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Editorial

What About Disability and Social Justice?

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RDS Editor

The Southern Poverty Law Center sent out a survey to educators after the election, asking them to describe the impact of the election on the school climate for people of color, religious minorities, women, and people who are LGBT. They recently issued a report that indicates that 90% of respondents believe that the election has had a negative impact on the school climate for marginalized students. Missing from this valuable piece of research is people with disabilities. Why? Are people with disabilities negatively targeted or discriminated against based on their disability? Given that students with disabilities are twice as likely to be bullied than their non disabled peers, I would say the answer is "yes". Hate crimes and hate speech against people with disabilities, although prevalent, are largely unreported. Although the incident earlier this year in Chicago where a young white man with an intellectual disability was tortured by four blacks was widely publicized, the focus was primarily on racial motivations for the crime, not on disability. I would suggest that the reason why people with disabilities are not thought of as part of the spectrum of people with identities adversely affected by the election is because it is generally accepted that belittling, bullying, excluding and disregarding people with disabilities is a normative and acceptable practice.

I am deafblind and I grew up in the 1970's in San Francisco. I reached Kindergarten age the same year as the passage of federal special education legislation required that children with disabilities receive a "free and appropriate public education" in the "least restrictive environment." My local public school's answer to that predicament was to recommend educating me in a basement room, by myself, where I could receive "special attention." Throughout elementary school, though I went to several different small, private Montessori schools (the basement was a deal breaker for Mom), I was constantly ostracized and teased by other children. No one would play with me at recess. If they did play with me I was always the "cootie" and they would run screaming from me, yelling "cootie catcher, cootie catcher." I was rarely invited to birthday parties. I was always the last one picked for team sports. Even "Benji Booger" got picked before me. During middle school the teasing and exclusion escalated. Boys pushed their noses up against the blackboard, imitating my need to stand close in order to see. Everyone left the table in the cafeteria when I sat down with my tray. Girls "spread the word" to anyone not in the know that I was "weird" and "unpopular." One girl screamed at me in shop class that she "hated me" even though I barely knew her. An enlightened boy whispered, "You are a sexy fox," directly into my hearing aid from the seat behind me on the school bus, every day, for two years.

Forty years after activists with disabilities occupied the Federal Building in San Francisco for 28 days to protest lack of implementation of civil rights legislation imbedded in the Rehabilitation Act, and twenty-five years after the passage of the Americans with Disabilities Act, we are still not widely recognized as a distinct minority group who experience discrimination and wrongful treatment similar to that experienced by other minority groups. We are also not recognized as a people who have built a positive and evocative group identity on the ruins of past discrimination and the foundations of present stigma.

Society still views people with disabilities as defective folk whose only hope is to be normalized. This is the same argument as the one that says the only hope for equality is for women to be more like men, for Blacks to "act white", for gays to go straight, and for Jews to accept Jesus as their savior. Today, in order to be recognized as a valid minority, we have to claim our identity in a way that is apologetic, medicalized, and exceptionalized. We have to claim to be different because we are substandard. First we must prove that we are "really disabled." We must show that we are "unable to perform normal life activities." We must be "unable to work." Yet at the same time, society demands that people with disabilities be deserving, and not expect too much. People with disabilities should be "otherwise qualified" to apply for a job. We should not expect that "equal treatment" will result in "equal access." And we most certainly should not expect anything beyond a "reasonable" accommodation.

Although thankfully my middle school years are behind me, even as a well-educated, well-employed adult I continue to experience the negative impact of how society views me as a disabled person. Sometimes it is seemingly unimportant things, like the fact that I cannot go to the movies with my daughter because although the theater professes to have an assistive listening device, the battery is always dead or the static makes the device unusable. Sometimes it is things that are hard to name or pin down, what other minority communities would call "microaggressions," like being called "arrogant" behind my back at my workplace because I am always "being negative" about access issues. And sometimes I experience plain old fashioned blatant discrimination, like when the cab driver who was about to stop instead accelerates and zooms past me or the bus driver shouts to me and my (clearly vested) Service Dog, "Hey, you with the dog, where your papers? I ain't movin this bus until I see some papers."

Is it no wonder then that people with disabilities are lost and marginalized even within other minority rights and identity conversations? How can disabled people find themselves to be deserving, equal and powerful under the shroud of a society and a political system that shuns them as equal citizens?

People with disabilities need to claim their identity, and claim it with pride. If we view ourselves as abnormal, sub human, and undeserving of dignity and respect, we will be lost. Many similarly stigmatized groups have achieved more success then we have in convincing others that we can be both different, a minority group with a distinct identity, and the same, human beings who are just like everyone else. This shift in perspective goes hand in hand with changes to the political system, not before it nor behind it. The law, through the very act of protecting the civil rights of a group of people, shapes the identity of that group of people. The trick is to shape that identity in a way that will actually result in civil liberties. Disability rights laws and policies need to be modified, and in many cases they need to be interpreted differently. But disability also needs to be integrated more fully into the general civil rights discussion, and that includes research, policy making, and the public consciousness.

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Research Articles

Exploring Disability Policy in Africa: An Online Search for National Disability Policies and UNCRPD Ratification

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Abstract: This research brief presents a search for national policies on disability and UN CRPD ratification in African countries. The results of the search found that over half of the countries in continental Africa have a current disability policy and that the majority of countries have ratified the UN CRPD. Many of the countries that have neither ratified the UN CRPD nor implemented national policies on disabilities are characterized by conflict and/or weak or absent governments. We anticipate that the results could be beneficial in providing a scope of disability policy in Africa and in helping to easily identify policy and/or geographic locations for future detailed policy analysis.

Keywords: national disability policy, UN CRPD, Africa

Introduction

National disability policies intend to acknowledge the meaning and experience of persons with disabilities in society by granting both individual and collective rights (Leshota, 2013). Although people with disabilities are included in general human rights instruments, policies specific to disability are necessary because in the past, "traditional human rights instruments provided persons with disabilities nominal protection, but the interpretation of these instruments often discounted persons with disabilities rights" (Harpur, 2012, p.5). In other words, people with disabilities require increased protection and acknowledgment of rights, as their basic rights are often violated in an inaccessible or ablest society. Contributions from the disability rights movement and the rise in prominence of the social model of disability has led to the emergence of disability policy as a “legitimate issue on the policy agenda” (Vaughn, 2003, p.12). In addition to ensuring the innate human rights of persons with disabilities, disability policies can also acknowledge the inherent contribution that persons with disabilities make, including in the cultural, social, and economic aspects of society (Vaughn, 2003). Once implemented, national disability policies demonstrate a government’s responsibility to propel a collective eagerness for rights of persons with disabilities, with the hope of identifiable social progress (Aldersey & Turnbull, 2011). The theoretical framework supporting this study aligns with what Barnes (2007) terms a “reinterpretation of disability,” whereby “the main problems faced by people viewed as disabled…stems from disabling environmental, economic, and cultural barriers” (204). Disability, therefore, is a human rights and socio-political issue that necessitates relevant international and national policies.

Following the landmark entry into force of the United Nations Convention on the Rights of Persons with Disabilities (UN CRPD) in 2006, many countries have fulfilled promises imbued in the ratification of the CRPD to formally promote disability rights through their national policies. The Convention aims to globally “promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity” (United Nations, 2006, Article 1). Although rights instruments unique to Africa acknowledge concerns for persons with disabilities, their content can often be based on "deficit/medical rather than the social/rights model of disability" (Combrinck & Mute, 2014, p.314). Indeed, although there are several human rights instruments and institutions in Africa that should be commended for their initiative to protect the rights of persons with disabilities, their written contents can often lack detail, clarity and overall influence (Abbay, 2015). Likewise, Oyaro (2015) states that current African regional documents regarding disability fail to meet the standards of international human rights policies, such as the CRPD, which view disability as a holistic issue using the social model of disability as a framework. Thus, some rights demonstrate progressive realization, while other rights do not; this is why conforming to the CRPD is so important, as it upholds a human rights model (Birtha, 2013). Nations that have ratified the Convention commit to formulate or re-evaluate their national disability policy to align with the CRPD (Mittler, 2015).

The purpose of this research brief is to share the process we used to identify which countries in Africa (a) have a national disability policy; and (b) have ratified the UN CRPD. The resulting findings are presented in a map and narrative form. The sharing of the policy gathering process, as well as the identification of existing disability policies, may assist future researchers to conduct further in-depth analysis and critique of the individual policy documents identified.

Methods

To conduct an exploratory search for the national disability policies of African countries, two researchers independently searched for policies before comparing results among the full research team. We defined disability policy as an instrument used by a national government that is multisectoral and targeted toward public issues related to people with disabilities (Scotch, 2000). We used a Boolean search on CINAHL, Google, Advanced Google, and the Queen’s University Library Database using these key search terms: (a) Africa disability policy, (b) disability policy, (c) disability law, (d) disability act, (e) disability bill, (f) disability rights, (g) disabled, (h) handicap, (i) rehabilitation, (j) law, (k) action plan, (l) strategy, (m) framework, (n) document, (o) UN CRPD report, and (p) country specific names. We searched each phrase independently and in conjunction with one another. Results from this phase of the search yielded the identification of 15 policies. Next, we explored several websites in depth, including the WHO, specifically the WHO MiNDbank, the International Labor Organization, the World Bank, Disabled People’s International, International Disability Alliance, Handicap International, and a number of UN sites, including UN Enable, UN CRPD, UN Treaties, UN Development Program, and UN Development Group. This exploration resulted in an additional 21 policies. We searched relevant government websites of each country (e.g., Ministry of Health and Ministry of Social Welfare), as well as news websites such as Global Accessibility News, and African websites of organizations who advocate for disability rights, such as Somali Disability. Moreover, we conducted a hand search of eight targeted journals, outlined in Table 1, to further identify policy.

Table 1: ***List of Hand-Searched Journals***

Title of Journal
African Human Rights Law Journal
African Journal of Disability
African Journal of Physiotherapy and Rehabilitation Sciences
Disability and Rehabilitation Journal
Harvard Africa Policy Journal
International Journal of Disability, Community and Rehabilitation
Journal of Disability Policy Studies
South Africa Journal of Occupational Therapy

The titles, dates, and abstracts of articles were scanned to verify that they were relevant to disability and/or rehabilitation policies in Africa. We cross checked reference lists for other relevant articles and/or for policy documents. The articles that described African disability policies provided an opportunity to conduct further targeted searches to locate the policy document. If a policy document was mentioned in the above searches but not available online, we contacted the authors of the articles to request access to policies discussed in the study. This yielded one result. Lastly, we emailed nine individuals who we identified as potentially well positioned in the field of disability (e.g., University professors, research fellows, the CEO of the Africa Disability Alliance, a program manager of the Secretariat of the African Decade of Persons with Disabilities, a member of VSO International) for advice and further direction on locating specific policies. This yielded one result.

We excluded two questionable policy documents because factors indicated that they may be out of date (e.g., no date, and no additional recent sources mentioning its existence). We excluded a third policy because recent academic literature (Aldersey, 2013) indicates that it is no longer in effect. Figure 1 visually depicts this full search process.

In sum, as a result of our extensive search, we were able to identify 35 disability policies that we believe to be current or relevant national policy documents. Of the 35 documents we identified to exist, we were able to obtain 27 soft copies. Of the 27 soft copies, 21 are accompanied by evidence (e.g., recent journal articles, UN CRPD reports and legitimate news sources) to further support their continued application or relevancy. For the remaining eight documents in which we were unable to obtain a soft copy, we were able to verify their existence through evidence in both grey literature and scholarly journal articles.

Results

Ultimately, we compiled a list of a total of 35 documents, which include more currently relevant policies, laws, reports, and plans of action. Figure 1 illustrates the results of our comprehensive online search of African countries, identifying countries that have a national disability policy and/or those that have ratified the UN CRPD, and those that have neither a policy nor have ratified the UN CRPD.

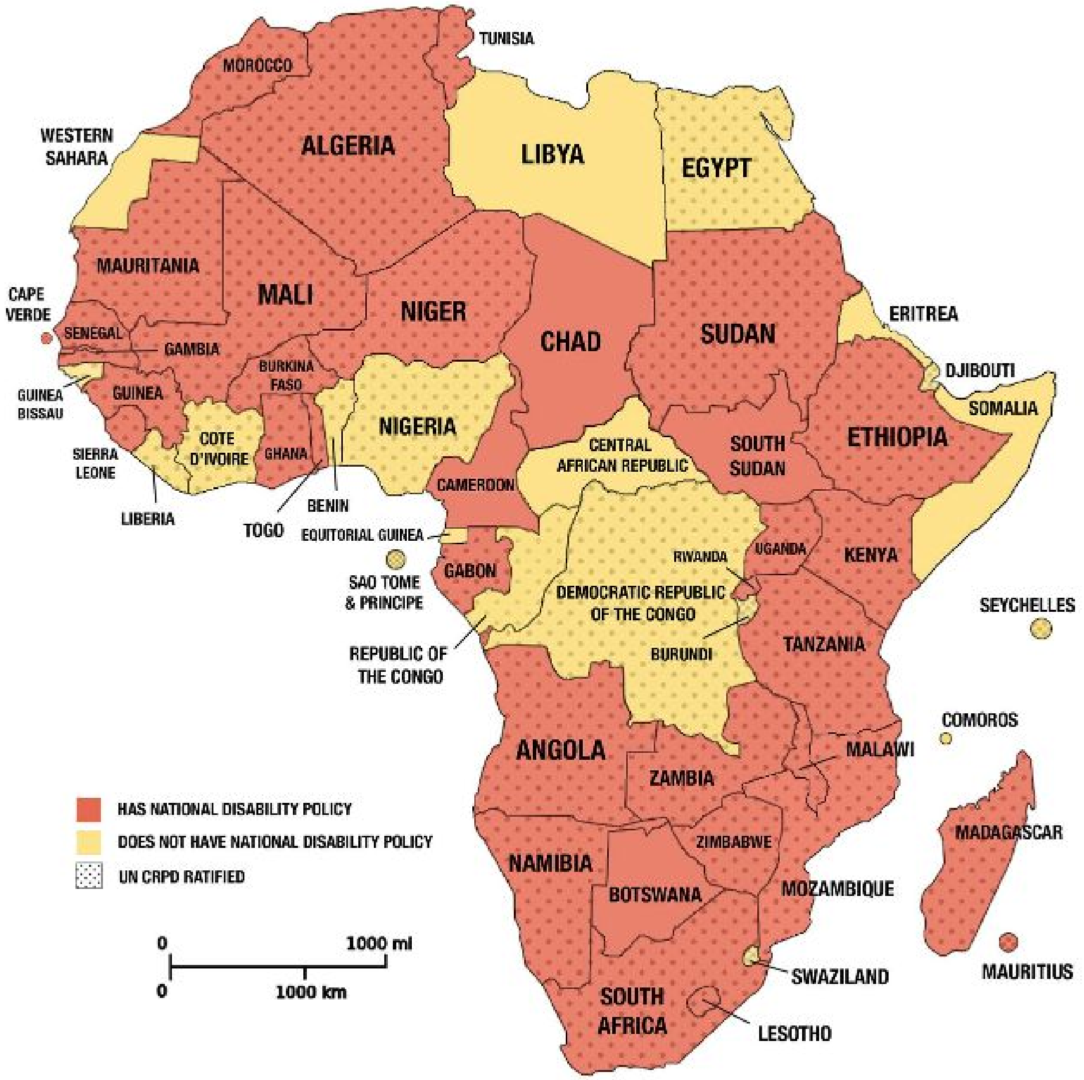

Figure 1. Map of Africa. This figure illustrated which African countries have a national disability policy, which African countries does not have national disability policy and which African counties that have been ratified UN CRPD.

At the time of research (May, 2015 – April, 2016) of the 55 African countries included in the search, we found evidence that 44 have ratified the UN CRPD, and 35 have a national policy on disability. Table 2 outlines each African country, the title and year of their most current national disability policy, and, if applicable, the date in which each country ratified the

UN CRPD. Countries for which we were unable to find evidence of a current national policy or UN CRPD ratification include: Central African Republic, Comoros, Equatorial Guinea, Eritrea, Libya, and Somalia. Western Sahara is not recognized as a state by the UN, and thus has also not ratified the CRPD.

Table 2: ***List of African Countries with National Disability Policies and Applicable UN CRPD Ratification Date***

Country	Title of National Disability Policy Document	Year	UN CRPD Ratification
Algeria	Law No. 02-09 on the Protection and Promotion of Disabled Persons	2002	4 Dec 2009
Angola	Persons with Disabilities Act, Law no. 21/12	2012	19 May 2014
Benin			5 Jul 2012
Botswana	National Policy on Care for People with Disabilities	1996	
Burkina Faso	Law no.012-2010/AN on the Protection and Promotion of Disabled Persons	2010	23 Jul 2009
Burundi			22 May2014
Cameroon	Law no.2010/002 on the Protection and Promotion of Disabled Persons	2010	
Cape Verde	National Plan of Action for the African Decade of Persons with Disabilities	2006	10 Oct 2011
Central African Republic			
Chad	Law Bearing Protection for Disabled Persons	2007	
Comoros			
Cote d'Ivoire			10 Jan 2014
Democratic Republic of the Congo			30 Sep 2015
Djibouti			18 Jun 2012
Egypt			14 Apr 2008
Equatorial Guinea			

Eritrea			
Ethiopia	National Plan of Action of Persons with Disabilities	2012	7 Jul 2010
Gabon	Law no.19/95 Relative to the Organization of Social Protection of Disabled People in Gabon	1996	1 Oct 2007
Gambia	Integrated National Disability Policy	2009	7 July 2015
Ghana	Persons with Disability Act	2006	31 Jul 2012
Guinea	People with Disabilities Policy Directive	2004	8 Feb 2008
Guinea-Bissau			24 Sept 2014
Kenya	Act 14 - Persons with Disabilities	2003	19 May 2008
Lesotho	The National Disability and Rehabilitation Policy: Mainstreaming Persons with Disabilities into Society	2011	2 Dec 2008
Liberia			26 Jul 2012
Libya			
Madagascar	Law Relative to Individuals with Disabilities	1998	12 Jun 2015
Malawi	Disability Act	2012	27 Aug 2009
Mali	Persons with Disabilities Bill	2009	7 Apr 2008
Mauritania	Disability Act	2006	3 Apr 2012
Mauritius	National Policy Paper and Action Plan on Disability	2007	8 Jan 2010
Morocco	Social Integration for Persons with Disabilities	2008	8 Apr 2009
Mozambique	Strategy for Persons with Disabilities in the Public Sector	2009	30 Jan 2012
Namibia	National Policy on Disability	1997	4 Dec 2007
Niger	Disability Law	2014	24 Jun 2008
Nigeria			24 Sept 2010
Republic of the Congo			2 Sept 2014
Rwanda	National Council of Persons with	2013	15 Dec 2008

	Disabilities Strategic Plan and its Operational Plan for the Implementation		
Sao Tome and Principe			5 Nov 2015
Senegal	Social Orientation Law no.2010-15	2010	7 Sept 2010
Seychelles			2 Oct 2009
Sierra Leone	The Persons with Disabilities Act	2011	4 Oct 2010
Somalia			
South Africa	National Disability Policy	2010	30 Nov 2007
Sudan	National Policy for Disability	2003	24 Apr 2009
South Sudan	National Disability and Inclusion Policy	2013	
Swaziland			24 Sept 2012
Tanzania	The Persons with Disability Act	2010	10 Nov 2009
Togo	Act of April 23, 2004 on the Social Protection of Persons with Disabilities	2004	1 Mar 2011
Tunisia	National Disability Prevention Plan	2007	2 Apr 2008
Uganda	National Policy on Disability	2006	25 Sept 2008
Western Sahara			
Zambia	Persons with Disability Act	2012	1 Feb 2010
Zimbabwe	Disabled Persons Act	2010	23 Sept 2013

Discussion

The results of this policy search and retrieval demonstrate that many nations on the continent of Africa have taken steps to ensure the rights of their citizens with disabilities by creating national policies on disability and by ratifying the UN CRPD. It is notable that 32 out of the 35 nations that have national policies on disability have also ratified the CRPD. This may indicate a connection between ratifying the Convention and also ensuring the existence of national policies on disabilities. This study also illuminates the potential progress being made in public acknowledgement of the rights of persons with disabilities, as the majority of countries in Africa with a current national disability policy have also ratified the CRPD. It is interesting to note that many of the countries that do not have a national disability policy, nor have ratified the CRPD, are also those characterized by conflict and/or government impunity. This is likely to have played a role in disability policy creation, implementation, and CRPD ratification. Indeed, without "coherent, legitimate, and effective states", policy development and implementation is much more difficult to achieve (Joseph, 2003, p.159). Countries may also delay or refuse ratification of the CRPD because they do not believe they have the financial and infrastructural capacity to actually implement the policy. For example, countries that do not have a disability policy may not have the resources to execute quality research, an important factor in development and implementation of quality disability policies (Ohemeng, 2014). Additionally, nations may believe that the rights outlined in the CRPD either contradict or are not necessary to add to their current policies, as is the case in the United States (Blanchfield & Brown, 2015).

Still, the CRPD has been recognized to promote and interpret rights in order to maximize inclusion (Harpur, 2012) and was strongly embraced by African states (Lord & Stein, 2013). Perhaps one of the greatest impacts of the CRPD on the lives of individuals with disabilities relates to the structure it provides to groups, organizations and governments for targeted rights and support. For example, the CRPD has inspired policy proposals, such as by Elizabeth Kamundia, a disability rights scholar. Kamundia (2013) proposed that the state of Kenya implement article 19 of the CRPD, which promotes education, community based rehabilitation, government funding and overall independent living in the community for persons with disabilities. Another example comes from the Zambia Federation of Disability Organizations, which is encouraging the Zambian government and civil society to use the CRPD as a framework to implement disability rights (Birtha, 2013). Although it is already apparent that the Convention has the ability to influence state policies and provide disability organizations a useful structure to promote, advocate for, and implement rights for persons with disabilities, further research should explore how and if CRPD ratification has an empirical impact at an individual level.

In spite of widespread progress toward full ratification of the CRPD on the continent, there still remains a "lack of awareness of the potential of the CRPD" in the media, public, academia, and in the professional world (Mittler, 2005, p.6). With lack of knowledge of the CRPD, people with disabilities, families, and communities cannot hold their government accountable for implementation and fulfillment of policy. Schneider and Stein (2001), in the context of HIV/AIDS policy in South Africa, note that "the presence of individuals and groups, both inside and outside government willing to challenge and provide a critical mirror to government and the society, is key to the medium and long term success of…policy implementation" (p.729).

This research brief shows that the creation of national disability policies and ratification of the CRPD throughout the African continent has intended to enhance the quality of life for individuals with disabilities. However, it is important to note that there is a large distinction between producing a written policy and implementing and enforcing a policy. As well, there remains debate as to whether or not the CRPD is the most appropriate and effective policy document to be enforced. For example, the CRPD has been criticized for its overall appropriateness to the African context: Thomas Ong'olo of the African Decade Secretariat noted that discussions in New York were set by the affluent, and some issues discussed were not relevant to the African culture or economic status (Abbay, 2015). Inasmuch as the CRPD incorporates input from African states, it does not include an exhaustive list of issues most prominently facing Africa, such as the prevalence of HIV/AIDS, malaria, widespread poverty, and adverse cultural behaviours and rituals targeted towards persons with disabilities (Oyaro, 2015). Oyaro (2015) argues that a "specially doctored regional instrument would address unique regional issues and reaffirm the commitment to promoting human rights for a group that has historically faced and continues to face extreme discrimination and violation" (p.362). Further, Abbay (2015) suggests that Africa could benefit from a comprehensive regional convention on the rights of persons with disabilities as current regional legal frameworks are characterized as insufficient, ineffective and ill-defined. The "persistent lack of institutional coordination, proliferation, limited financing and human resource incapacities" contribute to the weaknesses of implementing African human rights instruments (Oyaro, 2015, p.359). A proposed regional convention might compliment the CRPD, rather than negate it. A major benefit to this convention involves the acknowledgement of local issues that international instruments do not recognize. A regional convention could also increase enforcement, compliance, and awareness about the status of current human rights of persons with disabilities at regional and national levels (Abbay, 2015). And while Oyaro (2015) argues that significant, Africa-specific issues have been left out of the final CRPD document, he asserts that it can still be considered a sufficient instrument to protect the rights of persons with disabilities in Africa.

For future research, it would be beneficial to investigate how well the national disability policies identified in this study are being implemented and adhered to in practice. This kind of information will reveal the true commitments of these states to create an inclusive environment for individuals with disabilities and will give us a more accurate indication of the status of persons with disabilities in African contexts. Specifically, further research questions may identify how ratification of the CRPD has impacted persons with disabilities in African contexts, on individual, organizational and/or national levels; what barriers exist for African governments to both ratify and implement the CRPD; and what accountability mechanisms are more effective in ensuring that states parties on the continent adhere to and implement international and national policy documents.

Limitations

This research brief is not without its limitations. First, the process of identifying policy documents using online methods proved particularly challenging as many nations did not have a fully digitized national policy archive or even national ministry websites with updated information. Online searches of public policy on the continent can be challenging, as many African countries, representing "only 7 percent of the globe's total Internet users" (Mlot, 2013, para. 1), may not have the same online infrastructure as other nations worldwide.

Furthermore, the digital divide between Western and African countries continues to expand despite Africa's technological advancements (Penard, Poussing, Mukoko, & Piaptie, 2015). It is difficult to ascertain whether or not the results of our study accurately depict the current status of disability policy creation and implementation in many African countries, or if the desired public policy was simply not available to us through internet-based searches. Nevertheless, we believe that the map created by this study gives an interesting picture of the status of electronically available policy documents on the continent.

Similarly, studies of public policy prevalence are rapidly out of date – a limitation also indicated by the WHO MiNDbank, through its disclaimer that it does "not warrant that the information in the Database is authoritative, complete, correct, accurate, or that resources contained in the Database have not been superseded by newer versions" (Disclaimer, 2015, para. 1). Given the ever-changing public policy environment, researchers should always verify that the policy documents they identify for analysis are the most current.

Conclusion

This research brief shares the results of an online search for African national disability policies. The results identify that out of the 55 African countries included in our search, 35 countries have a national disability policy, and further, 44 have ratified the UN CRPD. While the CRPD is a holistic document that views persons with disabilities through the lens of the social model of disability, it has not been spared criticism from policy makers in Africa. The absence of issues specific to the African context, such as the prevalence of malaria and HIV/AIDS, further highlights the importance of national policy documents to address needs of individuals with disabilities that are specific to particular nations. Although the literature indicates that the CRPD is a necessary instrument for identifying and promoting the rights of persons with disabilities, future research should explore how and if individuals with disabilities living in countries who have ratified the CRPD, are experiencing significant positive change at individual and social levels. We are hopeful that the results of this research brief, and our interpretation of the results, may be useful to other researchers in identifying and locating national disability policy for analysis of content and practice.

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Research Articles

Personal Autonomy and Disability

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Abstract: This paper presents different approaches to the concept of personal autonomy in the disability context. It draws attention to the ways the requirements for "competent" bodies and autonomy of the "incarnate" subject affect the usual way of understanding the autonomy of people with disabilities, i.e. a higher degree of physical dependence may be perceived as a lower degree of autonomy.

Keywords: the body, independence, dependence

Introduction

Reflections on the autonomy of people with severe disabilities are usually accompanied by ambivalence. This ambivalence is influenced by the fact that many people with disabilities, compared to healthy people, because of their health condition are more physically and/or mentally dependent on direct assistance or support of another person and/or adjustments of the environment. The degree of dependence is individual and related to the type, degree and progress of the disability, as well as the time of its origin, and duration. It is affected by personality, socio-spatial, and economical aspects, as well as other factors. A higher degree of dependency is usually perceived as a lower degree of personal autonomy. This ambivalence is also enhanced by some definitions of autonomy, where it is defined directly as the opposite of dependence (see below). Although every human being without exception is dependent on other people and environmental conditions, and the freedom to make his/her decisions and take actions is always relative, when thinking about autonomy, the aspect of physical self-sufficiency to be a requirement for the complete functioning of the body and mind is the aspect that is generally preferred. A number of routine and creative activities can be completed precisely and primarily due to their physicality. Being able to ensure one's needs using (their own) bodies (to stand up, sit, walk, eat, wash, read, write, talk, use the toilet, etc.) implies not only to be independent, but also not to be resigned to the mercy of others, their time and physical limits, moods, helpfulness, good will, paternalism or, conversely, lack of interest, etc. To have a fully functional body also means not to be an embarrassment, same not to burden or limit others, not to take away their capacity, etc. The moment of a physical change, when the freedom of the work(s) with one's own body is impaired or disabled, triggers psychological, social, economic and other changes, both in relation to its surroundings and oneself. It also reflects in the perception and definition of human autonomy, both with the people outside such a body and inside such a body.

Dictatorship of a Complete Body

The body and its functioning is not just an essential prerequisite for being here and now. Physicality takes upon itself, in terms of the sociological concept of a somatic-based society, social significance as well. According to Petrusek (2006, p.359), “the body and physicality are both not only the key conditions of our living in the world, but also a fundamental component of human identity.” According to the author, “Social, personal, and physical characteristics have the social meanings that are of different intensity and extent scale, and constitute substantial social differences, which are not always conscious” (Petrusek, 2006, p.359). Similarly, Lipovetsky points out the extreme demands that contemporary society places on the appearance and aesthetics of the body. A “young, slim, dynamic” dictate is based, according to Lipovetsky (1989, p.143), “On a narcissistic idea of success and performance, from which the value and the self-esteem of a man is inferred.” In addition, the dictatorship of the flawless body has reached proportions where "using a variety of methods and techniques we can transform our bodies based on different templates. ´When scrolling through the shiny magazines, one has the feeling that they all actually tell one story - about ways to remake themselves, ranging from diets, and changing one’s appearance, through home interior to the restructuring of our own soul; all this often disguised with a challenge to be yourself (Stasiuk, sec. cited in Bauman, 2007, p.100).

The standards that attribute different social meanings and values to the body critically reflect social constructivist views on the body and physicality (see for example Foucault 1963). For example, Shildrick (2011, sec. cited in Kolářová 2012, p.16) notes, “An ideal standard in the context of modern Western discourse requires that our bodies are complete with no missing parts, so that they are predictable and under our control, and most importantly, an incarnate subject is autonomous”. Kolářová lists in a similar critical sense that “to be healthy, fit, qualified, and thus normal has become the uncontested prerequisite of the full life of a modern man as well as the condition of the recognition of his civil status and humanity” (Kolářová, 2012, p.17).

In the context of the aforementioned views of physicality and the need for complete and predictable bodies that we have under control and which as such are one of the expected attributes of personal autonomy, the contact with people with so-called incomplete or unpredictable bodies is confronted by the existence of diversity - differences. That, on one hand, attracts attention (fascination by a monster, the stare), on the other it creates separation, rejection or resistance. Partly this is a natural biological response to the new and unknown, and therefore to that which does not fit in the system of the so far ordinary individual experiences with non-disabled bodies, and partly it is about a defensive (usually unconscious) psychological response to the encounter with one’s own vulnerability ...what if it happened to me? ...What if it happened to one of my relatives...?

Requirements for competent bodies and the autonomy of an incarnate subject significantly affect the way the personal autonomy, hence the autonomy of people with disabilities is understood. In addition, a particular person with a different body is in this sense seen as the way too concrete and straightforward evidence of everyone’s physical or mental vulnerability, including a (so far) healthy body, which is 'despite its seemingly successful independence susceptible to damage and breakdown (Shildrick 2011, sec. cited in Kolářová 2012, p.21). That damage and breakdown may yet come at any time, because, “The suddenness of these wounds, their irregularity and unsightly habit of coming every time from a different side - all this makes them unpredictable phenomena against which we are helpless” (Bauman, 2007, p.91).

Assuming that the so-called disabled body subconsciously reminds us of our own vulnerability, then in this sense, not everyone is able, face-to-face with a person with disabilities, to adequately process their contact with their own vulnerability. Despite some of the so-called more healthy ones being aware of the emotions (fear, uncertainty, panic, denial, resistance, etc.) they are feeling toward those so-called more disabled, they are not always aware, however, of the potential sources of these emotions stemming from unpredictable factors and, therefore, whenever possible, their own reality. While one person forces this potentiality out to less conscious layers of the psyche (It doesn’t concern me. It cannot happen to me.) the other person actively fights out the encounter with his/her own vulnerability (e.g. denying the limits of one’s body, putting a sharp boundary between oneself and those on the other side, etc.).

Either way, the way we see ourselves, and to what extent we are aware of the fragility of our own existence as well as the way we process the encounter with our own vulnerability is reflected in our perception of others. If the measure of all things is my view, where a sine qua non condition for the recognition of my autonomy is a self-sufficient body, then I can only accept with difficulty a different perspective on autonomy, where a self-sufficient body is not the necessary prerequisite.

The prevailing dictatorship of a complete body and the inability to cope with the existence of so-called incomplete bodies, as one of the age-old variants of human existence is, to some extent, a sign of a naive notion of the infinity of human possibilities, of the infinity of growth for Growth's sake. Bělohradský (2007, p.211) speaks of “the religion of the growth for Growth's sake.” Moreover, the era of a lack of ability to cope with even the existence of normal bodies has arrived. Plastic surgery today cannot only help, for example, to relieve body pain after heavy burns, but it can also, in the name of the so-called unlimited progress of human knowledge and the prospect of financial benefits, visually stop time, and therefore stop the aging of bodies (an old body seen as a mirror of finality). Anabolics and steroids, with the prospect of financial benefits, push the boundaries of artificial performance of top athletes; the natural human performance is no longer worthy of awards. Dolly, the sheep clone, started the next phase of so-called unlimited boundaries of human knowledge towards improving the ordinary or in the name of progress, only the fixing of incomplete bodies. In the name of progress and growth for Growth's sake, a memory of the natural order of things, which includes limits, is slowly disappearing, a pride is growing, and a humility which goes hand in hand with the understanding of ourselves and others is also gradually disappearing. Meeting with other, incomplete (and therefore 'disabled') bodies straightforwardly confronts everyone without exception with the finality of the frontiers, no matter whether individually human, or with the finality of frontiers of scientific knowledge, which some people are unwilling, incapable, or unable to reconcile.

A biological normality discourse complicates recognition of autonomous competence of the bearers of “other”, distinct bodies. A mechanical perception of a normal and a normally functioning body as a competent body, able to satisfy the needs of a person, to which it belongs, produces the idea that a healthy person is, or should be, or has the potential to be autonomous. From there, it is only one step toward a preconceived notion of the contrary – an unhealthy body produces dependence, limited competencies, which is, in relation to the autonomy, usually perceived as contradictory. The mechanical concept of a normal body includes a conflict - imperative of a self-sufficient body is an internal conflict, and in relation to this study it raises questions: Can a person who cannot move independently and/or speak and/or eat independently, be autonomous? Can a person with a severe mental disability be autonomous? If so, to what extent? If not, why not?

Answers to these and other related issues will be very different depending on who is asking and who is answering, and they will reflect both the initial, necessarily diverse, socio-cultural context, and one’s own individual concept of autonomy. Perception and interpretation of personal autonomy is always related to a personal and cultural context.

Pain and Addiction

Social and cultural perceptions about disability have been criticised for having neglected some important phenomena, which accompany disability (see for example Shakespeare, 2006). They include pain as an unmediated phenomenon. If pain is present, it usually changes one's view of the world. If the pain is persistent, it often changes even one’s values, priorities, and relationships to other people and to oneself. Someone who has been waking up in pain for a long time or permanently and is falling asleep in pain, as well as one who is close to such a person, address different priorities than someone who is struggling with the pain only temporarily or during an isolated episode. The pain aspect as one of the accompanying symptoms of some (but not all) types of disability is often left aside in social science debates on disability. On the contrary, it is in the centre of health science, natural, and theological debates. In the context of personal autonomy, pain is a subject of debates about the ethical dilemmas, such as the human right to die in dignity, the right to end one’s own life, and also sparks debate about the meaning of suffering that a permanent, deep pain brings.

Although pain accompanies some (not all) of the diseases, which partly cause a disability, it is usually automatically associated with disability. It is then often reflected in the perception of the image of people with disabilities as people who are sick, suffering (experiencing permanent suffering), powerless and weak. This tends to result in a fixation of the stereotype of disability = pain = dependence on treatment, and on others. In this case, the other body in the sense of helpless body or painful body' may pose a latent sense of threat to a person’s own sense of autonomy and his/her projection on people with disabilities in general. Non-dependence is not the same as autonomy.

Dependence vs. Autonomy

Autonomy includes many dimensions of human existence - physical, mental, cultural, spiritual, social, economic, political, geographical, etc. Its bearer can be an individual – then we usually talk about personal autonomy, but also a group, organization, state or other entities. The concept of autonomy is ambiguous as are most concepts or terms in the social sciences.

The origin of the term derives from the Greek (from the Greek Autos - self, Nomos - law), where it originally referred to the institutional definition of city-states (independence, sovereignty) in order to be able to organize, and determine their own internal affairs independently of any other power. In this original form, the concept meant legitimization of the city-states for a specific action on their territory; it had political and legal importance. At the same time, the concept had a relatively simple and measurable content, because at that time it defined a mostly practical thing - autonomy was given to the state, which was able to provide – grant to itself and spread the word to others about – its own binding rules of life in its territory, act upon them, and had control over their compliance. The city-state that had failed (was not able) to provide them, was surrendered to a different power and lost its autonomy. For our further considerations of personal autonomy it is important that the original meaning of the concept relates to a group of people living in a certain territory. From now on, it is used in this sense, especially in connection with the autonomy of nations and states.

Issues with the concept started at the moment when the philosopher Immanuel Kant moved it from a group-political level, where the city-state had quite clear outlines of the content and order, to the individual-moral level as the opportunity and challenge for the man himself, e.g. a rational being, ´to determine and comply with the law, which he self-imposed´ (Kant, 2011, p.18) in the 18th century. Kant continued the debate, raised already by Plato and Aristotle, on conflicting ethical and moral issues triggered by the autonomous will requirement. It is especially about the contradictions related to self-determination (will, wanting, freedom), and the legitimacy of enforcing the right to satisfy needs (liability, obligation) (see Kant, 2011; Aristotle, 2009; Plato, trans. 2003).

In the concept of man as a rational being, Kant saw not only the very person's ability to think rationally, but also and in particular that such a person based on rational consideration is able to determine right, i.e. moral rules for oneself and act on them. A prerequisite of man as a rational being is, according to Kant, not only that such person (1) rationally 'knows' what is “good” and “right” - and therefore moral, but he/she is also (with what is “good” and “right”) internally in harmony with it (even if this was in conflict with his/her natural mentality), and that (3) according to this is capable to (responsibly, i.e. morally) act upon it. The reason thus becomes legislative for moral conduct in the person.

Kant’s overturning of the autonomy concept from the social level (autonomy of the Greek city-states) to the individual level (personal autonomy) greatly complicated the originally clearly set outlines of the concept and measurability of its contents, because the order, from which the concept unfolded, was based on a human being and his/her abilities and skills to distinguish and determine what is Good' and what is Evil'.

A number of existing research and studies show that the interest in understanding the importance of autonomy continues to persist, and that the pursuit of its theoretical reflection has had a permanent basis in practice. Since the times of Kant and his predecessors, however, the concept has undergone, in pursuit of its theoretical definition, a significant change. At present, ambiguous meanings are ascribed to it, many having no ties to the original moral framework of the concept. From the theoretical perspective, meaning in the perspective of 'unordinary' language, this is a fairly controversial concept. Just like many other concepts in the social sciences, autonomy doesn’t, and in fact cannot, even have a stable and clear meaning. Collopy (1988, sec. cited in Horowitz et al., 1991, p.29) speaks of the “conceptual plasticity” of this, by many even considered incomprehensible, concept and reaching the final definition of autonomy to be a “demonstrably impossible task”. This plasticity is reflected in a series of attempts to define it in terms of diverse social science perspectives.

Contemporary philosophical thinking perceives personal autonomy generally as the ability of an individual to rationally act (Huber at al. 2005), or as self-management (Cole & Holstein, 1996), sometimes also in connection with a category of authenticity (Habermas, 2001; Ruppert, 2010). Psychology offers a view of personal autonomy as a category of quality - achieving autonomy is associated with the maturation of the personality and the ability of the autonomous personality “to resist social pressures in thinking and actions, make assessments based on one’s personal standards independently from the approval of others, and break away from conventions, collective fears and convictions” (Sýkorová, 2007, p.74). Autonomy of the personality is defined from a psychological perspective as ´the extent to which the man is himself and can freely choose his/her activity, its location, time and type, or if necessary choose inaction” (Hartl & Hartlová, 2000, p.65). From the medical perspective, autonomy is generally defined as independence on help from others; it emphasizes the cognitive area in terms of decision-making abilities or freedom of choice (Huber at al., 2005).

From a sociological perspective, autonomy is associated with the freedom of the individual, with the social behaviour theory, socialization theory, as well as the theory of power. According to Sýkorová (2007, p.34), “Personal autonomy is usually identified with individual freedom, autonomy, sovereignty, self-control; it is sometimes viewed as free will or choice, as well as a decision-making process.” The meaning of autonomy “is often acclimated to a functional, physical, attitudinal, emotional, and conflictual level. Personal autonomy is associated with privacy, dignity [...] personal integrity, and individual responsibility” (Sýkorová, as cited in Kalvach, Čeledová, Holmerová, Jirák, Zavázalová, & Wija, 2011, p.34). From the perspective of systems theory, autonomy represents the ability of the system to self-determination (Huber et al., 2005).

Schmidbauer (1994, p.35), for example, offers another definition, which defines personal autonomy as “self-determination, as opposed to dependence”, then Hartl and Hartlová (2010, p.65) as “autonomy, or independence, or functional autonomy.” Pichaud and Thareau (2007, p.97) define autonomy as “the ability to lead life according to one’s own rules. Being independent means to remain master of his/her own behaviour and way of life.” According to Ruppert (2010, p.84), “Real autonomy lies in the fact that one can unconditionally accept himself along with his/her own life reality and take full responsibility for his/her own life, whatever happens.”

A brief overview of attempts to define personal autonomy shows one of the reasons for a struggle with this concept - its definition depends on the individual value system, how a person thinks about autonomy and what kind of meaning he/she attaches (or doesn’t attach) to it. Despite the fact that it can be expected that there will be some common elements in people’s individual definitions of personal autonomy if they live together in a specific cultural context, ultimately, their definition will always be different. Some will emphasize in their definition independence, someone else responsibility, another one will place emphasis on authenticity, etc. This infinite definition pluralism of the personal autonomy concept is derived from disparate theoretical roots of the interpretative paradigm (especially hermeneutics, phenomenology, ethnomethodology, and social constructivism).

Although each of the above definitions explores personal autonomy from a different aspect and angle, the common denominator of most of them includes the two, at first glance, obvious aspects - freedom in the sense of making decisions about one’s own life and a capacity for intentional conduct. The selected contemporary definitions make it clear that most of them, unlike the original conception of Kant, lack emphasis on personal responsibility. Most listed definitions emphasize, in particular, the right to choose, the possibility to choose, to make decisions about one’s own life, as well as the right to maintain control over one’s life. Less emphasis, if any, is placed upon personal responsibility for one’s own choices, liability for one’s decisions and one’s actions, and duty to bear their consequences. However, it is two sides of the same coin - where there is the right and choice there should also be the duty and responsibility towards oneself and others. Either approach assumes awareness of boundaries, conscious recognition and respect of limits, which indiscriminately we all have, both the limits of our own body and mind, and the limits resulting from coexistence with others.

As cited by Sýkorová (Sýkorová, as cited in Kalvach et al., 2011, p.35), “Autonomy does not exist outside of social ties. [...] Social ties support autonomy, however at the same time, they restrict it; in the social space autonomy needs to be constantly negotiated in a reciprocal interaction of individuals. [...] Its achievement or sustainability is neither entirely certain, permanent, nor complete; it changes over time, depending on living conditions, social context, the nature and extent of the tasks with which people cope at the moment, on their competencies and on the criteria which are used to assess them and their performance in society”. According to the author, “Seniors and people with disabilities are more likely to be exposed to the risk of weakening or even complete loss of autonomy” (Sýkorová, as cited in Kalvach et al., 2011, p.37).

Personal autonomy is a subject of interest to research published, for example, by authors such as Sýkorová (2004, 2007), Heathcote (2000), Quinnan (1997), Räikkä & Varelius (2013), etc. Most of their studies focus on autonomy within the context of old age. In terms of the relationship between autonomy and disability the works of the authors such as Crittenden (1990), Reindal (1999), Ells (2001), Wang & Dovidio (2001), Cardol, Jong & Ward (2002), Huber et al. (2005), Leipoldt (2010), Krhutová (2013), etc. are relevant here.

Toward a Personal Autonomy in the Context of the Disability

Evans (sec. cited in Johnstone, 2001, p.61) points out the differences between the theoretical definition of the concepts of autonomy and dependence and their pragmatic interpretation: ´Autonomy is a person's ability to live the life he/she wants. Independence means that you will not have to rely on other people. But it is not necessarily the same thing´. Similarly, Barnes points out that people with disabilities - as well as people without disabilities - often interpret independence within the framework of their selection and choices – “Independence does not mean that a person can do everything themselves, since no one can regardless of whether or not they are disable, but indicates that the person is able to take control over their own lives and choose what kind of life they are going to lead” (Barnes 1996, p.109). It is a thought process that does not depend entirely on physical abilities.

Empirical research shows, or more precisely confirms different definitions of autonomy by people with disabilities and professionals who are involved in solving their living conditions. For example, Ells (2001, p.599) argues that, “Many people with disabilities need assistance with the so-called tasks of everyday living (ADL) such as bathing, dressing, cooking, shopping, etc. Need for assistance is generally perceived by helping professionals as a proof of dependence, or the inability of a disabled person to make decisions about their lives”. “While the professionals tend to define independence of people with disabilities in terms of personal care activities (ADL), people with disabilities tend to define independence as the ability to have control over their life, and make decisions about them” (Reindal, 1999, p.357). Autonomy, in particular for professionals, often coincides with the capability to completely carry out activities of daily living often resulting in the conclusion that the clients, who are not self-sufficient, cannot be autonomous.

Sýkorová (Sýkorová, as cited in Kalvach et al., p.35) notes the impact of these completely different concepts of autonomy, where, “The interaction models based on expectations of incompetence, i.e. the anticipation of independence of a disabled person (even in situations, where they are reasonably self-sufficient), anticipation of their inability to decide, or anticipation of their inability to be responsible for their own decisions, results in two effects: (1) on the side of a person with disability it is a weakening of their autonomy and the strengthening of their dependent behaviour, (2) on the side of others in their surroundings it is the strengthening of excessive protection and paternalism.”

In connection with the anticipation of incompetence, Sýkorová notes that, “It is the officials, specialists, professionals in helping professions, and last but not least, many relatives 'in the best interest' [...] of handicapped family members (or clients) who often define their needs for them, and more or less determine the extent and method of saturation of the disabled people's needs; they claim the right to control them, and supervise them” (Sýkorová, as cited in Kalvach et al., p.37). The notion of life with disabilities, showing just the “fatal consequences [...] of disability, which go hand in hand with the conclusions of the inevitable loss of personal autonomy,” seems, according to the author, “in the light of empirical evidence, unacceptable” (Sýkorová, as cited in Kalvach et al., 2011, p.37).

According to Pichaud and Thareau (2007, p.69), people represent the following personality types: (1) Autonomous and self-insufficient, (2) Autonomous, although self-insufficient, dependent more or less on others in some or most activities of daily living, (3) Self-sufficient, but non-autonomous, who satisfy their needs under the supervision of others, (4) Self-insufficient and non-autonomous, unable to satisfy the needs, or unable to decide what they need, or oblivious to what is good for them. If we look to that categorization from a greater distance, it is obvious that it doesn’t just concern people with disabilities.

The conclusion of this paper shows the concept of personal autonomy by a woman who is completely or largely physically dependent on the daily assistance of others. Despite the fact that their views cannot be generalized, they are offering a view that is still hidden both to many professionals and amateurs:

Jana Hrdá, 61 years old, an expert in the field of social services, quadriplegic

“Being autonomous means to me - to be credible, authentic, and myself. In particular, this means, however – to be an adult in the sense that one can consider and evaluate important information using both reason and emotion in relation to themselves and others, then make a mature decision and assume responsibility for it. I am autonomous, although the extent of my physical dependence on others is complete, daily, and permanent. I see it as an objective matter related to my disability. Therefore I naturally accept assistance from others. I train social services assistants in a way that is acceptable not only for me but also for anyone who provides the assistance – because this is also about autonomy – if I admit it to myself, I admit it to the other person as well. The person who helps me is an equivalent full-fledged being, is unmistakable and unique. The tool for my autonomy is not 'this' person; the tool for my autonomy is 'what' this person does” (Krhutová, 2013, p.54).

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Research Articles

Photovoice: Life Through the Eyes of People with Disability in North India

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Abstract: The authors used photovoice methodology to gain insight into the lives of 18 people with disabilities in rural North India. This project provided participants with an opportunity to express their joys and difficulties and provided important insights to help structure future programs and supports within the community.

Keywords: Photovoice, disability, community-based rehabilitation

Background and Introduction

It is estimated that about 15% of the global population has a disability (WHO, 2011b). People with disabilities are often some of the poorest in a community, on average having lower levels of employment and educational attainment than people without disabilities. Improving the lives of people with disabilities and their families is a significant challenge in India, as it is around the world.

According to the Indian government’s 2001 census, (Jeyalakshmi, 2011) the proportion of India’s population with disabilities is 2.1% and according to the 2002-2004 World Health Survey (WHO, 2011c) it is 25%. India ratified the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) in 2007, reinforcing that people with disability should be consulted about activities and policies affecting them. Despite the articulation of this core value within the UNCRPD – that of active inclusion of people with disabilities in policy and programming, community rehabilitation programs are rarely inclusive of the perspective of people with disabilities.

There is limited quantitative and qualitative research in India that characterises the situation for those with disabilities. It is important to include the perspective of those people with a disability, as they view things differently than those without a disability. However, their perspective is often difficult to elicit with traditional research tools, and so it is not included.

To help understand the voice of those with disabilities and responsively plan our program activities, we the research team trialled a novel research tool called photovoice. The point of interest was to determine whether this novel photographic tool could assist those with a disability to convey the elements of rehabilitation programs that are important to them. Likewise, the researchers sought to find out to what degree photovoice could enable the voices of people with disabilities, which are often overlooked and under-represented, to be heard.

By giving community members the opportunity to express their viewpoints through photography, the researcher gains a special insight into life within the community. Additionally, the photographs taken create empathy for those with a disability where otherwise it is difficult to imagine or understand how life looks from their perspective.

Catalani & Minkler (2010) identified three types of outcomes in photovoice projects (see Figure 1): (a) enhanced community engagement in action and advocacy; (b) improved understanding of community needs and assets, which in turn could have community or public health benefits; and, c) increased individual empowerment.

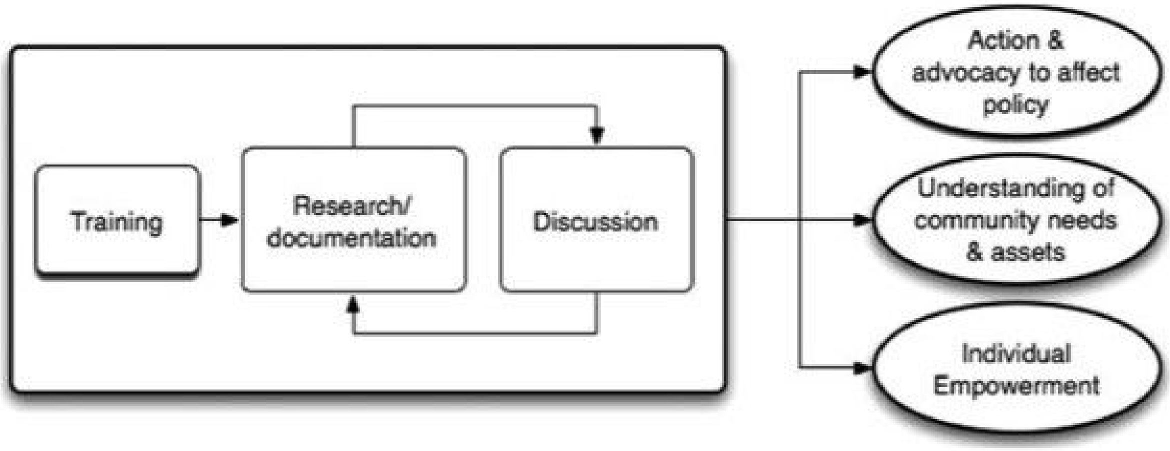

Figure 1. Three Types of Outcomes in Photovoice Projects

Research Questions

In what ways can using photovoice methodology provide an understanding of the lives of people with a disability from their own perspective? This research also aimed to investigate how photovoice methodology could influence self-advocacy for people with disabilities, enable them to raise awareness of their lived experience and advocate for their own rights.

Materials & Methods

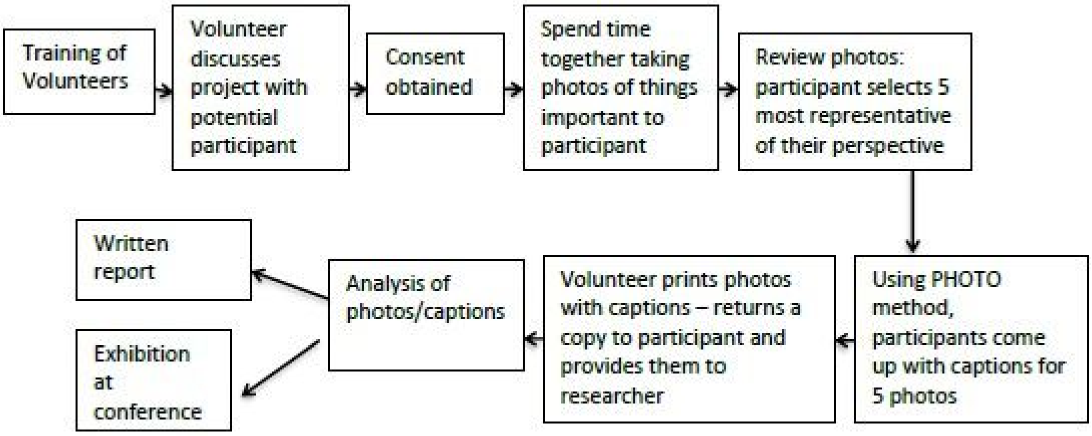

Figure 2. Ten-Point Framework of Photovoice

Hergenrather's ten- point framework for undertaking photovoice research (figure 2) was applied to the study, together with an adapted set of Hergenrather's questions for participants (Hergenrather, Rhodes, Cowan, Bardhoshi, & Pula, 2009). The ten steps were as follows:

1. Identification of community issue: The study area was in the state of Uttarakhand, North India. When speaking with people with disabilities it became apparent that they felt misunderstood and that their priorities were not considered.
2. Participant recruitment: A mixture of convenience and purposive sampling was used to recruit 18 people with various disabilities (see Table 1). A person was eligible to participate in the study if they had a disability, were living in Uttarakhand and were already linked to two existing community based rehabilitation (CBR) programs. Participants were purposively selected so as to ensure representation of various disabilities.

Data collected from 18 different participants are shown in the following table. The variables of the table include code, sex, age (years), disability description and photos.

Table 1: Overview of Participants

Code	Sex	Age (years)	Disability description	Photos
P1	M	4	Left infantile hemiparesis with difficulty walking and with motor activities	Figure 3 Figure 5

P2	F	14	Moderate severity cerebral palsy and intellectual disability, walks with support	
P3	F	23	Moderate locomotor disability, walks with assistance Limb length disparity	
P4	M	45	Severe locomotor disability - non-mobile, post-polio	Figure 10
P5	M	9	Mild intellectual disability, speech difficulties, minimal vocabulary	
P6	M	18	Severe locomotor disability and depressive symptoms Unable to walk	
P7	M	15	Dysmorphic, moderate intellectual disability, social impairment and speech impairment	
P8	M	62	Locomotor (amputation of both feet) and requires crutches to walk	Figure 4
P9	M	50	Spinal injury, requires support to walk	Figure 6
P10	M	4	Moderate spastic quadriplegic cerebral palsy	Figure 7
P11	F	7	Moderate developmental delay and locomotor disability	Figure 8
P12	M	7	Severe autism	Figure 9
P13	F	45	Mild intellectual disability	
P14	F	10	Fine motor skills impairment, mild intellectual disability, speech difficulties	
P15	F	15	Moderate intellectual disability, mild impaired mobility, right hand affected, seizure disorder	
P16	M	7	Moderate autism spectrum disorder	
P17	F	18	Undiagnosed syndrome: physical deformity and	

			epilepsy	
P18	F	55	Moderate locomotor disability prevents walking	

3. Photovoice training: Thorough training of current CBR staff and CBR volunteers was a key aspect of the photovoice methodology, as research shows a positive relationship between the intensity of training and community participation (Catalani & Minkler, 2010). The training provided information on the goals and aims of the study, including ethics, safety and consent.
4. Camera distribution and instruction: Each participant was given a camera for 24-48 hours. The person with a disability and/or the carer received specific technical training from trained volunteers/staff on how to take photographs using the camera.
5. Photography: The participants were advised to take the photos in their home or local village environment. Volunteers/staff were available to support people but they were specifically trained not to interfere unnecessarily and to accept all photos even if they might be considered irrelevant or of poor quality.
6. Identification of photo assignment: After a discussion with local staff and community members in which culturally appropriate wording was determined, participants were given the following instructions: *"Please photograph people, places and activities that are important to you,"and, "Please photograph people, places and activities that make you feel important."*
7. Photo assignments discussion: After taking photographs, participants reviewed and selected the five most representative pictures of what was important to them, and were asked the following questions:
    a. Describe the picture: what is happening?
    b. Why is this important?
    c. What does this tell about your life?
    d. What does it show about opportunities to improve your life? (Adapted from Hergenrather et al., 2009)
8. Data analysis: A thematic analysis of data from the photographs and the descriptions of these photos was completed independently by two researchers. Each researcher used a grounded theory approach to iteratively group the data into categories and subcategories representing the perspectives of people with

disabilities. The themes identified by each researcher had high coherence. The lead author then combined the two analyses to arrive at the common themes represented in the results.

9. Presentation of photovoice findings: In addition to publishing the results, photovoice findings are typically presented through a public photo exhibition. This was conducted as part of a session on photovoice at the Asian Conference on Intellectual Disabilities. Key photos representing the themes were printed and presented at the conference.
10. Creation of plans of action for change: Interrelated with the presentation of photovoice findings at the exhibition, participants were empowered to create plans of action for change.

Results

As outlined in Table 1, there were 18 participants with disabilities from 14 villages enrolled in this photovoice study. This included five adults, ten children under the age of 15 years old, and three adolescents aged between 16-25 years. The severity of disabilities ranged from mild to severe, and five of the participants had multiple disabilities. Two had speech impairment, two had autism, one had developmental delay, two had cerebral palsy (CP), one had an undiagnosed syndrome, five had locomotor disability, four had other forms of physical disability, and six had intellectual disability. For three participants with more severe/multiple disabilities, their respective carers helped them interpret the photos. The data from the 18 participants produced 95 photos with accompanying commentaries. The following themes and sub themes were found.

Family and Friends

The importance of strong, trusting and dependable relationships with family and friends was a dominant theme with many photos taken depicting family members. In describing the photos, participants expressed both love and, often in the same sentence, appreciation of the care they provided. As this boy with autism says:

> “I love my grandma, she looks after me whole day”. (P1)

Figure 3. Photograph of primary carer (the grandmother) of P1

Various quotes described their primary care givers as a strong and reliable support with whom they had developed strong bonds through large amounts of time spent together.

The carer was often referred to as the paternal grandmother – a common phenomenon in the village where both parents are employed in subsistence economies. A child with autism demonstrates:

> *"I wanted a picture of ammi (paternal grandmother)… She looks after me, takes me to different places, gives me my favourite food. I wanted to give her a photo of herself. Will you give this photo to me? I want to give it to her. It will make her happy."* (P2)

Various pictures and descriptions also detailed the role of friends. Friends clearly provided meaning and overcame the boredom that was described as typically accompanying disability:

> *"I love my niece and nephew. My brother used to live with us until he got married. Now they live separately but his children come every evening to spend time here. So I spend time with them. When the children are not around I feel bored. But I don't like too much noise."* (P3)

Many people with disabilities were dependent on friends for companionship, and also relied on them like they did on their family members for practical support such as travel and personal care.

A number of the commentaries on photos specified how the person with a disability desired to express love and appreciation in a tangible way. This reciprocity of caring and contributing to their family seems to be important, as did the interdependent nature of their friendships:

> *"This picture is of my friends… helps to have support. My family… my friends support me, especially when I have to travel somewhere, they take me with them. They have*

> *their own difficulties and I try to help them too."* (P4)

Concern about the family's ability to care for the person with a disability in the long-term was expressed when speaking with carers:

> *"We hope that we can teach him to do basic things. We have opened an account in the bank for him so that when he is older he will have his own money. Nowadays, everyone cares only for themselves. Who knows what will happen after we are gone? We are hoping that if he has money of his own, his siblings may be willing to look after him."* (P5)

With little access to a reliable social security or disability care system, the ongoing role of care typically falls to siblings and other relatives when the parents and grandparents are no longer able. In India and other low and middle-income countries the dependency on family is prominent and often perceived as permanent.

Employment, Financial Security

The importance of employment for people with disabilities was evidenced in the photos and descriptions of most participants. In most instances the importance of employment was closely related to the desire for financial security for these mostly poor families:

> *"... [It's] difficult to run a household with only one income... being poor is the worst thing especially when I am disabled."* (P6)

This clearly describes the double burden of disability and poverty. Evidently, in a country with little dependable social security, employment is key. Employment provides not only financial security, but also contributes to self-esteem, identity and inclusion in society. One participant with locomotor disability describes:

> *"Through hard work like this I have never considered myself disabled. I always thought I should live and encourage others. I should not beg. I should not have to stretch my hand before anyone... my desire [is] to encourage people with disabilities as much as possible and to use my body in service. That is my desire."* (P4)

Employment was perceived as an effective way to be respected by family, friends and the community. Where those with a disability described their employment, it was mostly in the informal economy and consisted of contributing to subsistence farming and domestic chores. One example described how a boy with intellectual disability was able to contribute:

> *"... He looks after the cattle... follows them around and makes sure they get back home safe. He also looks after them here, washes them and makes sure they are ok."* (P7)

However, many who had capital, such as a family business or farms, complained that they were no longer able to work in their fields, local shops or restaurants. For example, one man who had lost the use of his arm describes:

> *" I own fields, but unlike my other fellow villagers, I cannot plough or till my own fields."* (P8)

Figure 4. Photograph of worker in the fields adjacent to the house of participant P8

Once unable to work due to their disability, finding alternative employment was difficult. The data showed that opportunities for work were limited due to the disability and others' discriminatory attitudes:

> *"The main problem is employment. Even if they are able to learn a trade, they have no equipment. Even if they have equipment, they have no place… The main thing is employment. If there is employment we don't even need a pension."* (P4)

The participant quoted above iterates that employment is the most important thing for him. He also describes how vocational training is hard to get for a person with disability, and often makes little difference to employment opportunities. Another adult with locomotor disability comments similarly:

> *"I have studied until fifth standard [grade]. I tried to learn some trade but could not get any help, like every human being looks for help. But I did not get any help. I did try to learn a trade but going up to the junction is difficult for me. You must have noticed how far it is from here. To go to the place where I must learn the trade – that also will be difficult."* (P6)

A photo showing people walking to work demonstrates a sub-theme about the prevalence of corruption that magnifies the difficulty of people with disability getting pensions and work reservations. Its photographer describes how he has been trying to get a government job through the quota reserved for those with disability but he was told they are 'not available':

> *"Only those with contacts, only they get [a job]. A lot of people who have contacts [got one]. I've not been able to develop a contact yet. I think that I should get a job based on my ability."* (P3)

Another participant commented along similar lines:

> *"There are opportunities but with corruption, it is difficult to access these opportunities"* (P6)

Social Attitudinal Barriers

The data showed that attitudinal barriers not only contributed to difficulty in gaining employment but also to social exclusion and a feeling of being unwanted. A person with locomotor disability described his experience of trying to fix his tricycle:

> *"People see and pretend not to see... no one is willing to help. Most people in the village don't even know my name. They just call me 'lungda' [cripple]. How can I move forward without support?"* (P6)

Another adult with locomotor disability described similar discriminatory attitudes:

> *"Many people pass comment about my disability… People also think that despite being disabled why does he keep joining people, and why do people respect him? But I don't listen to them."* (P4)

Other such comments were common in the data, and the participants identified tackling such discrimination as an important area for action.

Physical Barriers and Travel, Transport, Accessibility

The data indicated that even if people with disabilities were welcomed by their community, physical barriers perpetuated exclusion. In the home, there were barriers to using basic facilities, e.g. access to sanitation. A boy with post-polio paralysis commented:

> *"I wish this wash basin could be reachable to me."* (P1)

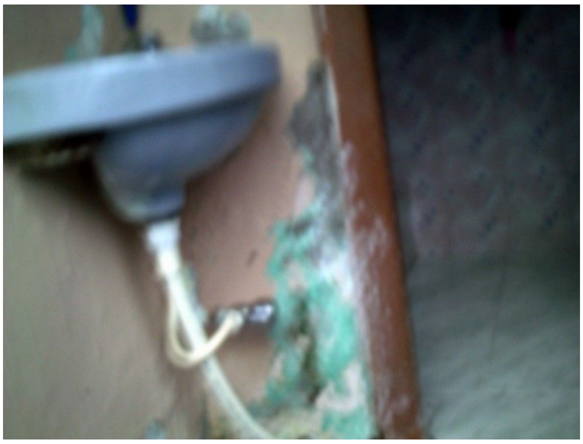

Figure 5. Photo of wash basin that is out of reach of participant P1

The most significant barriers the data highlighted relate to movement in and between villages. Such barriers, identified by 13 of the participants, typically limit their independence, mobility and community involvement. A 50 year-old man with locomotor disability describes his photo:

> *"Due to my physical impairment, I just sit at the door. I would wish to go to and fro from this door."* (P9)

Figure 6. Photo of the open doorway through which a man (P9) with locomotor disability looks

Assistance was only partially effective due to cost. Many thought they might benefit from transport assistance, like a modified scooter, and that it would increase their independence and participation:

> *"....It [is] so much easier to have my own scooter... [a] scooter will help me be independent... [I] will not have to depend on somebody else to go with me or take me depending on their plans."* (P4)

However, such aids were expensive. There was some evidence of people accessing government accessibility schemes, in particular for tricycles and subsidised public transport. Yet even where transport was available there was little evidence of environmental modifications to facilitate the person with a disability to move around their community:

> *"You see, I got the tricycle from the government for free. It is helpful for short*

distances, but in the rain, when we have to travel long distances, or when we have to go up a slope, the tricycle is very difficult." (P4)

Even if tricycles were available in the mountains, they would be difficult to use unless there were significant modifications to roads and paths. A number of people with disabilities commented that current roads and paths are difficult to access on a tricycle. The lack of community infrastructure and support to overcome these barriers was also evident in the data, which highlights both the importance of lobbying for more accessible roads and the theme of inclusive transport options:

"I took the picture of the path leading to the house. It is very difficult to manoeuvre the tricycle through the path to my house." (P6)

Nature, Beauty, Food, Recreation

Though not always a priority for disability community based programs, enjoyment of nature, recreational activities and food were considered important by those with a disability. An appreciation for nature was described as being important by various participants. Several photos and their descriptions demonstrated the value of nature to many with a disability. A child with cerebral palsy and another with developmental delay commented, respectively:

> *"I am inspired from this tree, I daily see this tree."* (P10) and *"I love nature especially flowers. I wish I could have a garden like this"* (P11)

Figure 7. Outside the house of participant P10, showing housing, greenery and a two men in the yard.

Figure 8. The garden of participant P11, including the mountains in the distant background past the garden fence.

One example demonstrated how the love of nature can translate into increased wellbeing and participation. The parents of one child with an intellectual disability explained why he took a photo of a bullock cart:

> "That was the first picture he took. He loves his animals. Every day he wakes up in the morning and cares for them. He spends a lot of time with them... Maybe that's why he took the picture of the bull. As compared to before, he has become quite independent now. He knows all that he must do and wakes up in the morning and does all the tasks one after another." (P5)

Photos were taken of many objects relating to recreational pursuits such as a television, a playground and animals. It is clear that recreation was valued by many children as a means of enjoyment, passing the time and engaging with others. However, where children were excluded from recreational activities, there were feelings of resentment. A child with autism who commented on his photo illustrates this:

> *"All the children are playing. No one wants to play with me."* (P12)

Figure 9. Three children holding hands in a circle (P12)

Food was featured in many photos. It was described not only as a source of enjoyment or comfort but also as something that helped children gain self-confidence and engage in the community. Food can be a very effective tool to assist with development, as was indicated by the explanation of a photo of biscuits taken by a child with an intellectual disability:

> "*He loves biscuits. He knows which is his favourite one. He walks to the shop by himself, and points to the one he wants. He knows that he has to give money and will [get] change in return. He does not know how much change he will get back. But the shop owner knows us well and he sends the right change back. R*** knows to walk carefully on the road and to cross carefully. Sometimes I give him a list of things to buy. He will take the list and give it to the bhaiya and bring back what he gives. He is slowly becoming more independent."* (P5)

Spirituality

The data demonstrated that spirituality was important to the participants. Spiritual beliefs provided many with an explanatory framework for disability, and in so doing provided comfort, promoted acceptance of the disability and helped define a sense of purpose to the disability. A lady with an intellectual disability explained:

> *"There are lots of problems… This is all the work of god. It is not as if it is the work of men. A lot of people laugh. There are so many who cannot even walk, who need a lot of help from others. I thank God that at least I can walk about [with] the help of my stick. I can bathe myself, wash clothes, cook food."* (P13)

Other participants also referred to god or faith as a source of strength for them to face their difficulties. A man with a locomotor disability took a photo of a temple and explained:

"I allow only god to dictate how I live my life. I choose to live in a way that I am not dependent on anyone. The strength I need, god gives. Belief in god keeps me going... that he is there, with whatever difficulty I have been given." (P4)

Figure 10. Photo of a pink temple taken by participant P4

Discussion

Photovoice proved to be a useful methodology in raising awareness about issues that are important to those with a disability. The different ages and disabilities provided different and unique insights and challenged any homogenous notion of disability. Consistent with previous uses of photovoice, it was a simple and inexpensive method, which will assist in program planning, raising awareness and most importantly giving voice to the voiceless (Jurkowski, 2008). Even within this small sample there were examples of how this approach enabled people with disabilities to tell their own story and advocate for their own rights, such as transport. In response to the research question, the photovoice methodology provided an understanding of the lives of people with disabilities from their own perspective. It revealed aspects of life that are of significant value to people with a disability, including family, access to transport and employment, overcoming social and physical barriers, the enjoyment of nature, food and recreation and spiritual belief. These results support most of the important elements in the WHO CBR matrix, which indicates five components for response and 25 important elements to consider. Additionally, however, the study highlights areas, such as spirituality, that are deemed important to people with disability but absent from the CBR matrix (WHO, 2011a) .

Family was central and valued in the experience of those with a disability in India. Children and adults thought positively of these dependent relationships, which differs from the typical western mindsets that view dependence on family as a weakness in the pursuit of independence and autonomy. Rather than becoming obsessed about independence from their family, people with a disability showed the desire to remain in close contact with their families, to be able to contribute to the family unit in a meaningful way, or, at the very least, to be able to demonstrate their appreciation of their family.

A key issue for the participants in this study was that of gaining employment, and the associated barriers for a person with a disability. Providing adequate employment is an area in which many CBR programs struggle. In India there are government schemes, like the Mahatma Gandhi National Rural Employment Gurantee Act, that provide a guarantee of minimum work whether living with or without a disability. These schemes are largely non-operational in rural areas. Thus, efforts need to be made to ensure that people can avail themselves of existing programs. The data suggest that a certain degree of this entails encountering corruption, which often means that the intended beneficiaries are not included. Creative schemes need to be considered, as suggested by one person with a disability in this project:

> *"If we can have an area for the disabled to set up stalls for shops, we can pay rent for the space… but we should advocate that [the government] give us the land."* (P13)

The study demonstrated how valuable work is for people with disabilities, not only in providing a livelihood but also in providing a sense of identity and integration into the community. This makes it an even higher priority for CBR programs.

Areas that might not otherwise be incorporated into a CBR program were raised as important. For example, with a focus on therapy and inclusion, one of the most basic aspects of normal life is overlooked. That is, recreation may be particularly important for the mental health of those with a disability, who may feel a lack of enjoyment and meaning due to their impairments. Beyond mere enjoyment and the use of play as therapy, recreation also provides an opportunity to promote the inclusion of children with disabilities in society. The study has shown that this is often not the case; children were excluded from play and were sometimes teased as part of play.

Likewise, the results highlight that people with disabilities value the natural environment yet it has limited place in formal therapy. It could be that there are opportunities, therefore, to incorporate exposure to or interaction with the natural environment into therapy or use it to promote livelihood activities such as farming. This was the case with one participant who had autism: his focus on nature allowed him to be trained to be a shepherd, which helped with his general development and skills acquisition. However, in the authors' experience, few CBR programs in India incorporate interaction with the natural environment as part of therapy and special education. This research encourages programs to develop alternative ways of approaches to early intervention, education and vocational training for people with disabilities.

As mentioned previously, spirituality was another aspect that was shown to be of importance to those with a disability, yet is not often incorporated in CBR projects, and indeed the CBR matrix. The study shows that religion can be key to individual and community life, yet CBR projects have difficulty incorporating religion whether for reasons, such of religious tensions in the community or other. Given that religion is often central to individual and community life in India, it would be beneficial to further investigate the impact of religion on disability with a view to assisting individuals and communities to achieve optimal outcomes in CBR projects.

The intrinsic effect of undertaking the research with the participants was not the focus, however, a number of participants informally reported that having the camera gave them a certain status and respect in their village. One reported that others from the village wanted to play with him and be part of the exercise. The participants also reported that they felt empowered in that they had a means to tell their story (camera) and an audience to listen (the researchers). It is recommended that a process evaluation be undertaken to formally record the impact of the research on the participants themselves.

Limitations

The limitations in this study included its small sample size, the technical aspect of the photography exercise and the timeframe given for photography. A sample size of 18 is consistent with most photovoice studies, which have had between five and 13 participants

(Catalini et al., 2012; Jurkowski, 2008; Vaugh, 2011). Generalisations cannot be made from the small study population, however the study still does provide insight into the lived experiences of people with disabilities in the selected community, and highlights some areas that are omitted from CBR practice. This study design is well suited for exploring such areas (Hergenrather et al., 2009).

The technical side of taking photos could have been improved, as many of the photos were blurred or of poor quality. This might limit the usability of the photos for advocacy and awareness raising exhibitions. More thorough training could have been provided to the participants on how to use the camera, and participants could have been more closely supervised. However, the study team estimates that the quality of the photos partly reflects some of the challenges faced by people with disabilities in communicating and, thus, giving participants freedom to take photos without close supervision allowed them to tell their story sufficiently for the purposes of this research.

The limitations of the research and limited access to cameras meant participants only had access to cameras for short timeframes. A wider range of photographs would have been likely if cameras had been shared for a longer period of time, as has been done in other studies (Catalani & Minkler, 2010; Hergenrather et al., 2009; Vaughn, 2011). This would allow participants to familiarise themselves with the technical side of the camera, and possibly better tell their story and explore how to use the camera for advocacy. As the cameras are still owned by the programs, it is planned is to utilise them for such purposes in the future.

Another improvement that was suggested by the participants, and has been used by others (Catalani et al., 2012; Jomhari, Gonzalez, & Kurniawan, 2008; Warren, Knight, Holl, & Gupta, 2014) was the use of alternative/additional technology, such as video (Videovoice) or Youtube to showcase findings. This is increasingly easy with the advent and widespread usage of smart phones, which avoid the difficulty of training participants to use unfamiliar devices. However, to protect the confidentiality of those with a disability, and particularly of those with intellectual disabilities, the distribution of media needs to be restricted or limited by strict ethical guidelines. Where the internet and smart phones are involved becomes increasingly difficult. The potential for damage is significant if images and videos are misused.

Conclusion

Photovoice projects are intended to be action-orientated research whereby there is an intention to use the data to empower people with disabilities and advocate for their rights (Catalani & Minkler, 2010). In parallel to this paper, these findings have contributed to a set of recommendations and the photos have also been exhibited, with permission, in public forums, including the Asian Federation on Intellectual Disability conference. The results were presented back to the study communities and the participants have been encouraged to use their photos to raise awareness and advocate on issues of importance to them.

In conclusion, despite the limitations and risks of the photovoice approach, it can be an effective methodology to draw attention to issues faced by otherwise voiceless and marginalised groups, such as those with disability.

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Swedish Citizens with Cerebral Palsy or Spina Bifida – Perceived Experiences of Social Life and Employment

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Abstract: This article offers insight into the ways in which people with cerebral palsy and spina bifida reflect upon their experiences of participation in relation to social life and employment. The qualitative method was used to explore experiences of participation among adults with CP or SB, using semi structured interviews. Participants expressed a desire to make a contribution to the labor market, to have sustainable relationships and to be accepted by others.

Keywords: Disability, Participation, Employment

Introduction

Participation is important to human health and is crucial for psychosocial development. The International Classification of Functioning, Disability and Health define participation as involvement and engagement in a life situation (WHO, 2001). It states the level of social engagement and the ability to accomplish goals in life are important factors that influence a person's perceived participation (Salter et al., 2005). When the ICF is used for rehabilitation, full participation in society is considered a key concept for people living with a chronic disability (AlHeresh & Keysor, 2015; Shakespeare, 2013).

In today´s Sweden, the political climate is dominated by the social model of disability. This means that disability is defined as socially and politically influenced discourse around interpretation of physical differences (Byrne, McLaughlin, Byrne, & McLaughlin, 2007; Shakespeare, 2013). According to the social model, impairments exist but how they are viewed is socially constructed. Therefore the social model makes a fundamental distinction between impairment and disability, where the latter means constraints of activities caused by a current social organization, which might exclude people from social contexts in society (Goodley, 2001). In this study, disability is understood in terms of socially created disabling barriers that prevent people with disabilities from participating in society on equal terms with others. However, unlike the more traditional social model, this view does not exclude an understanding of disability as significant in some people's lives, for example because of chronic pain from a specific impairment (Shakespeare, 2013).

From a Swedish historical perspective, disability has been a factor in discrimination and exclusion from large parts of society and the present disability policy is the result of developments over the last two hundred years (Kjellberg & Hemmingsson, 2013; Schaap Williams, 2013). Ignorance, disregard, superstition and fear are societal factors that have hindered persons with CP and SB and complicated their struggle for participation in society (Edwards, 2008; Riddle, 2013). However, recent international social policies have been formulated to promote acceptance, integration and inclusion for this group. Despite these policies, participating in today's society requires physical skills and people with CP or SB might be in need of personal assistants or assistive devices in order to participate on equal terms (WHO, 2001).

Internationally, The United Nations Convention on the Rights of Persons with Disabilities (2011) recognizes the right of people with disabilities to have equal opportunities in the labor market and to participate in an open, inclusive and accessible work environment. The CRPD also emphasizes the importance of employment as one of the means of reaching full participation. However, according to Kaye et al. (2011) and Barnes and Mercer (2005) employers still generally have negative attitudes toward people with disabilities. Employers were reported to have difficulties with costs, legal liability and ignorance when it came to hiring and retaining a person with a disability (Kaye et al., 2011; Roach, Short, & Saltzman, 2011).

In Sweden the work participation rate among adults with CP or SB is high when compared internationally, with a previous study (2014) showing a 66% participation rate as a result of the system of wage subsidies (Törnbom et al., 2014). This means that the employer reaches an agreement with the state about what percentage of the wage they each are willing to pay (Törnbom, Lundälv, Jesperson, Sunnerhagen, & Grimby, 2011). A Swedish study presented that 19 persons working full or part time had wage subsidies and the others were competitively employed (Marie Törnbom et al., 2014).

Through participation, people can learn abilities and competencies, associate with others and find a new purpose in life. However, previous research suggests that the presence of cerebral palsy (CP) or Spina Bifida (SB) might lead to participation that is less varied and involves fewer social relationships (Stewart et al., 2012; Marie Törnbom et al., 2014; Yeung, Passmore, & Packer, 2008).

People diagnosed with CP or SB and their experiences of living in today's Swedish society have not yet been widely explored. People with disabilities in general, and with CP and SB more specifically, should be able to take part in society under the same conditions as others. Therefore, it´s very important to uncover issues and areas of inequality in society for these groups (Shakespeare, 2013; Van De Ven, Post, De Witte, & Van Den Heuvel, 2005).

The purpose of this article is to describe experiences and perceptions about participation of adults with CP or SB with regards to their social life and employment.

Methods

A qualitative method was used to collect views held by adults with CP or SB about participation and to examine phenomena that have not been widely explored before. To explain issues from the perspective of the participants' own experiences, perceptions and interpretations of events, in-depth interviews were chosen (Cope, 2014; Patton, 2002). Content analysis was used to achieve a better understanding of the individuals' perceptions by asking them to describe their lived experiences and to describe and analyze the subjects that were brought up by the researchers (Graneheim & Lundman, 2004; Kondracki, Wellman, & Amundson, 2002). The study was approved by the Regional Ethics Review Board in Gothenburg and all participants gave written informed consent.

Participants

All persons invited to participate had been patients at an adult habilitation unit at the Department of Rehabilitation Medicine, Sahlgrenska University Hospital, Gothenburg. In a previous interview that took place in 2009, the patients from the adult habilitation unit were asked if they would like to participate in an upcoming in-depth interview. Twenty patients agreed to participate, aged 35-55, 9 females, 8 with SB and 12 with CP. Civil status; 8 were cohabiting and 6 of them were married, 12 lived alone.

All had completed year 9 of secondary school and 16 had completed upper secondary school. All were Swedish speaking and lived in Gothenburg. Twelve always or occasionally used a wheelchair , 4 were in need of crutches and 3 were walking independently. Eight were employed full time and 7 part time; 9 had wage subsides and 6 were competitively employed. Four had full time disability pension and one was unemployed.

Data Collection

In line with a qualitative approach, the aim was to elicit thoughts and feelings about experiences of importance for the participants. Before the interview started, all participants were given a letter with information about the study and their right not to participate or to refrain from answering any of the questions. One of the authors conducted the semi structured interviews of 45-75 minutes at a location preferred by each participant. The questions were directed to the participant's experiences within the following themes of employment and social life (Cope, 2014). These themes were chosen in accordance with the current political debates in Sweden about persons with disabilities and their conditions in the labor market, as well as their ability to lead a social life (Socialstyrelsen, 2010). These themes were also chosen beforehand to ensure clear boundaries and to avoid an immense amount of data (Patton, 2002). Participants were asked to think about their experiences of participation within each theme.

In-depth interviews were chosen to encourage explanatory answers and two-way communication. To yield important insights in the themes, we used open ended and follow-up questions that varied depending on the answers, for example: "Can you tell me more about that job?" (Kondracki et al., 2002). To increase the validity of the interview process, themes and ideas were reflected back to the participants, to make sure that we understood the responses correctly (Cope, 2014). The interviews were audio taped with the participants' knowledge. Anonymity and confidentiality concerning the collected material was assured.

Data Analysis

All interviews were transcribed verbatim and the analysis began with two authors reading the transcripts of all interviews several times, to attain a sense of the whole. Two members of the research team developed a coding scheme based on key concepts that appeared in the material and were related to the research questions. This coding scheme was revised in an ongoing process as new transcripts were read and discussed by members of the research group (Graneheim & Lundman, 2004).

In accordance with the conventional content study design, the interview material contained narratives within each theme (Graneheim & Lundman, 2004; Kondracki et al., 2002). Conventional content analysis (CCS) was appropriate to use in this study to help describe experiences and thoughts where existing theory or research literature is limited. In line with the CCS we allowed categories and names for categories to flow from the data, which is an apparent advantage with this method (Hsieh & Shannon, 2005). This assisted in delving deeper into the data to allow new insights to appear, also described as inductive category development (Patton, 2002). In this case, participants spoke a lot about themselves, aside from their experiences within the labor market and their social life. This resulted in an additional theme that was labeled; "personality and characteristics".

Results

The results are presented under the following major themes that emerged from the interviews: employment, social network and personality and characteristics. Supporting quotes from the participants are provided to represent different perspectives and to exemplify each theme.

Employment

Being Valuable

At the time of the interview, 10 people had employment and 7 were unemployed. Participants who were employed felt pride and satisfaction from working. Relationships with co-workers were mainly described as valuable. Several said that it was important for them to contribute to and to feel needed in society. All participants stated explicitly that they wanted to be like "everyone else" and to have the right and ability to support oneself:

> "I'm happy at my job! I know that I'm needed here and that I can accomplish things … it's fun being somewhere where things happen … ah where you see that you're doing something useful"(4).

The participants wished to perform something they had competence in doing or felt good at:

> “Yes, it’s probably because I have a job that I can do, I´m good at my job. And we have nice colleagues, it’s a good (working) environment. It’s okay if you make a mistake. Ah, in other words, it’s a really good job”(12).

Most participants were working within the field of computers but held different views of what impact the disability had had in choosing their field of interest:

> “That I’m interested in computers is only because I saw this as a possible occupation for me. I wasn’t a computer nerd to start out with, I’ve become one. But it is also my biggest interest”(3).
>
> “It’s a meaningful interest that I didn´t choose because of my handicap. Sure, it’s very easy to sit in front of a computer with my kind of handicap. But for me … this was a passion, which I would have had even without my handicap. I’m convinced of that”(4).

Several participants explained that they had been encouraged by their parents or by someone from school to develop computer skills. This was often said to be an appropriate interest for someone with a physical disability:

> “Yes, I realized that I can’t manage a job where you have to move around a lot. What I need to do is to sit still in a chair and write”(12).

Being Unemployed

The unemployed participants were not content with their situation and the most common reason for this was that they wanted to make a contribution to society and they found this difficult as people who were unemployed. Several participants also felt bored on a daily basis and in some cases merely observers of society:

> “I was there for five years, until I couldn’t stay any longer … and I was probably going to get a permanent position but then they realized that they couldn’t afford to have me there. It was something about their funding… it was the best work I’ve ever had…otherwise I’ve mostly been unemployed”(9).

Several participants said they had lost their position because of economic circumstances at their workplace and the procedure of being dismissed was described as irregular or even illegal in some cases. A shared experience was being fired from a job that they liked, without an opportunity to get a reallocation and with difficulty in finding a new job:

> “I became redundant, as they call it…But can you reallocate me? I asked. To another department or something…but that wasn´t possible. There was no position! So I had to go! And they thought that I should go into early retirement. And that was all there was for me. But I’m only 37! So that was really sad for me”(13).

Participants articulated sadness at the loss of employment and a growing emptiness in their new life. How they would spend their days was not predictable anymore:

> “When I had a job I felt meaningful because, like, I came there every day. And knew what I would do. And there wasn’t any uncertainty, like I think now; ‘what should I do today?’ I was active in a completely different way and everything was easier”(9).

Several of the job-seekers assumed that employers would focus on their limitations and difficulties and that this would affect their employability negatively. The participants reported that a general negative attitude among employers came out of ignorance and thought that the employers were not used to dealing with people with disabilities. One factor for employers to avoid hiring someone with disabilities was thought to be a fear of increased expenses:

> “I can’t like… go into a shop and look for a job like normal people… because they would see right away that… “he’s handicapped!” And then I´m not even considered. It´s too expensive for them to have me”(2).

It was common for the unemployed to be aware of how others would react to their appearance. Being educated beyond high school and having contacts on the labor market were seen as important factors for getting an attractive job despite their disability:

> “My dream was to come out into the regular labour market, but it doesn´t work the way things are today... or it would work, with the right kind of help…if they’re open and want to put effort into having me there, but the truth is that this can be very difficult”(1).

Out of the participants who had a job, all except one had education beyond high school, i.e. the Swedish equivalent of upper secondary school. Participants without education beyond high school said they would like a higher level of education, if that would give them better opportunities for getting a job.

Social Life

Participation in society was described as being part of a social context in which you are valued in a positive way. Having social support and sustainable relationships were considered key elements for a wider experience of participation. Examples of how participants defined the meaning of participation:

> "This is when you are around people, who want you there … when you feel welcomed. I am wanted here (at work), I am needed at home and with my friends"(7).

> "That is when someone asks for my opinion ...and wants me to be involved in something that we share"(3).

The presence or absence of relationships affected how participants spoke of their experienced level of participation.

Characteristics of Social Life

Almost all participants claimed to have fewer social relations compared to what they had had during childhood and adolescence. The former period was often filled with leisure activities, along with which came acquaintances and friends. In this sense, participants experienced a growing emptiness when they reached adulthood and were no longer a part of a compulsory activity schedule.

A majority of the participants met regularly with their family and a few close friends. It was also common for the participants to describe their personal assistant as a close friend. Some participants wanted more friends and others felt content with a small social life. Most of the participants socialized with friends in someone's home, by making dinner together, or watching TV.

Getting Out and Meeting New People

Several participants expressed difficulty in finding contexts where they could form new relationships. It was also hard to find the courage to participate in social activities. In addition, a few said that they were dependent on personal assistants to mediate social relationships and some feared that stereotypical assumptions about disabilities could get in the way of forming new relationships. Three participants said they had difficulties talking to new people in general:

> "I'm a loner, so there isn't too much of seeing other people. But sometimes I want to meet and talk with other people, even though it´s hard to talk to them. I like that, exchanging thoughts. And hanging out with close friends"(1).

A lack of energy, shortage of money or too few hours with transportation services or a personal assistant were factors that the participants highlighted as barriers to participating socially as much as they wanted to. Two participants felt very isolated and considered their opportunities to get out and socialize to be strictly limited:

> “If I’d had more (assistance) hours I would have lived like an ordinary 42-year-old…I wouldn’t think that the minutes are ticking away and I´ll probably have to go home now. You shouldn´t have to think like that…Being at home; it’s worse than a prison actually! In my opinion, everyone should have the right to go out and meet other people”(2).

Social Media

For many participants, experiences of social interaction were not limited to social contacts face-to-face, but included communicating over social media. All participants had friends and other contacts online. A majority had found close and meaningful relationships this way. Being engaged in a social life online was considered to be a clever tool for making new friends. Two participants spoke about the advantage of not having to explain or deal with questions about their disability in the process of forming new friendships:

> “I’ve met new people there (on Facebook) so it’s really fun…even if you haven’t met someone in person it feels like you’ve known each other for a long time…and I don´t always have to present myself as someone who is disabled, and that I don´t consider lying, it gives me an opportunity to withhold the truth when I want to focus on other aspects of myself…and I get in a really bad mood when the internet is down and I can´t speak to them”(13).

Others did not enjoy this form of social interaction:

> “I like to speak to people that I can see and who are real. It´s so weird for me to be friends with someone I haven´t actually met in real life…I meet many, many people face-to-face every day at work and that means a lot to me”(12).

The employed participants tended to be more negative towards having social relationships online, whilst this type of social interaction was more common among the unemployed.

Personality and Characteristics

Participants who considered themselves to be engaged in, and content with, their lives also communicated a positive view of themselves and of people around them. Certain characteristics that appeared in relation to these narratives were: a constant struggle to solve everyday problems, positive thinking in general, being tolerant in the case of failures and an ability to trust oneself and others:

> "I've never seen myself as an outsider or a person who´s not welcomed. If I've felt that this doesn't work, I never think that this isn't for me… instead I try to find a solution so that I can participate…I believe that if you look happy and extrovert, and if other people can see that, you'll be met in a positive way"(15).

> "Yes, well, everyone can have an influence. It's just that you have to try… I've never felt that I can't do this or that, I've probably had just as much fun and dealt with about the same difficulties as everyone else"(16).

Being Involved in Different Activities

Those who expressed a greater feeling of participation commonly expressed a feeling of being able to cope in everyday situations and an ability to enjoy most days in life. Several participants also used a strategy of putting a minimum focus on their disability and the pain that followed. To make that easier, participants got involved in different projects, such as work and leisure activities; for example swimming, floor hockey or family and friends. These activities had enabled them to feel engagement in their lives. A mental strength and an ability to find alternative solutions in difficult situations were also articulated in these narratives:

> "I think that all people have obstacles, it doesn't have to do with whether you sit in a wheelchair or not. I've always known that I can do things…for me it hasn't been a question of whether I can do something or not. It's about when I'll do it!"(3).

Feelings of Insecurity or Resignation

Some participants felt ambiguous about their social skills and their ability to participate in daily life. Several said they wanted to take part in an activity, for example: singing in a choir or attending swimming classes, but did not have the confidence or emotional strength to put this into action. An uncertainty about how they would be met by others stopped them from trying:

> "by others stopped them from trying; And other days I can feel that I'm just a burden. Like last fall I just felt like a burden all the time … it was hard for me even to go out and shop for milk. It was like everyone was watching me in a negative way"(13).

One participant said that her poor financial situation made her feel ashamed in social situations and sometimes like a second-class citizen, which in turn held her back from being socially active:

> "Sometimes I notice that people don't even want to look at me, and don´t talk to me. I feel that I'm probably an inconvenience for people. That other people see it like that. But it also has to do with my social situation... If I'd had nicer clothes and a nice car, people would take me more seriously"(9).

Several participants were conscious about the future, and their personal financial situation was described as unpredictable. A tougher political climate in Sweden was brought up as a cause for worry:

> "It's harder now and you don't know how it's going to be in the future. And if I really face the truth, I don't think that there are going to be any improvements in my case. I probably won´t ever get a job… I only hope that it won't get worse"(14).

Some participants articulated that they had been overprotected or that they had missed support in general during childhood. Participants expressed how their upbringing had had an influence on their self-esteem:

> "No, they (my parents) stopped me all the time, they never supported me in anything…and they've been very overprotective and they still are today. In fact, they didn't want me to get a driver's license, so they stopped me getting it. They told me that I could never do it. And in the end I believed them, and I cancelled my driving lessons"(13).

Participants who seemed more positive and confident participated to a greater extent than those who said they felt insecure. Therefore, the participant's expressed attitudes towards themselves in relation to others, played a vital role for their level of participation.

Discussion

To our knowledge this is the first study to explore experiences of social life and employment perceived by adults with SB and CP.

Participants described social and psychological consequences that they had experienced as a consequence of being unemployed for a long time. The results showed that the most important area of participation, according to the participants, was to have a job. Furthermore, participants who were content with their social relationships felt included and engaged in everyday life to a greater extent than those who had fewer friends or felt isolated. Access to a social life was thus important to achieve an experience of participation.

Employment

Participants explained how they wanted to feel valuable and able to contribute to society. Some participants thought of having a job as the equivalent of being like anyone else, which had a high priority. This is similar to another study which argued that participants gave priority to being independent and contributing to society (Yeung et al., 2008).

In this study, participants who were unemployed did not have an education beyond high school, whereas a majority of those who were employed did. Michelsen et al. (2005) found that the most significant factor in achieving employment in their study was education beyond high school. In addition, several previous studies showed that the frequency of higher education beyond high school is lower in participants with CP or SB than for the average population (Bjornson, Kobayashi, Zhou, & Walker, 2011; Frisch & Msall, 2013). This is presented for both developed and developing countries (Andersson & Mattsson, 2001; Michelsen et al., 2005; Tornbom, K., Tornbom, M., & Sunnerhagen, K. S., 2013).

A number of the participants had been fired from a job. According to the participants, this was due to their employers' financial situation and discrimination against disabled people in general. These findings are similar to those described by Kaye and colleagues (2011), who found that people with disabilities thought that ignorance and increasing costs were the main reasons for employers not to employ or to keep an employee with disabilities. It is also shown that prejudices and discrimination against people with disabilities sometimes have an impact on the labor market (Chacala, McCormack, Collins, & Beagan, 2014; Verhoef, Bramsen, Miedema, Stam, & Roebroeck, 2014). Previous studies have found that (part-time) paid work is one of the three most frequently identified problems among young adults with CP and that they consider problems with work to be very important (Livingston, Stewart, Rosenbaum, & Russell, 2011; Nieuwenhuijsen, Donkervoort, Nieuwstraten, Stam, & Roebroeck, 2009; Verhoef, Bramsen, Miedema, Stam, & Roebroeck, 2014). The Central Bureau of Statistics in Sweden states in a report that the possibilities of gaining employment after many years away from the labor market, and having a disability, are relatively low in Sweden (Central Bureau of Statistics, 2016).

The right for people with CP and SB to have and retain employment is of great value for their feelings of participation in society (Cope et al., 2013; Tornbom, Jonsson, & Sunnerhagen, 2014). However, this is not so much a question of the moral standards of citizens and politicians in general, as it is about what each employer considers profitable for business. Employers that are frightened of increasing costs or other problems are more likely to employ someone without a known disability (Kaye et al., 2011). Nevertheless, the way employers interpret the value of hiring someone with a disability is highly dependent on laws and general attitudes and prejudices about people with disabilities that exist in society (Barnes & Mercer, 2005; Shakespeare, 2013).

Social Life

According to the narratives of this study, a great majority of the participants had a small circle of friends and acquaintances, while some felt isolated or alone. These findings are similar to those of Jonsson and colleagues (2008) concerning adults with CP and their social life. Having a very small number of friends or not being part of a context in which you can form new relationships might result in feelings of isolation. Previous research has also shown that strong social support networks and community ties help people with disabilities to reduce negative stress and enhance their self-esteem (Tornbom, Tornbom, & Sunnerhagen, 2013).

Participants who said to be content with their social relationships felt included and engaged in everyday life to a greater extent than those who had few friends or felt isolated. These findings are confirmed by Yeung et al. (2008) who found that meaningful, social relationships increased feelings of inclusion and participation, while isolation and loneliness led to the opposite. For this reason, a person needs to be appreciated and accepted by others in order to fully participate in society (Livingston et al., 2011).

A previous study concerning young adults with CP and social participation has identified different supports that helped the participants in becoming more socially active (Stewart et al., 2012). Highly valued characteristics in this study were having social skills and a social personality. Additionally, the authors argued that these qualities might not be developed enough among participants who spent a lot of time by themselves (Stewart et al., 2012). Insufficient social skills, as a cause of loneliness, might therefore discourage people with CP and SB from taking initiative to create new relationships (Sawin & Bellin, 2010; Shakespeare, 2013).

Having a Few, But Important, Relationships

Half of the participants said they had a few close and meaningful relationships, although they did not see themselves as active members of society. A previous study about loneliness and friendship showed that some participants with CP explained that their current living situation did not support the development of friendships. Participants said they did not participate in social contexts where they could find new relationships (Ballin & Balandin, 2007). Yeung et al. (2008) pointed out another aspect of the social life among persons with CP. In order to participate in society, it is important to have the abilities and opportunities to form relationships on your own, without being dependent on, or getting too much help from someone else i.e. a personal assistant. In addition, only associating with a few assistants and your immediate family can result in a way of living in which a person feels comfortable in these contexts, although not participating in public spheres in society (Yeung et al., 2008).

Having a Social Life Online

In this study, being engaged in a social life online was considered a clever tool in creating new friendships and this form of socialization was mostly performed by the unemployed participants. These participants reportedly appreciated that they could be anonymous in social interactions online. Being able to avoid or not having to explain, or expose one´s disability was seen as liberation by some participants.

Personality and Characteristics

According to several studies, the severity of a disability is not a predictor for the perceived level of participation or quality of life (Albrecht & Devlieger, 1999; van der Slot et al., 2010). Nor did this study show a correlation between the extent of the disability and the experienced level of participation. However, we did find a correlation between the level of participation and personal characteristics that are presented in the results.

Van der Slot et al.(2010) showed that self-esteem can correlate with participation. The authors showed that a higher level of self-esteem was associated with enhanced participation among young adults with a disability, including young adults with CP. Our results indicate a similar phenomenon. Even though we did not measure the participants' level of self-esteem, we did notice that the participants who spoke more about their abilities and competencies also perceived a higher level of participation in their own lives. Our study also showed that participants who carried out and took pleasure in their current roles and were intellectually aware of their achievements, in comparison to what they could expect from their physical functions, experienced participation to a higher extent than those who found this more difficult.

Sorenson (2007) has investigated different variables associated to the nature of social experiences among persons with disabilities, such as; self-esteem and activity participation, which had a positive correlation to social participation. Additionally, according to Abraham et al. (2002) community participation appears to be related to a higher self-esteem in adults, or older participants, and it seems that participation also enhanced self-esteem in this group. These findings strengthen the line of argument that personality plays a vital role, when it comes to the experience of participation.

Conclusions

Participation in society was, by the participants, described as being part of a social context in which you are valued in a positive way. Having social support and sustainable relationships were considered key elements for a wider experience of participation. Furthermore, employment was important for the participants in this study to feel as though they were participating in society. Several participants described being fired from a job in an unusual way, without the possibility of reallocation or reemployment elsewhere. How the participants felt about themselves in relation to others also played a vital role for their experience of participation.

According to the Swedish government, the main goal is to create a social community based on diversity; a society designed to allow disabled people of all ages full participation in society. The foundation of the Swedish disability policy is that all people have equal value and equal rights (Lundalv, Larsson, Tornbom, & Sunnerhagen, 2012). However, it is important to keep in mind that equality not only stands for formal rights. It also means having equal opportunities in taking on various societal roles such as; employee, friend, student or member of an association. To reach these goals, society must take action and work against ignorance, negative attitudes and values on different levels (Yeung et al., 2008).

Limitations

A number of the participants in this study were members of a disability organization or politically active, which may lead to them being not entirely representative of the wider CP or SB population, as they were likely more able to communicate their opinions effectively. As researchers in the field of social work and rehabilitation, we may have brought our own professional perspectives to the research process. We recognize our subjectivity as inevitable and acknowledge that it might have influenced the way in which we conducted this study.

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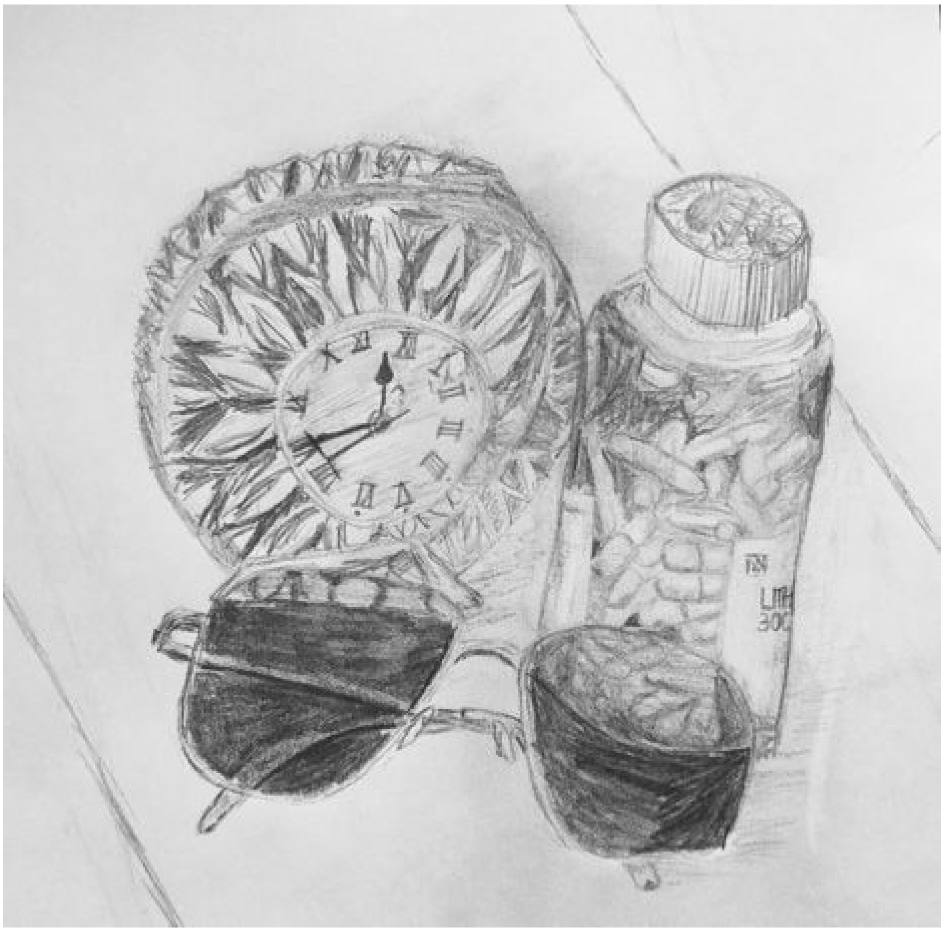
Creative Works

Three (or Infinite) Lenses: Translucent Still Life I

Kai Rands (PhD)



Description: A pair of folded sunglasses sits on a table in front of a round crystal clock with roman numerals and a bottle of capsules. The base of the clock and the bottom of the pill bottle can be seen through the top of the sunglasses. Part of the pill bottle label can be seen: "Lith. . .300. . . ."

Artist statement

The drawing prompts the viewer’s contemplation of lenses on three different levels. (By lens, I mean a device that transforms the user's experience in some way and designates a focus.) First, disability studies serves as a lens. Simi Linton (1998) has noted that disability studies is “a prism through which one can gain a broader understanding of society and human experience” (p. 118).

Second, on a literal level, the drawing includes three translucent objects that serve as lenses. The textures of the clock, the bottle, and the sunglasses create a proliferation of lenses refracting the viewer's focus in numerous directions. On this literal level, the lenses interact with one another so that the viewer has multiple views. For example, the sunglasses influence the experience of viewing part of the clock and part of the bottle, and hence, the view of some of the pills.

On a third level, the three objects prompt the viewer to contemplate the ways in which the objects function as metaphorical lenses. Time, represented by the clock, has served as a lens shifting my own experience of disability and disablement as well as designating different focuses. The disability studies perspective that nondisabled folks are "not presently disabled" draws on the lens of time to frame experience. Moreover, by problematizing the nondisabled/disabled binary, disability studies theorists point out that someone can be concurrently disabled and (en)abled in various ways, proliferating the lenses of time in the present moment. The other two items are also personally significant to me. Moods, and thus mood stabilizing medication, serve as lenses that affect my experience of the world. The third object, sunglasses, enables certain experiences of the world during migraines. Just as on the literal level the lenses interact with one another, on the metaphorical level, the lenses are experienced in ways that interact. For example, the experience of migraine can prompt shifts in mood and shifts in mood can influence the experience of migraine. Both can influence one's experience of time.

Dr. Kai Rands is an independent scholar, artist, educator, and activist focusing on queer and trans studies and activism as well as disability studies and activism.

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Best Practices

Infusing Disability Studies within Special Education: A Personal Story

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Abstract: Special education has historically been understood as a service provided to students with disabilities who are perceived to be too impaired to successfully progress in the general education curriculum and classroom. This perception has been reinforced through teacher preparation programs that rely heavily on the medical model of disability to prepare both special and general education teachers. While there is an increased push both legislatively and socially for more inclusive practices in education, this over-reliance on the medical model does little to nurture inclusive attitudes and worse, perpetuates deficit assumptions of disability. This paper seeks to explore how the infusion of Disability Studies into the teacher preparation curriculum might be used to foster more inclusive attitudes.

Keywords: disability studies, special education, teacher preparation

Introduction

I eagerly began my career as a special educator in 1993 as the lead teacher in an Early Childhood Special Education (ECSE) classroom in the [northeastern U.S. In the southwestern U.S.] My preparation program successfully prepared me for working with children with disabilities, which was reflected in my ability to identify developmental delays and effectively implement instructional and behavioral strategies to address them. I relied heavily on the disability-specific information I had acquired during my time as a pre-service teacher and successfully applied it in my new teaching position. Over the next 15 years, I continued to hone my practice and utilize my "specialized" training to teach students with disabilities in a variety of settings. In 2008, I decided to pursue my doctorate in special education and felt confident that I had acquired the foundational knowledge necessary to successfully complete my program. I rarely questioned my ability to meet the needs of my students and relied on my knowledge of disabilities to provide quality instruction. That is, until I began my second semester in my doctoral program. At that time, I was introduced to the field of Disability Studies, which encouraged the critical analysis of special education practices and interrogated the assumptions of the medical model of disability. I had no awareness of the medical or social models of disability and I was intrigued. This course was the catalyst for my professional transformation from an educator steeped in the medical tradition of special education aimed at "fixing" students, to an educator passionate about raising disability awareness and offering students opportunities to chart their own educational course. The field of disability studies has forever changed the way I understand, respond to, and teach all students. For this reason, I believe that integrating a disability studies perspective into the special education teacher preparation curriculum would offer a framework for interrogating the disability as deficit narrative reflected in many special education policies and practices.

The infusion of disability studies into existing special education teacher preparation courses could afford other students the opportunity to begin their careers as special educators armed with the professional knowledge that comes from a medical model perspective of disability and the dispositions that emerge from the understanding that disability is not merely a characteristic that exists in the person; it is a social, cultural, and political phenomenon (Ashby, 2012).

Prior to 1975 and the passage of the Education for All Handicapped Children Act, now reauthorized as the Individuals with Disabilities Education Improvement Act (2004), the very nature of having a disability often prevented children with disabilities from accessing educational opportunities. The perception that children with disabilities require substantively different educational approaches led to the development of two separate educational systems. The formulation of two separate categories of students, disabled and non-disabled, provided the rationale for educating students in separate programs and even in completely separate systems (Gartner & Lipsky, 1987). Through this best practices paper, I intend to analyze how special education, as practiced in the United States, is heavily informed by the medical model of disability, which suggests, “Difficulties in schooling belong to the student instead of being a product of school and student interaction” (Biklen, Ferguson, & Ford, 1989, p. 262). This perspective has tremendous implications for determining who receives special education services, what types of services are provided, how services are provided, and where they are provided. I will first present how the medical model is reflected in special education legislation, specifically addressing the evaluation process and the development of Individualized Education Programs (IEP). I will also explore how the medical model, left unchallenged, can serve to perpetuate narrow conceptions of disability as deficit. I will then discuss how the social model of disability could be used to interrupt the dominant discourse of the medical model and offer broader conceptions of disability as natural human variation. Finally, I will illuminate the challenges associated with maintaining a primarily medical model perspective of disability in the field of special education in the United States and how intentionally and systematically infusing a social model of disability perspective could be used to address these challenges citing specific examples from the Inclusive Elementary and Special Education program at Syracuse University.

Individuals with Disabilities Education Improvement Act (IDEIA, 2004)

Special education was originally conceptualized as a set of specialized services designed to ensure educational equity and access for students with disabilities (Ferri, 2008) who could not be “effectively” or “appropriately” educated within the general education environment. The initial special education law and subsequent reauthorizations involve six basic principles: 1) the right to access a Free, Appropriate Public Education (FAPE); 2) the development of an Individualized Educational Program (IEP); 3) the right to access services in the Least Restrictive Environment (LRE); 4) the right to an appropriate evaluation; 5) the right of parents and families to participate in each step of the special education process; and 6) the assurance of procedural safeguards to protect the rights of children with disabilities and their parents/families as they participate in the process (IDEIA, 2004). These six principles were intended to support the education of children with disabilities, however, in some cases they have served to maintain and perpetuate the exclusion of children with disabilities from the very educational opportunities they were intended to provide. Two of the six principles designed to ensure the appropriate education of children with disabilities have been criticized for their medicalized perspective of disability, which often result in exclusionary practices: the evaluation process and the IEP. In the next two sections, I will reveal how the medical model of disability is reflected in these two principles and the issues that arise related to the educational experiences and opportunities afforded students with disabilities. Additionally, I will present how the social model of disability could be used to address these issues and build a more comprehensive, holistic approach to the education of students with disabilities.

Non-Discriminatory Identification and Evaluation

In order for children with disabilities to receive special education services, it must be proven that their medical label or impairment is the “cause” of their educational difficulties and that special education and related services are the “cure” (Triano, 2000). The medical model of disability recommends a scientific approach to disability, which is mirrored in the educational evaluation process through which students are identified, evaluated and labeled based on a perceived “norm”. The evaluation process relies on the distinction between that which is “normal” and that which is “pathological” (Hardman, Drew, & Egan, 1996). This is problematic in a number of ways; 1. It assumes that evaluations are objective and useful; 2. It assumes that students with disabilities are fundamentally different from their nondisabled peers; 3.It is hyper focused on diagnosis and prescription, which places the student as the problem rather than the system; and 4. It has resulted in the overrepresentation of non-white students in special education (Skrtic, 1991). “Schools enact a form of ability profiling by relying on cultural narratives and deficit discourses, identifying, labeling, and sorting students based on their perceived risk rather than their potential or promise” (Collins, 2003, p. 192 as cited in Ferri, 2008).

In order for students with disabilities to receive special education services, they must be labeled according to one of the 13 disability categories described in IDEIA (2004). This too, assumes that students with disabilities can and should be assigned to a particular “category” in order to receive the most specialized instruction targeted to address identified deficits. While we are aware of the issues associated with labeling and categorizing human beings, we continue to engage in this practice under the guise of providing the most appropriate, individualized and specialized education for students with disabilities. From a medical model perspective, this is seen as useful and objective since students identified with a specific disability can be afforded access to instruction specially designed for working with individuals with that specific disability. However, focusing solely on remediating deficits fails to take into consideration other aspects of disability. In other words, hyper focusing on deficits associated with disability can result in more segregated educational placements, less opportunities to participate with nondisabled peers, and less time devoted to developing students' strengths and areas of interest.

Using a Balanced Approach to Eligibility Determination

The evaluation process is required in order for students with disabilities to receive special education services. That is an educational reality. The challenge then, is how to approach the eligibility determination process from a more balanced perspective that not only addresses deficits, but also identifies and capitalizes on students' strengths. From a social model perspective, the eligibility determination process should also take into consideration how the current instruction and educational placement plays a role in the students' inability to successfully progress in the general education curriculum and classroom. During the eligibility process, the classroom context is rarely taken into account (Harry & Klinger, 2006); it is only the student, not the system or larger educational context, which is deemed deficient and in need of intervention (Ferri, 2008, p. 418). To provide a more balanced approach to the eligibility process, the social model of disability would advocate for the examination of the broader classroom context including the teacher's personal perceptions of disability and his/her instructional and behavioral approaches and the student's experiences in a variety of school-related activities and settings. One way this could be accomplished is through a comprehensive classroom evaluation.

An evaluation that involves direct observation of the classroom and the instruction could provide critical information in the eligibility determination process. During direct observation, a professional, knowledgeable about the social model of disability, would evaluate the classroom and the instruction for accessibility. Is the student physically and intellectually able to access the content? What strategies are being used to support the student's learning? How is the student engaged in the instruction? How often is the student allowed to practice the skill and in what ways? Does the student have access to differentiated instruction? Are varied response formats offered? This type of structured observation would provide additional data that could inform the eligibility process.

Additionally, an informal interview of the classroom teacher by a professional knowledgeable about disability studies would also provide relevant information. The traditional eligibility determination process involves collecting information from the classroom teacher related to student performance. This approach would include exploration of the teacher's underlying perception of disability because as Pohan and Aguilar (2001) assert, professional beliefs and behaviors are shaped by personal beliefs. An interview that engages the classroom teacher in critical reflection on personal beliefs could result in changes to instructional delivery and increased access to content. Change hinges on our ability to confront potentially negative and/or outdated normative beliefs that determine who is worthy of an education, which students are deemed able, and who is pushed and who is left behind (Ullucci & Battey, 2011). Most teacher preparation programs view disability from a medical model perspective, which focuses on deficits and deviation. This perspective is likely to influence how instruction is delivered and to whom, which has important implications for evaluating students for special education services. Not only would this interview process examine how the classroom context plays a role in the academic progress of the student, it could provide a powerful opportunity for teachers to challenge deficit notions of disability.

Another method for achieving this balanced approach to eligibility determination would be to ensure that professionals involved in the process have a comprehensive understanding of the social model of disability. Most professionals in the field of special education come from disciplines heavily steeped in the medical model. For example, speech and language pathologists are trained to diagnose and treat speech related issues; occupational and physical therapists are trained to diagnose and treat fine and gross motor related issues; school psychologists are trained to evaluate and diagnose intellectual deficits; and special education teachers are trained to diagnose and remediate educational and behavioral deficits. To promote an evaluation process that would provide a balanced approach to disability determination would require knowledge of both the medical and social models of disability. Special education professional preparation should challenge individuals to think critically about the influence of the medical model on educational practices and offer a competing perspective from which to interrogate medicalized assumptions of disability. While this would be beneficial for the evaluation process, it would also provide an increasingly balanced approach to the routinely deficit-oriented approach to developing the IEP, which is the second principle of IDEIA that will be addressed.

The Individualized Education Program

Once a student is evaluated and determined eligible for special education services, an IEP is written. The IEP is an annually written educational program for each child with a disability who is eligible to receive special education services (Baglieri & Shapiro, 2012). This plan is intended to provide the framework for accessing a free, appropriate, public education (FAPE), which typically involves the determination of what services will be provided, how often they will be provided, and where they will be provided. Determining what services will be provided is theoretically dependent upon the needs of the student rather than the student's disability, however historically the educational setting is often aligned with the disability diagnosis (Baglieri & Shapiro, 2012). For example, students who are eligible for special education services because they are cognitively impaired often receive services in a segregated classroom for students with cognitive impairment rather than in general education with their same-age peers. Though this is somewhat less prevalent today, it continues to remain problematic for students with disabilities such as Autism, moderate to profound cognitive impairments, and severe emotional impairments for whom specialized instruction in segregated programs is often recommended (Kurth, Morningstar, & Kozleski, 2014).

The medical model of disability is reflected in the IEP as it serves as the framework for providing specialized instruction based on the student's disability-related deficits. The section often referred to as the "heart of the IEP" involves a detailed description of the child's current levels of academic performance and describes how the disability affects his/her participation in general education (Baglieri & Shapiro, 2012). The sharing of all assessment data related to the student's academic and behavioral performance, which must indicate a significant deviation from grade-level norms, provides the rationale for the provision of special education services. Students in special education are operationally defined with reference to their position on the normal curve (Cochran-Smith & Dudley-Marling, 2012). Once this information has been clearly outlined, the remainder of the IEP is developed around the academic, behavioral, and/or transition needs of the student. This includes the development of measurable educational and functional goals and objectives, methods for measuring progress, a description of the supplementary aids and services to be provided, and identification of classroom and assessment accommodations. While the IEP is intended to be "individualized" for the student, recent proliferations of online IEP development software have reduced this to a list of drop down (menu) options for goals, objectives, and accommodations.

A Balanced Approach to IEP Development

The prescriptive nature of the IEP aligns with medical model perspectives where the primary concern is the proper diagnosis of the disability and the implementation of appropriate treatment (Baglieri & Shapiro, 2012). "Steeped in medical and deficit models of disability, special education positions disabled students as objects of a clinical and diagnostic gaze that leaves little room for alternative ways of knowing about disability experience" (Ferri, 2008, p. 421). From a social model perspective, the IEP provides an exceptionally narrow view of the disabled student and offers only one small section to record the student's strengths and one small section to discuss parents'/families concerns for their child's education. This seems counterintuitive to an educational document that is intended to assist in the development of an individualized education plan. The individuals involved in the evaluation process are typically the individuals that are also involved in the development of the IEP. Therefore, if the professionals involved were knowledgeable about the social model of disability, they could facilitate the development of a more student-centered, rather than deficit-based, IEP. "The thrust of social models is to interrupt the dominance of the medical model, in order to more fully understand and challenge the ways that deep-seated assumptions and beliefs about the nature of impairment and disability prevent the equal participation and status of disabled persons" (Baglieri & Shapiro, 2012, p. 29).

The Present Level of Academic Achievement and Functional Performance (PLAAFP) currently focuses on reporting data related to student progress in effort to identify academic and behavioral needs that will be addressed throughout the remaining sections of the IEP. While this section is designed to focus on student deficits it is equally as important to consider how the classroom and instructional approaches utilized serve to support or challenge the student's ability to progress in the general education curriculum. This section should provide a more comprehensive and holistic view of the student, which would include strengths as well as needs. The implementation of direct classroom observations and semi-structured interviews of classroom teachers during the evaluation process would yield important information to inform the development of the IEP. One section of the PLAAFP addresses the student's ability to make progress in the general education curriculum, which aids in the identification of accommodations that will be offered to increase the student's ability to access and make progress in the general education curriculum. The data collected through direct classroom observations and the teacher interview during the eligibility determination process would be useful for identifying ways the classroom environment and instruction could be structured to promote student learning. For example, if it is discovered through classroom observations and teacher interview that the student responds well to visual representation of information, then this should be included in the PLAAFP or if the data reveals that the teacher offers limited opportunities for the student to respond orally versus in writing, this could be indicated in the PLAAFP, which would support the development of appropriate accommodations. In this way, the PLAAFP would provide a more comprehensive overview, which would more accurately and appropriately inform the development of goals, objectives, and supplementary aids and services.

In order to move away from a deficit-oriented approach to special education, professionals in the field must have knowledge about the models of disability and how they have influenced the development of special educational theories, policies, and practices. This could begin with the preparation of special educators.

Promoting a Balanced Approach Through The Preparation of Pre-Service Teachers

Historically, special education has looked to behavioral psychology, medicine, and psychometrics for its theoretical grounding (Cochran-Smith & Dudley-Marling, 2012) and in turn, its preparation of special education teachers. Until recently, teacher preparation programs were predominantly categorical in focus and were designed for the purpose of training individuals to teach students with specific disabilities. This assumes that the categorical markers and characteristics of various disability labels are the most salient ways of knowing about student disability in schools (Young & Mintz, 2008). From this perspective, effective teaching of students with disabilities is a matter of identifying the requisite skills that comprise learning and determining the skills in which students are deficient and then identifying the most effective methods for teaching these skills (Cochran-Smith & Dudley-Marling, 2012). Given that much of special education teacher preparation is grounded in the medical model, I believe it is critical to raise pre-service teacher's awareness of the social models of disability in effort to interrupt the dominant medical model perspective that narrowly views disability as "…a fixed and identifiable construct, an immutable part of the person" (Ashby, 2012, p. 91).

An underlying assumption in the quest for recruiting, developing, and retaining effective special education teachers, is that who teaches our students matters a great deal

(Rock & Billingsley, 2015). If this is the case, it stands to reason that preparing future special education teachers for working with students with disabilities and their families should also include a foundational understanding of the social model of disability that addresses the social and political contexts that create and perpetuate hierarchies of ability and disability (Ashby, 2012). The intention of this paper is not to suggest that the social model should replace the medical model of disability, rather that the social model should be used as a way to interrogate and challenge the assumptions inherent in a medical perspective of disability that "…reduces human variation to simple and concrete binaries: able-bodied/disabled and normal/abnormal" (Douglas, 1966 as cited in Ashby, 2012, p. 91). A balanced approach that recognizes the contributions of the medical model while simultaneously challenging its over-reliance on the normal/abnormal binary using the social model of disability would strengthen the professional preparation of pre-service teachers.

Teacher education programs are responsible for preparing pre-service teachers to engage in the professional discourse of special education as practiced in the U.S., which means providing knowledge related to the 13 disability categories, characteristics frequently associated with specific disabilities, administering and interpreting assessments, and identifying and implementing evidence-based strategies for teaching students with disabilities. These concepts are also reflected in the Council for Exceptional Children (CEC) Ethical Principles and Practice Standards, which inform much of the practice of preparing special education teachers. CEC is the largest international professional organization dedicated to improving the educational success of disabled students and is exceptionally influential in the field.

A Balanced Approach to Teacher Preparation

The benefits of infusing a disability studies approach in the traditional preparation of special education teachers includes encouraging pre-service teachers to consider how special education terms such as; disability labels, categories and programs take on meaning for the teachers and staff and become cultural signifiers of student's abilities and potential for inclusion and future academic success (Ashby, 2012). For example, when presenting pre-service teachers with information related to the disability category, cognitive impairment, from a medical model perspective, the focus would be on how the Intelligence Quotient (IQ) is used to determine whether a student has a cognitive impairment and the common academic and behavioral characteristics associated with cognitive impairment. This type of instruction, left unchallenged, could lead teachers to believe that students with cognitive impairments do not belong in classrooms where they are required to use higher-level thinking skills and instead have him/her receive math instruction in a different classroom where s/he can focus on basic math facts (Ashby, 2012). Infusing a disability studies perspective would encourage pre-service teachers to critically analyze how labels may be used to categorize, stigmatize, and exclude students with disabilities from educational opportunities that could enhance post-secondary outcomes.

There are a variety of ways to infuse disability studies into existing special education teacher preparation programs rooted in the medical model of disability. For example, hiring professors with a background in disability studies and special education would provide opportunities to naturally introduce disability studies perspectives within the program's existing content. This also provides an avenue for raising faculty's awareness of various disability models and could lead to collaboration and co-teaching of existing courses. Syracuse University offers an Inclusive Elementary and Special Education program where all students are prepared to apply for dual certification in elementary and special education upon graduation from the program. Their program has successfully infused a disability studies perspective with the goal of preparing all elementary teachers for teaching all children. Their program reflects key tenets of disability studies including "…listening to and learning from individuals with disabilities and their parents and guardians as experts on the experience of disability, a commitment to integrating technical information about teaching and learning while at the same time understanding that teaching includes subjectivity as well as conscious theoretical framing" (Ashby, 2012, p. 90). To achieve this, Ashby (2012) describes several core assignments implemented as part of the program such as:

1. Conducting classroom observations for the purpose of noting the language used by the teacher or teachers and how that language positions students in the classroom.
2. Required readings that address the overrepresentation of students of color in special education and the ways in which labeling, special education, and tracking have been used to resegregate students of color.
3. Assigning first person narratives as a way to consider multiple perspectives.
4. Guest speakers with disabilities are invited to share their experiences of disability and to share their expertise in other areas as well.
5. IEP development stresses the role of parent, family, and student involvement in all phases of the process.

These types of assignments could be easily implemented within a traditional teacher preparation program however, to achieve the most favorable outcome, the instructors and faculty should be knowledgeable about disability studies and eager to engage students in critically analyzing the ways in which special education is implemented in practice.

Conclusion

Balancing the medical model approach with the social model approach to disability within the requirements of IDEIA (2004) and pre-service teacher preparation would offer a more comprehensive understanding of disability. This holistic approach would support and promote the development of a truly "individualized" program for students with disabilities where the classroom context, instructional approaches, and student performance were all considered equally as part of the evaluation for and implementation of special education services. If disability is perceived as the complex interplay of impairment with broader social and environmental contexts, then it is critical to include an examination of the classroom environment and the instructional approaches used to educate students with disabilities. The student cannot continue to be the primary focus in the evaluation for special education services if we are to effectively and appropriately offer specialized educational programming. We must also consider how the educational environment contributes to or minimizes the impact of the impairment through direct classroom observations and teacher interviews conducted by experts in both the medical and social models of disability.

In this time of rapid educational reform, pre-service teacher preparation programs must analyze their current practices and evaluate their effectiveness for preparing high-quality, future special educators for increasingly diverse classrooms. While preparation informed by the medical model of disability is necessary for ensuring that pre-service teachers are knowledgeable about how special education services are delivered across the U.S., it does little in the way of preparing them for addressing how disability is defined and represented in society. If the goal of education is to prepare students for the complexities of adulthood, it seems pertinent to ensure that future teachers have a comprehensive foundation for understanding disability from multiple perspectives.

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