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Editorial

Cripping Concepts: Accessibility

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Accessibility is a keyword for disability studies, one that is often taken for granted in its everyday deployment. According to the Oxford English Dictionary, use of “accessible” as an adjective dates to the fourteenth century when it denoted being “capable of being entered or approached” and “readily reached.” It was not until 1961 that “accessible” began to signify the ability to be “readily understood.” As a noun, “access” derives from the fourteenth-century Old French “acces” (signaling both the “coming on” or “attack” of an illness or emotion) and from the Latin “accessus” (“a coming to, an approach”). Within these etymological origins there resides a tension between “access” as a kind of attack and “access” as an opportunity enabling contact. This tension is important for disability scholars and activists as the dual inflection of both attack and contact highlights the centrality of the boundary work of inclusion and exclusion to all forms of struggle within disability politics, studies, and activism.

Such boundary work is apparent not only in the historical emergence and circulation of “accessibility” as a concept but also in our everyday accessible practices within disability studies and disability activism. For example, within the history of social movements, use of “access” as a noun emerged throughout the eighteenth and nineteenth centuries as it became associated with the US liberal politics and calls for “equal access” to public accommodations regardless of race or color. The use of “access” and “accessible” dramatically increased from the 1950s onward as a result of developments in civil rights, the rise of disability rights struggles, and new forms of technology like the personal computer and the sidewalk curb cut designed to improve urban-landscape navigability. With this usage, “access” denotes a kind of opportunity. According to Bess Williamson, it conveys “the importance of recognizing external barriers that prevent disenfranchised persons from gaining access to resources” (2015, 15). This meaning is perhaps expressed most obviously through the International Symbol of Access (1969), the ubiquitous white graphic depicting a wheelchair user, faced to the right, presented on a blue background (Fritsch 2013). This symbol is deployed to depict access to ramps, elevators, and entrances easily entered by wheelchair users.

In contemporary usage, gaining access to resources is the primary meaning “access” takes, where people clamor for “access to jobs,” “access to healthcare,” and “access to housing”

(Williamson 2015, 15). Through “accessibility,” people can participate in or access something that would otherwise exclude them on the basis of mental or physical impairment, educational or class status, gender identity, or other factors. With this particular usage, “accessibility” is primarily achieved through a “checklist approach”—something can be deemed accessible when a space is barrier-free for people using wheelchairs, has non-fluorescent lighting, has gender-neutral washrooms, where American Sign Language interpretation is available, is free or has sliding-scale fees, has integrated a range of ways for people to participate, offers childcare, is scent-free, et cetera. As a checklist approach to inclusion, “accessibility” conforms to an understanding in which difference is an individual problem to be accommodated. By accommodating and including individuals in this way, the fight for accessibility draws upon and reiterates the liberal rights-based approach to social change. Consequently, it is valorized and celebrated as a self-evident good that solves (or might eventually solve) the problem of exclusion.

When used in this way, “access” is generally conceived as an individual state of affairs in which the problem of exclusion to be resolved arises within a particular body incapable of gaining access. By taking accessibility into account and by providing “equal access,” this problem is ostensibly solved. However, behind this conception resides the assumption that some bodies naturally fit whereas others need “access.” As such, the socially just thing to do is to extend access to those who do not easily fit. In this way, demanding access to a space or event can inadvertently reinforce the naturalization of “able” bodies while reinforcing the individualization of impairment, class or educational status, and gender identity. As disability scholar Tanya Titchkosky has pointed out in The Question of Access: Disability, Space, Meaning, this is because “access” is not solely about a lack of inclusion; instead, it is a way of “perceiving, talking, and acting” (2011, 13) that is concerned with some aspects of everyday-life access while others remain unnoted. Although every instance of life could conceivably be regarded from the standpoint of access (since establishing access is the precondition to doing anything), current conceptions tend only to implicate those considered abnormal or who do not easily fit into activist spaces as normally constituted. “The fight for the rights to access may get people in,” Titchkosky notes, “but that is only half the issue.” In her view, “developing critical relations to access that are committed to recognizing how it already interprets embodied difference is the other half” (2011, 28). In this way, “access” can rectify exclusion; however, such efforts remain incomplete without a critical assessment of how those exclusions first came to be and how they continue to function.

Despite attempts by disabled activists to emphasize that it is not the problem of any individual body but rather social relations that set up barriers to access, contemporary mobilizations of “access” tend to reinscribe the idea that access is about some bodies and not others. In this way, and despite the “social model” advanced by many disability activists, the problem is once again individualized. In its dominant figuration of disability access (a wheelchair user who requires a ramp, elevator, or automatic door opener), the International Symbol of Access makes this tension emblematic.

For radical disability activists, the tension in “accessibility” also arises from use of the term to denote inclusion in an unjust system—or, as activist organizer AJ Withers (2015) terms it, “accessing privilege.” In this view, a truly radical approach to accessibility requires considering the tensions between “accessibility” as a solution or checklist versus “accessibility” as an ongoing negotiation. For radical disability activists, the potential of “accessibility” is precisely to mark “access” as an ongoing and shifting process rather than as a mode of solving individualized problems. As disability justice activist Mia Mingus (2014) remarks, “we need to go beyond just inclusion and beyond just trying to make spaces accessible” in order to ask what liberatory access would look like, not only for disabled people but for “all of our communities.” One strategy for achieving this reformulation can be observed in what Mingus (2011) has termed “access intimacy.” Here people are encouraged to “get,” “understand,” or anticipate someone’s access needs and, in so doing, produce or practice “crip-made access” and “crip solidarity.”

But even as we begin reimagining “accessibility” as a shifting process rather than as a mode of solving individualized problems, and even as we present “accessibility” as a self-evident good, it remains common practice to deliberately limit access in all sorts of ways. And so, while “accessibility” is regularly presented as a way of extending social inclusion to those who have historically been marginalized by ableism or other forms of oppression, this conception of “access” regularly (though rarely explicitly) comes into conflict with “security culture,” “safe space,” or forms of intellectual engagement such as dense theoretical writing or complicated word usage not deemed to be “readily accessible.” Like “accessibility,” these forms of exclusion are also commonly presented as a self-evident good, in which access is deliberately restricted for some in order to create a different kind of access, or community, for others. Importantly, the access barriers created by “security culture,” “safe spaces,” or through particular kinds of intellectual engagement like “inaccessible” writing, are usually taken to be necessary. Indeed, these practices are often necessary in order to create boundaries to achieve certain goals (scholarly, activist, otherwise). The result is that the assumed good of creating access is pitted against the assumed good of creating community, or deepening our understanding of our ourselves and our world. Here, far from being a self-evident good, “access” functions as a kind of attack upon boundaries that have been constructed for a particular purpose. Thus, while frequently proclaiming the good of access, scholars and activists contradict this proclamation through everyday exclusionary practices that are deemed necessary and important. Balancing exclusion and inclusion requires that we are able not only to recognize the difference but also to enact that difference through the opening and closing of those boundaries we control.

And yet the question remains: how might we address the divide in practices between celebrating access and acknowledging the need for particular exclusionary spaces? If, despite its violence, exclusion is a category we want to embrace in certain moments (for example, in calls for sovereignty or in contests over occupation), then it may be through “access” as a boundary practice denoting both “contact” and “attack” that we might find the means of navigating this fraught terrain (Fritsch 2016).

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Research Articles

# Understanding Disability from the Views and Experiences of Taiwanese People with a Physical Disability

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**Abstract**: This qualitative study explores the experiences of 7 Taiwanese people with physical disabilities in Taiwan through three in-depth interviews with each participant. Despite disability legislation, participants identified experiences of community exclusion. We argue that their exclusionary experiences reflect embedded cultural attitudes and call for greater recognition of these influences to help foster inclusion of disabled people in Taiwan. Recommendations for researchers and policy-makers are provided.

**Keywords**: disability; qualitative research; Taiwan

# Introduction

Taiwan is located in the middle of the Western Pacific festoon of islands; although its total area is only about 36,000 sq. km, it serves an important role as an East Asian crossroad (Department of Geography at National Taiwan Normal University, 2001). Today's Taiwanese society is a result of various cultural influences over a long period. In the 17th century, Taiwan had been occupied by Dutch settlers for 38 years (1624-1662). In 1661, the Ming Dynasty's Zheng Cheng-Kung defeated the Dutch and Taiwan was unified with China. Since then, an increasing number of Han Chinese from the southeastern coast of China immigrated to this nearby island, and during 1895-1945, Taiwan was occupied by Japanese settlers. In 1949, the Republic of China government withdrew from Mainland China and moved to Taiwan where it remains this day (Department of Geography at National Taiwan Normal University, 2001). Currently, the population in Taiwan is estimated at 23,483,793 (Department of Statistics Ministry of the Interior, 2015).

In Taiwan, the “People with Disabilities Rights Protection Act” (referred to simply as the disability legislation) is the most important social welfare policy for this group of people (Ministry of the Interior, 2009). It was enacted in 1980, and the latest amendment in 2015 aims to “protect the legal rights and interests of people with disabilities, secure their equal opportunity to participate in social, political, economical, and cultural activities fairly, while contributing to their independence and development” ("People with Disabilities Rights Protection Act," 2015). However, as a result of people’s preconceived ideas and the government’s insufficient promotion of more enlightened attitudes, many Taiwanese people see disability as a punishment, and some fear that it might be contagious (Department of Social Affairs of the Ministry of the Interior, 1994; Holroyd, 2003; Huang et al., 2009). The stereotyped view of the Taiwanese public is to see people with a disability as being inferior to others. Therefore, for example, non-disabled people might think individuals with a disability are of no use to society because they need to be taken care by others for their entire life. Disabled people are expected to fight against the difficulties they encounter with great effort, rather than expect their community to make accommodations for them (Department of Social Affairs of the Ministry of the Interior, 1994; Holroyd, 2003). Thus, a common attitude toward disabled people is that they are objects of charity. Consequently, there are many instances of discrimination against disabled people, despite legislation against such discrimination (Department of Social Affairs of the Ministry of the Interior, 1994; Wang, 2002; Y. L. Wang, 2010a, 2010b). The inequitable treatment of people with disabilities in Taiwan means that they are more likely to be isolated and segregated, stigmatized and considered to be a disadvantaged minority (Hsieh, 1997; Wang, 2002; Yuan, 1981).

In Taiwan, the three strongest influences on the cultural understanding of disability are traditional Buddhist beliefs, Confucianism and the Chinese language, which all have significant impacts on Taiwanese values, attitudes and behaviors in the interactions that occur between the individuals and society (Berry, Poortinga, Segall, & Dasen, 2002; M. Y. Chang & McConkey, 2008; Charlton, 1998b; Huang, Fried, & Hsu, 2009; Iwakuma & Nussbaum, 2000; Miles, 1995, 2000, 2002; Shih, 1996).

# Buddhist Beliefs as a Cultural Influence

Buddhist beliefs such as reincarnation and karma have an important influence on the cultural understanding of disability in this context (Holroyd, 2003; Huang et al., 2009; Miles, 2002). In Buddhism, reincarnation means people have cycles of lives and karma refers to how people’s right and wrong conduct in the past influences their deserved happiness or their suffering in the present (Miles, 2000). Having a disability is seen as a type of temporary suffering in this existence because of personal wrongdoing in earlier lives. Being reborn disfigured or suffering humiliation in karma is more usefully interpreted as an educational force, making progress towards perfection rather than as a retributive destiny (Miles, 2000).

**Confucianism as a Cultural Influence**

Additionally, the Chinese family and relationships among its members have been deeply affected by Confucianism. As Holroyd (2003) states, parents, influenced by Confucian teachings of a duty-bond obligation to be a “right and proper” person (p. 4) and of “bringing honor and avoiding disgrace to the family” (p. 5), expect their children to become successful people in society and bring honor to their own family (Chou, 1998; Holroyd, 2003; Kuo & Kavanagh, 1994; Shih, 1996; Szalay, Strohl, Fu, & Lao, 1994). Therefore, having a child with a disability challenges the traditional philosophy of Confucianism in several ways. First, having a disabled child disturbs family harmony, because he or she cannot be expected to conform to social and cultural norms, such as how to behave respectfully and appropriately (Holroyd, 2003; Huang et al., 2009). Secondly, parents of adult children with a disability cannot expect their offspring to care for them in old age. They also have to take care of their adult children for longer than would otherwise be necessary, a situation that challenges the Confucian notions of reciprocity and parent-child obligations (Holroyd, 2003). Having a disabled child is therefore seen as a shameful thing for many Chinese families because the family is apologetic to its ancestors; having such a child also implies unsuccessful social performance because it does not meet the cultural expectation of bringing honor or reputation to the family (Yueh Ching Chou, 1998; Holroyd, 2003; Huang et al., 2009; Iwakuma & Nussbaum, 2000; Mink, 1997; Shih, 1996). The belief that disability stems from supernatural causes leads to two extremes in attitudes toward disabled people: “Either overprotectiveness or discrimination” (Iwakuma & Nussbaum, 2000 p. 242). Such is the case also in Taiwan. On the one hand, new-borns with a disability in Taiwan might lack care and love, because their family members are ashamed of having a disabled child, and thus feel that they have lost face. On the other hand, a disabled child might be overprotected by their family members, because of the strong obligation of family ethics to look after their disabled family member (Holroyd, 2003; Iwakuma & Nussbaum, 2000; Kuo & Kavanagh, 1994; Shay, 1990; Shih, 1996; K. Y. Wang, 2002).

# Language as a Cultural Influence

One of the keys to understanding attitudes toward disability in a specific culture is language (Charlton, 1998a). Charlton (1998a) states that “the words used to describe disability are loaded with social connotations” (p. 66). Stone (1999) says that in Chinese culture “both impairments and illness are constructed as products or signs of imbalance: internal imbalances of yin and yang, heat and cold; external imbalances in family and social relations, between ancestors and descendants, spirits and mortals, rulers and subjects” (p. 140). Moreover, many Chinese characters with offensive meanings that are used to refer to people with a disability, such as “idiot”, “simpleton” or “mad person”, contain animal radicals or components related to evil spirits or lifeless objects (Stone, 1999). This use of dehumanizing and Otherness-creating symbols signifies the cultural attribute of intolerance and non-acceptance of disability within Chinese culture (Stone, 1999). The interlacing of the influences of traditional Buddhism, Confucianism, and language has led to the cultural understanding of disability in Taiwan where people with a disability have tended to be excluded from their own culture, because of the negative perceptions towards disability.

# The Need to Investigate the Views and Experiences of Taiwanese People with a Physical Disability

While there is a growing body of research in Taiwan on disabilities, most studies have focused on people with intellectual disabilities and their families. For example, Chou and other co-authors (2007) applied Cross-Cultural Quality of Life Indicators to understand the life quality of adults with intellectual disabilities who live with their families in Taiwan. Their findings suggest that although many people with intellectual disabilities live in the community, they are isolated and segregated with their perceptions of social inclusion scoring at the lowest level. Furthermore, Chou, Pu, Lee, Lin and Kröger (2009) studied how aging female family carers of adults with an intellectual disability or mental illness perceived the impact of stigma on their life quality in Taiwan. These authors applied four scales to measure the carers’ perceived stigma, health, social support and quality of life. They found perceived stigma had the most negative impact on quality of life for these two groups of aging, female carers.

Yet, while the number of registered disabled people in Taiwan is increasing each year (in 2012, the Monthly Bulletin of Interior Statistics identified 1,104,849 people with disabilities accounting for about 4.75% of the overall population) it is people with a physical disability who account for the largest group of the disabled in Taiwan, with those that only have a single physical disability accounting for around 34% of the total, and those having multiple disabilities accounting for 10%.

Vehmas (2004) points out the importance of listening to the lived experiences and perspectives of people with a disability for conceptualizing a realistic understanding of disability. He says:

“The way people without impairments view people with impairments and their chances for well-being and good life inevitably is based on their experience and point of view as nondisabled persons. Thus, when defining disability, without hearing the subjective voices of those seen as disabled, we can only construct an external, the kind of ‘objective’ model that does not explain much of individuals’ experiences – it would merely be a projection, ‘our’ view of ‘them’” (p. 220).

Thus, the need to explore in depth the everyday lived experiences of people with a physical disability, living in the Taiwanese cultural environment is essential to a deeper and wider understanding of their lived experience of disability in this context (Chiu & Han, 2010; Lin, 2012). The purpose of this study is to explore the views of individuals with a physical disability in Taiwan about their ordinary everyday lives with a disability in the community, and to have these views acknowledged.

This study was approved by the Human Research Ethics Committee of Queensland University of Technology in Australia.

# Methods

## Sample

The main aim of this study was to explore the understanding of disability from a Taiwanese perspective, based on the views of disabled people. In line with this research aim, purposive sampling was used to locate and recruit participants from two non-government disabled welfare organizations in two counties of Taiwan. Researchers used purposive sampling to locate particular types of people for in-depth investigation (Neuman, 2004). Purposive sampling facilitated the exploration of a deeper understanding of a specific field of study which the participants (with their experiences as a person with a physical disability living in Taiwan) were able to provide, rather than representing the larger population of this group of people. Participants were invited from two disability organizations. Interested participants were then invited to contact the first author directly by return mail, e-mail, or phone call. A total of seven native participants took part in this study, and have been given the following pseudonyms: Pearl, Joyce, Hilda, Venice, Judy, Yugo and Mary. All participants either lived in urban areas, or shifted between rural and urban areas. Background information on the participants is given in Table 1.

# Table 1: Background information of the seven participants

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
| Participants | Gender | PhysicalDisability | Age | Job(Full time) | Institutional-ized Experience | Living situation |
| Pearl | Female | Poliomyelitis | In thirties | Office clerk | Yes | Alone |
| Joyce | Female | Muscle Fibrosis in left leg | In twenties | Office clerk | No | Family |
| Yugo | Male | Cerebral Palsy | In twenties | Student | No | Family |
| Mary | Female | Poliomyelitis | In fifties | Booking clerk | Yes | Family |
| Hilda | Female | Spinal Cord Injury | In sixties | None | No | Family |
| Judy | Female | Poliomyelitis | In fifties | None | Yes | Family |
| Venice | Male | Poliomyelitis | In fifties | Running a shop | Yes | Alone |

#

# Procedure

After obtaining each participant’s consent, the first author conducted three in-depth interviews with each participant. She interviewed each participant once a week for as long as it could match their schedule. She also allowed sufficient time between interviews for participants to think about what living with a physical disability means to them and reflect on the issues raised in the interviews. The interviews lasted from one and half hours to three hours and were held at participants’ homes, as agreed to by both the first author and the interviewees. This ensured the participants’ comfort and control of the interview process. Member checking (Creswell, 2007, 2013) was used to assist the credibility of the findings, and was undertaken by the first author with study participants following each interview session to see whether the interviewer’s understanding of the information obtained in the previous interview session was correct. With the participants’ agreement, the interview was audio-recorded and then transcribed.

# Analysis

The grounded theory approach was adopted to guide the data analysis process with its emphasis on beginning inductively and returning to the data deductively to construct a unique understanding of living a life with a physical disability from the perspective of the study participants (Charmaz, 2003, 2006). In line with Charmaz (2003), the interview data were coded to identify central themes, patterns, ideas, and concepts existing within the data (Hesse-Biber & Leavy, 2006). Furthermore, memo writing was used extensively throughout the data analysis process to elaborate emerging concepts and to stimulate new ideas by reading through and sorting memos (Charmaz, 2006; Hesse-Biber & Leavy, 2006). Writing and comparing memos continuously throughout the research process helped the researchers to remain immersed in the analysis and to discover concepts (i.e. categories and their subcategories) which were able to reflect the interview data. This process, in turn, led to an increase in the level of abstraction of the analysis (Charmaz, 2006).

# Results

With the focus of the present study on presenting participants’ understanding of disability from their lived experiences and views of living with a physical disability, the grounded theory “it is more than just the impaired body” developed from a wider study is not included here, but interested readers can refer to Lin, Knox, and Barr (2014) for details.

The findings showed participants felt excluded from society because of their physical disability, and spoke of their desire for greater inclusion. Specifically, grounded in participants’ views and experiences of living with a physical disability in Taiwan, three themes were identified by the researchers. These are described below.

## The Importance of Social Networks

The participants raised many issues in relation to their social relationships in the interviews, with the three main relationships being family relationships, friendships, and intimate relationships. Firstly, the family played a key role for most participants in supporting them to live their life as a person with a physical disability in a way they wanted to. Because the participants felt excluded from other non-disabled members of their communities, they felt terrified at the prospect of living without family support. Sustained family support was thus the most significant form of support in many of the participants’ lives, and the loss of this was seen as a disaster. For example, Mary lost significant family support because of the death of her husband and the growing up and moving away of her children. In addition, aging was making her body even weaker. She said, “If no one is here, what should I do!?” [Mary’s emphasis, sounding anxious]. Although the participants wanted to have sustained family support, they also expressed two concerns. The first one was becoming a burden. For example, Hilda very poignantly pointed out the following situation with her daughters, “Now…they are encumbered with financially assisting me. They also need to eat and to raise their children.” The second concern was about losing their current support. Yugo and Joyce relied heavily on their parents’ support. However, they understood that this would be gone after their parents died. As Joyce said, “It is impossible to depend on them my whole life.”

The participants also shared many of their experiences of, and perspectives about, friendship. Some stated that they felt happy and could get support from their friends. For example, Yugo stated, “I enjoy very happy and lively interactions with them!” In contrast, some participants said they felt lonely because they lacked friends. For example, Pearl talked about a lack of friendships. She said, “In my heart, I feel friends are far away from me and I don’t have friends.” Participants with good friendships stated that these friendships were based on the qualities of reciprocity and companionship, so they could receive emotional and physical support from their friends. For example, Yugo described reciprocity as follows: “They help run errands for me and lift me in and out of the car. And I help them with their assignments. Sometimes I also have to play a role as a psychological counsellor to resolve their emotional problems.” Some participants stated they made efforts to manage their friendships, and others encountered many difficulties in developing such relationships.

In addition to the common experience of being excluded from friendship, participants reported that they experienced great difficulties in building intimate relationships. For example, after Joyce experienced having a short intimate relationship with a non-disabled boy, and absorbed the social attitudes from people around her, she found this prospect had been hampered by her disability:

“My mum said if my foot were not like this, I might fall in love very easily. Because I have heard it for a long time, if my foot were not like this today … perhaps I would have a boyfriend waiting for me already. Perhaps I would have already walked into the church to get married.”

As for the further development of a romantic relationship into marriage, participants felt that such a relationship was unlikely with a non-disabled person. For example, Venice stated that, “A handicapped person marrying a non-handicapped individual divorces easily!” More specifically, the participants saw considerable difficulties in developing intimate relationships, because they felt that non-disabled people saw them as a burden and/or as asexual. Venice recalled how a non-disabled person questioned his sexual ability. He recounted, “He asked me, ‘If you went to…a red-light district, how would you do it?!’...So the handicapped like us also give people a feeling. You are all out of order!” Therefore, intimate relationships seemed the most difficult kind for most of participants to develop, with Joyce noting sadly, “I think it is a thorny path!”

## Little Support from Disability Legislation

The participants also stated that one of the factors influencing the way they understood disability was disability legislation in Taiwan, with their views on this being marked by feelings of economic insecurity and a general lack of support. First, the participants stated that their employment rights were not guaranteed by the legislation, and noted that many employers in Taiwan would rather pay a penalty than hire a disabled individual. Yugo stated, “A boss might not care about this disability legislation and he won’t care if he is fined!” Furthermore, several participants were hired full-time and got job equal to their education levels. They asserted that they experienced significant inequalities at work because of their disability. For example, Mary did not get equal payment for her work, adding that, “I am low-cost labor!”

The second reason why the participants felt that disability legislation in Taiwan was not very useful was that it provided limited support. Participants identified limitations such as lack of accessibility, unfair resource distribution, lack of awareness of available support, and an inefficient bureaucracy. For example, Joyce mentioned several times in the interviews that she felt official attitudes were always bureaucratic and did not really aim to help people with disabilities. She stated, “I always think the Act is . . . manipulated by the upper level administrators.” The participants thus considered that they were excluded from greater economic and social participation in Taiwan.

## Cultural Attitudes Towards Their Disability

A few participants pointed out that they felt more accepted by Taiwanese culture now than they had in the past because of improved social attitudes towards people with a disability. For example, Yugo said, “I definitely heard that [disabled people were useless] before! But that was an idea before! Now I can’t say it doesn’t exist, but fewer and fewer people have such an idea now!” However, overall the participants stated that they felt rejected by, and excluded from, their culture much more than accepted by it. The cumulative discrimination that they experienced inevitably led to their not feeling accepted or valued in Taiwanese culture. When discussing cultural understanding of disability, the participants stated that they experienced discriminatory and distressing attitudes from non-disabled people. For example, Pearl found many parents of non-disabled children did not accept people with a disability. She told of her experience of going to a supermarket. “Parents will pull their children away when we are around.” The participants noted that others would often use abusive language with them, seeing their disabilities as a punishment due to karma, as well as seeing them as inferior to able-bodied people. For example, Joyce felt uncomfortable about how non-disabled people tended to use unpleasant words for her, noting that she had been called “a cripple [and] a lunatic, which is offensive language.”

# Implications

## Enhancing Inclusion of People with Disabilities in Taiwan

Before further discussing the implications of this study, some limitations should be acknowledged. First, these findings should not be generalized to all Taiwanese people with a physical disability, as they may apply only to the study participants. Furthermore, the issues of gender, ethnic, and age-related experiences, the differences between those individuals with congenital or acquired disabilities, and the experiences of those who live in institutions rather than in the community, as well as people with a broader range of disabilities, were not specifically addressed in this study.

The lived experiences of participants’ social networks, their views on disability legislation, and experiences of cultural attitudes toward their disability showed their understanding of disability in Taiwan, and together can explain how they feel excluded from society. Firstly, the participants stated how having a disability significantly influenced the development of important social relationships. For example, Pearl felt that she did not have access to friendship, while Joyce did not have access to intimate relationships. These individuals thus experienced great isolation, loneliness, and lack of support from the communities in which they lived. The participants all expressed a desire to be included in the wider community, but also stated that they had difficulties in interacting with others because of how people reacted to their disabilities. While living their lives within the Taiwanese context, participants experienced the negative attitudes towards them such as prejudice and discrimination that are common across many cultures, regardless of cultural differences (Swain, 2004). As Shakespeare (2006) notes, people with a disability are usually less likely to be well integrated into social networks and friendship circles, and thus tend to “experience significantly greater isolation and loneliness” (p. 170). Shakespeare (2006) further argues, “Even where disabled people have friends and companions, they may find it harder to experience everyday intimacies which non-disabled people take for granted” (p. 173).

Building and sustaining social relationships are fundamental principles of inclusion (Bigby & Frawley, 2010; Chenoweth & Stehlik, 2004; Clegg, Murphy, Almack, & Harvey, 2008; Reinders, 2002). However, in disability research there has been limited discussion of friendship, sexuality, or loneliness, and much of the research which has dealt with these issues relates to people with intellectual rather than physical disabilities (Lin, 2012; Shakespeare, 2006). Thus more research is needed to find out how best to increase the social inclusion of people with physical disabilities.

As for reducing discrimination against disabled people in Taiwan, while the Taiwanese government has passed legislation that aims to achieve this, most of the participants felt that it was ineffective in practice, with it still being very difficult for them to find employment. The deep-rooted cultural prejudices against people with disabilities that exist within Taiwan thus remain a significant blight on the lives of such individuals (Grech, 2012; Meekosha & Soldatic, 2011). Their experiences and views of the economic insecurity in Taiwan reflected the most common experience of living with a disability in the world, which is poverty. In the modern world, employment is a significant aspect of adult identity, and it is no exception for people with a disability. However, many disabled people are unemployed, underemployed, and underpaid, resulting in extreme poverty for their families (Grech, 2008, 2012; Priestley, 2001).

# Taiwan and the UN Convention on the Rights of Persons with Disability (CRPD)

With the global trend to emphasize human rights for people with a disability, such as enforcing the UN Convention on the Rights of Persons with Disability (CRPD) in 2008, perceptions of disability have been changing, and there is now growing support for greater community participation by people with a disability (Barnes & Mercer, 1995; Chang, 2007; Hayashi & Okuhira, 2006; Hsieh, 1997; Jayasooria, Krishnan, & Ooi, 2006; Kim, 2010; Oliver, 2009). Indeed, Kim (2010) argues that “the CRPD has placed people with disability on the global agenda, highlighting their need for greater inclusion in society and recognising them as citizens to be valued and respected” (p. 103). The inclusion of people with a disability has thus become recognised as a global issue. The spirit of CRPD is to see people with a disability as having the same human rights as those without disabilities, and it aims to change the disability policy paradigm from one of exclusion to inclusion (Melish, 2007; K. Y. Wang, 2008b). CRPD argues that people with a disability should be valued and respected (Kim, 2010), and it is a move “toward a ‘social’ or ‘human rights’ model that focuses on capability and takes inclusion, individual dignity, personal autonomy and social solidarity as the principal points of departure” (Melish, 2007, p. 8).

However, Wang (2008b) finds that, in practice, disability legislation in Taiwan remains far from the spirit of CRPD. She argues that rights for people with a disability in Taiwan refer to how they get subsidies, services or payments, and thus the related private groups and many disabled citizens tend to focus on this. This shows that while the government does aim to provide this group of people with support on an individual basis, it does not work to make society more accessible to all citizens (Melish, 2007), as the participants in the present study experienced. Exclusion is still a common experience. Moreover, this type of disability legislation often ensures that people with a disability must depend on social welfare, thus diminishing the control that they have over their own lives (Abberley, 1995; Hughes, 2002). The interlacing of Buddhism beliefs, Confucianism, and language in Taiwan forms the negative cultural attitudes towards disability, which the legislation in Taiwan struggles to deal with. Thus, discrimination is embedded in and permeating these people’s everyday lives (Oliver, 2009).

This reality is quite different from the spirit of CRPD, which sees rights for people with a disability as an ethical and moral issue (K. Y. Wang, 2008b). Although Taiwan is not a member of the UN, it must also work to ensure that human rights of people with a disability are recognized. More specifically, the government must aim to see improving the rights of people with a disability as a broader societal responsibility and obligation (K. Y. Wang, 2008a, 2008b). According to Article 8 of the CRPD , one of the ways to achieve this is by “initiating and maintaining effective public awareness campaigns” (Committee on the Rights of Persons with Disabilities, 2008). Kim (2010) emphasized that “without effective and organized political representation of people with disability, such important policies may remain as merely “intended” policies, or lack legal binding even if adopted” (p. 110). The League of Welfare Organizations for the Disabled has been the voice of Taiwanese people with disabilities. It advocates for their rights and welfare by demanding legislative change and raising public awareness (H. H. Chang, 2007; Shieh, Chang, & Huang, 2005). The groups working for people with a disability in Taiwan should continue to monitor how the human rights of people with a disability are being protected, and help to identify any substantive concerns in this regard (Melish, 2007; The League of Welfare Organizations for the Disabled, 2009). Studies such as the present one provide a critical forum for the voices of individuals with a physical disability to be heard and for their knowledge to be valued so their concerns can be effectively reflected to policy and practice provision. Advocating rights for people with disability via political participation campaigns and related research can ensure that the voices of people with a disability are heard. Their voices can become the basis for highlighting the upholding of their human rights and thus provide the opportunity for greater social inclusion both in Taiwan and other parts of the world.

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Research Articles

Assessing the Impact and Uses of the Disability Common Fund Among Persons with Disabilities in Kumasi Metropolis in Ghana

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**Abstract:** The Disability Common Fund (DCF) is a social protection program aimed at alleviating poverty among persons with disabilities in Ghana. Since its introduction, little has been done to examine if beneficiaries use the fund for its intended purposes. The study was conducted to assess beneficiaries’ perception of the sufficiency of the fund, what the fund was used for and the possible impact on the lives of beneficiaries in the Kumasi Metropolis, and make recommendation for improvement. This cross-sectional quantitative study obtained survey data from120 beneficiaries of the fund in the Kumasi Metropolis. Findings indicated that the DCF was used for a variety of purposes, which could be beneficial to the recipients of the fund. These included procurement of assistive devices, awareness creation, enabling the environment, payment of school fees of dependents and assisting beneficiaries to access healthcare. Although respondents complained of the insufficiency of the fund and delays in releasing of funds to the beneficiaries, the fund has had some positive impacts on their lives. It is recommended that the fund be increased and disbursed in a timely manner in order for the DCF to serve its intended purpose.

**Keywords:**Social protection, disability common fund, Ghana

# Introduction

The United Nations Convention on the Rights of Persons with Disabilities [CRPD] (2006, p.4) defines persons with disabilities to include “those who have long-term physical, mental, intellectual or sensory impairments, which interacts with various barriers, [and] may hinder their full and effective participation in society.” In spite of the fact that persons with disabilities constitute a large proportion of the population of the world, their needs and concerns are often excluded from policy making and service provision (Erb & Harris-White, 2002; United Nations Educational Scientific and Cultural Organization [UNESCO], 1995). This exclusion creates numerous barriers for persons with disabilities and limits their participation in socioeconomic activities (Schmid, Vezina & Ebberson, 2008; World Health Organization [WHO], 2011). As a result, many persons with disabilities lack access to social and economic resources and services, and thus have lower outcomes in terms of participation in health care, education and employment than persons without disabilities (WHO, 2011).

Consequently, a greater number of persons with disabilities are poor and constitute a large proportion of the world’s poorest population (Fitzgerald, 2007; Mitra, Pošarac & Vick, 2011). According to Handicap International (2006), it is estimated by the United Nations that about 82% of persons with disabilities live under the poverty line and 20% of the world’s poorest people are persons with disabilities. Their situation may be exacerbated by their disability itself. For example, persons with disabilities may incur extra cost associated with their disability such as costs arising from the need for special medical attention, transport and personal assistance (Mohapatra, 2004). However, persons with disabilities in lower income countries such those in sub-Saharan Africa are at a greater risk of experiencing economic and social challenges than their counterparts in higher income countries (Filmer, 2008; McClain-Nhlapo, 2007; Mitra & Sambamoorthi, 2006; UNESCO, 1995).

Although little is known about the living conditions of persons with disabilities in Ghana, the available data suggest their situation in comparison with their counterparts without disabilities, is worse. According to Slikker (2009), care and support for persons with disabilities in Ghana is still based on the traditional charity model of disability and this has limited their rights and capabilities to participate in mainstream activities. Most persons with disabilities in Ghana therefore are unemployment, have low level of formal education, and are poor (Slikker, 2009; Sultan & Schrofer, 2008).

To alleviate poverty among persons with disabilities and to increase their participation in socioeconomic activities, various policy and programmatic interventions have been implemented by the government of Ghana over the past decade. Social protection, in the form of cash transfers, is one of the programs being implemented to reduce poverty in the country, and it is increasingly becoming an important initiative in combating poverty among persons with disabilities. There are two main cash transfer programs in Ghana. The first is Livelihood Empowerment Against Poverty (LEAP) which seeks to alleviate poverty but acts as a general safety net and focus on a broad category of poor people including persons with disabilities (Abebrese, 2011; Oddsdottir, 2014). The second is the National Disability Scheme which incorporates an improved system of economic and social benefits, commonly known as the Disability Common Fund (DCF).

The DCF was introduced in 2005 to respond to the financial needs of person with disabilities. The DCF is a 2% allocation of the District Assembly Common Fund for persons with disabilities in the districts, municipalities and metropolis across the country. The District Assembly Common Fund is a quarterly cash transfer from the central government to the local governments (metropolitan, municipal and district assemblies) for developmental projects initiated by the local governments (National Council for Persons with Disabilities [NCPD], 2010). The aim of the DCF is to reduce poverty among persons with disabilities, especially those who are not employed in the formal sector. The fund can be used for a variety of purposes by the beneficiaries, which are spelt out in the guidelines for disbursement of the fund. Some of the activities include to procure assistive devices and technical aids and to undertake income generation activities such as farming and trading (NCPD, 2010; SEND Ghana, 2010). It can also be used to support education for children with disabilities and build capacity of persons with disabilities and their organizations (Sackey, 2009). Since the District Assembly Common Fund is disbursed to the local governments quarterly, the DCF is also disbursed to the beneficiaries quarterly.

To make the DCF sustainable and effective in addressing poverty on time and regularly. However, there seem to be some challenges affecting the smooth operation of the fund. According to a report by SEND Ghana (2010), about 55% of the local governments in 50 districts across four administrative regions (Greater Accra, Northern, Upper East and Upper West Regions) had implementation challenges. However, data on the implementation, challenges, and the impact of the DCF on the beneficiaries are scanty in many of the local government areas. This study was therefore aimed at providing some information about the use of the fund and its impact on beneficiaries in Kumasi Metropolitan (the second largest local government area in Ghana), and to make recommendations on how it could be improved.

# Materials and Methods

## Study Design

The study was a cross-sectional design and focused on only persons with disabilities who have benefitted from the DCF and were residing in the Kumasi Metropolis. A quantitative data collection method was used to elicit information on the uses of DCF and its impact on the lives of beneficiaries from the respondents. Since the aim of the study was to examine the uses and impact of the DCF on persons with disabilities in Kumasi Metropolis, a quantitative method was useful because it permitted gathering data from a large number of respondents in the metropolis. This made it possible to make a fair generalization of the findings to cover persons who benefitted from the fund in the Metropolis.

## Study Population and Sample Size

As stated above, the respondents in the study were persons with disabilities who benefited from the DCF and residing in the Kumasi Metropolis. Purposive sampling was used to recruit study respondents. Prior to the data collection, an introductory letter was obtained from the Department of Social Welfare, which is responsible for disbursing the fund, to inform the Kumasi Metropolitan branches of the Ghana Blind Union (GBU), Ghana National Association of the Deaf, and Ghana Society for the Physically Disabled (GSPD) about the study. The introductory letter explained the purpose of the study, the eligibility criteria, and the role of respondents in the study. The researchers attended meetings of these associations and identified prospective study respondents. Individuals who were beneficiaries of the DCF and consented to participate in the study were enrolled to respond to the questionnaire. In all, 120 beneficiaries comprising of physically (57), hearing impaired (35) and visually impaired (28) people were recruited to participate in the study.

## Data Collection Techniques and Tools

The study was quantitative and so questionnaires were used to collect data from beneficiaries who were willing to participate in the study. The questionnaires had both open and close ended items, including Likert scale items of five responses (1– strongly agree, 2– agree, 3-neither agree nor disagree, 4– disagree and 5- strongly disagree). Some of the questions included frequency of disbursement of the fund, utilization of the fund, perceived impact and challenges encountered when accessing the fund. The questionnaires were self-administered, but the researchers assisted the respondents by clarifying questions which respondents did not understand. Participates without formal education spoke in the local language (Twi) and this was carefully translated to English by the researchers with assistance from a research assistant. Also, a sign language translator was hired to assist us to communicate with deaf respondents. All the data gathered from respondents was checked by the researchers to ensure completeness and consistency. Additionally, all data was kept confidential to ensure the safety and confidentiality of respondents; only the researchers had access to the information.

## Data Analysis Procedure

The Statistical Package for Social Science [SPSS] v20 was used to analyze the data. The data obtained from the respondents was entered into SPSS file and frequencies of the responses computed for categorical variables. Tables were used to represent the frequencies. Responses on the open-end questions were analyzed thematically. The responses were coded and categorized using the codes. Using the codes, all statements that were similar were grouped together to form themes. Two main themes, with subthemes, emerged from this section. They are utilization of the fund and challenges encountered to accessing the fund.

## Ethical Consideration

The Committee for Human Research Publication and Ethics at Kwame Nkrumah University of Science and Technology reviewed and cleared the study protocols prior to the implementation of the study. Among the significant issues that were considered include informed consent, confidentiality and data protection. Respondents’ anonymity was ensured throughout the study and the assurance of strict privacy motivated them to enroll. A written informed consent, translated from English to the local language (Twi), was signed by the respondents prior to their enrolment in the study. For hearing impaired respondents who could not read the written informed consent, an interpreter translated it for them.

# Results

## Demographic Characteristics

Table 1 summarizes the demographic characteristics of the respondents in the study. As indicated in the table, most of the respondents (80%) were from Disabled People Organizations (DPOs) such as Ghana Society of the Physically Disabled, Ghana Blind Union and Ghana National Association of the Deaf. About half (50.4%) of the respondents were above 40 years while a few of them (2%) were between 10 and 20 years. The average age of the respondents was 28 years. With respect to respondents’ educational status, 15% had no formal education while 16.7% had tertiary education. On respondents’ marital status, 41.7% were single while less than 5% were co-habiting. In addition, 53 respondents, constituting over 40% had no job.

#

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# Table 1: Socio-Demographic Characteristics of Respondents

|  |  |  |  |
| --- | --- | --- | --- |
| Variables | Characteristics | Frequency | Percentage |
| Age (n=120) | * 10- 20
* 21 – 30\*
* 31 – 40\*
* 41 – 50\*
* ˃ 50
* *Min/Max*
 | 22632342615/65 | 1.721.726.728.721.7 |
| Gender (n=120) | Mean * Male
 | 2875 | 62.5 |
|  | * Female
 | 45 | 37.5 |
| Level of Education (n=120) | * No formal education
* Primary
* Secondary
* Tertiary
* Other
 | 1837342011 | 1530.828.316.79.2 |
| Marital Status | * Single
 | 50 | 41.7 |
|  | * Co-habitation
 | 5 | 4.2 |
|  | * Married
 | 39 | 32.5 |
|  | * Separated
 | 12 | 10 |
|  | * Divorced
 | 11 | 9.2 |
|  | * Widowed
 | 3 | 2.5 |
| Occupation | * Trading
 | 22 | 18.3 |
|  | * Government (Civil Servant)
 | 20 | 16.7 |
|  | * Farming
 | 6 | 5.0 |
|  | * Apprenticeship
 | 19 | 15.8 |
|  | * None
 | 53 | 44.2 |

## Disbursement of Funds and Expenditure

Table 2 presents respondents’ income levels, frequency with which they received the fund and their monthly expenditures. It was found that 59.9% of the respondents had received the fund for one year whereas only 2.8% indicated they have been receiving the fund for four years. However, on how often they received the fund, a majority (73%) said they received it once a year whereas 10.8% said they received it quarterly. In relation to the amount received, about half of respondents (52.3%) stated that they received between Ghana Cedis [GHC] 200-500 whereas 7.3% received above GHC 1000.

The study also sought information on the monthly expenditure of respondents focusing on the amount spent on healthcare, education and food. For monthly expenditure on food, less than 10% of the respondents indicated spending between GHC 450-600. For healthcare, 10% spent between GHC 23-28 while less than 5% spent between GHC 5-10. In relation to education, 20.4% spent between GHC 250-300 on their dependents while 15.3% indicated spending between GHC¢ 100-150.

# Table 2: Monthly Expenditures and Amount Received by Beneficiaries

|  |  |  |
| --- | --- | --- |
| Variables | Frequency | Percentage |
| **Number of years for receiving the fund**  |  |  |
| * 1 year
 | 64 | 59.3 |
| * 2 years
 | 25 | 23.1 |
| * 3 years
 | 16 | 14.8 |
| * 4 years
 | 3 | 2.8 |
| **Duration of receiving funds (n=111)** |  |  |
| * Every quarter
 | 12 | 10.8 |
| * Every 6 months
 | 6 | 5.4 |
| * Once a year
 | 81 | 73.0 |
| * Others
 | 12 | 10.8 |
| **Amount received**  |  |  |
| * Below GHC ¢100.00
 | 15 | 13.8 |
| * GHC ¢100.00 – 200.00
 | 23 | 21.1 |
| * GHC ¢200.00 – 500.00
 | 57 | 52.3 |
| * GHC ¢500.00 – 1000.00
 | 6 | 5.5 |
| * Above GHC ¢1000.00
 | 8 | 7.3 |
| **Monthly expenditure on dependents food (n=105)**GHC ¢30.00–150.00GHC ¢150.00–300.00GHC ¢300.00–450.00GHC ¢450.00–600.00Other |

|  |
| --- |
| 1533 |
| 26 |
| 21 |
| 10 |

 |

|  |
| --- |
| 14.331.4 |
| 24.8 |
| 20.0 |
| 9.5 |

 |
| **Monthly expenditure on dependents healthcare (115)**GHC ¢5–10.00GHC ¢11.00–16.00GHC ¢17.00–22.00GHC ¢23.00–28.00Other | 531481219 | 4.327.041.710.416.5 |
| **Monthly expenditure on dependents’ education (n=98)**

|  |
| --- |
| GHC ¢100.00–150.00GHC ¢150.00–200.00 |
| GHC ¢200.00–250.00 |
| GHC ¢250.00–300.00 |
| Other |

 | 1421192024 | 15.321.419.820.423.5 |

## Uses of the Fund

Respondents claimed that they used the fund to create awareness of disability issues (70%), to develop their organizations (100%), to access health care (97.1%), to access education (100%), to train themselves in employable skills (96.7%), to acquire technical aids and assistive technology (100%) and to engage in income generation such as farming and trading (94.3%). It is important to mention that the cash for organizational development, awareness creation and training in employable skills are often given to the leaders of the DPOs to organize such programs for their members.

# Table 3: Activities Beneficiaries Use the Fund

|  |  |
| --- | --- |
| Activities fund was used for  | N (%) |
| Awareness raising **(n=120)**  | 93 (77.5) |
| Organizational Development **(n=98)** | 98 (100) |
| Training in employable skills **(n=92)** | 89 (96.7) |
| Income generation activities **(n=105)** | 99 (94.3) |
| Educational support for children, students and training **(n=99)**  | 99 (100) |
| Provision of technical aids, assistive devices **(n=74)**  | 74 (100) |
| Registration on the NHIS **(n=69)** | 67 (97.1) |

As indicated above in Table 3, all the participants said they used the fund to acquire assistive devices. Table 4 presents information on the assistive devices acquired by respondents using the DCF. While 54% respondents mentioned using assistive devices, 46% indicated otherwise. Out of the 54% respondents who said they were using assistive devices, 75% purchased the device using the DCF. For instance, out of the 30 visually impaired respondents, 18 said they were using a white cane while 12 mentioned using eye glasses. All the 18 users of white canes purchased their device from the fund while 9 users of eyeglasses acquired the device through the fund. With regard to the physically impaired, 15 mentioned using crutches while 3 were using wheelchairs. Out of this, 9 said they bought their crutches with the fund and all of the 3 users of wheelchairs acquired their devices with the fund.

# Table 4: Assistive Devices Acquired with the DCF

|  |  |  |
| --- | --- | --- |
| Type of devices | Stated needs  | Provision by DCF |
|  | ***N (% of Total Respondent)*** | *N (%)* |
| **Visual impaired** * Eye glasses
* White cane
 | 12 (10%)18 (15%) | 9 (7.8%)18 (15.3%) |
| **Physically impaired*** Wheel chair
* Crutches
* Braces
 | 3 (2.5%)15 (12.5%)5 (4.2%) | 3 (2.5%)9 (7.5%)2 (1.7%) |
| **Hearing impaired*** Hearing aid
 | 9 (7.5%) | 6 (5.1%) |
| **Other** | 3 (2.5%) | 2 (1.7%) |
| **None** | 55 (46.1%) | 69 (58.4%) |
| **Total** | 120 (100%) | N/A |

## Challenges

Data from the qualitative component of the questionnaire provided insights into some of the challenges beneficiaries encountered when accessing the fund. The major challenges were delays in release of funds, insufficiency of the fund and misuse of funds by beneficiaries.

## Delays in Releasing the Fund

One of the major challenges identified was delays in releasing funds, which affected the utilization of the fund. All the respondents indicated that sometimes they did not receive the fund on time. For example, some claimed they had not received the fund for more than two years while some claimed they had not received it at all. The following are some of the written comments from the respondents:

“The funds do not come regularly as it was proposed. The initial arrangement was that the fund should come quarterly. However, taking 2014 as an example, only two tranches out of the four came. Currently we are almost entering the first quarter of 2015 but have still not received it (A physically disabled male respondent).”

“The money is supposed to come quarterly but mostly it comes once a year and even that there are times we were told government did not release any fund to the district assembly and so there was no fund available for us (A female deaf respondent). “

“I have been applying for the fund for the past five years but I’m yet to be given anything. I know few people who are benefiting from the fund. It is worrying that they have named the fund for disabled persons but we do not get it and no one is telling us what is happening to our money (A male visually impaired respondent)*.”*

## Insufficiency of the Fund

Another challenge which was mentioned by the respondents was the insufficiency of the fund, making it hard for beneficiaries to invest the money received in useful ventures. Some of the written comments suggest that beneficiaries were displeased with the amount they received:

“I know the common fund can’t help all of us. I wanted to make a container so I informed them but they didn’t give me enough money to make it. They only gave me GH 500. I begged them to provide me with an amount I could use for the container and I also will work-out for the things I wanted to sell but they didn’t do it (A male deaf respondent)*.*”

“My mother is in the village she buys goods from there and sells them in the city. If I should decide to join her for such business, GH 500 is too small to buy much good to come and sell. I always complain at our meetings. I asked them more questions but they don’t give me any good answer. Sometimes they refuse to answer me (A female deaf respondent)*.”*

Findings from the study revealed that beneficiaries used the DCF for a variety of purposes, which highlighted the usefulness of the fund to the beneficiaries. However, there were many challenges that have hindered the use of the fund.

# Discussion

Generally, persons with disabilities are more likely to be disadvantaged in terms of access to social and economic resources and opportunities than their counterparts without disabilities due to a myriad of barriers they encounter (Gooding & Marriot, 2009). It is therefore important that they are supported by the state to cushion the effects of barriers so that they can participate in socioeconomic activities on an equal basis with others. This explains the rationale for the introduction of social protection programs such as cash transfer programs for persons with disabilities in many countries (Filmer, 2008; Schmid, Vezina & Ebberson, 2008 & Tabor, 2002). As described earlier, the ultimate aim of the DCF is to reduce poverty among persons with disabilities, especially among those without employment in the formal sector (National Council for Persons with Disability, 2010). The fund is therefore meant for activities that would directly or indirectly improve the living condition of recipients by offering beneficiaries the opportunity to engage in economic activities.

The findings of the study revealed that beneficiaries of DCF invested their share of the fund in various activities such as providing education for their children, acquiring assistive devices and accessing health care. They also used the fund to undertake activities that would empower them and make their organizations more effective in advocating for their rights. These findings suggest that beneficiaries in the study area were using the fund for the intended purposes; the activities they used the fund for have the potential to impact positively on their lives. Without the fund it would have been difficult for some of the beneficiaries to undertake some of the activities they engaged in.

However, it is doubtful if the fund is making the needed impact on the lives of beneficiaries in the study area due to the numerous challenges associated with the fund coupled with the current harsh economic situation in the country and the general socioeconomic situation of persons with disabilities in Ghana. As the findings indicated, a large number of the beneficiaries in the study were without higher education and unemployed, and so were unlikely to have other sources of income apart from the DCF. Also, the amount received was too small to make significant change in the lives of beneficiaries, and there were often delays in disbursing the fund, making planning towards any meaningful investment difficult. According to SEND Ghana (2010), beneficiaries of the DCF often waited for a long time before receiving their share of the fund and many received the fund just once a year instead of four times, and this affected the utilization of the fund. Thus, although the DCF has the potential to mitigate the cost of living of the beneficiaries, they may be unable to invest the fund in activities that would cause the necessary impact. This finding is also consistent with other studies elsewhere, which found that disability grants, especially in developing countries, are inadequate to match the large number of applicants and so individual allocated was too small to significantly reduce poverty among persons with disabilities (Gooding & Marriot, 2009).

Studies have shown that the direct impact of social grants to vulnerable populations is not limited to their direct pocket expenditure but extends to other people, sometimes distantly related (Barrientos & DeJong 2006). This is especially so in the extended family system in Ghana where individuals may depend on other family members for support, and in fact, some persons with disabilities are breadwinners of their extended family members in Ghana. This means that some beneficiaries of the fund may be sharing the meagre cash they received with other family members, making investing in long term sustainable projects impossible.

# Limitations of the Study

The Kumasi Metropolis is the second largest metropolis in Ghana and has a lot of business activities, which present many opportunities and also challenges for persons with disabilities in the area. Conditions in the metropolis are therefore likely to be different from the situation for persons with disabilities living in other areas, such as rural environments. Moreover, the amount individuals received in other areas may be different and used differently. This makes generalization of the current findings impossible. Indeed, the studies could not even target all beneficiaries in the Ashanti region; the region is vast with many rural settlements. Thus, although the findings from the current study provide some useful information that could be used to improve on the management of the fund, more studies from different contexts are required to better understand how the fund is used, what factors influenced its use and the impact of the fund on beneficiaries. It should also be noted that the impact of the investment in terms of alleviating poverty among beneficiaries cannot be determined easily because individuals living condition is influenced by a complex web of factors and this is often depended on the subjective judgement and preference of the individual (Oddsdottir, 2014).

# Implications of the Study

The study has implications for cash transfer programs in Ghana. Firstly, the finding that many of the participants had low educational attainment and were without employment points to the need to institute programs to promote education and employment of persons with disabilities. The Education Ministry should team up with other ministries and agencies such as the ministry of Gender, Children and Social Protection to increase access to education for persons with disabilities. With good education, many persons with disabilities will be employed and reliance on the DCF will reduce, thereby making more funds available for the few who apply. Also, persons with disabilities should be given relevant vocational training so that they could invest the fund in profitable activities. These programs should target women with disabilities since they are more vulnerable.

It was found that the DCF was not released on time and, as a result, beneficiaries would have to wait for a long time for the fund to be released. It is therefore recommended that the Ministry of Finance should release the DCF quarterly as spelt out in the guidelines for disbursement of the fund. This will enable beneficiaries to receive the funds early for their planned activities. It is also suggested that the quota of the District Assembly Common Fund allocated to persons with disabilities should be increased from the current 2% to 5%.

# Conclusion

The study examined the impact of DCF on the lives of persons with disabilities in Kumasi Metropolis. The study found that the fund was useful as it assisted persons with disabilities in their small businesses and farming activities, helped them pay their children’s school fees, purchased assistive devices and ensured that they had access to healthcare. However, the study found that the DCF was insufficient for beneficiaries and their families. The study found that the level of education, employment and income among beneficiaries was low so cash transfers are unlikely to improve their socioeconomic status. It was found that delays on the part of government in releasing funds to the district assemblies affected the ability of persons with disabilities to put the fund into proper use. Thus, although the DCF is a good initiative by the government of Ghana, efforts must be put in place in order to ensure that the fund achieve its objective. The government should make sure that funds allocated to districts are released on time so as to enable beneficiaries to have regular access to the funds.

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Research Articles

A Study of the Impact of Disability Studies on the Perceptions of Education Professionals

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**Abstract:** Scholars in the field of Disability Studies (DS) have asserted that introducing future and current educators to the field of DS may impact their perceptions of disability and their practices in supporting students with disabilities. However, little empirical research exists on how introduction to DS actually shifts their perspectives. This study examined the impact of Disability Studies online modules on the perceptions of education professionals. Results of this study suggested that participating in online modules and learning about Disability Studies did impact the ways in which some participants viewed disability, as well as their views on supporting students. These findings suggest that online DS learning modules could be a powerful tool in preparing education professionals to work with students with disabilities.

**Keywords:**inclusive education; online learning; teacher preparation

Despite a push over the last 40 years to include students with disabilities more authentically in general education classrooms, many students with disabilities continue to be educated in segregated settings (U.S. Department of Education, 2012). The education system has made progress with some groups of students, such as those with learning disabilities (U.S. Department of Education, 2012), however, rates of access to general education environments for other groups of students, such as those with developmental disabilities have actually declined over the past ten years (Smith, 2012). Although many factors such as policy and funding may play a role in student access to general education contexts (Ainscow, Booth, & Dyson, 2006; Taylor, 1978), teacher training and professional development are certainly a key consideration in increasing access (Leatherman & Niemeyer, 2005). For example, Jordon, Glen, and McGhie-Richmond (2010) found that teachers who received training in supports and services for students with disabilities were much more likely to include students with disabilities successfully. Continuing to research effective ways to shape teacher perceptions and practices related to access for students with disabilities is of utmost importance.

To date, teacher training related to students with disabilities has relied heavily on the “medical model” of disability. Teachers are taught to view a student’s disability as a problem that needs to be fixed (Valle & Connor, 2011). Often, the student is removed from the general education classroom until he or she is “fixed” or behaves more like the other “normal” students. Thus, the student is allowed back into classroom with peers without disabilities on the condition that the disability is eradicated or minimized. For example, a student with a significant reading disability may be placed in a self-contained (aka segregated) setting with the intent that the disability may be minimized through intensive therapy. Only when the student is able to read better is he allowed back into the general education classroom. This view of teaching and learning can be problematic because not only can it be used to justify segregated settings, it may lead to lack of opportunity to access a general education classroom.

It seems that many special and general educators are so immersed in the “medical model” way of thinking described above, that they may not consider the ways in which segregation of individuals with disabilities can act as a form of oppression, or the ways that segregation can ultimately hinder students’ academic and social success (Valle & Connor, 2011). Introduction to these ideas may at first create some friction between “old” and “new” ways of thinking, but may also ultimately lead to transformation of perceptions and practice related to supporting students labeled with disabilities in schools (Ashby, 2012). For example, teachers may recognize how improperly separating students with disabilities from the general population creates a sense of ableism in schools (Hehir, 2002). Therefore, introducing pre-service and in-service teachers to disability studies (DS) concepts could be a way to promote increased advocacy around inclusive education, and more inclusive educational practices (Ashby, 2012; Connor, Gabel, Gallagher, & Morton, 2008). This study explores how (if at all) online learning modules in Disability Studies shape teachers perceptions and practices related to inclusion of students with disabilities in K-12 schools.

# What is Disability Studies in Education and Why Should Teacher Educators Care?

Disability Studies (DS) is a growing field that focuses on the phenomenon of “disability” across a wide range of areas including law, medicine, history, art, and media (Linton, 1998). DS views disability as a social, political, and cultural phenomenon (Goodley, 2012). For example, we used Linton’s (1998) definition in framing our work in this study:

“Disability Studies reframes the study of disability by focusing on it as a social phenomenon, social construct, metaphor, and culture utilizing a minority group model. It examines ideas related to disability in all forms of cultural representations throughout history, and examines the policies and practices of all societies to understand the social, rather than the physical or psychological, determinants of the experience of disability. Disability Studies both emanates from and supports the Disability Rights Movement, which advocates for civil rights and self-determination. This focus shifts the emphasis from a prevention/treatment/remediation paradigm, to a social/cultural/political paradigm. This shift does not signify a denial of the presence of impairments, nor a rejection of the utility of intervention and treatment. Instead, Disability Studies has been developed to disentangle impairments from the myth, ideology, and stigma that influence social interaction and social policy. The scholarship challenges the idea that the economic and social statuses and the assigned roles of people with disabilities are inevitable outcomes of their condition” (p. 8).

Specifically, Disability Studies emphasizes the difference between the “medical model” and “social model” of disability. The “medical model” positions disability solely within the individual. Essentially the individual is looked at as “broken” and in need of being fixed (Baglieri, Valle, Connor, & Gallagher, 2011). Conversely, DS views disability through a “social model” lens. The social model presupposes that disability is situated in political, social, and economic contexts. The environmental, social, and political barriers society places upon individuals with impairments determine how “disabled” such individuals are in each context.

From a DS perspective, a person’s “disability” is directly related to how disability is represented and defined in current society. Furthermore, disability and impairment are viewed as two distinct entities. An impairment represents a person’s difference such as a person who is blind and his or her difference in ability to see, while a disability elucidates the barriers society places on such a person. In other words, DS emphasizes social and attitudinal barriers rather than individual impairments. For instance, a person may have an impairment such as a difference in the way the brain decodes the written word. However, the person is not “disabled” until society begins to place barriers such as lack of accessible text. If the text is made accessible through audio format for example, he or she may not be considered disabled. The focus is not on “fixing” the person so that the brain reads words in the same way, but rather on removing the barriers by creating pathways that would allow access. Thus, DS does not view a person’s disability as something that needs to be fixed or cured but focuses on removing the barriers that “create” the disability.

Disability Studies in Education (DSE) is based on Disability Studies principles and emerged from the field of DS. DSE applies the definition and framework of DS to the field of education (Ferguson & Nusbaum, 2012). DSE seeks to “promote the understanding of disability from a social model perspective” and to “challenge social, medical, and psychological models of disability as they relate to education” (American Educational Research Association Disability Studies in Education Special Interest Group [AERA DSE SIG], 2007). DSE offers the “why” to the “how” of high access strategies for all students, such as Universal Design for Learning (UDL; www.cast.org) and differentiating instruction (Tomlinson, 2000); situating access to general education curriculum and contexts within a social justice and civil rights framework (Lipsky & Gartner, 1996). For example, teachers may learn about how to differentiate instruction and the research base associated with increasing access for students with disabilities, yet they may not fully understand why such access is important, and why this access should be considered a civil right. When a DSE framework is introduced, teachers then have a strong social justice framework from which to situate their practice.

The social justice framework associated with DSE not only relates to instructional practices such as UDL, it applies to assumptions about inclusive education overall. From a DSE perspective, inclusion is viewed as a social justice issue for individuals with disabilities. DSE explores how individuals in the education system can remove social and policy barriers that prevent students with disabilities from accessing general education curriculum and contexts. For example, teachers simply assume every student will be included and that it is their job to develop an environment and access to curriculum where that can happen (Connor, Gabel, Gallagher, & Morton, 2008). Thus, DSE assumes that teachers play a significant role in creating and supporting access for students with disabilities in inclusive environments.

Given the importance of the role of teachers, introducing teachers to DSE concepts can assist them in understanding WHY inclusive opportunities are so important, and WHY our current system of education and overreliance on the medical model prevents students from accessing inclusive educational opportunities. For example, Ashby (2012) discusses how a program “grounded in disability studies principles” demonstrates “how a disability studies framework can inform and enrich teacher preparation” (p. 89). Ashby explains that teachers who have “traditional” views of individuals with intellectual disabilities may have assumptions about the deficits of these students as well as their inability to be included in general education classrooms. If the teacher is aware of the “social model” or social construction of disability, he or she may question some of these assumptions and be more aware of the social and political barriers that are in place. As Freire (1970) states, we must be able to identify sites of oppression in order to address them.

## Lack of Exposure to DSE Concepts in Teacher Education

DSE assumptions run counter to current mainstream policies and practices associated with special education in K-12 school, and offer ways to view special education policy and practice from a critical lens. DSE scholars often stress that DSE is not rehabilitation, special education, or any other field involved with “fixing” or “curing” a disability (Linton, 1998; Ferguson & Nusbaum, 2012). Not surprisingly, many in the field of “traditional” special education have been wary of DSE and actively critiqued a DSE approach to special education, even suggesting that DSE concepts will lead to the destruction of special education as a field and profession (Anastasiou & Kauffman, 2012). Therefore, it is not surprising that despite the impact DSE may have on educator’s perceptions and practice in regard to individuals with disabilities, many teachers and teacher educators are not exposed to DSE concepts, and are often unfamiliar with the field as a whole (Cosier & Pearson, 2016).

## Empirical Research on the Impact of DSE

As teachers and teacher educators, we suspected that one reason teachers and teacher educators may lack exposure to DSE concepts may be the scarcity of research on how, if at all, introduction to DSE may change perspectives and practice. Although many scholars have written about the possibilities for DSE to change perspective and practice, or have offered anecdotal information in this area (Ashby, 2012; Baglieri, Bejoian, Broderick, Connor, & Valle, 2011), at the time of this study, we could not find empirical research associated with how, if at all, a web-based introduction to DSE changed teachers’ perceptions and practices associated with special education and disability. Thus, we sought to add to the field of DSE, by exploring how, if at all, online DSE modules impacted teachers’ perspective and practice.

## Online Learning Modules for Pre-service and In-service Teachers

Over the past few decades, there has been an increase in popularity of online learning for pre-service and in-service educators (Chitanana, 2012; Brown & Green, 2003). Online learning is rapidly becoming the preferred model by teachers because of its convenience and suitability for educator’s busy lifestyles. This approach to learning allows teachers to avoid staying after hours, missing instructional days, or attending weekend workshops for professional development. Holmes, Signer, and MacLeod (2010) state “the online environment incorporates a level of convenience for the participant, as it can eliminate the need for travel, childcare, and scheduled class sessions” (p. 76).

Another aspect to online education is the way in which it provides accessibility to the learner. Online education helps meet the needs of participants who best learn outside of traditional classroom settings; participants with and without disabilities. By presenting information in an online format, each participant has the opportunity to personalize his or her educational experience (Smith & Basham, 2014). Learning online provides individuals with the ability to access material at their own pace and through various modalities. Further, it gives a way to control their learning environment to meet their needs (e.g. sensory processing) (Smith & Basham, 2014). While online material does not change the content for the learner, it can make the material accessible when it may not be otherwise.

Not only are online modules convenient and potentially more accessible, they can also be effective for teachers. Holmes, Signer & MacLedo (2010) posit that quality professional development must contain “experiences that are purposefully designed, situated in rich context centered in classroom instruction, and successfully integrated with powerful learning tools for teaching and learning” (p. 77). These are essential components in any platform for effective learning. As long as these are the components within the online learning platform, the online learning platform can be just as effective as a face-to-face approach.

The benefits of online learning, including accessibility and convenience complement the work of DSE in many ways. Connor, Gabel, Gallagher, & Morton (2008) indicate that DSE has its own set of tenets, one of which is to promote inclusive and meaningful access to education. Learning in an online format may create avenues for learning and/or break down barriers inherent in traditional “in-person” professional development (Smith & Basham, 2014). Providing an alternative way to gain knowledge allows participants to focus on their strengths and work at their own pace. In this way, online learning promotes equity and access to education and goes hand in hand with the principles of DSE.

# Theoretical Framework: Transformative Teacher Education

This research is situated within the framework of Transformative Learning Theory (TLT) (Kitchenham, 2008). Transformative Learning Theory is a “deep structural shift in basic premises of thought, feelings, and actions” (Transformative Learning Centre, 2004). Mezirow et al., (2009) defined transformative learning theory as “learning that transforms problematic frames of references to make them more inclusive, discriminating, reflective, open, and emotionally able to change” (p. 22). This conceptual framework analyzes how individuals learn new information and how their thoughts, or frames of reference, can be reframed based on this new information. The changes, or transformation, become a structural shift in ideas, feelings, and actions that are viewed as positive and promote growth (Merriam, 2004).

Paulo Freire (1970) explored the theory of transformative learning in which he referred to conscientization or consciousness. This concept of critical consciousness can be described as “a process in which learners develop the ability to analyze, pose questions, and take action on the social, political, cultural, and economic contexts that influence and shape their lives” (Dirkx, 1998, p.3). When an individual obtains new information, he or she is able to engage in a deeper understanding of his/her world, and can then make changes based upon new information. Thus, people begin to develop a critical consciousness and their perceptions and practices are subsequently altered. This critical consciousness is developed through processes of critical reflection and reflective discourse, which support “transformative learning” (Feinstein, 2004, p. 109).

As part of the critical reflection and reflexive discourse, individuals engage in a process of constant learning and reconstruction (Kitchenham, 2008). Mezirow (2000) claimed that the types of learning included the following: (a) elaborating existing frames of reference, (b) learning new frames of reference, (c) transforming habits of mind, and (d) transforming points of view. These changes in perspectives allow for existing experiences to be understood in new ways (Cranton, 1994; Daloz, 1986). The development that occurs with TLT is ongoing and leads to “greater autonomy in thinking” (Mezirow, 2000, p. 29). In consideration of this study, transformative learning allows adults to develop their existing frames of reference by critically examining and questioning their beliefs and assumptions.

# Statement of Problem and Research Questions

Given the lack of Disability Studies content in teacher preparation programs, and the lack of opportunities current teachers have to Disability Studies related information, there is certainly a need for a space where in-service and pre-service teachers can access such information. In the context of this study, the researchers sought to explore how (if at all) online professional learning modules on Disability Studies transformed the perceptions and practices of in-service and pre-service teachers. Specifically, we wanted to know if teachers began to develop a critical consciousness based on this new information and if a structural shift occurred in ideas because of this information. This study focused on the following research questions: (1) Do teachers and education professionals have knowledge of the area of Disability Studies; and (2) How (if at all) do online Disability Studies modules impact teacher and other education professional’s perceptions and practices related to educating students with disabilities?

# Method

## Participants

To explore how individuals in the education field understood the fundamental concepts of Disability Studies, and how these concepts could influence their perceptions and practices, the researchers sought out individuals working in education, or those interested in the field, to participate in the modules at their own leisure and in their own environment. A link to an anonymous survey was located at the bottom of each module page. We used random sampling in this study, and a total of 47 individuals participated; 39 were in professions related to the education field (e.g. teacher, behavior interventionist, speech language pathologist), four identified themselves as parents of individuals with disabilities, two identified themselves as college students taking courses in special education or disability related topics, and one identified as an advocate. In addition to profession, the survey asked respondents to identify the number of years of experience in the field of education. Experience in the field ranged from 0-15+ years, and education of participants ranged from some college to possessing a doctoral degree (see Table 1).

When engaging in the modules, a total of 22 individuals participated in one module, while the other 25 viewed two or more modules. The most visited page was A message about DSE, which provided a general overview of DSE as a field. Approximately 47% of participants visited (N = 22) this page. Other most visited pages were Social Model and Individualized Instruction, which were visited by 23% (N =11) and 21% (N=10) of participants respectively. Other modules including Community Building, Intro to DSE and Developmentally Appropriate Practices (DAP), and Eugenics were viewed by 8 participants (17%). Segregation as a Teaching Strategy and Parent – School Professional Partnerships (PSPP), as well as the Resource page of the site were viewed by 6 participants.

# Table 1: Participants and Responses

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| Number of participants | Area within the field of education | Years in the field | Education Level | Exposure to DS prior to modules   | Yes, the module(s) changed the way I think about special education & supporting student with disabilities in school?  |
| Yes | No | Yes | No |
| 4 | Special education K-12 | 0-15+ years | 4/Masters | 2 | 2 | 3 | 1 |
| 6 | Special Education Pre-K/Early Childhood  | 0-15+ years | 3/Bachelor3/Masters  | 4 | 2 | 3 | 3 |
| 6 | General education K-12 | 3-15 years | 3/Bachelors3/Masters | 3 | 3 | 6 | 0 |
| 3 | General Education Pre-K/Early Childhood | 0-15+ years | 3/Bachelors | 1 | 2 | 2 | 1 |
| 7 | Pre-service educators | 0-2 years | 2/Some College1/AA2/Bachelors2/Masters |  5 | 2 | 6 | 1 |
| 5 | Teaching Assistant/Paraprofessi-onal | 0-2 years | 1/Some College2/Associates1/Bachelors1/Masters | 0 | 2 | 2 | 0 |
| 4 | Faculty | 15+ years | 1/Masters3/Doctorate | 3 | 1 | 3 | 1 |
| 4 | Related Service Provider | 3-15 years | 1/AA3/Masters | 1 | 3 | 3 | 1 |
| 4 | Parents | 0-15+ years | 2/Some College2/Bachelors Degree  | 2 | 2 | 1 | 1 |
| 4\* | Student/Doctoral Students | 0-15 years | 1/Bachelors1/Masters1/Doctorate | 3 | 0 | 2 | 1 |

\* **Note:** One participant declined to answer.

## Website and Online Learning Modules

The website is designed for pre-service and in-service teachers, as well as anyone in the education field seeking knowledge in the area of DSE (www.chapmandisabilitystudies.com). The website contains multiple pages within the site. Each page is considered a module. Each module provides information on a topic in the education field as related to DSE. The modules generally follow similar formats. Each module begins with an introduction to the topic, followed by a video and/or additional text that explore the topic in more depth. The text and videos are followed by essential questions, objectives and additional content for participants to consider and explore. Lastly, each module concludes with additional recommended readings and resources at the bottom of each page. For example, the Social Model of Disability module begins with a short description of the difference between the social model and medical model by DS and DSE scholars such as Valle and Connor (2011) and Linton (1998). This introduction is followed by a cartoon by Michael Giangreco (2002) that asks participants to consider how the cartoon relates to the social model of disability. The cartoon is followed by the essential questions such as “How can social model thinking be integrated in the educational system?” and objectives including “Describe the how the social model differs from the medical model of disability.” The essential questions and objectives are followed by additional content that describes the “social model” and “medical model” in further detail, including a link to an animated explanation of the social model on YouTube (<https://www.youtube.com/watch?v=9s3NZaLhcc4>). Lastly, the page includes recommended readings on the social model such as Hughes (2010) and Shakespeare and Watson (2002).

The website includes a recommended order of modules for participants to follow. The first recommended module titled Intro to DSE provides an overview of definitions of disability, asks participants to reflect on their own experiences with disability, and introduces fundamental concepts of DSE. Following the introduction of DSE, the site recommends that the participant explore the Social Model module which provides brief content on the history of disability and lends itself to detailed information on what the social model of disability means, and how it is constructed. This module assists participants in understanding how society disables individuals, and demonstrates the difference between impairment and disability.

The next two modules are called Developmentally Appropriate Practices (DAP) and Segregation as a Teaching Strategy. The DAP module looks critically at developmentally appropriate practices as it guides curriculum and provides a framework for early educators to determine whether children are making progress towards developmental milestones. The module illustrates how a child’s lack of progress in meeting developmental stages leads to intervention services, to “fix” the child, which aligns with the “medical model” or special education philosophy. Segregation as a Teaching Strategy helps participants understand the relationship of segregation to gender, race, and disability, and examines segregation of individuals with disabilities in K-12 schools and the broader community. The module focuses on supporting the development of new ideas for teaching students with disabilities that promote inclusion.

The module titled Sped vs. DSE provides a more in-depth background of DSE, distinguishes the differences between Disability Studies and Special Education and displays them in a visual format as two separate disciplines. This module helps participants understand how the approach of two these philosophies differ in the field of education.

The Individualized Instruction, Community Building, and Parent-School Professional Partnership modules provide an overview of classroom practice and parent-teacher collaboration from a DSE perspective. The Individualized Instruction module analyzes whether the practice of individualized instruction hinders the influence of inclusive practices, or students with disabilities being educated in the general education setting. Furthermore, the module reiterates how individualized instruction is not, or should not be, specific to special education programs.

The Community Building module examines the importance and purpose of community building in inclusive classrooms. It also identifies the benefits of community building for students with and without disabilities in inclusive classrooms, and provides educators with practical strategies to support building communities in their classrooms. The Parent-School Professional Partnerships (PSPP) module examines the partnership between parents and the school professionals and its historical emergence in the education system, with a specific focus on special education.

 The last module in the series is titled Eugenics in Education. This module strives for participants to understand the American Eugenics Movement and how it contributed to the segregation and sterilization of individuals with disabilities. It is designed for educators to learn about the link between eugenics and the historical practices related to identifying, labeling and classifying individuals considered “abnormal” or “deviant.”

The last page on the site offers a variety of resources, which relate to DSE and inclusion. The resources include websites, blogs, academic readings, books, and movies that can provide support as an extension to professional development for educators. For example, the page includes links to additional websites with Disability Studies-related information as well as links to resources related to inclusive education.

## Survey

The e-survey used in this study focused on the participants’ knowledge of Disability Studies prior to using the online modules and their knowledge of Disability Studies acquired after participating in the modules. Further, the survey was intended to explore whether or not participating in the modules changed the perceptions and practice of those working in the field of education. Participants were able to access the survey through a link posted on each page/module. The survey consisted of 12 questions/short answers, some of which included the participant’s position, and years in the field of education. Other questions and short answers related to the participants experience with Disability Studies and/or special education:

1. Were you exposed to Disability Studies prior to viewing the modules?
2. If you had been exposed to Disability Studies, please explain how?
3. How do/would you define Disability Studies?
4. Explain how (if at all) participating in the module(s) changed the way you think about special education and supporting students with disabilities in school?

To view the survey in its entirety, go to chapmandisabilitystudies.com.

## Analysis

In order to answer the research questions, we used non-experimental quantitative descriptive analysis, a one sample t-test, and qualitative thematic analysis (Braun & Clarke, 2006). We were interested in identifying trends such as the number of participants who had prior knowledge of or exposure to Disability Studies and the modules respondents decided to access. Furthermore, in order to answer research question 2 regarding whether or not participation in the modules changed their view of special education services and supports for students with disabilities, we used a one-sample t-test to assess whether there was a statistically significant difference between respondents who answered “yes,” and those who answered “no.” Due to the sample size, we chose to use descriptive statistics to analyze sub-groups (McMillan, 2012).

In addition to the quantitative analyses, we used qualitative analyses to identify themes regarding where or how individuals received training. Thematic analysis allowed the researchers to ground the analysis in our current transformation theory framework (Braun & Clarke, 2006). The theoretical framework and our specific interest in participant change or transformation drove the analysis in this study. This type of analysis tends to provide a more detailed analysis of particular aspects of the data (Braun & Clarke, 2006).

# Results

## Changes in Perceptions

About half of the participants (47%; N= 24) in the study had not heard of Disability Studies prior to participating in the online module. Those that had heard of DS before indicated that they had learned about it from various sources such as friends or in a college class. 46 participants responded to whether participating in the modules made them think differently about disability and/or special education, with total of 32 respondents indicating “yes,” that participating in one or more modules changed his or her view on special education policy and/or practice. Conversely, 14 of those participants responded “no.” Results of the one sample t-test indicated a significant difference between participants who answered “yes” and those who answered “no” to the question of change in perspective (t(45)=2.56, p=.05).

We continued to analyze responses of sub-groups using descriptive statistics. Of the 24 respondents who indicated they had not heard of Disability Studies before, 18 (75%) indicated that using the modules made them think differently about special education policy and/or practice. Of those who had heard of DS before (N=22), 10 (45%) indicated that participating in the modules changed their perspective on special education policy or practice. There did not appear to be a pattern regarding which modules participants completed and whether or not they felt it changed their perspectives or practice.

Analysis of the qualitative responses include 35 out of the 47 participants who responded to the open-ended questions related to how the modules changed perceptions or practice. Many participants indicated that they found the modules simply informative as they had never heard of Disability Studies; others indicated the modules made them question certain educational practices. Participant responses also resulted in three overarching themes: the social model and social justice, the need for change in special education, and individualized approaches to teaching.

## Changes in Perspective of Disability

A number of participants discussed how the modules changed their overall view of disability or gave them a perspective they had not considered. For example, one participant mentioned:

“The first video where everybody is talking, murmuring, and staring at the able bodied man is thought provoking. While it certainly is a little over the top, the point is well taken. Severely disabled people always get stared at and I'm sure talked about. This module made me think what it would be like to live disabled.”

Another respondent indicated that the modules made him or her consider the negative connotation a disability label may carry:

“I had never even thought of how disability was labeled in the dictionary, nor had I thought of how a person might feel being labeled by a word with such a negative meaning. This study has changed my perspective and has piqued my interest in learning more about disability studies.”

Similar responses indicated that these modules helped clarify the field of Disability Studies. One participant simply mentioned, “I learned the true differences between Special Education and DS.” Another participant mentioned how the modules helped clear up her misconceptions about Disability Studies as a field. “I thought it was an area that focused and fine-tuned educators knowledge on Special Needs programs. I didn't consider the societal aspect of disabilities being a specialization.” A third participant indicated similar thoughts, “The difference between disability studies and spec. ed was eye opening and I feel that most teachers can benefit from training.” These responses suggest that these modules helped to clarify the common misconception that Disability Studies is synonymous with special education and rehabilitation.

## Social Model and Social Justice

Many participants indicated how they began to see the social model of disability more clearly. For example, one participant stated, “This really approaches it from a broad social view and aims for better educational outcomes. The political and social context is taken into consideration here and the need for action for change in those spheres is addressed.” Another participant indicated, “I always think about how students and families deal with daily life and prejudices, however this really brought it to another level.” Furthermore, a participant indicated seeing society as a whole moving toward more inclusive models, “Society is changing at a rapid pace and so are our students. I feel we are going toward a push-in model and full inclusion, rather than removal from the general education class.” These remarks suggest that teachers not only gained a clearer understanding of disability as a social construction, but were also “moved to action.”

 There were clear connections between the need for social justice and change. One participant commented:

“Disability Studies is the change that is needed. I have always felt strongly about changes that need to be made to treat all students/people equally and with respect. Disability Studies champions this cause and will be the driving force to better education systems in the future.”

Another participant articulated a similar view of the need for change, “I am more determined than ever to do everything in my power to educate parents about the damage Common Core type thinking will do to our wonderful, unique students with learning disabilities.” These comments suggest that participants recognized the advocacy and social justice related aspects of Disability Studies and that these resonated with them in meaningful ways.

## Need for Change in Special Education

The educators who participated in this study indicated that the modules made them see a need for change in current special education practices or policy. One educator began to see the need for change in teacher training:

“I, more strongly now than before I read the modules, feel the need for changes in the credential programs to teach all future teachers to teach all students. Now that I know there is a field of study out there working on changes, it gives me hope for the future.**”**

Another educator referenced need for changes in current special education law:

“The concept of redefining the law by evaluating our methods is necessary. The children we once taught in the 70s with disabilities are now our colleagues so their feedback and the data we take daily should influence if not dictate necessary changes in the law.”

 In addition, yet another participant indicated, “It reminded me that special education often supports the problem.” Similarly, a general education teacher stated, “Perhaps the end result of the special education system actually hinders the progress of disabled individuals, rather than helping them, as intended.” Lastly, a participant remarked:

“As I have started to study Disability Studies, it has kind of blown my mind in that I feel like I'm having to unlearn everything I have learned in the past. I have always supported inclusion in schools, but it is making me look more at the trends in school where that doesn't happen as much as it should.”

## Individualized Instruction

Participants also commented on “individualized instruction” in a variety of ways. For example, one participant discussed possible lack of individualized instruction in self-contained settings, “Having students in special day classes with extra staff but it may not be individualized through worksheets and work packets.” Two participants discussed individualized instruction in terms of how they could improve planning for individualized instruction in the classroom. One stated, “ I am a general educator who has a high volume of students on IEPS- reading about Disability Studies has caused myself to be very aware of the practices of my own school. I have also been trying to focus on my students unique abilities instead of what they cannot do.” The other participant expressed similar sentiment when stating, “The piece on individualized instruction was the most helpful. I am already approaching lesson design with a clearer vision for learner outcomes and seeing the student opposed to the groups they could fit into.”

# Discussion

The results of this study suggest that Disability Studies can impact perspectives and practices of teachers and education professionals in the field. The statistical significance of the t-test indicated that these modules could change perspectives on special education and disability. This research supports anecdotal evidence from scholars such as Ashby (2012), who have seen results within teacher education programs. Some participants began to view special education from a critical lens, which is imperative in addressing some of the practices that serve to unnecessarily segregate students with disabilities in schools. More participants who had not been exposed to DSE prior to the modules indicated that the modules impacted their perceptions. A further detailed exploration on the impact on participants who had and had not been exposed to DS would support a more in-depth understanding of this response and the possible impact of the modules. Overall, the results suggest that inclusion of a Disability Studies approach in teacher preparation and professional development may help in-service and pre-service teachers understand the importance of the social model and of questioning oppressive special education practices at their schools.

## Possibilities for Enriching Teacher Preparation Programs and Professional Development

Ferri (2006) posits that we should be “teaching to trouble” in our educator preparation programs. Cochran-Smith et al. (2009) insist that including social justice issues in teacher education is essential in preparing teachers to work in today’s diverse schools. Introducing teachers to the social model allows them to not only see the sociopolitical aspects of disability, but to identify the societal changes that need to be made in order to create more access for students with disabilities. We need to prepare teachers, paraprofessionals, and related service providers not only to provide quality instruction, but to also act as change agents.

DS provides a platform for focusing on issues of social justice and disability. Teacher educators may embed DS into their curriculum and move beyond basic theories and methods, to promoting a deeper understanding of the impact of special education practices. For example, the Segregation as a Teaching Strategy module covers the oppressive nature of segregation in education, as well as the connections between segregation, race, gender, and disability. This allows students to observe the “social model” of disability in action. As teachers begin to acknowledge the social and political aspects of disability, they may consider those aspects more when making decisions about when and how to educate students with disabilities.

Teacher advocacy for students with disabilities can be a powerful tool in supporting the success of students with disabilities. As is evidenced by this research, teachers may then be more ready and willing to advocate on the behalf of the students with disabilities as they are more attune to the sites of oppression. Teachers seemed to realize that current special education practices require change if students with disabilities are going to be afforded full access to general education curriculum and peers. They seemed more ready and willing to advocate for these changes. Introducing these teachers to the advocacy-based language of Disability Studies provides them with the tools to articulate the need for changes in oppressive practices they witness at their schools.

## Ease of Access Through Online Modules

Yang and Liu (2004) indicate that teachers view online professional development and training as very effective. Thus, these modules may be viewed as an effective tool for teachers and teacher educators. Furthermore, given the costs and time concerns associated with “in person” professional development, these modules could be a useful tool for folks who are interested in learning more about DS, without the cost or time commitment. These modules are free and accessible to teacher educators, parents and others in the U.S. and abroad that are interested in introducing their students to a DS approach. Teachers can choose to access one or many modules related to DS at their leisure and on their own time. This is an important component of increasing access to the field of Disability Studies in Education.

## Limitations

Although we consider this study to have relevant implications for the field of special education and Disability Studies, we certainly acknowledge its limitations. Use of a larger sample size would improve the generalizability of results. Furthermore, we may want to find more ways to reach out to possible participants through social media and email contacts. This would allow for follow-up interviews that may provide for a richer description of changes in perspectives and practice related to the modules. Lastly, we hope to revise and refine the survey in order for it to more accurately assess the changes in perspectives and practice that are attributed to participation in the modules.

# Conclusion

In conclusion, our preliminary findings indicate that online modules are a relevant avenue for introducing teachers to DS concepts, and that Disability Studies can change the perceptions and practices of current and future teachers and related education professionals such as school psychologists and parents. Thus, DS can certainly enrich the current curricula in teacher preparation programs and professional development. Many would consider Disability Studies on the “fringe” of mainstream special education practices that only a few special education teacher preparation and doctoral programs in education offer as a course of study. However, given the results of this study and the benefits of introducing Disability Studies to teachers, it seems a great time for Disability Studies to become a more significant part of teacher education and teacher professional development programs. These online modules are just one way of many to support access and opportunities for inclusive education for people with disabilities.

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# Creative Works

“Can't C Me.”

Shawn Robinson, Ph.D.

**Keywords**: learning disability, poetry, identity

 *“The stares of a million pairs of eyes and you'll never realize you can't C Me…” Lesane Parish Crooks.*

I contextualize my poetry by using the lyrics of the song “Can't C Me” written by Lesane Parish Crooks. As a Black male with a learning disability (i.e., dyslexia), I was warehoused in an educational system that has been designed to segregate and incriminate instead of emancipate or educate (Blanchett, 2010; Ferri & Connor, 2005; Hoyles & Hoyles, 2010). Between third and twelfth grade, I not only felt segregated as a student in special education, but was also left academically behind (Robinson 2014; 2013). The majority of my educational journey, I felt hopeless about obtaining a bright future because I couldn't read, and had low self-esteem (Robinson, 2015a; Burden, 2005; Wang & Neihart, 2015). Further, my voice was silenced as a Black male who had been identified with multiple labels, and written off (Connor, 2006, 2005; Ferri & Connor, 2014; Gillborn, 2015). To date, there are scholars who examine the intersectionality of race, disability and giftedness (Barnard-Brak, Johnsen, Hannig, & Wei, 2015); however, the voices of Black males living at the intersection of dyslexia and giftedness, and how they understand their position in the education system are nonexistent in those scholarly reviews (Petersen, 2006; Robinson, 2016a). A major factor of their voices being absent is that there are some teachers who frame students’ academic potential from a ‘deficit’ perspective (Robinson, 2016b). Therefore, this poetic account will serve two purposes: (1) shatter all notions that Black males with dyslexia in special education can’t succeed academically, and (2) offer an inside perspective of how it feels knowing that there are a million pairs of eyes staring at me, but some teachers “Can't C Me.”

# Poem: “Can't C Me.”

 Imagine the pain of being constrained because of your ethnicity;

Only to be seen as an “other” and treated like a Black southerner;

In an all-White community, being a Black male in special ed. gave some teachers an anxiety attack;

Much of my educational journey was spent receiving restrictions, and crucifixion, and receiving a conviction of being illiterate;

Most of my programming was behavior based, because many teachers didn't see me as savior;

I was segregated, and academically unmotivated;

My anger of not knowing how to read, misled many teachers belief in my ability, and caused me much grief;

This left me dreaming, and screaming;

My roars were loud as a dinosaurs, and could be heard across four generations of war;

During my entire K-12 journey, administrators called more strikes against my inability to perform, rather than questioning the teacher’s ability to help me transform;

There I sat, a Black male in special ed. who lost it;

My hopes shattered;

I ended up in an alternative high school because I kept getting suspended;

Still unable to read, I fought with many teachers, and was still a second thought;

My reading disability went unnoticed, which left me ineligible for college;

 Most teachers told me I wouldn’t succeed;

I was told college wasn't an option by many teachers who also questioned my knowledge;

Yet, I met a college professor who acknowledged my frustration, and said my anger was the result of misidentification;

He accepted me into college (and I eventually became his successor);

Finally, I graduated high school reading at an elementary level;

Six years later, I received my bachelors;

Five years after, I earned my Masters, and felt like a scoutmaster;

Seven years later, I received my Doctorate in Language and Literacy, became my professor’s successor, and now working my way to become an assistant professor.

In summary, throughout my K-12 journey I had a million pairs of eyes staring at me, but my potential (i.e., giftedness) went unnoticed as some teachers “Can't C Me” because of my “otherness” and the associated stigma (Robinson, 2015a; Yosso, 2005). Yet, as a former special education student, I shattered all notion that Black males with dyslexia within the PK-20 system can’t academically succeed (Robinson, 2016). Furthermore, it is my moral obligation to not only help Black males in special education learn to read, and received appropriate language and literacy curriculum, but also recognize their gifts so they do not experience teachers “Can't C Me” mentalities (Robinson, 2015b).

**Dr. Shawn Anthony Robinson** is an independent scholar and dyslexia consultant. His research focuses on the intersection of giftedness and dyslexia, and writes about gifted Black males with dyslexia. He brings a wealth of academic experience, training and knowledge about the psychological development of dyslexia. Dr. Robinson has written peer-review articles that discuss African American males with dyslexia, which is an understudied area of scholarship. Dr. Robinson attended an alternative school, graduated high school reading at an elementary level, and understands the hardship of not being properly identity, written off, and placed into special education without proper academic services. He created the Triple Identity Theory, which is a comprehensive model to understand gifted Black males with dyslexia. Dr. Robinson’s research has been highlighted in [NBC News](http://www.nbcnews.com/news/nbcblk/man-searching-link-between-racial-bias-dyslexia-n481126) in an article titled “This Man is Searching For a Link Between Illiteracy and Racial Bias.”

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Best Practices in Disability Studies

Questions, Questions: Using Problem-Based Learning to Infuse Disability Studies into an Introductory Secondary Special Education Course

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**Abstract:** This essay describes how an introductory special education course for future high school general education teachers became disability studies friendly through problem-based learning. Course structure and content are described, including opportunities for introducing disability studies concepts. Instructional challenges related to problem-based learning and maintaining a dual content focus are considered.

**Keywords:**Disability Studies Pedagogy, Special Education, Problem-Based-Learning

For many years our higher education institution did not require secondary education majors to learn about students with disabilities or special education. When the state introduced that requirement, the first author was given the task of developing a single introductory course that would be taken by all secondary education majors. The course would serve 20 different secondary education programs housed in three different colleges – each outside the college of education and human development where the new course would be located. Also, the course would serve undergraduates, some graduate students, and teachers in an “alternate routes to certification” program. In any one class there would always be students from multiple majors and different levels of school experience.

Concurrently, our institution offered professional development on problem-based learning (PBL) and the first author began developing the new special education course around PBL principles. This approach, which capitalizes on the interests and questions of students by engaging them in exploring authentic issues, seemed like a good fit for acknowledging the diversity of backgrounds and disciplines that students would bring to the course. The course was positioned as an introductory one that would not teach students everything they needed to know, but would provide them with language, concepts, and principles they would need to navigate the current landscape of U.S. schools, support the learning of diverse students, help them locate professional resources for future use, and give them practice with collaborative learning approaches. The overarching goal was to support their acquisition and application of knowledge about working with academically diverse student populations. In line with a situated case approach to PBL (Jonassen & Hung, 2015), students would engage collaboratively across disciplines to make educational decisions related to realistic scenarios involving students who had been identified for special education services.

# What is Problem-Based Learning?

Problem-Based Learning (PBL) is a sociocultural approach to learning in which the instructor acts as a facilitator of a student-centered learning process (Savery, 2015). The PBL learning cycle (Duch, Groh, & Allen, 2001) supports students in learning how to approach problem-setting, thinking critically, and determining how to acquire knowledge. Problem-setting asks students to examine complex, authentic scenarios, identify what they know (or think they know) about the situation, frame problems, and identify specific issues to investigate. Then students research what is known about their identified issues and possible solutions. The instructor selects an overarching “problem” and provides an instructional framework to support students’ learning of critical concepts, with questions and contributions from each student also determining the focus of learning activities. PBL capitalizes on the power of collaboration through small groups working to synthesize what they have learned from their research in order to construct new knowledge and understanding. Finally, students present their solutions to a larger audience. They highlight critical principles and practices, and reflect upon their learning as well as any unanswered questions.

# Why Disability Studies?

Although it was not an explicit goal at the time, the course design opened up instructional space for critique and engagement with disability studies ideas about disability and special education. Initially, the course design purposefully up-ended a more traditional approach to introductory special education courses, which often focus on learning about the characteristics of children within each of the federal special education disability categories and the major trends in services. Instead, the course designers adopted a socio-ecological perspective, nesting questions about individuals and teaching practices within questions about classrooms and school communities influenced by historical practices and cultural values. Students would be expected to learn about adolescents with disabilities and the major features of the current special education system and its practices, but also to understand that special education as they might know it is not a given; it is a structure created in response to particular concerns at a particular time, wedded to a larger education system that positions disability in particular ways, and subject to further change in response to new questions and knowledge about teaching and learning.

This socio-ecological and sociocultural framing of the course created an alignment that we characterized as “disability studies friendly.” Operating within the constraints of state and professional mandates to deliver a special education course, we still determined ways to infuse disability studies concepts. Connor, Gabel, Gallagher, and Morton (2008) identified one of the primary tenets of disability studies in education (DSE) as “contextualizing disability within political and social spheres” (p.448), which was explicit in the course design. Further, the course introduced students to foundational concepts of “equitable and inclusive education opportunities and full and meaningful access to all aspects of society” (p. 448). Although students in the course would learn about special education categories of disability and characteristics typically ascribed to people with disability labels, the course also problematized disability and normality (Baglieri et al 2011; Lawrence-Brown, 2014).

# Course Structure

The course was built around four overarching questions, one per unit. Composite cases of middle and high school students with disabilities served as anchors for problem-setting. Instructor objectives and student questions were examined through a combination of whole class, small group, and individual work that engaged students in investigations, discussions, and reflections. Several types of learning assessments allowed students to present what they were learning while also prompting them to identify additional questions as they moved through the units.

## Course (Unit) Questions

1. Who are adolescents with exceptional learning needs?
2. Which instructional principles and practices should teachers employ in academically diverse classrooms?
3. How can classroom and school communities be shaped to support the success of adolescents with exceptional learning needs?
4. How do historical, legal, and values frameworksinfluence educational decisions regarding delivery of services and supports to exceptional adolescents?

A potential conflict between the special education focus of the course and alignment with a disability studies perspective is immediately apparent in the use of the special education terminology of “exceptional,” which is the phrase commonly used in the state. This reflects the ongoing tension in the course between helping students to become familiar with the lingo of the profession in which they would be immersed while also opening up discussion around such words. In fact, the word “exceptional” becomes the subject of discussion quite quickly in the process as students begin to synthesize information related to their first investigations about who “exceptional” adolescents are.

The order of the questions (units) is intended to situate adolescents who have been identified for special education services within an unfolding socio-ecological model of interactions involving characteristics of individual students, teaching practices, classrooms and school communities, and historical, cultural, and legal frames. We flipped this from more traditional approaches that often start with law and history and then walk students through the IDEA categories of disability. In this course, we wanted to focus first on students with disabilities themselves, in the hope that the student cases would serve as more personalized anchors when later discussing abstract legal principles and cultural practices.

## Cases

Central to this approach is the use of composite cases of adolescents with various disability labels. Elements of each case are revealed in each unit. For example, in the first unit only the student’s name and IDEA funding label are revealed. In the second unit, more details about the students and their lives are shared, such as ethnicity/race, socio-economic situation, family context, and present levels of academic performance. Unit three places the student in a problematic scenario at the school, and the fourth unit centers on decision-making meetings such as the student’s IEP or a manifestation determination meeting. Cases rotate across groups; each unit and group members stay together. In a typical class of 25-35 students with small groups of five, there are always more cases than units. This means that each group will work closely on only four cases. However, because the final learning assessments for each unit involve presentations by each group to the whole class, all cases become the subject of discussion across groups. And, what is learned in each unit can build upon previous groups’ work.

## Don’t Let This Happen to You!

The class is organized into heterogeneous groups by major to increase the likelihood that students will raise different questions and perspectives about what they think they know, do not know, or want to learn. Group work is not always easy and some students have had little practice collaborating. This issue is tackled early in the course by sharing a graphic of a pie chart (uncredited source, http://i.imgur.com/zXGrx.jpg) that humorously suggests the majority of “what I learn from group projects” is more likely to be about how much I hate people and how to do entire projects on my own, instead of how to work with others to learn information. Students are encouraged to discuss examples of how group work can go wrong and consider proactive strategies for successful group work in response to three questions:

* What can we do to ensure equitable distribution of effort?
* How can we create opportunities to learn from each other during discussions?
* How can we ensure that our final products are more than the sum of individual parts?

Each group creates its own “code of conduct.” This code becomes the basis for peer evaluations throughout the semester.

## Unit Objectives

As each unit is launched, the instructor shares learning objectives, which includes students identifying their own questions. For example, the content learning objectives presented to students in unit 1 are:

* Learn characteristics of exceptional youth including their strengths, needs, concerns;
* Introduce some core concepts (e.g., self-determination, transition); and
* Identify your questions to investigate.

Also, students are reminded of ongoing “process” objectives related to improving oral and written communication skills, practicing collaboration skills, and becoming familiar with professional resources.

## Problem-Setting

Students are given a handout at the beginning of each unit particular to their assigned case and the focus of that unit. After reading, they note experiences or questions they think are relevant for learning more about the case and discuss these with their group. Before leaving class, each group member claims a unique question to investigate. The questions should complement each other and address what the group members think is most important to know (at least at that point in time).

The process of problem-setting is sometimes difficult for students who are used to being told what they need to learn. Students may struggle to come up with questions – or don’t realize that they are asking legitimate questions. For example, a student may say, “I don’t even know what a learning disability is so how can I ask a good question?” and the instructor might reply “One possible question is –What IS a learning disability? Who decides a student will be given a label of LD? Or, how is a learning disability different from other disabilities?” Some students who are more familiar with disabilities may argue that all kids are different – and the instructor might say “True! So your question might be “what is the range of characteristics typically associated with a label such as LD?” The students may also struggle identifying a question that aligns with the unit theme. As current and future teachers, students seem to gravitate toward “how to” questions about pedagogy and less often ask “why” or “in what context” questions.

The instructor also takes time in the first unit to identify some resources students can use to locate answers to their questions. Students are encouraged to use multiple sources of information to answer their questions, including a traditional textbook, journal articles, educational databases, and professional and advocacy websites. The instructor provides links to online assigned readings for the unit and supplementary resources on related topics for students who want background information or to explore other aspects of a topic.

## More Questions

Often at the beginning or end of a session, the instructor will introduce a quote or graphic that is intended to provoke further discussion. For example, in the first unit, a chart illustrating risk ratios for being identified in one of three IDEA disability categories (specific learning disability, intellectual disability, emotional/behavior disorder) based on one’s ethnicity or race is shown. Students are asked to consider what issues the graphs highlight and what might explain these differences. This begins a conversation about the role of professional judgment and other factors involved in formal identification of disability. These extra questions open up spaces for socio-culturally-focused discussions about disability, with students examining their previous assumptions.

The instructor also may pose questions intended to prompt students to consolidate ideas and make connections to new concepts. For example, at the beginning of unit 2 on instructional principles and practices the class is presented with the following quote: “Barriers to learning are not, in fact, inherent in the capacities of learners, but instead arise in learners’ interactions with inflexible educational goals, materials, methods, and assessments” (Rose & Meyer, 2002, p. vi). Each group is asked to discuss: What is the message here? How does this connect to what we learned in unit 1?

## Learning Assessments

There are three types of assignments that occur in each unit. Posts are individual students’ written summaries of what they learned through their brief investigations into their selected questions. The summaries are shared with group members and become a foundation for the end-of-unit Group Presentations, which vary in format by unit. In unit 1 groups prepare an oral presentation about characteristics of adolescents with the disability label they researched. For unit 2, groups prepare a skit that demonstrates instructional practices that could be used in a secondary academic classroom to support learning for their case study student as well as other students. At the end of unit 3 each group creates a conference-style poster to present how they have framed the problem scenario involving their case student, the classroom, schoolwide, and community options they identified for responding to the scenario, considerations to be weighed about implementing those options, and their group’s recommendations. In unit 4 students participate in a role play of an educational decision-making meeting involving their case student.

This role play is not graded, but is the basis for a final case analysis that is completed individually. The analysis is an opportunity for students to demonstrate what they have learned across the course by explaining what could or should have been done to promote a student-focused decision-making process. All of the unit presentations have an important formative purpose. The class learns about each of the cases by listening, observing, and asking questions of their peers while also permitting the instructor to clarify ideas, point out important themes, or introduce new ideas that may be relevant.

The third type of unit assessment is a Participation/Peer Evaluation, in which group members’ give feedback about the preparation, contribution, and communication of each member of their group. In addition to the recurring learning assessments, midterm and end-of-semester exams requiring multiple choice and brief essay responses are given as a way to hold students individually accountable for learning core special education content and demonstrate insights about that content.

## More Framing Questions and Concepts

In addition to the overarching questions, questions generated by the students, and incidental discussion questions, other smaller questions and related concepts that are intended to frame each class session are inserted throughout the syllabus. Table 1 shows examples of framing questions that the instructor might use to introduce syllabus session topics and guide students’ engagement with the readings for each unit.

# Table 1. Examples of Framing Questions Posed by the Instructor for Sessions and to Guide Reading

|  |  |  |  |
| --- | --- | --- | --- |
| Unit 1 | Unit 2 | Unit 3 | Unit 4 |
| Sessions* Course Introduction
* Congratulations!
	+ What Do You Know?
	+ Problem-Based Learning Expectations
* Meet Your First Case Student
	+ Who Are You?
	+ Getting to Know All About You
* A Transition Perspective
	+ Who Will I Become?
* Other Perspectives
	+ Who is Asking?

ReadingWhat is the difference between "people first" and "identity first" language? When is it appropriate to use each?How do cultural factors complicate the idea of "disability" or "exceptionality"? | Sessions* Accessing the General Curriculum
	+ What’s That Mean?
	+ Leveling the Playing Field vs. Changing the Game
* 2 Big Ideas About Instruction
	+ Differentiating
	+ Universal Design
* Rethinking Special & General Education
	+ What’s “Special”?
	+ A New Continuum?
	+ What Works?
	+ What Does That Look Like?

ReadingWhat does "access to the general curriculum" have to do with being inclusive?Which of these evidence-based teaching techniques would be valuable in a general education setting? And, why? | Sessions* Taking a Schoolwide Perspective
* What is SWIFT?
* What is SWPBS?
* What is “culturally relevant” SWPBS?
* Meet Your Student
* What’s Going on Here?
* Let’s Play POCR (problems, options, considerations, recommendations)
* Classroom Management
	+ What Does This Mean for Your Student?

ReadingWhy are schoolwide practices important to the success of students with disabilities?What school practices encourage family involvement? | Sessions* How Did We Get Here?
* Why Does "Special" Education Even Exist?
* Why Do We Do It This Way?
* Meet Your New Student
* You Are Invited (to an important meeting)!
* What Do We Need to Consider?
* Cultural Reciprocity
* What Do We Value?

ReadingWhat values do these laws and principles represent?How can an IEP become more than a compliance document? |

# Ideas and Openings

Certain ideas commonly arise in response to all of these questions and openings for introducing disability studies perspectives can be anticipated. Some of these occur in every semester; others are unique to cohorts. Within the first unit, which asks “Who are adolescents with exceptional learning needs?” students quickly determine there are a variety of definitions for each disability, and the variability within and across categories of disability requires a teacher to “get to know” individual students. Discussions ensue about the intersections of adolescent identities as students transition to new roles beyond school, how the fixed or growth mindsets of teachers and students influence learning opportunities, and how teachers support promoting self-determination. Occasionally, students who identify with particular disability labels (e.g., Asperger syndrome, learning disability) have shared their personal experiences in class discussions and presentations.

In unit 2, which focuses on instructional principles and practices, concepts of interest to students include differences between accommodations and modifications along with the practices associated with differentiation and universal design for learning. Students sometimes struggle with the idea of special education as a spectrum of instructional services and supports that vary in intensity and by context rather than a continuum of more or less restrictive placements. This seems to be especially true for students with limited experiences in inclusive high school settings. The counter to this conceptual barrier is helping students to develop an understanding that many of the instructional practices that teachers can use to engage students with disabilities in learning (e.g., graphic organizers, learning strategies) work well for students without disability labels, too. Upon reflection, some students have suggested that using practices that work for a wide variety of students is “just common sense.”

In unit 3, which is about creating classroom and school communities, we introduce the concept of culture by thinking about the necessary ingredients for implementing school-wide approaches that support belonging and learning for all students, such as the SWIFT model (McCart, Sailor, Bezdek, & Satter, 2014) and school-wide positive behavior supports (SWPBS) (Nocera, Whitbread, & Nocera, 2014). Students are generally comfortable with these concepts even as they recognize barriers to implementation that relate to school structures and teacher mindsets about discipline. For example, some students have had experience in schools where SWPBS was poorly implemented with a misguided or inconsistent emphasis on tangible rewards for student behavior rather than pro-actively cultivating a culture of positive, learning-focused supports. Learning about disproportionate use of punitive disciplinary measures (e.g., restraint, seclusion) on students from ethnic/racial minority groups, especially those with disabilities is often a troubling issue. Students are not typically aware of this issue, which leads to further discussions about why particular categories of students experience discrimination.

Finally, in unit 4 we examine the historical, legal, and values frameworks that influence educational decisions about individual students. Class lecture and discussion focus on the continuing influence of eugenics and historical schooling practices, the role of disability advocacy and rights, legal principles of major disability laws, especially IDEA, and student roles in decision-making. Role plays can lead to discussion about the tensions inherent in making student-centered educational decisions given a schooling system that historically has been structured to sort students by ability and presumed destination (e.g., “college-bound”). Unit 4 also provides an opportunity to examine cultural practices as learned, shared and embodied. Coupling this idea with Kalyanpur and Harry’s (2012) model of cultural reciprocity prompts students to consider how their own values influence their interactions in educational decision-making with students, families, and other professionals.

# More Problems, More Questions (for the Instructors)

Adopting a PBL approach and dual curricular focus on special education and disability studies has presented challenges related to implementation of the PBL model, instructor knowledge of special education and disability studies concepts, and constraints of a single introductory course. As noted in reviews of PBL literature (e.g., Strobel & Van Barnevedl, 2015), students may be uncomfortable if their expectations about their role in class do not align with those inherent in a PBL course. For example, an undergraduate once commented to the first author (in an early course evaluation) that the instructor should just tell students what they need to know instead of making them do so much work to find information. As a result, the instructor learned to engage students at the beginning of the course in conversation about the rationale for using a learning process focused on more than just the “right answer.” Other students have reflected at the end of the course that they were initially uneasy, but became appreciative when recognizing that they had opportunities to participate more actively in learning about issues of importance to them and encounter different perspectives on those issues. Similarly, novice instructors such as the second author may find that it takes some practice to become a facilitator. Leading discussions and determining when and how to push students’ thinking can be more challenging than lecturing. This can be especially true when exploring topics, such as the intersection of disability and race, that students may have had limited previous opportunities to discuss openly. Further, a diversity of students across majors, ages, degree programs, and experiences with disability and teaching, amplifies the need for the instructor to scaffold students’ collaborative work.

Another important challenge to consider is that maintaining a dual focus in the course on special education and disability studies is dependent upon the goals of the instructor. The course can be taught as it was originally designed - an introduction to special education without explicit attention to disability studies concepts – and this has been the case at our institution where different instructors have taught the course over time. The course structure creates opportunities for, but does not guarantee engagement with disability studies perspectives. Also, the instructor’s prior experiences may influence the learning opportunities in the course. For example, the second author had limited experiences with inclusive schooling practices and initially struggled to offer authentic examples of such practices when pressed by students. The first author had experiences in community-based programs for adults with developmental disabilities as well as researching an inclusive high school and working with in-service teachers for several years, which facilitated sharing a range of examples for students to consider. While having “real life” experiences is helpful, the primary issue given the PBL framework is the instructor’s use of those examples in ways that encourage students to ask meaningful questions and explore issues more deeply. Thus, even an instructor with limited personal experience on a particular topic can promote inquiry by using videos, guest lectures, and other sources to supplement discussions.

In our context, a major constraint is the fact that the work occurs within a limited number of instructional hours. Students will move on to their discipline-related methods courses, where there may be more or less attention to disability and diversity. Also, The “alternate routes to certification” (non-degree) students who are currently teaching may report to the class that they struggle with implementing some practices in their classrooms, which then impacts the undergraduates’ views of course concepts. In response, the instructor may remind students of the introductory nature of the course and the reality that novice teachers will develop practices over time within a supportive context. There is also tension between moving conversations forward and letting students dig into particular points. The instructors exercise judgment throughout the course about what content must be covered and what content can fall by the wayside while pursuing an unexpected issue raised by students’ questions. One course is unlikely to provide sufficient time to engage in the critical reflection and practices that would lead to inclusive practices, but can be an opportunity to disrupt dominant understandings of disability and special education.

# Conclusion

PBL is not the only way to encourage students to think critically about special education and disability. Engaging students in discussions about realistic cases using questions framed from multiple perspectives are featured approaches in books such as Disability and Teaching (Gabel & Connor, 2014) and Cases in Special Education (Danforth & Boyle, 2000). Using a situated case-based PBL approach that emphasizes student engagement in problem-setting and question development has been valuable in our context. It has allowed us to address the institutional goal of introducing students to special education while also creating space for the instructors’ goal of helping students to problematize special education and disability. Based upon end-of-semester course evaluations and reflective discussions with other instructors who have taught the course over the last several years, we have noted a few common ideas students take away. Many seem to recognize that they have a bigger responsibility for teaching students with a wide variety of differences, including those with disabilities, than they initially thought. They also identify practices they can incorporate into their teaching repertoire, permitting them to fulfill their commitment to reaching as many learners as they can. They also have a better appreciation for the complexities of schools and special education; realizing that what had seemed to be a “given” is in fact open to inquiry and sometimes responsive to advocacy. Some persist in wanting clear parameters for defining disability as a set of individual characteristics while others become more comfortable with the idea that the social context of disability must be considered.

As with any single course, there are limits to what can be accomplished. We have not conducted follow-up activities with graduates to determine what ideas and practices travel with them as they become established in schools. In alignment with Danforth and Naraian (2015, p. 82), it is our hope that:

“…When teachers recognize the significance of working through competing knowledge bases that pervade a community at any point in time and draw on a range of instructional options to serve their students, they are enacting a differential consciousness. They are simultaneously exercising a form of collective agency that has greater transformative potential than a polarized response based on abstract ideals of social justice.”

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Multimedia

'Autism in Love' Review

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**Abstract:** This article provides a review of the documentary film *Autism in Love* by Matt Fuller, a film that profiles the romantic lives of four people affected by autism. In addition to an overview of the basic themes of the movie, the review also contains excerpts of an interview with the film’s director.

**Keywords:** autism, film, documentary

Autism in Love is the portrait of four very different people and their unique searches for romantic love.  One of the only things uniting these very different individuals is that their lives are affected by autism. Their varied stories are revealed in a series of interviews drawn from a year first-time director Matt Fuller spent listening to them reveal their most personal experiences with love.

Through these often remarkably revealing interviews we learn that, at least for some of them, it appears their greatest challenge in finding and keeping love has been navigating the stigma of autism. Two interviewees, Lindsey (a woman in a committed relationship) and Lenny (a single young man in his 20s) share their devastation from being made to feel “worthless” by others because of the stigma of their diagnosis. While Lindsey was eventually able to overcome this pain (but not forget it), in the course of the film, Lenny continues to struggle with these feelings. For him, his diagnosis seems to make what he sees as society's already impossible ideals of manhood even more unattainable.

While the film presents some unique challenges for those affected by autism, the overall focuses is on what is common to all who love and seek to love. This includes the importance of having larger networks of support: in the case of Stephen (a married man) we see how essential larger familial networks are for sustaining his marriage. Similarly, the young couple depicted (Lindsey and David) were able to meet in the first place because of a larger support network through which they were introduced at a conference on autism. We also see how essential these support networks are by seeing their absence in the life of Lenny, who seems to struggle to find such networks.

Focusing in on such basic, shared needs was a central aim of the film project. Speaking with RDS, director Matt Fuller notes that “we said very early on, if when you’re watching this movie [and] you forget you’re watching a movie about people with autism, but rather a story about people pursuing love, then we’ve done our job.”

With this in mind, the film also seeks to address some stereotypes people may hold about those affected by autism and their ability to love. The interviewee Stephen, both in his appearance and speech, has at least superficial similarities to Dustin Hoffman's character with autism in the popular 2000 film Rainman.  Despite these similarities (e.g., an apparent affective disorder coupled with unusual cognitive abilities—for example, Stephen is shown naming a random day of the week 15 years ago), Stephen is presented as someone, who despite considerable challenges, is capable of sustaining a long-term committed relationship.

Hoffman's character in Rainman, on the other hand, like many characters with disabilities in films, is essentially portrayed as an asexual being, someone wholly disinterested in (or incapable of) the physical comfort of others. This is surely one of the most significant contributions of the film: it reminds viewers, especially those who do not identify as disabled, of the simple obvious truth that those affected by autism remain sexual and romantic beings, an obvious truth rarely addressed in film.

The initial concept for creating such a film that might demonstrate ‘love on the spectrum’ came from Autism in Love’s Executive Producer Ira Heilveil’s. A clinical psychologist, Heilveil was hoping to help create a film to answer a persistent question he hears from anxious parents of children with autism: will my child be able to experience one of the most meaningful parts of adult life; will my child be able to grow to have a loving, romantic relationship?

Director Mat Fuller’s rich portraits of Stephen, Lenny, and David & Lindsey and their unique journeys towards love surely answers this. At the same time, the moving film ultimately leaves us with more questions than answers. For instance, what kinds of support (direct and intangible) do people affected by autism need? How may parents’ beliefs (and fears) about their children’s abilities, even if well intended, cause young people pain or even limit their own concepts of their own capabilities?  How may we best leverage a diagnosis to provide support? And, finally, how might all of these questions be considered in a way that best invites those meeting challenges to recognize their own self-worth and limitless capacity for love?
-R.R.

*Autism in Love*

Documentary

Run time 1hr:16mins

Educational Distributor: GOOD DOCS

Contact info: www.gooddocs.net

www.gooddocs.net/autisminlove

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