In Namibia, where most people with disabilities are not employed (and do not have insurance coverage of any kind), the costs of ICTs and other services can be prohibitively high (Van Rooy et al., 2012). In Namibia financial barriers are crucial. Despite this Kvasny and Keil (2006) found that providing computers, Internet access and basic computer education was a necessary but not sufficient condition for reducing the digital divide experienced by poor people and people with disabilities in urban areas. They argue that this is the case because of the way in which digital inequalities intersect with such structural inequalities as a lack of access to decent schools and poverty.

Barriers in access can be in the form of product and/or service design. This is especially so in developed countries where ICTs are widely available. ICTs use “standard” designs that are fixed in some hypothetical notion of “normality” which create barriers to access. Thus people with disability get excluded from the content of web pages that are not accessible to the specific interfaces they utilize (Goggin and Newell 2003). For people with disabilities accessibility and use are not incorporated in the technology as designers seek to normalize people with disabilities. Watling (2011) suggests that access ICT consists of adaptations to standard ‘off-the-shelf’ computers enabling individuals with physical or sensory impairment to independently use

them. Such adaptations consist of alternative keyboards, mice designs or navigation aids as well as software supporting text-to-speech and speech-to-text conversion. They include increased text size and altering of colors and contrasts. For people with disabilities access technology offers genuine opportunities for inclusion (Watling, 2011).

Graham (2011) reminds us that a whole array of other factors related to the politics and practices of access (such as gender, class, and age) are as prohibitive to ICT access as financial barriers. Similarly, Furuholt and Kristiansen (2007) mention age, gender, education, employment and financial capacity as crucial variables in accessing ICTs. In this regard he argues that telecentres and Internet cafes are often highly gendered spaces that can be unwelcoming to women in many countries. Older individuals are less likely to engage with the technology, simply due to their advanced age (Jones, 2004). Geography seems to play a part in the digital divide. Thus many countries lack broadband data transmission to rural and poor urban areas (Graham, 2011). Within rural areas, those with disabilities are at the short end. Furuholt and Kristiansen (2007) found that for Tanzania the digital divide was greatest, “between better educated, affluent, younger, English speaking men in developed cities and less educated, poor older, non-English speaking women in underdeveloped rural areas.” In rural Africa ICT deployment faces infrastructural bottlenecks such as electricity, IT penetration, teledensity, skills shortages and cultural resistance (Rao, 2005; Mosse and Sahay, 2005).

Data Source and Methods

This paper uses data from the Namibia 2011 Population and Housing Census as the main data source for analysis. The census collects background, demographic and socio economic information from all persons in the country. Information on disability status of individuals was collected under section B of the Census Questionnaire. Disability was defined as a long-term physical, psychological or mental condition that limits a person from carrying out everyday activities at home, work or school. It may be present from birth or develop during a person’s lifetime.

The main question used to establish whether an individual is living with a disability or not is: “Does (NAME) have any type of long term disability or limitation?”

During the Census, all people in private households and institutions were asked about types of long-term permanent disability or limitation. Ten types of disability were identified for this purpose (this is actually the language used by the Census): “blindness, visual impairment, deafness, hearing difficulties, mute/dumb, speech impairment, and physical impairment of lower and upper limbs, mental disability, albinism and autism.”

A total of 98, 413 persons in Namibia were living with disabilities. This paper will focus on a total of 95, 092 people living with disabilities who are aged 3 years and older to allow the analysis in relation with access to ICT. Descriptive statistics for variables of interest were computed. Cross tabulations were run to examine association and differences between variables of interest. These are presented in tables 1 to 4 and graphical form. A multivariate logistic regression analysis was performed to assess the probability effect of socio-economic and

demographic factors on access to ICT. This is presented in Table 5. The results are interpreted in term of odd ratios. The logit model is of the form:

$$\text{logit}(p) = \log\left(\frac{p}{1-p}\right) = \beta_0 + \beta_1x_1 + \dots + \beta_kx_k$$

The odds of access to computer, internet or cell phone can equivalently be determined in terms of probability of access, *p*, as:

$$p = \frac{\exp(\beta_0 + \beta_1x_1 + \dots + \beta_kx_k)}{1 + \exp(\beta_0 + \beta_1x_1 + \dots + \beta_kx_k)} = \frac{1}{1 + e^{-z}}$$

where $z = \beta_0 + \beta_1x_1 + \dots + \beta_kx_k$

A 5% level of significance was used as a decision rule on whether the variable is retained or not in the model through the backward ward model selection. Selection of independent variables was guided through the literature review.

Results

Table 1: Namibian population, aged 3 years and older, who have access to ICT services by type and area (Table contents explained in paragraph below)

	Namibia	Rural	Urban
	# (%)	# (%)	# (%)
Radio	1 316 565 (68.6)	707 623 (64.5)	608 942 (74.0)
TV	703 486 (36.7)	151 888 (13.8)	551 598 (67.1)
Computer	201 955 (10.5)	27 350 (2.5)	174 605 (21.2)
Cell phone	1 010 072 (52.6)	22 159 (2.0)	100 272 (12.2)
Newspaper (daily)	170 974 (8.9)	21 329 (1.9)	149 645(18.2)
Newspaper (weekly)	311 539 (16.2)	93 591 (8.5)	217 948 (26.5)
Internet (daily)	103 698 (5.4)	15 751 (1.4)	87 947 (10.7)
Internet (weekly)	64 303 (3.4)	12 599 (1.1)	51 704 (6.3)
Total	1 919 438 (100)	1 097 098 (57.2)	822 340 (42.8)

Of the 1.9 million Namibians aged 3 years and older, only 10.5 percent have access to computer, 5.4 percent have daily access and 3.4% have weekly access to the internet (Table 1). At 52.6%, access to cell phones is much more widespread. Access to computers, internet and mobile phones is much worse in rural areas than in urban ones (Table 1). The results show that overall people with disabilities are less than half as likely as their non-disabled counterparts to

have access to a computer (5% vs. 10%) and the gap in internet access is even wider. There is a significant difference in access to ICT services for people with disabilities and their place of residence (urban or rural) (Table 2). About 5 percent of people with disabilities in urban areas have access to a computer compared to only 1.0 percent in rural areas. Furthermore, 3.7 percent of people with disabilities in urban areas have internet access daily or weekly while only 1.3 percent in rural areas has internet access (Table 2). On the other hand the figures for people without a disability are 7.5% for urban areas and 1.5% for rural areas. However, a fairly high proportion of people with disabilities in rural areas have access to cell phones. This is not the case for urban areas where more people without disabilities (30%) have access to cell phones than people with disabilities (18%).

Table 2: Percentage distribution of population, aged 3 years and older, who has access to ICT services by disability status and area (Table contents explained in text above)

	Has Disability (%)		No disability (%)	
	Rural	Urban	Rural	Urban
Radio	43.3	21.1	36.5	32.3
TV	6.5	17.5	8.0	29.3
Computer	1.0	4.6	1.4	9.3
Cellphone	24.4	18.0	23.2	30.0
Telephone	1.1	3.6	1.2	5.3
Newspaper daily	1.0	4.6	1.1	8.0
Newspaper weekly	4.4	6.8	4.9	11.6
Internet daily	0.7	2.2	0.8	4.7
Internet weekly	0.6	1.5	0.7	2.8

$\chi^2 = 6799.122$ with $p < 0.001$ for the relationship between whether a person had disability or not and place of residence.

Table 3: Percentage distribution of population, aged 3 years and older, who have access to ICT services by disability status and sex (Table contents explained in text below)

	Has Disability		No disability	
	Females	Males	Females	Males
Radio	32.6	31.8	35.8	33.0
TV	12.1	11.9	19.5	17.8
Computer	2.9	2.8	5.5	5.3
Cellphone	21.5	20.8	27.9	25.3
Telephone	2.4	2.3	3.4	3.0
Newspaper daily	2.7	2.9	4.5	4.6
Newspaper weekly	5.5	5.7	8.6	7.9
Internet daily	1.5	1.5	2.7	2.8
Internet weekly	1.0	1.0	1.7	1.7

$\chi^2 = 32.579$ with $p < 0.001$ for the relationship between whether a person had disability or not and sex.

Although there is a significant relationship between whether a person has a disability or not and sex, the difference in access to ICT between male and females who have a disability is minimal (Table 3). To this end among females with disabilities 2.9% have access to computers while among males with disabilities 2.8% have access to computers. Similarly, access to daily and/or weekly internet for males with disabilities and females with disabilities is 2.5% (Table 3). The figures in Table 3 are much lower than those found in other parts of the world. For instance the statistics on world internet use show only 34.3% of the world population use the internet (InternetWorldStats, 2012). Internet penetration is 15.6% in Africa; 27.5% in Asia, 63.2% in Europe; 40.2% in the Middle East; 78.6% in North America, 42.9% in Latin America/Caribbean and 67.6% in Oceania/Australia. Among Americans living with a disability 54 % (compared with 81% of those without a disability) use the internet and 41% (compared with 69% of those without a disability) have broadband at home (Fox, 2011).

Table 4: Percentage distribution showing ICT Access Status for People with Disabilities by Core Activity Limitation (Table contents explained in text below)

(Terminology used by the Census)	Radio	TV	Computer	Phone (cell or fixed)	Newspaper (daily or weekly)	Internet (daily or weekly)
Blind	65.1	12.1	3.0	33.0	9.2	2.5
Visual impairment	68.1	27.7	8.6	50.3	20.7	7.6
Deaf	52.3	25.1	6.0	36.4	16.6	5.1
Hearing difficulties	56.3	17.7	3.2	33.8	12.3	2.8
Mute/dumb	59.8	29.2	6.3	41.8	17.2	6.0
Speech impairment	60.9	26.8	5.5	37.8	14.4	4.8
Impairment of arms	65.8	19.9	3.8	45.3	15.5	3.4
Impairment of legs	68.8	25.6	5.5	47.9	19.0	5.5
Mental disability	58.1	21.6	3.6	29.9	10.8	2.9
Albinism	63.9	26.2	7.5	47.5	20.5	7.4
Autism	59.3	23.4	4.1	31.4	11.6	3.2

There seem to be differences in access to computers, internet and mobile phone according to core activity limitation among people with disabilities (Table 4). People with disabilities whose limitations are classified as “visual impairment”, “albinism” and “mute/dumb” fare better than others with regard to access to computers. Those classified as “blind”, “hearing difficulties” and “mental disability” fare worse than others in computer access. For instance, it is important to note that 15% of those classified as “blind” have another disability. Most of them (26.3%) indicated that they also have hearing difficulties and physical impairment (25%) for the lower limb. The multiple disabilities may be compounding their disadvantage with regard to ICT. This pattern also holds with regard to daily or weekly access to the internet. On the other hand people with disabilities whose limitations are classified as “visual impairment”, “albinism” and “impairment of legs” fare better than others with regard to access to cell and fixed phones. Those classified as “blind”, “autistic” and having a “mental disability” fare worse than others in cell and fixed phone access.

Employment Status

For working age adults having a job can make it financially feasible to buy a computer; often, on the job, access to computers and the internet is also provided, along with training in how to use them. It is not surprising, therefore, that people with and without disabilities are more likely to have access to computers and use the internet if they are employed than if they are not (Figure 1). But even if they do have jobs, people with disabilities are significantly less likely to gain access to these new technologies than the non-disabled. Among employed people with disabilities 11.5 percent have access to a computer and 10.4 percent have access to the internet,

compared to 4.4 percent of their non-disabled counterparts. All around, rates are significantly lower among those without jobs.

Cell phone access is widespread among employed and unemployed people in Namibia. About two thirds of employed persons living with disabilities have access to a cell phone. But even slightly more than half of the unemployed persons with disabilities have cell phones.

Figure 1: Computer, internet and cell phone access by disability and employment status

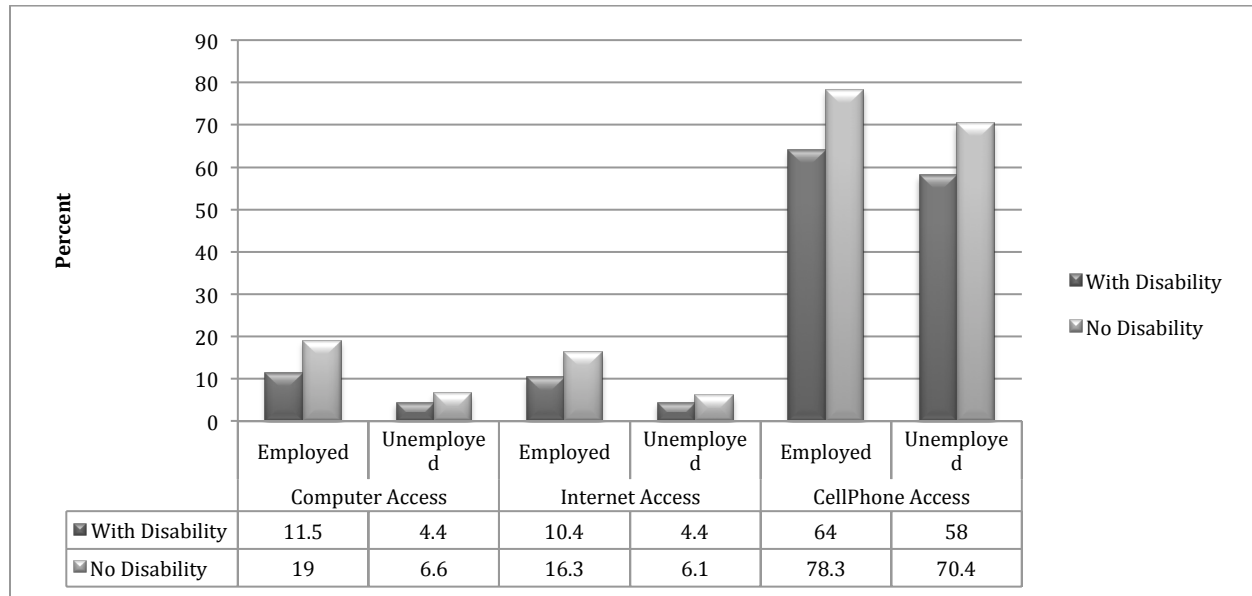


Figure 1
Table 1: Text Equivalent Table For 'Figure 1'

	Computer Access with Disabilities	Computer Access without Disabilities	Internet Access with Disabilities	Internet Access without Disabilities	Cell Phone Access with Disabilities	Cell Phone Access without Disabilities
Employed	11.5%	19%	10.4%	16.3%	64%	78.3%
Unemployed	4.4%	6.6%	4.4%	6.1%	58%	70.4%

Figure 1 shows that people with disabilities are less likely to be employed than people without disabilities. Having no access to computers and internet, makes all figures low, falling below 20%. There are fewer people with disabilities with cell phone access than for those without disabilities, but access to a cell phone greatly increases levels of employment for both groups.

Education Attainment

People who are well educated are more likely to have the skills and the financial resources necessary to buy and use computer technology. But, regardless of the level of educational attainment, people with disabilities have much lower rates of computer access and internet use than their non-disabled peers (Figure 2). Overall, computer, internet and cell phone

access increases with the level of education attainment. This pattern is consistent for person with and without disabilities. To this end among people with disabilities that have no education only 1.4% have access to a computer. Among people with disabilities 2.4 percent of those with primary education have access to a computer, 12.1 percent with secondary education have access to computers and 51.8 percent with tertiary education have access to computers. The comparable figures for people without disabilities are 3.1% (no education), 4.6% (primary education), 16.0% (secondary education) and 61.5% (with tertiary education).

Age

Age is an important factor that determines the use of modern technology. Overall, the results show that young adults are more likely to have access to a computer, the internet as well as a cell phone (Figure 3). However, in all cases, those with disabilities are less likely than those without disabilities to have access to all the three modern technologies. For example, only 7.6 percent of people living with disabilities in the age group 35-54 years have access to computer compared to 15.5 percent without a disability. Persons aged between 35 and 54 years who have no disability are two times more likely than those with a disability to have internet access. Cell phone access is widespread among all age groups, but is lower among young people (aged below 15 years), and higher among young adults where more than 50 percent have access to a cell phone regardless of whether they have a disability or not and is decreased among those aged 55 years and older.

Figure 2: Computer, internet and cell phone access by disability status and education attainment

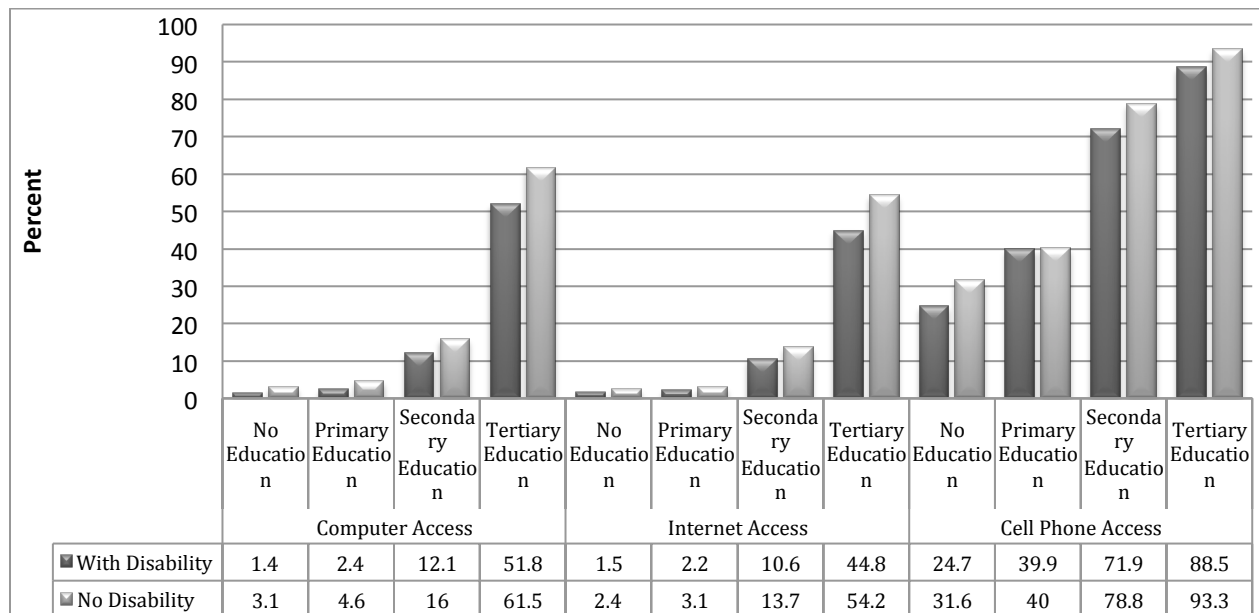


Table 2: Text Equivalent Table For 'Figure 2'

	Computer Access with disabilities	Computer Access without disabilities	Internet Access with disabilities	Internet Access without disabilities	Cell Phone Access with disabilities	Cell Phone Access without disabilities
No Education	1.4%	3.1%	1.5%	2.4%	24.7%	31.6%
Primary Education	2.4%	4.6%	2.2%	3.1%	39.9%	40%
Secondary Education	12.1%	16%	10.6%	13.7%	71.9%	78.8%
Higher Education	51.8%	61.5%	44.8%	54.2%	88.5%	93.3%

Figure 2 is a graph showing computer access and internet greatly increases chances for higher education, the figures indicating this is slightly less so for people with disabilities. Cell phone access improves education attainment for all education levels, with higher education spiking at 88.5% for people with disabilities and 93.3% for those without disabilities.

Figure 3: Computer, internet and cell phone access by disability status and age

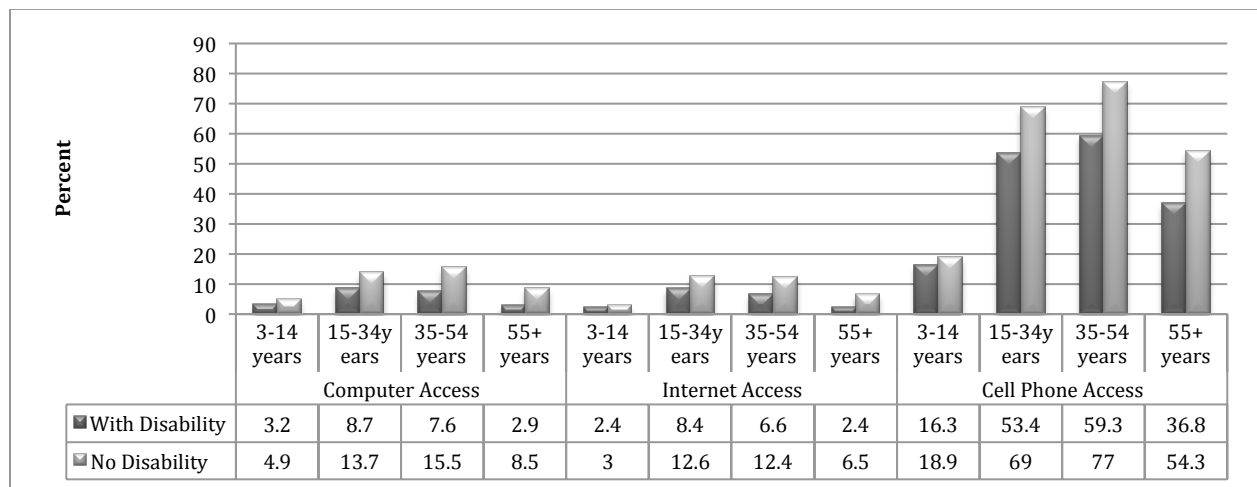


Table 3: Text Equivalent Table For 'Figure 3'

	Computer Access with Disabilities	Computer Access Without Disabilities	Internet Access with Disabilities	Internet Access without Disabilities	Cell Phone Access with Disabilities	Cell Phone Access without Disabilities
Ages 3-14	3.2%	4.9%	2.4%	3%	16.3%	18.9%
Ages 15-34	8.7%	13.7%	8.4%	12.6%	53.4%	69%
Ages 35-54	7.6%	15.5%	6.6%	12.4%	59.3%	77%
Ages 55 plus	2.9%	8.5%	2.4%	6.5%	36.8%	54.3%

Figure 3 is a graph showing that people of all ages lack access to computers and the internet, all figures falling below 16%. Access is even less for those with disabilities. Cell phone access is much higher for all ages, with and without disabilities, spiking at 77% for people ages 35-54. Though cell phone access is higher for people with disabilities than that of computer and internet access, it is still lower than access for people without disabilities.

Results from Multivariate Analysis

Computer access among persons with disabilities is associated with education level, age, place of residence, work status and region of residence (Table 5). The odds of having access to computer for persons with disabilities who are employed is 2.26 times that of those who are not employed. Additionally, access to a computer, the internet and a cellphone is positively associated with education attainment among people with disabilities. It is also important to note that access to a computer and the internet is negatively associated with age. The odds ratio for people with disabilities who are 15 years and older are less than 1.0, indicating that as a person with disabilities grows older, they are less likely to have access to a computer and the internet as compared to those who are young. Most young people with disabilities are likely to be attending compulsory school (primary & secondary), and remain challenged in accessing tertiary education. Only 4.6% of people with disabilities had tertiary education. However, regardless of age, those who are employed are more likely to have access to computers and the internet. Living in rural areas is negatively associated with access to a computer and the internet. The odds of having access to a computer and the internet for people with disabilities who live in a rural area are 0.31 and 0.61 respectively. This is an indication that people with disabilities who live in rural areas have little access to computer and internet as compared to those in urban area. There are also regional differences with regards to access to computers, the internet and cell phones among people with disabilities. Notably, people with disabilities who live in Omusati region are less likely than those in Caprivi region to have access to a computer (OR = 0.92) but twice as likely to have access to cellphone. Furthermore, people with disabilities in Kavango region are less likely to have access to cell phones than those in the Caprivi region. The results in Table 5 also indicated that those who have access to a computer are highly likely to have access to the internet. It must be pointed out that Omusati, Caprivi and Kavango are all rural regions in Namibia that experience high levels of poverty.

Table 5: Factors influencing computer access, internet access and cell phone access, among people with disabilities, 2011 Namibia Population and Housing census (table below is explained in above text)

Variable	Computer Access	Internet Access	Cell Phone Access
Work Status			
Not Employed	1.00	1.00	1.00
Employed	2.26 (2.22 ; 2.29)*	1.51 (1.48 ; 1.54)*	1.31 (1.29 ; 1.32)*
Place of Residence			
Urban	1.00	1.00	1.00
Rural	0.31 (0.30 ; 0.32)*	0.61 (0.60 ; 0.63)*	0.49 (0.48 ; 0.50)*
Age Group			
3-14yrs	1.00	1.00	1.00
15-34yrs	0.65 (0.60 ; 0.71)*	0.74 (0.68 ; 0.81)*	3.48 (3.36 ; 3.60)*
35-54yrs	0.74 (0.68 ; 0.81)*	0.57 (0.51 ; 0.63)*	4.60 (4.44 ; 4.76)*
55+yrs	0.93 (0.85 ; 1.02)*	0.58 (0.52 ; 0.64)*	3.07 (2.95 ; 3.19)*
Education Attainment			
No formal education	1.00	1.00	1.00
Primary Education	0.77 (0.74 ; 0.80)*	0.77 (0.74 ; 0.81)*	1.77 (1.74 ; 1.80)*
Secondary Education	4.08 (3.94 ; 4.22)*	2.00 (1.93 ; 2.08)*	3.69 (3.64 ; 3.75)*
Tertiary Education	28.81 (27.77 ; 29.90)*	5.61 (5.39 ; 5.85)*	4.70 (4.53 ; 4.88)*
Sex of Respondent			
Female	-	1.00	
Male	-	1.15 (1.13 ; 1.17)*	0.96 (0.95 ; 0.97)*

Discussion

This paper investigates access to ICT by people with disabilities vis-à-vis others in Namibia. In particular, we focused on access to computers, the internet and mobile phones. For each of these three indicators of ICT access, we investigated the main factors that predict differences. The digital divide in Namibia works to especially exclude those with disabilities. This also seem to be the case in many other developing countries (Vicente and Lopez, 2010; Samant et al., 2013). The study reveals that education level, work status, age and place of residence are important factors associated with access to ICT among persons with disabilities. Facer and Furlong (2001) also found an important socioeconomic gradient with respect to access to a computer. Gender inequalities also exist in access to the internet among people with

disabilities, with males being more likely to have access to internet than their female counterparts. This result is consistent with findings from Kent and Facer (2004), who reported that boys were more likely to report being involved in playing games and using the Internet at school. Research has revealed that the mobile phone is, for adolescents, a medium which permits communication (Davie, Panting, Charlton, 2004), and is a means for social inclusion (Adams and Fitch, 2006). The results are also consistent with many findings (Furuholt and Kristiansen, 2007; Graham, 2011; Rao, 2005; and Mosse and Sahay, 2005) that in the African context where ICT deployment faces infrastructural bottlenecks, people with disabilities are even more disadvantaged. We conclude that increases in people with disabilities' education and employment in particular may prove useful in increasing their ICT access in Namibia. Policies should target people with disabilities' education and employment.

The results of this study seem to extend the literature in a few ways. The current study indicates that people with disabilities classified as "blind", "autism" and "mental disability" experience the greatest degree of ICT disadvantages. For people with these kinds of disabilities, achieving and maintaining employment remains a significant challenge in Namibia. So is having an education. For instance, among people who are classified as "blind" only 16.1% had attained secondary or higher education. Most of them either had no formal education (55%) or had only primary education (29%). Yet education and employment empower people with disabilities as citizens and are important elements in accessing ICT in Namibia. There also seems to be greater discrimination against people with these kinds of disabilities. It is in this context that they experience greater ICT disadvantages. It is also in this context that policies should also take into account type of disability for a "one size fits all" approach will miss people with certain disabilities. Chadwick et al., (2013) for instance argue it may be necessary to distinguish between physical and intellectual disabilities in order to ascertain how specific types of disabilities may influence access to ICT.

This study indicates (Figure 1) that there is less disparity between employed and unemployed individuals with disabilities than without disabilities. We do not know exactly why this is so, although in Namibia there are a variety of governmental programs that attempt to help people with disabilities. Prominent among these is the disability grant. An amount of N\$ 600 per month (1USA \$ = 8.5 N\$) is paid to people 16 years or older that are medically diagnosed by a State doctor as being temporarily or permanently disabled every month. This may serve to reduce inequalities among people with disabilities that also affects access to ICT. As far as we know there no comparable schemes serving to reduce inequalities among people without disabilities in Namibia.

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Powers of Classification: Politics and Biology in Understandings of Intellectual Disability

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Abstract: Intellectual disability is commonly understood as a biological state of functioning that determines the cognitive capabilities of the individuals labeled so. By analyzing how intellectual disability is constructed through classification practices this article challenges this view, arguing that intellectual disability primarily is a political, normative and social diagnosis.

Key Words: construction of disability, bio-politics, deviance

Introduction

Intellectual disability is popularly understood as a condition of biological functioning, influencing cognitive development and thereby having extensive effects on the living conditions of the individuals labeled so. By this view, the field of social policy vis-à-vis intellectual disability, consists of governmental arrangements affecting the lives of the diagnosed individuals, as in group home living and sheltered employment, whilst the diagnosis as such is rendered outside the scope of politics. Often starting from this perspective, social scientific disability scholarship has, for the most part, devoted attention to the social conditions surrounding people with this diagnosis whilst taking the nature of the condition for granted. As noted by Tremain (2005) and Hughes and Paterson (2010), examinations starting from feminist and post-structural perspectives theorizing the relation between body, knowledge and politics, has been surprisingly rare within disability studies. The purpose of this article is to put into question some common assumptions on the relation between politics and biology in understandings of intellectual disability. As I hope to show by analyzing the classificatory construction, politics is not best conceived of as social practices exercised on already-there brains with given biophysical characteristics, but by what puts the category of “intellectual disability” into being in the first place.

The label of intellectual disability becomes a strong marker of identification for members of the group and has tangible consequences for diagnosed individuals. It will likely affect chances of getting a job in the regular labor market, where people with this condition will live, what schooling they will get, and so on. It is therefore vital to examine the implicit ideas operating through knowledge systems surrounding the condition, thereby seeking to open up new spaces for criticism and contestation. In this article, classification is analyzed as originating in ideas on deviance and from concerns on how various groups of people in society can be governed (Foucault, 1998; 2002). The on-going changes in classification of intellectual disability are, from this perspective, re-constructing the group as such, re-inventing it, and fine-calibrating it to fulfill rationalities of government. Starting from this perspective, it becomes possible to discern the political and normative stakes involved when constructing clinical definitions. This will be the principle task of this article.

Intellectual Disability and Biology

Politics and Biology in Disability Studies

To start with, it is necessary to lay bare how the relation between biology and politics is commonly interpreted within social scientific disability studies. Arguably, the analytical approach known as the “social model” of disability has strongly influenced disability research for the last three decades (Barnes, 2000; Shakespeare, 2006; Smith, 2005). It has also affected the ideological leanings of intellectual disability scholarship. The main proposition of the first version of the social model was its separation between impairment, which is taken to be the *biological* constitution of the body, and disability, which denotes the effects of discriminating *social* structures (Oliver, 1996). The social model’s core claim is that disability is caused by social organization rather than by biological functioning. Impairment, in this model, reflects the natural distribution of biological difference within any population. The reason why people with impairments are disabled is that impairments are not accommodated for by social organization (UPIAS, 1976; Oliver, 1996; Shakespeare, 2006). Consequently, one of the main goals of disability studies has been to identify and criticize discriminatory social structures.

Although the social model has been contested and developed into a family of analytical approaches (Shakespeare, 2006; Chappel et al, 2001; Rapley, 2004), it is fair to say that the identification of discriminatory social structures has been a main focus of disability studies up to this day. For the purposes of this article, what is of importance is an assumption underpinning the social model as well as the analytical perspectives that have developed from it, namely the idea that biology and society can be ontologically separated. This separation was put to the fore already by The Union of Physically Impaired Against Segregation (UPIAS) (1976) in what can be considered the founding statement of the social model, where disability is declared to be imposed on top of impairment and social factors imposed on top of biology. Consequently, the target of criticism from researchers starting from this perspective has often been mechanisms of power exercised on already-there bodies and brains. Thus, whilst questioning the authority of medical professions to decide how disabled people should *live* (Oliver, 1996), social model analysis concurrently neglects the power of medicine to define what disabled people *are*. The “being” of impairment is not necessary to problematize if “social” and “biophysical” are distinguished spheres. Although the separation between society and biology enabled criticism of disabling social structures, it simultaneously disregarded impairment as a question of politics.

Despite the fact that the social model has developed and been contested by rival approaches, present understandings of disability are still tainted by this division between the socio-political and the biophysical. Since the mid-nineties, a variety of criticisms have been leveled against the social model, occasionally pointing to its naturalized place of impairment (*see* Tremain, 2005; Hughes & Paterson, 2010), but more often arguing for social model analysis being over-simplifying and logically flawed (*see* Shakespeare, 2006). It has also been suggested that social model analysis neglects intellectual disabilities (Chappell, 1998; Chappel et al, 2001; McKenzie, 2013). At times intellectual disability has figured as proof of the opaqueness of a one-sided focus on discrimination, for example when Shakespeare and Watson (2001)

rhetorically asks how social organization possibly could accommodate for people with intellectual disabilities having equal opportunities on the labor market. Implicitly, what is argued is that the elimination of barriers never can eliminate disadvantage for people with cognitive impairments and by that intellectual disability is turned into a verification of pre-political and biophysically rooted hindrance (see also Anastasiou & Kauffman, 2011). In this way, the debates on the social model and intellectual disability have often focused on whether and to what extent the assumed biological realities of impairment needs to be accounted for in explanations of disability. Still, the sphere of biology and of impairment has remained de-politicized. Today, most western legislations and regulations, as well as dominating scholarly interpretations (see Harris, 2006; Carr & O'Reilly, 2007; Hvinden, 2009), adhere to various forms of relational models where disability is seen as stemming from the interplay between impairment, on the one hand, and social context on the other. The relational models can be interpreted as the result of a compromise between the social model and the biological focus of the clinical mainstream (Harris, 2006,). Yet, the social model and the relational approaches share the assumption that politics and discrimination only appear *after* impairment (see Rapley, 2004; McKenzie, 2013). No matter if the biophysics of brain functioning is irrelevant to disability (as in the social model) or as forming relations to social context creating disability (as in the relational models), the existence of a socially untouched biology is essential to how disability is conceptualized.

This separation between biophysics and society produces theoretical blind spots that constrain criticism of how intellectual disability is *put into being*. The problem with this separation is that it cannot provide tools to analyze how phenomena such as classification and clinical interpretations of intellectual disability are embodying mechanisms of power, precisely because classification and medical knowledge are dealing with pre-political impairment. But how impairment is made knowable, how certain biophysical features are rendered objects of science and dressed up in discourses of “pathology” and “disorder”, and how these divisions and labels are functioning within social policy, are all matters of politics. And this we can only acknowledge if the separation between biophysics and politics is collapsed (see McClimens, 2007).

The Body Politic and Power of Life

On the one hand clinical diagnoses are of vast influence for targeted individuals. On the other, and despite the critical aspirations of much social scientific disability scholarship, these systems are with few exceptions (for example Rapley, 2004; Simpson, 2012) either seen as unproblematic or simply overlooked. In response to the shortcomings of the dominant research paradigm, new theoretical vantage points are needed.

Butler (1993) has suggested that every reference to a body works as a further formation of that body, directing attention to the social constitution of what is considered “natural” in our biology. Instead of understanding social structures as layered “on top” of bodies, as in social model analysis, this perspective understands knowledge of bodies as intertwined with the normative powers operating in society. Thus, rather than being imposed on top of the body, society is always there at the moment when our biophysical features are made objects of knowledge. In addition, the very placement of impaired brains in the domain of biophysics is a potent expression of a power functioning by making certain phenomena appear unproblematic,

non-political, and beyond the reach of criticism. Following Butler, I will approach impairment and biology as part of a socio-political field, which hopefully facilitates understanding the self-narratives of people labeled with intellectual disability in ways more attentive to the experiences of how diagnosed individuals comprehend their own condition.¹

A second theoretical proposition guiding my analysis is provided by Foucault's (1998) conception of bio-politics, suggesting that there is an intrinsic connection between systems of knowledge production and the governing of the individuals comprising the population. In order to govern the population the population has to be known, which means that ways of subdividing and ascribing characteristics to different segments of the citizenry are integral aspects of government. The production of knowledge on various groups in society is central to how society distributes wealth, plan social policy interventions, incite certain ways of being and acting in society, and so on. Instead of approaching classification and the medicine of intellectual disability as reflecting upon a world outside and before politics, the notion of bio-politics help us see how these are aspects of the ordering of society (Caswell et al, 2010).

The theoretical perspective sketched here is neither meant to imply that the social model, or any other critical perspective, should be abandoned, nor does it ignore the important criticisms and the vibrant activism that these conceptions of disability have produced. Instead it acknowledges that disability studies on intellectual disability needs to be complemented to further new targets of criticism and contestation.

Intellectual Disability as Social and Statistical Deviance

Turning now to the examination of classificatory practices, it is necessary to start with a short introduction to the basics of the classification of intellectual disability.

For the second half of the 20th century and up to this day, all globally used classification systems have defined intellectual disability as the concurrent featuring of intellectual and adaptive behavior deficits at the onset of the developmental period of life. These criteria are operationalized as an IQ-score below 70 and significant limitations in adaptive behavior estimated by clinical professionals. The newly released DSM-V (2013) downplays intelligence on behalf of adaptive behavior, but IQ-testing remains integral to the suggested classificatory toolbox also in the new diagnostic manual (APA, 2013). DSM, together with the ICD-10 of WHO and the classification system of the American Association of Intellectual and Developmental Disabilities (AAIDD), dominate classification of intellectual disabilities today and have historically agreed on the basics of what intellectual disability is.

According to the dominating classification systems there is no single cause or prognosis for the category of intellectual disability since this is a generic term for a host of more specific types of impairments (Harris, 2006). Moreover, it is maintained that genetic, medical, psychological, and environmental factors all contribute to determine the level of cognitive and adaptive disability (Bennet, 2006, p. 343) and that many cognitive impairments can conjoin in one individual (Carr & O'Reilly, 2007). In order to see the politics involved in conceptions of what intellectual disability is, I will first have a closer look at the practice of measuring deficits in intelligence and thereafter examine the notion of adaptive behavior.

IQ-testing

IQ has arguably been fundamental to the formation of present understandings of intellectual disability. The emergence of IQ-testing and psychometrics in the early 20th century fundamentally altered the practice of classification. Premising the shift was the idea that human intelligence could be summarized and measured as an individual characteristic. In turn, the new test instruments introduced what was perceived as scientific measurements of cognitive capabilities, replacing subjective judgments by parents, community inhabitants and state authorities. The introduction of intelligence testing also meant that the historical inclination to bundle together individuals with intellectual disability with other groups, for example the poor of the Middle ages or the physically impaired during the 19th and early 20th century (Stiker, 1999), was abandoned in favor of a careful segmentation that separated this group from other marginalized groups.

IQ is not and has never been a straightforward measurement of intelligence, but of intelligence compared to the rest of the population. IQ-scales are normed so that the average member of the population has an IQ of 100. Hence, IQ-tests do not measure intelligence in absolute terms, but in relation to the statistical norm that the test is constructed for. It is assumed that IQ is normally distributed in a bell-shaped curve peaking at an average IQ of 100. Putting the cut-off point at an IQ of 70 designates two standard variations below average, which means that 2.27% of any population assumed falls under the bar if the test is correctly constructed. Therefore, in theory, IQ-test results show how good individuals are at solving psychometric tests compared to the general population and the 2.27% performing worst will meet this criterion. Consequently, the cut-off point of an IQ of 70 precludes the possibility that more than approximately 2-3% of the population is intellectually disabled. No matter how many children with syndromes associated with intellectual disability are born or not born, the share of the population with an IQ under 70 will remain at about 2.27 % as long as the tests are up-to-date and the assumption of normal distribution is correct. It can thus be concluded that there are no necessary linkages between IQ-testing and the biology of cognitive functioning, precisely since IQ is a statistical measurement that only makes sense relative to the population that the test is constructed for.

In some clinical work on the condition, it is maintained that IQ is not normally distributed since there is a “genetic bump” at the lower end of the bell-shaped curve caused by biological pathogens, such as genetic disorders and pre-natal damages (Bennet, 2006). This means that among those with an IQ under 70 there are individuals with IQ scores that can be attributed to the “genetic bump” and individuals with IQ scores where IQ can be attributed to normal distribution. This introduces a division between normally distributed abnormal intelligence and abnormal intelligence stemming from identified pathogens. However, the categories are equated in classification practice. Even when intelligence is associated with a specific genetic syndrome, pathogenic biology does not guarantee a specific IQ-range. You can have an associated syndrome with an IQ higher than 70 and you can have an IQ below 70 without an associated syndrome. Naturally, the lack of pathogens appearing precisely at an IQ of 70 begs the question why the cut-off point should be placed at this particular point. It is also notable that the

placement of the IQ cut-off point both have been revised and debated throughout the 20th century. The absence of biophysical characteristics that correlates to the IQ 70 criteria indicates that this cannot be a decision abstracted from social norms. In retrospect, this placing has been interpreted as stemming from a general impression that 2-3 % of the population are intellectually disabled judging from their “real world behavior”, that is, on a judgment that 2-3% of the population behaved in ways that called for societal responses. Interestingly, the originator of the IQ 70 cut-off point, the psychologist David Wechsler, provided no references or guidance to any clinical studies justifying the placing of the IQ 70 yardstick when it first emerged in a 1944 article (quoted in Flynn & Widaman, 2008). Justifications of the placing of the cut-off point are notably scarce also in the contemporary clinical literature (see Bennet, 2006; Carr & O’Reilly, 2007). Thus, rather than explicit clinical judgments about brain functioning, the rationales for the design of the IQ-criterion seem to be a social judgment about how a large share of the population needs to be segmented by classification systems. Implicitly, the IQ-70 cut-off carries a judgment on what and how people are, deeming that 2-3 % of the population need to be specified and it is assumed that psychometrics is able to do the sorting.

Every now and then clinical works on intellectual disability maintain that the placing of the cut-off point at IQ 70 can be scientifically validated. Consider for example Carr and O’Reilly (2007) referring to numerous publications stating that IQ 70 is confirmed by deficits in adaptive functioning, which is the other criterion for being intellectually disabled. This reflects that there is a high correlation between adaptive behavior deficits and an IQ under 70. Thus, the accusations of arbitrariness in the placing of the cut-off point are met with the argument that those with an IQ of 65 are deemed intellectually disabled also by their level of adaptive functioning, whilst those with an IQ of, let’s say, 75, are not. This naturally begs the question why two criteria are necessary in the first place. It also exposes a peculiar figure of reasoning where two criteria taken to be independent from each other still can be inferred from one another. If this really is the best way to validate that IQ 70 is the correct place to draw the boundary between pathogenic and normal brain functioning, the rationale of the IQ criterion boils down to the idea that people with an IQ of less than 70 behave in ways that constitute pathology, despite the fact that no biophysical pathogens are necessary to be diagnosed.

The peculiarities sketched here can serve as a neat illustration of the operations of mechanisms of bio-politics. The rationale behind IQ-testing is the perception that a segment of society, approximately 2-3% of the population, is behaving in ways that calls for socio-political measures. Although these measures have changed since the emergence of intellectual disability, from incarnation and confinement to group home living and decentralized support systems, classification is still a tool of government rather than an instrument of medicine describing naturally existing phenomena. IQ tests did not provide new knowledge of a group already existing; it invented a group in a way that conformed to specific understandings of the relation between intelligence and behavior and contributed to the assumption that a large share of the population needed to be targeted by interventions. This explains why the enormous heterogeneity within the group of intellectual disability is beside the point; the category is not meant to speak uniformly with respect to medicine and biology, but with respect to social policy and government.

The interesting point to note here is how these underlying rationales and justifications of IQ testing, when examined more carefully, contradict the way intellectual disability is almost universally presented in the clinical literature as a natural phenomenon, existing regardless of context and ingrained in bodies. For example, both Harris (2006) and Carr and O'Reilly (2007) provide plenty of descriptions of etiological traits leading to the condition and advises on how the condition can be prevented by, for example, genetic counseling. Yet, no biophysical indicators are to be seen in IQ test results. This inclination to locate intellectual disability within the individual as a "natural" phenomenon is exposed when comparing discourses on the IQ test results of the intellectually disabled with discourses on IQ gaps of other low-performing groups. For example, a host of studies have shown that people of color averagely fall 15 points below caucasian people on IQ tests in the United States (Borthwick, 1996). This is most often attributed to a host of environmental factors, such as education, early cognitive stimulation, and socio-economic background. However, in the clinical depictions of IQ and intellectual disability, social factors are continuously downplayed in favor of biophysical pathology. Likewise, although the general intelligence paradigm holds that IQ is the outcome of biological *and* environmental factors (Bennet, 2006), the IQ of people with intellectual disabilities is most often exclusively understood in terms of the former.

In summary, the use of the IQ 70 yardstick is founded in conceptions on certain behavior which calls for governmental action. Its technique is to measure deviations from a socially embedded norm turned into statistics, which in turn requires a line to be drawn between what is normal and what is not. Where to draw this line can never be a decision extracted from notions of normality. Furthermore, the influence of social factors on IQ test results may potentially mean that people with mild forms of intellectual disability are diagnosed on having had unfavorable social circumstances, which is something completely different than the view that intellectual disability is resulting from pre-political impairment.

Adaptive Behavior

Diagnosing intellectual disability is not restricted to only doing IQ tests. Harris(2006) asserts that diagnosing is about comprehensive assessment and individualized case formulation performed by clinical professionals. The combination of intellectual and adaptive capacities means that psychometric testing should be complemented with measurements of adaptive functioning.

The adaptive behavior criterion in the fourth edition of DSM reads:

“Concurrent deficits or impairments in present adaptive functioning (i.e., the person’s effectiveness in meeting the standards expected for his or her age by his or her cultural group) in at least two of the following areas: communication, self-care, home living, social/interpersonal skills, use of community resources, self-direction, functional academic skills, work, leisure, health, and safety” (Mash & Wolfe, 2010, p. 276).

Also the ICD-10 invokes comparisons with similarly aged peers and members of one’s cultural group into the definition of adaptive behavior, as does the AAIDD. What varies between

the different classification systems is how adaptive behaviors are statistically grouped and factored, although they all typically measure various aspects of communication, self-management and everyday living. The relative component of adaptive behavior, referring to what is normal for individuals within the same age and cultural group, means that adaptive behavior deficits consists of little more than once again resorting to a notion of what is not considered normal. In much the same way as with IQ test results, there can be numerous reasons for failing to live up to adaptive behavior criteria, linked to identified biological conditions or not. Thus, like IQ, the adaptive behavior criterion fails to form a necessary linkage to bio-pathology.

The construction of the adaptive behavior criteria also raises questions on the rationales behind choosing these particular areas of measurement – why communication skills, why personal safety, and why self-direction? These are neither self-evident nor self-evidently measured, as the on-going scientific controversies on measurement technologies of adaptive behavior testify to (Arias et al, 2013). Rather than approaching adaptive behavior as connected with some kind of natural truth about what a normal or disabled brain is, these criteria seems to function as yardsticks to measure the capacity to get by in the modern western societies where they were constructed. Because, although adaptive behavior does not speak of biology, it says a whole lot about how one is functioning in contemporary western society. Therefore, as Foucault analyzed madness as the absence of work, we might ask with Rapley (2004) why adaptive behavior deficits can't be translated into the absence of norm-following behavior in areas valued by society. There is nothing intrinsically problematic with this, but it definitely shows that adaptive behavior does not exist outside of how it is measured. And it needs to be acknowledged that the practice of estimating adaptive behavior deficits is intrinsically linked to norms about what normal and appropriate behavior is and that the judgments passed emanate from how such norms are interpreted by the psych-professionals carrying out the tests.

The Intellectual Disability Criteria – Circularity and “Deviance”

Returning to Butler's suggestion that bodies are constituted in discourse, the criteria for being diagnosed with an intellectual disability can be seen as an example of such constitution. The technologies that are allegedly used to *describe* an independently existing “disordered cognition”, in fact functions to *manufacture* the condition of intellectual disability as such. IQ and adaptive behavior become intrinsic to how the brains classified are understood, specifying what their important features are and why they qualify as pathological. In this way, the present comprehension of what intellectual disability is was not *discovered*, but *created* by techniques of measuring intelligence as IQ and adaptive behavior.

Now, what we see in the definitions of intellectual disability is that the symptoms are equated to the label itself (*see* Rapley, 2004). This effectively turns into a loop of circularity as soon as one tries to render the definition of the group explanatory. How do we know that someone is intellectually disabled? It is because they have sub-average intelligence according to IQ tests and are unable to care for themselves according to behavioral measurement assessments. Then, why do they have low IQ and why are they unable to care for themselves? It is because they are intellectually disabled, which means that they have sub-average IQ and adaptive behavior problems. And so on. In this way the label of intellectual disablement explains nothing more than the criteria constituting it. This begs the question, if not explanation, what might be

the purpose of the diagnostic criteria? Looking at classification as a practice of bio-politics, the answer is that the knowledge production of intellectual disability criteria functions as a tool to define whom social policy should target. This decision can never be separated from norms on normal behavior and functioning. The enormous diversity within the group of people labeled with intellectual disability is rendered obsolete by this underlying rationale: it does not matter that the label slates over an array of considerable differences, what matters is that the classificatory instruments can detect individuals that are perceived as calling for governing.

When we approach the diagnostic criteria for intellectual disability as an indicator of biophysical functioning, it will appear as logically peculiar and non-explanatory upon closer scrutiny. What actually causes intellectual disability is a social judgment that consists of designating IQ 70 as the appropriate yardstick and in picking a specific list of indicators capturing adaptive behavior. It is the very assumption that these instruments are able to specify pathology, that constitutes intellectual disability as pathological. Thus, viewed upon from a perspective of bio-politics, classifying intellectual disability can be seen as a social practice with the aim of defining a segment of the population that is already perceived as differing from the societal norm. As a result, individuals with very different conditions, with very different help needs, and with very different cognitive functioning, are bundled together under one label.

Importantly, this argument pertains to the whole range of people labeled intellectually disabled, not just people with mild or moderate impairments. Intellectual disability is always a diagnosis of deviations from the norm – whether it is considered small or obvious. It may be that the construction of classification means that some “mildly” disabled individuals could have been deemed “normal” as the relative measurement criteria creates liminal zones of ambiguity, whilst it might seem obvious that individuals with severe intellectual disabilities always will be in need of social services of some sort. However, the practices of framing intelligence, behavior, or the need for help within an overarching binary scheme of normal-“deviant” are social and discursive. Indeed, the reasons for people with mild and severe intellectual disabilities being sorted under the same label, as well as the very existence of a label indicating that these groups are similar, cannot be understood as separated from socio-political considerations.

Returning Deviances to Nature

Despite the fact that biophysical functioning is not necessarily tied to the classificatory criteria for intellectual disability, the clinical literature depicts the condition as a phenomenon that can be comprehensively explained by understanding the brains and genome of the individuals labeled so. In this section I will argue that such biologization of intellectual disability serves as a discursive method for inscribing the social and statistical deviation detected by classification schemes onto the biology of the brain by returning the normative perception of “deviance” to nature.

Notably, cognitive functioning is not static, but constantly changing over a lifespan. IQ can increase as well as decrease and behavioral skills can be learned and un-learned. Modern neuroscience has effectively falsified depictions of the static and predestined “machine brain” (Changeux & Edelman, 2001; Changeux, 2004). This means that environmental factors, for individuals situated at the upper end of the intellectual disability scale, potentially can push over

the IQ 70 threshold and, similarly, that some individuals might be intellectually disabled by merit of the absence of favorable circumstances. However, examples of people labeled intellectually disabled getting their diagnosis taken away are very rarely described. The clinical literature often notes the importance of early interventions, a nurturing upbringing, good education, stable family relations, and so on, in order to enhance cognitive development (Carr & O'Reilly, 2007; Bennet, 2006), but resists the logical conclusion that "intellectually disabled", the way it is currently defined, is something that one can cease to be. Instead the condition is almost unequivocally talked about as something one is and will continue to be.

This results from there being dual modes of defining intellectual disability: as below normal IQ and behavior deficits, which may change, and as something tied to one's being, no matter what. The discursive tool used to turn the fluid and unclear deviations detected in classification into a static condition, is the concept of *etiology*, denoting the origins of pathology. Conditions such as Down syndrome and Fragile-x syndrome are examples of etiologically defined sub-categories of intellectual disability. It is commonplace in the clinical literature to assume that intellectual disabilities have etiological traits and that these traits, most often, are biophysical whether they are known or not. By this assumption it is also implicitly suggested that intellectual disability is pathological. However, the dividing line that specifies pathology is not possible to detect in people's brains; this is an assumption made, pertaining to the behaviors that the classificatory measurements aim to detect. Thus, by referring to intellectual disability as having etiological traits, the underlying assumptions on normality and deviance are naturalized and framed as located in a biophysical realm prior to culture and norms. When put into a discourse of "pathology", it establishes a framework for understanding the intellectually disabled brain, making deviations appear as an effect of some detectable biophysical pathogen, although this is precisely what the classificatory definitions of intellectual disability fail to detect.

The references to etiology also means that the fluidness of cognitive abilities – potentially pushing one over the IQ 70 threshold – is replaced with a label that cannot be escaped; you are born and you die with a genetically defined condition such as Down syndrome, even though your intelligence or adaptive behavior might be changing. This is another indication that there are two concurrent ways of understanding intellectual disabilities, the ways designated by the classification systems and in terms of etiology by reference to the origins of what one's bodily functioning is like. One important function of the discourses of etiology is camouflaging that it is the placement of the IQ cut-off point and the specification of the adaptive behavior criterion, that determines the division between intellectually disabled and "normal" people.

This brings us to the relation between the overriding category of intellectual disability and the associated sub-diagnoses. There is no necessary link between these – you can have one of the associated conditions but an IQ over 70 or meet the criteria without any discernable sub-diagnose. But precisely such a link is assumed in much of the clinical literature. Consider for example Harris (2006) approvingly quoting Bourneville as the person "finding out" in 1880 that intellectual disability is "caused" by brain pathology. This statement is possible only given the premise that adaptive behavior deficits together with an IQ under 70 are self-evidently pathological. This, as I have shown, is a normative statement and in addition highly questionable. In fact, at the logical point where it becomes meaningful to search for etiological traits it has already been taken-for-granted that there is something to search for. Only after pathology has

been taken as fact does the need to scrutinize the biology of people with intellectual disabilities emerge. At the same time, the biophysical expositions masquerade as the real causes of intellectual disability, thereby obscuring the normative character of diagnosis.

Thus, what I propose is a reversal of the commonly suggested order of appearance of intellectual disability and etiology. Whilst mainstream intellectual disability research holds that etiology explains why one meets the criteria for being intellectually disabled, I suggest that a social and cultural recognition of these people as deviating from the norm is primary; the IQ and adaptive behavior-criteria produce a way of specifying this group and only thereafter follows the idea that the origins of difference should be traced; the recognition of “deviance” is and has always been primary to the search for its causes. Etiology functions as the implicit ideology that seeks to explain every abnormality in behavior and mind as bio-pathology, thereby rendering the social judgments appear as “natural” by returning them to the body. Once we have accepted the assumptions of etiology and pathology it becomes necessary to detect every aspect of intellectually disabled beings, to trace every thread that has lead up to their constitution, and to do so by carefully examining the biology of their brains. This project can be interpreted as premised on the body having a privileged status as a source of truth, understood as “natural”, “real”, and/or “authentic” (Urla & Terry, 1995). The myth of the body as a source of truth explains why societies have repeatedly returned to the materiality of the body to solve social anxieties, whether concerning race, sexual orientation or sex, all proven by history, or concerning intellectual disability, as my analysis shows.

A last thing to note on the biologization of intellectual disability is how it discards the legitimacy of the voices of people labeled with the condition. The exclusion of people with intellectual disabilities from research concerning their own lives is well documented (McClimens, 2010) and given the authority of the clinical sciences, simply put, there is no room for questioning, resisting or even affirming the label “intellectual disability” as long as the diagnosis is seen as a matter of medical professionalism dealing with biology. The biologization of intellectual disability thereby creates a discursive barrier precluding and delegitimizing the voices of people with this condition from expressing their own comprehensions of their diagnosis. Destabilizing assumptions on what intellectual disability is that are taken for granted, is therefore serving as a political strategy facilitating criticism and creating space for discussion for people with intellectual disabilities. This ties well in with the inclusive and participatory research agenda that has been advanced by some advocates and disabled activists.

Conclusions

From a perspective of bio-politics, classification and clinical accounts of intellectual disability both function as ways of providing knowledge that government can act on; ways of carving out a group perceived as needing management. By this view, the accumulation of clinical knowledge and the practices of classification can be seen as intertwined with modalities of government and the recognition that there are people in society behaving in ways that must be managed, serves as the incitement for forming the diagnosis in the first place. In order to maintain the idea that people with intellectual disabilities are distinctively “other” from “normal” ways of being, the deficits detected by the classification schemes are re-located in the brain of labeled individuals – not by strategy, but by rationales working within the clinical literature on

the condition. Thereby, intellectual disability is discursively anchored in the biology of the brain and this concurrently functions so as to depoliticize the condition as such, making it appear as “natural” and having an ontologically independent existence. When examined more closely, however, we find that the construction of the disabled brain is imbued with norms about what constitute normal functioning. All of this shows that there is no way of knowing intellectual disability in a social or historical vacuum. Ideas on normality that are permeating contemporary western societies, along with rationalities on how behavior perceived as “deviant” can be managed, are indeed the foundations that knowledge on intellectual disability is built on. These arguments can be read as an attempt to ontologically relocate the brain within intellectual disability discourse, moving it from the realm of nature to the realm of politics. Such a theoretical move, I argue, provides an impetus for criticism that does not restrict itself to the organization of public services, but that places the very being of the intellectually disabled at the center of attention as an issue of social politics. In turn, as the authority of medicine and psychiatry starts to tremble, this might leave more room for narratives of individuals labeled with the condition.

It is important, however, to be careful when discussing what these findings imply. Surely, many people labeled intellectually disabled are helped by getting access to support and services, which, it can be argued, is enabled by classification and diagnosis. Thus, the efficiency of classificatory practices in finding individuals unable to manage their own lives may be interpreted as proof of the legitimacy and effectiveness of such systems. However, the arguments proposed do not imply that people should not get access to social services, but that the formation of “intellectual disability” as a target group for such services must be understood as political and therefore open to contestation. This does not render classification meaningless *per se*, but offers an incentive for us to explore it and debate it as an issue of politics rather than as the “nature” of how some people function. As long as classification and clinical descriptions of intellectual disability are seen as pre-political, any discussion on the merits, dangers, powers and aims of classification is precluded. If anything, the criticism I have sought to formulate here should urge us to abandon the firm separation between biology and society that presently pervades understandings of diagnosing intellectual disability.

Lastly, the prevailing discourse on intellectual disability not only obscures the political rationales inherent to knowledge production on the classified brain, but also restricts people labeled with intellectual disabilities from formulating what their condition means. Chen and Shu (2012), for example, have convincingly shown that the labeling of people as intellectually disabled can create experiences of stigmatization. Simultaneously, the existence of this diagnosis functions to generate the appearance of a homogenous group, instilling the impression that “intellectual disability” is *one* specific way of inhabiting the world. Tucker (2010) has argued that the knowledge systems of medicine and psychiatry not only concern how bodies are made sense of, but also affects the experience of embodying a medically defined biology. This directs attention to how individuals with intellectual disabilities come to identify and understand themselves as belonging to this certain category of being human. Therefore, to politicize the “nature” of intellectual disability is not speaking for or on behalf of people with intellectual disability, but seeks to designate a space for them to speak from by showing that the formation of how intellectual disability is seen is contingent on highly normative and political ideas that

should be addressed in a critical and public discussion, one that people with intellectual disability have a right to be a part of.

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Endnotes

1 See Roets, 2009; Roets et al, 2008 for excellent examples of how such understanding can be accommodated by de-naturalizing impairment

Color for Color

Roselyn Perez
California State University, USA

I dream in silver and orange.
No rhymes, no companionable spirit,
the landscape
a prism of contrasts,
seldom traveled.
If only you could find your way
those autumn leaves and tinkling bells
would guide us through each dip, swell,
until one becomes the other.

Birds in fields of pumpkin
await our audience,
their atonal melodies drift
like a mist that illuminates
Fish explode upward, like fireworks,
retreating with the sun

Into the glittering depths

Staring across phantasms, my breath
held, as the winged creatures
exhale like trumpet blares,
I wait, listen, still apart.

Morning strikes with its blue and gold, which never stand alone,

Then a sound pulses intense as firelight.
It's a match striking, one heart picking up the beat of its pair
warm, bright, orange and silver.

Roselyn Perez is the fifth of six children, all girls. Two of her sisters, as well as herself, have lived with Retinitis Pigmentosa all of their lives. She is 27 years old, resides in southern California, and is studying creative writing and psychology at California State University, Northridge.

Book Review

Title: *In the Shadow of Disability: Reconnecting History, Identity and Politics*

Author: Pieter Verstraete

Publisher: Opladen, Germany: Barbara Budrich Publishers, 2012

Paperback: ISBN: 978-3-8474-0223-3

Cost: Paperback: \$24.65 on Amazon, 133 pages

Reviewer: Steven E. Brown, Ph.D.

Verstraete's book, based on his doctoral dissertation in Educational Sciences, is a deliberately provocative look at disability issues from new perspectives. The origins of this analysis began when Verstraete, now a postdoctoral research fellow at the Flemish Fund for Scientific Research Flanders/KU (Catholic University) Leuven, in Belgium, was asked to do research in educational initiatives for individuals with disabilities.

In the course of this research, he came across a photograph of two people riding (or posed on) a tandem bicycle in the early 1900s. The mystery of the photo, for Verstraete, is that a young adult deaf-blind lady sits in the front, or lead, position of the bicycle. How does she control the bicycle? This question led to an investigation of disability that focuses on shadows, identity, Michel Foucault, solitude, and politics. Much of this review is in Verstraete's words, to share the flavor of the writing. For example, in a paragraph about shadows and Foucault, Verstraete writes:

“We all lived and live in the shadows of and were and still are not capable to escape from the innumerable, dynamic and complex strategies that separated man from an undefined light source. For Foucault it was simply impossible to get rid of power relations and one therefore had to cope with the idea that man was continually asked to behave in this way or another way” (p. 66).

Much of the book reflects the theme of the above quote, which is how people are influenced by and react to power. Verstraete shows there are other ways, than are currently standardized, of looking at disability. In the concluding and summative chapter he writes:

“Up till now historians of disability have been urged to look out for those places where persons with disabilities are silenced in order to reveal their voice.... I am convinced that if one does not want to get trapped into the lure of visibility...one also has to invite historians of disability to look for those silent places where new forms of life can express themselves” (p. 120).

From silence and shadows, Verstraete focuses on presenting analyses of disability in unusual ways and this applies to activity; he notes, “persons with disabilities are just like able-

bodied persons confronted with a power-knowledge nexus that wants all of us to become active citizens, one that does not distinguish anymore between those who are and those who are not disabled” (p. 121).

He concludes that for him disability history could be an imaginative search for, “new ways of behaving, other forms of life and new ways of speaking” (p. 122). In other words, disability and disability history open opportunities to look at the world in new ways, if only we take advantage of those opportunities.

There are aspects of *In the Shadow of Disability* that disability studies practitioners are likely to find frustrating, such as the notion that activity or productivity is not for everyone, which is hardly a new idea in disability rights circles; and others that are likely to be inspiring such as looking within shadows and silences for spaces hitherto unexplored.

The book would have benefitted from better proofreading to catch a number of typos and an inconsistency when nineteenth and twentieth centuries are sometimes used interchangeably. But these are minor quibbles for an interesting and stimulating book that may benefit graduate students and researchers of disability studies, but is unlikely to find a place with undergraduates or outside the field of disability studies.

Steven E. Brown, Ph.D. recently retired as Professor of Disability Studies and *Review of Disability Studies* Media Reviews Editor at the Center on Disability Studies, University of Hawaii. He can be contacted at sebrown@hawaii.edu.

Book Review

Title: *Green Care: For Human Therapy, Social Innovation, Rural Economy and Education*

Editor: Christos Gallis

Publisher: Nova Science Publishers, Inc. New York, NY, 2013

Hardcover: ISBN: 978-1-62417-479-7

Cost: \$175, 356 pages

Reviewer: Naomi Rombaoa Tanaka, M.S.

Green Care: For Human Therapy, Social Innovation, Rural Economy and Education, edited by Christos Gallis, is a compilation of writing from all over the world about the importance of nature on human health and in therapy. Although Green Care is not a new concept, this work sparks new ways of thinking about issues surrounding it. The book has four parts: 1) Introductions: Origins, Definitions, and Theories of Green Care; 2) Effects of Green Care on Human Health: Current Scientific Research Results; 3) Social, Political, and Education Aspects of Green Care; and 4) Green Care in the World: Practice and Trends in Europe, Japan, and U.S.

The book was written in hopes of becoming the main textbook for multidisciplinary scientists, teachers, university professors, decision makers, and students of all levels, including PhD candidates, and practitioners. Gallis feels the book is relevant for all disciplines, as Green Care has many widespread health, social, economic, and educational benefits. For example, Sempik and Bragg, in the chapter, "Green Care: Origins and Approaches," cite numerous authors around the topic of Green Care's benefits, concluding:

"Combining the effects on health of physical activity and contact with nature, recent studies have found that 'green exercise' (the synergistic effect of engaging in physical activities whilst simultaneously being directly exposed to nature) results in significant improvements in mental well-being, self esteem and mood measures, as well as leading to significant reductions in blood pressure" (p. 20).

While I believe this is an important and relevant resource, I hesitate to recommend this book, or any book for that matter, as *the* main resource for everyone. A single book simply cannot provide all pertinent information about Green Care's wide spectrum of activities and contexts. This book, however, provides enough information to pique one's interest in Green Care, thus serving as a gateway to additional resources and necessary learning. One of the biggest strengths of this book is its variety of international authors and examples of Green Care's successes from around the globe. For example, chapter nine's authors from the United Kingdom discuss how Green Care socially connects people, providing benefits to participants' well-being. Chapter fifteen's author from Japan discusses the benefits of horticulture and animal assisted therapy. Chapter sixteen provides an American view on the benefits of farming for health. I

appreciate the multiple perspectives of the benefits of farming, gardening, forest bathing (visiting a forest park for relaxation and recreating while breathing in earth aromas similar to aromatherapy), and interacting with animals in nature, to name a few activities. Examples like these clearly show Green Care is essential to our health and well-being. The book has universal and personal appeal, such as Green Care's ability to: create connections between people as well as with the environment; build and sustain healthier physical bodies so we are more energetic and productive; and provide a natural framework that fosters appreciation and gratitude. With positive benefits such as these, Green Care seems like a possible solution to many challenges we currently face in American society.

In addition, the book's description of Green Care is inclusive, focused on building community instead of creating barriers. It has a Person First approach, inherently valuing our strengths as well as addressing needs. The book includes examples of how Green Care can help people with physical and mental disabilities, such as the use of Green Care farming with people with psychiatric diagnoses to foster healthy relationships, animal care for children with Autism Spectrum Disorders, and gardening with people with physical disabilities to strengthen motor skills and educational goals. However, the main point of the book seems to be how Green Care is *good for all people*. Green Care for all—with or without disabilities-- simply makes sense.

If you are open to learning about health and wellness from a holistic, non-pharmaceutical perspective, this book is a must read. It provides a multitude of invaluable insights, compelling readers to immediately put down the book and go outside to experience Green Care firsthand.

Naomi Rombaoa Tanaka, M.S. in Early Childhood/ Elementary Special Education, is a Project Coordinator at the Center on Disability Studies, University of Hawai'i at Mānoa. She may be contacted at nrombaoa@hawaii.edu.

Book Review

Title: *Re-membering: Putting Mind and Body Back Together Following Traumatic Brain Injury*

Author: Ann Millett-Gallant

Publisher: Author (CreateSpace Independent Publishing Platform, Charleston, SC), 2013.

ISBN: ISBN: 978-1490524733

Paper: \$8.99, 132 pages

Reviewer: John Derby, PhD

Ann Millett-Gallant's *Re-membering: Putting Mind and Body Back Together Following Traumatic Brain Injury*, is a self-published memoir "about being congenitally physically disabled and experiencing traumatic brain injury" (back cover). Millett-Gallant focuses primarily on her recovery from a 2007 mobility scooter accident that resulted in an extensive hospital stay and lengthy rehabilitation characterized by memory loss and recovery amidst a host of physical, mental, and social highs and lows.

The memoir begins with a gripping account of Millett-Gallant's accident and her mindset of feeling perpetually lost. After outlining the non-linear, collage-like structure of the book and its major components in the introduction, Chapter 1 explicitly discusses the accident, hospital stay, and early recovery. Millett-Gallant draws from clues such as family member notes and journal entries, hospital photographs and fMRI scans, personal drawings and collages, and others' stories, to reconstruct this period. Following a medically induced coma, she worked through paralysis, pneumonia, almost complete memory loss, inability to speak, cranial reconstruction, new prosthetics, marriage, and returning to work, most of which involved physical or mental setbacks, progress, and eventual resolution. The tone of the first chapter is casual and accessible to a broad audience interested in disability, Disability Studies, and the intersection of disability and art. Sizable attention is paid to interpersonal relationships with close family members and friends, especially her mom and dad. She divulges considerable pain, anxiety, and self-blame, but emphasizes hope.

Subsequent chapters incorporate substantial information on traumatic brain injury, contemporary art history, and art therapy as well as on key figures and iconic visual culture that pertains to these topics. Chapter 2 incorporates traumatic brain injury research into the author's experience of the condition. Chapter 3 addresses Millett-Gallant's physical rehabilitation, which is contextualized by her preexisting disability and the need to fit new prosthetics—twice! Chapter 4 and the conclusion resolve the memoir by discussing the pivotal role of art therapy in Millett-Gallant's journey.

The major payoff of Millett-Gallant's memoir is her ability to weave her scholarly expertise tightly throughout the book, creating an atypical art book that culls from a variety of loosely connected artifacts and fields of study. Central to the discussion is analysis of relevant

visual culture, including medical images of Ann's brain and skull and her own artwork, especially collages produced in art therapy.

In the opening pages of the introduction, Millett-Gallant introduces her collage "Remembering," after which the book is titled, as an "accidental masterpiece," which, although "hardly a masterpiece in the conventional sense," functions as an expression of inner strength, encompassing the overlapping and sometimes competing aspects of raw energy with frustration, confusion, randomness, impulsivity, and imperfection in a therapeutic manner (p. 11). The lone contention of the book is not the amateur quality of Ann's collages, but rather her chief assertion that "Art can be therapeutic within and beyond one's work with an art therapist" (p. 119). While art *can* be therapeutic, it is not *necessarily* therapeutic, and we should be cautious not to mistake the author's success and enthusiasm as an endorsement for self-management of our own mental health.

John Derby, PhD, is Assistant Professor at the University of Kansas, Department of Visual Art. He may be contacted at johnderby@ku.edu.

Dissertation Abstracts

1. *Angry characters and frightened souls: Patients and family explanatory models of bipolar disorder in Taiwan* Yi-Feng, C.L. ProQuest Dissertations & Theses, 2013. [PhD Dissertation] United States: California: Alliant International University, 2013. Publication Number: 3605214.
2. *Fathers' Lived Experiences of Having Children Diagnosed with Autism* Schrader, M. T. ProQuest Dissertations & Theses, 2013. [PhD Dissertation] United States: Minnesota: Walden University, 2013. Publication Number: 3606631.
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4. *The Effects of Training on Police Sensitivity to Autism Spectrum Disorder* Chovanec, T.A. ProQuest Dissertations & Theses, 2013. [PhD Dissertation] United States: California: Alliant International University, 2013. Publication Number: 3608154.
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