

Research

Stigma: Barriers to Culture and Identity for People with Intellectual and Developmental Disabilities



Stigma: Barriers to Culture and Identity for
People with Intellectual Disability

Natasha Spassiani & Carli Friedman

Reference:

Spassiani, N., & Friedman, C. (2014). Stigma: Barriers to culture and identity for people with intellectual disabilities. *Inclusion*, 2(4), 329-341. <http://dx.doi.org/10.1352/2326-6988-2.4.329>.

Abstract

This exploratory paper examines disability culture and identity for people with intellectual disability. In doing so, we argue that the stigma around intellectual disability severely impacts people with intellectual disability's sense of culture and identity. This stigma causes internalized ableism and leads to people with intellectual disability disassociating from others with intellectual disability in an attempt to cope with this stigma. True community inclusion for people with intellectual disability can only occur when this stigma is removed. Fortunately, as we argue, the self-advocacy movement is making great strides in doing so. The self-advocacy movement must be supported in order to achieve true inclusion and a sense of culture and identity for people with intellectual disability.

Keywords: Culture, Identity, Stigma, Intellectual Disability, Self-Advocacy, People First

Stigma: Barriers to Culture and Identity for
People with Intellectual Disability

It is not so much that we do not see a 'person' or 'a real human being' when we encounter someone with so-called profound [intellectual disability]. It is rather that we do not see any culture. We see no meaning to the behavior: there are words but no discourse; events but no story. (Ferguson & Ferguson, 2009, p.74)

People with disabilities have been oppressed due to environmental, organizational, and attitudinal barriers, marginalizing them from fully participating within the social realm; fortunately the contemporary disability rights movement, which is directly controlled by people with disabilities, is challenging the stigmatizing views about the disability community. This movement involves grassroots organizations, issue-specific lobby groups, direct action coalitions and their allies all rejecting the socially constructed barriers of disability and providing a more accurate representation of the abilities of people with disabilities (Dowse, 2001). The functionality of a movement operates at a cultural level through the shared experiences of the members of which it comprises (Dowse, 2010).

The disability rights movement, which began in the 1960s, marked a significant shift in how disability was represented to the public. People with disabilities made a conscious decision to take control of how they would present themselves to mainstream society and began an independent living movement that advocated for the fundamental right for people with disabilities to be able to live and participate in the community. Consequently, centers for independent living for people with disabilities were developed and became the location for some of the first instances of disability culture (Kupper, 2009).

The question 'what is disability culture' has sparked much debate within the disability community, such as: how is it best defined? Which types of disabilities does this culture predominantly represent? Or, more importantly, which disability types does this culture exclude?

Despite these debated questions, there appears to be a general consensus that disability culture is much more than a shared history of oppression and resilience (Brown, 2012; Gill, 1995). Rather the attention is concentrated on what people with disability have created (Brown, 2012).

Specifically, disability culture has been defined as the art, language, symbols, beliefs, values (Gill, 1995), artifacts and experiences created by people with disabilities as a means to present and identify with disability pride (Brown, 2012). Having a disability culture allows people with disabilities to represent themselves on their own terms. Needless to say these representations are in stark contrast to how dominant culture portrays this minority group. Disability culture respects and celebrates individual differences and is empathetic to the pain discrimination has created for both individuals with and without disability (Kupper, 2009).

To outsiders disability culture may appear to be cohesive with a unified disability identity; however, this culture is more fragmented than initially portrayed. People with physical disabilities predominantly shape disability culture (Chappell, Goodley, & Lawthom, 2001). Moreover, disability scholars have criticized disability culture for historically excluding and marginalizing specific groups of people with disabilities within what they argue to be a heterogeneous community (Dowse, 2010). For example, the experiences of people with multiple identities – those with disabilities who are also women, LGBT, ethnic minorities, older people, and/or children – and those with severe impairments and multiple disabilities were underrepresented within disability culture (Morris, 1996; Robinson & Stalker, 1998; Vernon, 1999). While work on multiple identities and disability has been expanding (see e.g., Bell, 2011; Erevelles & Minear, 2010; Garland-Thompson, 2006; Ostrander, 2008; Mpofu & Harley, 2006; Sandahl, 2003; etc.), identity discussions tend to center around one specific identity depending on context or how it impacts others (Ostrander, 2008; Mpofu & Harley, 2006; Vernon, 1999).

Since the disability community, however, is a heterogeneous group with varying disabilities, severities of impairments, and a range personal experiences, one is left to question how these factors impact the representations of people with disabilities within disability culture as well as how, if at all, disability culture grants full access and participation of all members who choose to identify with the disability movement (Dowse, 2010).

Intellectual Disability and Disability Culture

Disability scholars have argued that people with intellectual disability are viewed as ‘nonhuman’ and have been ignored in disability theory (Goodley, 2001). The disability movement has fought against professionals to claim the right to define disability in their own terms. There appears to be an unspoken uneasiness about examining intellectual disability in terms of having a culture or even an identity, and this is evident in the way society continues to associate people with intellectual disability as being deculturized (Goodley, 2001), and by not attaching meaning to their behaviors (Ferguson & Ferguson, 2009). People with intellectual disability are seen as being isolated, alone, and dependent (Abbott & McConkey, 2006; Carlson, 2010; Cummins & Lau, 2003; Ditchman et al., 2013; McConkey, 2007). They are also seen as the outsiders of society (Carlson, 2010; Milner & Kelly, 2009).

This leads one to question how people with intellectual disability are to identify with a movement, which excludes them. Additionally, how do people with intellectual disability view their own identity? These are important questions that require examination in order to better understand how people with intellectual disability identify, if at all, with disability culture. Yet, little research has critically examined disability culture as it specifically pertains to individuals with intellectual disability (Beart, 2005).

The research conducted has typically examined identity—how an individual identifies or is identified with a set of social narratives, ideas, myths and values (Siebers, 2011)—and culture separately. For example, Dagnan and Sandhu (1999) examined the impact of social comparison and depression on people with intellectual disability's sense of identity. Similarly, Antaki, Walton, and Finlay (2007) examined how social aspects of identity can be prioritized and reinforced for people with intellectual disability. Neither explored these impacted on people with intellectual disability's sense of cultural collective identity. However, we argue that these two social phenomena – identity and culture – are interrelated. A culture is made up of a group of people who share a collective identity, thus, in order for this group relatedness to occur one must first possess an identity that they are able to relate to. Although they studied people with psychiatric disabilities, Onken & Slaten's (2000) research exemplifies this as they found that as participants developed a sense of self, their shame associated with disability was significantly lessened or removed and their pride and sense of disability culture increased. Alternatively, individuals who do not have a sense of identity may be able to use culture to help them develop one.

Not surprisingly, there is limited research that has specifically examined people with intellectual disability in regards to identity and culture (Beart, 2005). Moreover, as mentioned, the research that has been conducted in this area has commonly examined these two social phenomenon independently of each other. It is important that we acquire an understanding of the interplay between identity and culture experienced by individuals with intellectual disability, especially since this group has experienced a dramatic shift from being institutionalized and having their voices silenced to community integration and advocating for community participation. For these reasons, the purpose of this paper is to provide a critical examination of

disability identity and culture specifically as it pertains to people with intellectual disability. We argue that the stigma around intellectual disability severely impacts people with intellectual disability' sense of culture and identity. This stigma causes internalized ableism and leads to people with intellectual disability disassociating with others with intellectual disability in attempt to cope with this stigma. As there is very little research about intellectual disability and culture, this exploratory paper unearths both theory and new questions based on our findings.

Labels and Identity

Whether or not a person with an intellectual disability chooses to identify with the label 'intellectual disability,' it is this label that grants them access to the resources and services they need (Davis & Jenkins, 1997). Access to resources and services are vitally important to facilitate independent community living for people with intellectual disability. Thus, whether an individual chooses to identify or reject their social identity of being 'intellectual disabled' may not matter as much as the individual needing to identify with this label to access needed supports.

Intellectual Disability as Social Construction

The social model of disability recognizes an individual's impairment (biological) and their disability (social construction) to be separate. According to social model, intellectual disability is a socially constructed category, which results in stigmatization—a person's differences are seen as a negative by the dominant culture (Goffman, 1961; Jahoda & Markova, 2004). It is this negative social construction that limits opportunities to develop social networks, employment, independent living, getting married, or having children (Chappell, Goodley, & Lawthom, 2001).

The social model has been criticized for predominantly advocating for people with physical disabilities, while simultaneously oppressing other individuals with different

disabilities, thus causing those individuals whose disabilities that are not physical to feel disenfranchised from the movement (McClimens, 2003). It is argued that the experiences of individuals with disabilities who fall within these marginalized groups do not 'fit' the social model and thus are not represented (Thomas, 1999). More specifically, it is suggested that the social model fails to acknowledge the impact which impairment and illness may have in restricting the full participation of people with disabilities and how these illness/impairment restrictions affect the lived experiences of these individuals (Thomas, 1999).

Moreover, it has been suggested that the political nature which surrounds the everyday actions of people with intellectual disability has not allowed this group to take advantage of the emancipatory benefits which the social model has provided for people with physical disabilities or to identify with the disability movement (Chappell et al., 2001).

Misunderstanding Intellectual Disability

The term 'intellectual disability' is a relatively new reframing that was advocated for by people with intellectual disability. The shift in terms advocates for individualized supports as well as better reflects how people with intellectual disability choose to be represented, and current professional practices centered around functional behaviors and contextual factors (Luckasson & Schalock, 2013; Schalock, & Luckasson, 2013; Schalock, Luckasson, & Shogren, 2007). The term 'intellectual disability' was a critical step in gaining improved understanding, societal reciprocity, the involvement of people with intellectual disability in the development and delivery of services, inclusion, and fairness (Luckasson & Schalock, 2013).

Yet, Beart, Hardy, and Buchan's (2005) literature review of people with intellectual disability and identity found people with intellectual disability struggle to understand the term 'intellectual disability,' and do not fully comprehend why they belong to this category. Similarly,

a study by Davis and Jenkins (1997) found participants commonly described having an intellectual disability as a physical disability and not cognitive. For example, participants described people with intellectual disability as having missing fingers, mobility issues, or seizures (Davis & Jenkins, 1997).

People with intellectual disability experience stigma due to their label and these experiences of stigma have emotional consequences for individuals with intellectual disability (Beart et al., 2005). It has been suggested that people with intellectual disability do not understand their identity because of their inability to define the term ‘intellectual disability’ (Beart et al., 2005). However, it can be argued that many people without an intellectual disability would struggle to define this term properly, and thus it is unfair to conclude that people with intellectual disability are unaware of their identity simply due to their inability to provide an accurate definition of the term ‘intellectual disability.’ Moreover, the shift in terms may be confusing to some people with intellectual disability because they might associate the new term with similar negative connotations as ‘mental retardation.’ With the change of any new term it requires time, advocacy, and education for people to understand.

Frustration and Stigma

People with intellectual disability are frustrated with the label of ‘intellectual disability’ and research has shown that they are aware of the stigma that surrounds the term ‘intellectually disabled’ (Dagnan & Waring, 2004; Ditchman et al., 2013). This somewhat relates to the disability hierarchy. The hierarchy of disability, which is present in both within mainstream society and the disability community, creates and reinforces stigma and oppression (Caldwell, 2011; Charlton, 1998; Deal, 2003; McClimens & Taylor, 2003). This hierarchy places intellectual disability towards the bottom while “people with physical and visual disabilities have

greater political, social, and economic opportunities and support systems” (Charlton, 1998, p. 97). This hierarchy is exemplified in mainstream society in language; words such as ‘stupid,’ ‘dumb,’ or ‘idiot’ are extremely common. Regardless of intention, every time one of these words is used, the hierarchy of intelligence is reinforced and people with intellectual disabilities are marked as less than. People with intellectual disability are also often stigmatized and marginalized within the disability community. There is distancing in order to avoid the stigma and stereotypes associated with intellectual disability (Deal, 2003; McClimens & Taylor, 2003). For this reason, it is not surprising people with intellectual disabilities would want to distance themselves from the label in order to avoid these effects. While we want to be clear that we do support individuals’ rights to choose how they identify, we suggest stigma and negative cultural narratives make this a loaded choice.

Moreover, according to Davis and Jenkins (1997) an individual being socially labeled as ‘intellectually disabled’ interferes with their own self-identity in regard to their personal development (Davis & Jenkins, 1997). These frustrations are further heightened when siblings attain the goals desired by those individuals with intellectual disability, such as being hired for a certain job or being able to drive (Davis & Jenkins, 1997). The impacts of this stigma are again increased when parents practice ‘paternalistic control’ to shield their child from being exposed to this label. Despite parents’ well meaning, ‘paternalistic control’ does not necessarily prevent individuals with intellectual disability from becoming aware of the stigma which is associated with having an intellectual disability (Beart et al., 2005). Instead, this shielding can reinforce the shame related to having an intellectual disability even further.

These effects can become even more oppressive when the power dynamics that exist within relationships are factored in. Beart et al. (2005) suggests that people with intellectual

disability' self-identity is oppressed by the power dynamics that exist within the relationships they hold with others. For example, women with intellectual disability who desire children have their self-images oppressed when their parents and others tell them that they cannot be mothers as they are unable to care for a child or that their children may be born 'like them'. Similarly, men and women with intellectual disability are discouraged when speaking about their aspiration to marry (Davis & Jenkins, 1997). It is these oppressive comments that may affect the self-identity of people with intellectual disability as they are constantly struggling with the power dynamics in their relationships between their own desires and the desires of their parents and others.

Coping as Barrier to Group Identity

Not only do individuals with intellectual disability typically distance themselves from their oppressive label as a means to cope with the stigma (Ditchman et al., 2013; Finlay and Lyons, 2000; Werner, Corrigan, Ditchman, & Sokol, 2011), this stigma also manifests through relationships with others through a form of internalized ableism. Individuals with intellectual disability' engagement in social comparison may also play an important role in the way stigmatization is experienced (Dagnan & Waring, 2004; Finlay & Lyons 2000). Individuals with intellectual disability describe their peers to be less socially desirable and attractive when compared to individuals without intellectual disability (Gibbons, 1985). This suggests that individuals with intellectual disability understand the stigma and oppression which is associated with being identified as having an 'intellectual impairment' and choose to actively disassociate from this socially constructed identity.

These effects are seen in a study conducted by Jahoda & Markova (2004) that examined adults with intellectual disability awareness of and response to stigma. After examining twenty-

eight adults living at home or within a long-stay hospital setting, Jahoda and Markova found that individuals both in the hospital and at home reported being discriminated against as a result of their intellectual disability. More specifically, adults living within institutions commented on the stigma by discussing how they were treated inhumanely within the hospital setting. For example, participants spoke of the lack of freedom, privacy, and respect they experienced (Jahoda & Markova, 2004). There was also a resistance to how they were perceived and identified by others, with labels such as ‘residents’, ‘patients’, ‘high-grade’, ‘low-grade’, and were aware that they were treated differently (more poorly) than those ‘outside’ (individuals living within the community – the general public) (Jahoda & Markova, 2004). Furthermore, hospital participants were aware of the stigma associated with living in an institution, and used downward comparison when speaking about others living in the hospital as a potential coping means to deal with the stigma associated with their current living conditions (Jahoda & Markova, 2004). Although some participants spoke in a superior manner when comparing themselves to their peers, they did acknowledge that they experience problems with learning (Jahoda & Markova, 2004).

Participants discussed how they felt moving out of the institution and back into the community provided them with an opportunity to experience a new identity as they would no longer need to conform to the role of a patient (Jahoda & Markova, 2004). Participants expressed that once they transition out of the hospital and back into the community they would have to make a conscious effort to distance themselves from their stigmatized past by not disclosing that they used to live in an institution and not allowing their peers from the hospital to visit them in their community home (Jahoda & Markova, 2004). The shame and stigma that comes with institutionalization needs to be shifted from the behaviors and impairments of those with intellectual disability to the prejudiced system that isolated people out of fear and institutional

biases. Oppression plays a central role in the history of people with intellectual disability. However, it is this collective oppression and struggle for independence and communal respect that is an important component of disability culture (Gill, 1995).

Although individuals in home settings had slightly better results, they still revealed the need for more inclusion in these settings. Individuals living in home settings discussed their need for agency and the importance of demonstrating achievements (Jahoda & Markova, 2004). For example, they discussed that their transition into a community home would demonstrate to family members that they are able to be independent adults. Participants discussed how living independently would provide them with a new opportunity to change their identity to be more positive. However, participants expressed concerns that their new identity would still be undermined by society due to the stigma of having an intellectual disability. These examples show how, in addition to other systemic issues, people with intellectual disability' identities are hindered by stigma and ableism.. In doing so people with intellectual disability cannot see that there is nothing wrong with interdependence despite the fact that we all need it. This indicates a clear area for empowerment.

Not only do living settings impact people with intellectual disability sense of identity, they interact with stigma in other settings. People with intellectual disability understand they are not truly included because of the stigma and segregation of day settings. Jahoda and Markova (2004) found participants were aware of the stigma associated with day programs, and how they were segregated from others leaving a negative impression on people with intellectual disability. This was an area of conflict for individuals as they tried to develop their new sense of identity in community settings.

Self-Advocacy

It has been suggested that having a variety of positive roles that individuals with intellectual disability can identify with may act as a buffer to the negative socially constructed identity they experience (Paterson, McKenzie, & Lindsay, 2012). For this reason self-advocacy is particularly important for people with intellectual disability to engage in so that both their lived experiences and their interpretations of disability can be represented accurately (Dowse, 2010). Self-advocacy has been defined by the intellectual disability community as

‘independent groups of people with disabilities working together for justice by helping each other take charge of our lives and fight discrimination. It teaches us how to make decisions and choices that affect our lives so we can be more independent. It also teaches us about our rights, but along with learning about our rights we learn responsibilities. The way we learn about advocating for ourselves is by supporting each other and helping each other gain confidence in ourselves so we can speak out for what we believe in.’ (Caldwell, Arnold, & Rizzolo, 2011)

Self-advocacy includes rejecting labels of discrimination and disempowerment, making choices, and exercising civil rights.

The People First movement began in the 1960s in Sweden and spread to the United States in 1974 (Shapiro, 1994; Williams & Shoultz, 1982). The name originated from individuals with intellectual disability who rejected their socially constructed labels as being ‘handicapped’ or ‘mentally retarded’ and advocated for being seen as people first (Shapiro, 1994; Williams & Shoultz, 1982). A small group of individuals with intellectual disability started the movement because they felt prior self-advocacy groups were predominantly under the control of professionals. For this reason, People First was created as a self-advocacy organization directly lead by individuals with intellectual disability (Armstrong, 2002). It advocates for service providers, professionals, and mainstream society to listen to the voices of people with intellectual disability (Armstrong, 2002).

The self-advocacy movement has been influential for the intellectual disability community as it has provided a collective and positive identity for people. Unlike the social model of disability that focus on the dominant social and economic ideologies which have created disability, the self-advocacy movement draws upon issues which are related to the stigmatizing label of disability (Chappell et al., 2001). The self-advocacy movement has allowed people with intellectual disability to reject their socially constructed labels and demonstrate the self-determination they encompass even while constantly encountering society's discrimination and oppression (Chappell et al., 2001). The self-advocacy movement is a productive vehicle to gain respect, agency, and citizenship for people with intellectual disability.

Citizenship is equality of participation through individual and collective actions that support full inclusion (Armstrong, 2002). The self-advocacy movement challenges the definition and political practice of the rights of citizenship because people with intellectual disability are commonly denied it (Kliwer, Biklen, Kasa-Hendrickson, 2006). Armstrong (2002) states that intellectual disability is a socially constructed label intended to manage and control a 'troublesome' minority group. In examination of self-advocacy as a vehicle for people with intellectual disability to gain citizenship, Armstrong (2002) argues that the effectiveness of self-advocacy to promote citizenship must go beyond advocating for societal participation of people with intellectual disability, but also challenge the stigmatizing labels of disability as these 'disabling' labels affect the citizenship status of individuals with disability.

Challenging who Belongs

There has been limited research that has involved people with intellectual disability, and what research has been conducted has typically involved those identified as 'mildly' intellectual impaired; however, this is only 75-85% of the intellectual disability community (Groce, 1992).

Thus, there is a serious gap within the literature that has ignored 15-25% of the population (Groce, 1992). This may suggest that it is easier for social theories to explain intellectual disability in those who appear to exhibit 'less' impairment and display more 'natural' behaviors, than to understand others who do not function according to the rest of society's norms (Watson, 1996). Yet, the examination of people with severe impairments can point to revealing paradoxes. Carlson (2010) points out,

the lives of severe cases are often deemed not worth living, assuming that they are doomed to a life of inevitable suffering. But we also find the opposite depiction: the severely intellectually disabled individual can also be portrayed as *incapable of human suffering* by virtue of the fact that she does not possess the same capacities as a 'normal human being...because some individuals are assumed to be so impaired that they *cannot* suffer. (emphasis original; p. 184)

People with severe cognitive impairments can also highlight issues that are unique even to those with intellectual disability who have less severe impairments (Carlson, 2010). Either pole within the category of intellectual disability – from those with severe impairments to those who may pass as invisible because of their proximity to the margins of able-bodiedness – cannot represent everyone from this group; for this reason, it is important that people with a wide range of intellectual impairment are included.

Not only does self-advocacy provide a positive and collective group identity, and challenge the requirements of citizenship, it also provides a source of social and community support for *all* members, where individuals are able to establish meaningful relationships in a safe environment (Armstrong, 2002). Self-advocacy has the ability to show mainstream society that even individuals who have 'severe' intellectual disability are still active and contributing members within this movement.

Self-advocacy groups generate a collective sense of self-empowerment (Buchanan & Walmsley, 2006; Caldwell, 2011; Simons, 1992) and group cohesion where each individual has their own way of contributing to the group. Some members are more visibly active, while others play a more passive yet not less significant role. Everyone is valued as an important contributor to the community, creating a unique culture that helps to remove stigma. The following observational vignette of a self-advocate with autism and intellectual disability serves as an example of the dynamics present at a self-advocacy group for people with intellectual disability:

‘Rachel arrives at the meeting by minibus from the local ‘Autistic Community.’ She does not speak often. She spends her time quietly and apparently contentedly smelling her fingers and looking around the room. She doesn’t appear to interact with any of her friends. At break-time Bill asks her if she would like a cup of coffee or tea. Erica, who lives with Rachel, replied, ‘She likes coffee don’t you Rachel?’ Bill looked at Rachel, ‘Coffee then?’’ (Goodley, 2001, p. 220)

Even people who appear to be passive and inactive due to their intellectual disability can still contribute to providing a collective self-empowerment for the group. More specifically, Rachel, who is seen as the passive advocate in this example, is the catalyst that allows Erica to advocate for her as Erica knows Rachel likes coffee and would probably like some. In order for someone to be an advocate they do not have to have a dominant personality, expressed through their words and actions. Even those individuals who are present at self-advocacy groups, who are more passive in their behavior, can still be seen to have important roles within the overall group dynamics (Goodley, 2001). Therefore, the assumption that people with ‘severe’ intellectual disability are inactive, noncontributing members to the self-advocacy movement or even mainstream society is an assumption made on false pretenses (Goodley, 2001). It may be beneficial for future research to examine the self-advocacy group cohesion and the different roles fulfilled by members with varying intellectual disability. Additionally, it would be interesting to

acquire a better understanding of the experiences of the ‘passive’ advocate and if these people identify with being activist or not.

Self-Advocacy Fosters Culture

Disability culture is active in both public and private life; hospitals wards, special schools, peer-support groups, charity camps, jail, and community living centers are all places where people with disabilities have gathered together—enthusiastically or reluctantly—to engage in discourse about disability history (Gill, 1995; Kupper, 2009). It has been suggested that disability culture may enlighten mainstream society in understanding that it would be beneficial and productive to accept and integrate disability into society, rather than forcing people with disabilities to fit into an ablest society which continues to resist accepting disability (Brown, 2012). A reason for this resistance is that dominant culture continues to view disability as a medical diagnosis which requires treatment and a cure, rather than being socially construction (Llewellyn & Hogan, 2007).

Gill (1995) suggests eight core values of disability culture that represent the political struggle and echo disability art, goals, and behaviors. These core values include: accepting human difference; accepting human vulnerability and interdependence; living an unpredictable life of unknown; disability humor; developing future plans which are both realistic and aware of potential obstacles; the ability to understand and empathize with other members about conflicting social messages; and completing tasks in an untraditional creative and adaptive manner (Gill, 1995). According to these eight core values, we suggest that the intellectual disability community fits well within disability culture.

A critical examination of the People First movement shows evidence of the core values of culture suggested by Gill (1995). The self-advocacy movement embraces human differences and

understands that individuals have different disabilities, but one should not be restricted by their (dis)abilities (Caldwell, 2011; Caldwell et al., 2011; Shapiro, 1994; Williams & Shoultz, 1982;). The self-advocacy movement welcomes individuals who are mildly, moderately or severely intellectually disabled (Shapiro, 1994; Williams & Shoultz, 1982). The intellectual disability community has developed a culture which acknowledges and accepts human vulnerability and interdependence, this is evident during self-advocacy meetings where the group utilizes the different abilities of individuals to assist others where needed. For example, those individuals who are able to read can help non-readers understand the current agenda, or an individual with cerebral palsy who is unable to hold the microphone to speak may be assisted by another member in doing so (Williams & Shoultz, 1982). These examples also speak to how the intellectual disability community is able to complete tasks in an untraditional yet resourceful, creative, and adaptive manner. Additionally, members of this movement often speak about how learning to be a self-advocate has been a life changing experience and they are passionate about helping empower other individuals like themselves to lead a higher quality of life (Caldwell, 2011; Shapiro, 1994; Williams & Shoultz, 1982).

People with intellectual disability are aware of the unpredictable life they lead because of their dependence on supports, services, and resources in order to successfully live independently in the community (Ferguson & Ferguson, 2009; Jahoda & Markova, 2004; Johnson, & Traystadottir, 2005). People with intellectual disability have goals and plans in place as to what they want to achieve as a unified group (Ferguson & Ferguson, 2009), but are aware of the obstacles which are likely to occur and display patience when obstacles arise (Johnson, & Traystadottir, 2005). People with intellectual disability have been able to negotiate between the contradictory social messages of mainstream society and their own beliefs about their abilities.

People with intellectual disability have individually and, collectively as a group, rejected the oppressive dominant ideologies which surround having an intellectual disability and advocate for their right for citizenship, community integration and participation (Williams & Shoultz, 1982). Despite the fact that society may assign less meaning to their actions, the examples above provide support that the intellectual disability community poses aspects of Gill (1995) core values of disability culture.

Discussion

The purpose of this paper was to provide a critical examination of disability identity and culture specifically as it pertains to individuals with intellectual disability. It is evident that the intellectual disability community has been ignored within larger disability culture; however, through the examination of the self-advocacy movement the intellectual disability community has demonstrated similar core values that aligned with disability culture. According to Gill's (1995) core values of culture, it is evident that people with intellectual disability do exhibit similar values encompassed by disability culture. To be clear, we are not necessarily arguing that there must be a separate intellectual disability culture; we are suggesting that the intellectual disability community fosters culture—one that can be unique to other disabilities—and this culture *can* fit within the larger overarching disability culture.

Future research is needed to gain an in-depth understanding of the dynamics involved related to the intellectual disability community functioning within the larger disability culture. Life histories research may be a potential avenue for future research as it is able to bridge the gap between an individual's experiences and the general culture of a particular social group, and in doing so, the reader is able to comprehend the feeling and emotion behind an individual's story and how it related to the social implications discussed (Goodley, 1996). However, it is important

to be sensitive in how researchers examine culture as to ensure that the experience for participants is not a disempowering one. Additionally, researcher should be reflective of their own biases and how their own personal views may affect the interpretation of an individual's story (Goodley, 1996).

Promising Practices

We as a collective society must alter our perceptions of intellectual disability and begin to view the actions and behaviors of people with intellectual disability as meaningful and purposeful, rather than irrelevant and insignificant. The disability community must embrace people with intellectual disability as being part of their culture as they share similar values and characteristics that encompass disability culture. As people with intellectual disability strive for independent living and meaningful participation in their communities it is important that policies and services are appropriately meeting their needs. People with intellectual disability may be able to reject the stigma associated with their intellectual disability label by being meaningfully involved in disability community and the disability rights movement. People with intellectual disability should be key players in voicing their needs, concerns, and wants, however, this is much more difficult if they dissociate themselves from the self-advocacy community or the larger disability community.

The self-advocacy movement has been an integral part in providing unity among people with intellectual disability to regain power. People with intellectual disability can join together in solidarity to improve access to accessible school program, employment opportunities, health care services, and community-based programs. By advocating for services, people with intellectual disability will be actively participating in their communities and consequently challenging

dominate and stigmatizing ideologies that have portrayed people with intellectual disability as passive, voiceless, and dependent.

The intellectual disability community has established advocacy organizations, which have helped build a positive sense of identity and culture among this group. For example, sport and arts/media organizations have been developed specifically for people with intellectual disability. We would argue that these types of organizations have been influential in showcasing the abilities of people with intellectual disability and have allowed outsiders to rethink how people with intellectual disability have been traditionally portrayed. Organizations such as the Special Olympics or Down Syndrome in Arts & Media have provided a welcoming environment for people with various types of intellectual disability.

Advocacy organizations, such as sports and arts/media groups are important because people with intellectual disability are able to display their personalities, skills, and talents to their fellow community members; this in itself can be empowering, and may also improve an individual's self-identity as well as strengthen a community. Moreover, research has shown that individuals who associate themselves with a community experience physical and mental improvements in their health, when compared to individuals who do not report having meaningful social supports (McAdams, 1969). This is an important finding as people with intellectual disability are typically associated with poor physical and mental health (Dagnan & Waring, M. 2004; Rimmer & Yamaki, 2006); thus being part of a community may be able to improve a person's quality of life and health outcomes. A sense of community may bring happiness, acceptance and purpose to an individual's life as they are able to actively participate, and feel as though they belong to a community where they are able to give back.

It is important for families, individuals, and practitioners to support both the larger self-advocacy movement and individuals with intellectual disability as they foster identity, culture, and community. Support people can either hinder or support depending on their proximity power and their willingness (or lack thereof) to support self-advocates access to power through self-determination. Nonnemacher and Bambara (2011) stress the importance of quality of interpersonal relationships with support people for the most effective self-determination.

Although self-advocacy can help people with ID transcend from a passive role to an active one, Goodley (1997) cautions that support people can serve as impediments. If these support people believe in society's stigmatized views of intellectual disability they can only help support self-advocates in moving so far and "self-advocacy will always be a continual struggle against perceived pathology" (Goodley, 1997, p. 370). However, if support people conceptualize disability in accordance with the social model, the self-advocacy will be much more successful.

By having people with disabilities meaningfully engaged in the community they are also able to be out in the community representing their identity on their own terms (Forber-Pratt & Aragon 2013; Gill 1995). Thus leading them not only to embrace their identity but also to educate others about having an intellectual disability, consequently, forcing community members to question stereotypes. Future research is needed to examine the elements involved in self-advocacy and how disability culture, identity, and stigma influence individuals as they interact with their communities. In doing so, we especially advocate for participatory research methodology that meaningfully engages people with intellectual disability and allows them ample opportunities to voice their experiences, opinions, and concerns.

It is our hope that this paper directs attention to intellectual disability identity and culture, including the recognition that their actions are meaningful, as these areas have been unjustly

ignored. It is vitally important that we begin to view people with intellectual disability with the same respect that has been warranted to people with physical disabilities. If this does not occur we fear that we will once again limit the inclusion and the lives of people with intellectual disability. To label a group of people as being without culture would be to label them as uncivilized, uneducated, or at worst less than human; these views would dangerously mimic historical attitudes of how society viewed people with intellectual disability and they are simply unacceptable.

References

- Abbott, S. & McConkey, R. (2006). The barriers to social inclusion as perceived by people with intellectual disabilities. *Journal of Intellectual Disabilities, 10*(3), 275-287.
- Antaki, C., Walton, C., & Finlay, W. M. L. How proposing and activity to a person with an intellectual disability can imply a limited identity. *Discourse & Society, 18*(4), 393-410.
- Armstrong, D. (2002). The politics of self-advocacy and people with learning difficulties. *The Policy Press, 30*(3), 333-345.
- Beart, S., Hardy, G., & Buchan, L. (2005). How people with intellectual disabilities view their social identity: A review of the literature. *Journal of Applied Research in Intellectual Disabilities, 18*(1), 47-56.
- Bell, C. (Ed.) (2011). *Blackness and disability: Critical examinations and cultural interventions*. Germany: LIT Verlag.
- Brown, S.E. (2012). Disability Culture. Independent living institute newsletter. Retrieved from <http://www.indepedentliving.org/newsletter/12-01.html>
- Buchanan, I., & Walmsley, J. (2006). Self-advocacy in historical perspective. *British Journal of Learning Disabilities, 34*(3), 133-138.
- Caldwell, J. (2011). Disability identity of leaders in the self-advocacy movement. *Intellectual and Developmental Disabilities, 49*(5), 315-326.
- Caldwell, J., Arnold, K., Rizzolo, M. K. (2011). Envisioning the future: Allies in self-advocacy report. Chicago: Institute on Disability and Human Development, the University of Illinois at Chicago.
- Carlson, L. (2010). *The faces of intellectual disability: Philosophical reflections*. Bloomington: Indiana UP.

- Chappell, A.L., Goodley, D., & Lawthom, R. (2001). Making connections: The relevance of the social model of disability for people with learning difficulties. *British Journal of Learning Disabilities, 29*(2), 45-50.
- Charlton, J. (1998). *Nothing about us without us: Disability oppression and empowerment*. Berkeley, CA: University of California Press
- Cummins, R., & Lau, D. (2003). Community integration or community exposure? A review and discussion in relation to people with an intellectual disability. *Journal of Applied Research in Intellectual Disabilities, 16*(2), 147-157.
- Dagnan, D., & Sandhu, S. (1999). Social comparison, self-esteem and depression in people with intellectual disability. *Journal of Intellectual Disability Research, 43*(5), 372-379.
- Dagnan, D., & Waring, M. (2004). Linking stigma to psychological distress: Testing a social-cognitive model of the experience of people with intellectual disabilities. *Clinical Psychology and Psychotherapy, 11*(4), 247-254.
- Davis, C.A., & Jenkins, R. (1997). 'She has different fits to me': How people with learning difficulties see themselves. *Disability & Society, 12*(1), 95-110.
- Deal, M. (2003). Disabled people's attitudes toward other impairment groups: a hierarchy of impairments, *Disability & Society, 18*(7) 897-910.
- Ditchman, N., Werner, S., Kosyluk, K., Jones, N., Elg, B., & Corrigan, P. W. (2013). Stigma and intellectual disability: Potential application of mental illness research. *Rehabilitation Psychology, 58*(2), 206-216.
- Dowse, L. (2001). Contesting practices, challenging codes: Self advocacy, disability politics and the social model. *Disability & Society, 16*(1), 123-141.

- Erevelles, N. & Minear, A. (2010). Unspeakable offenses: Untangling race and disability in discourses of intersectionality. *Journal of Literary & Cultural Disability Studies*, 4(2), 127-145.
- Ferguson, P.M., & Ferguson, D.L. (2009). Winks, blinks, squints and twitches: Looking for disability, culture and self-determination through our son's left eye. *Scandinavian Journal of Disability Research*, 3(2), 71-90.
- Finlay, W.M.L., & Lyons, E. (2000). Social categorizations, social comparisons and stigma: Presentations of self in people with learning difficulties. *The British Journal of Social Psychology*, 39(1), 129-146.
- Forber-Pratt, A.J., & Aragon, S.R. (2013). A model of social and psychosocial identity development for postsecondary students with physical disability. In M. Wappett & K. Arndt (Eds.) *Emerging perspectives on disability studies* (pp. 1-22). New York: St. Martin's Press LLC.
- Garland-Thomson, R. (2006). Feminist disability studies. *Signs*, 30(2), 1557-1587.
- Gibbons, F.X. (1985). Stigma perception: Social comparison among healthy mentally retarded persons. *American Journal of Mental Deficiency*, 90(1), 98-106.
- Gill, C. (1995). A psychological view of disability culture. *Disabilities Studies Quarterly*, 15(4), 16-19.
- Goodley, D. (2001). 'Learning difficulties', the social model of disability and impairment: Challenging epistemologies. *Disability & Society*, 16(2), 207-231.
- Goodley, D. (1997). Locating self-advocacy in models of disability: Understanding disability in the support of self-advocates with learning difficulties. *Disability & Society*, 12(3), 367-379.

- Groce, N. (1992). 'The Town Fool': An oral history of mentally retarded individuals in a small town society, in P.M. Ferguson, D.L. Ferguson & S.J. Taylor (Eds.) *Interpreting Disability: A qualitative reader* (pp. 175-196). New York: McGraw-Hill.
- Hirsch, K. (1995). Culture and Disability: The role of oral history. *Oral History Review*, 22(1), 1-27.
- Jahoda, A., & Markova, I. (2004) Coping with social stigma: People with intellectual disabilities moving from institutions and family home. *Journal of Intellectual Disability Research*, 48(8), 719-729.
- Johnson, K. & Traystadottir, R. (2005). *Deinstitutionalization and people with intellectual disabilities: In and out of institutions*. Philadelphia: Jessica Kingsley Publishers.
- Kliwer, C., Biklen, D., & Kasa-Hendrickson, C. (2006). Who may be literate? Disability and resistance to the cultural denial of competence. *American Educational Research Journal*, 43(2), 163-192.
- Kuppers, P. (2009). Disability culture anchor essay. In S. Burch (Ed.), *Encyclopedia of American Disability History*. New York: Facts on File.
- Levine, H.G. & Langness, L.L. (1986). Conclusions: Themes in an anthropology of mild mental retardation, in L.L. Langness & H.G. Levine (Eds.) *Culture and Retardation*. Kluwer: D. Reidel Publishing Company.
- Llewellyn, A., & Hogan, K. (2000). The use and abuse of models of disability. *Disability & Society*, 15(1), 157-165.
- Luckasson, R., & Schalock, R.L. (2013) What's at Stake in the Lives of People With Intellectual Disability? Part II: Recommendations for Naming, Defining, Diagnosing, Classifying, and Planning Supports. *Intellectual and Developmental Disabilities*, 51(2), 94-101.

- McAdams, D.P. (1986). Motivation and friendship. In S. Duck & D. Perlman (Eds.), *Understanding personal relationships: An interdisciplinary approach* (pp. 85-105). Beverly Hills: Sage.
- McClimens, A. (2003). The organization of difference: People with intellectual disabilities and the social model of disability. *Mental Retardation*, 41(1), 35-46.
- McClimens, A. & Taylor, S. (2003) The Organization of Difference: People With Intellectual Disabilities and the Social Model of Disability. *Mental Retardation*, 41(1), 35-46.
- McConkey, R. Variations in social inclusion of people with intellectual disabilities in supported living schemes and residential settings. *Journal of Intellectual Disability Research*, 51(3), 207-217.
- Milner, P. & Kelly, B. (2009). Community participation and inclusion: People with disabilities defining their place. *Disability & Society*, 24(1), 2009.
- Morris, J. (1996). *Encounters with strangers: Feminism and disability*. London: The Women's Press.
- Mpofu, & Harley, D. (2006). Racial and disability identity: Implications for the career counseling of African Americans with disabilities. *Rehabilitation Counseling Bulletin*, 50(1), 14-23.
- Nonnemacher, S. L., & Bambara, L. M. (2011). "I'm supposed to be in charge": Self-advocates' perspectives on their self-determination support needs. *Intellectual and Developmental Disabilities*, 49(5), 327-340.
- Onken, S., & Slaten, E. (2000). Disability identify formation and affirmation: The experiences of persons with severe mental illness. *Sociological Practice: A Journal of Clinical and Applied Sociology*, 2(2), 99-111.

- Ostrander, R. N. (2008). When identities collide: Masculinity, disability and race. *Disability & Society, 23*(6), 585-597.
- Paterson, L., McKenzie, K., & Lindsay, B. (2012). Stigma, social comparison and self-esteem in adults with an intellectual disability. *Journal of Applied Research in Intellectual Disabilities, 25*(2), 166-176.
- Rimmer, J.H. & Yamaki, K (2006). Obesity and intellectual disability. *Mental Retardation and Developmental Disability Research Review, 12*(1), 22-27.
- Robinson, C., & Stalker, K. (1998). *Growing up with disability*. London: Jessica Kingsley.
- Sandahl, C. (2003). Queering the cripp or crippling the queer? Intersections of queer and cripp identities in solo autobiographical performance. *GLQ: A journal of Lesbian and Gay Studies, 9*(1-2), 23-56.
- Schalock, R. L., & Luckasson, R. (2013). What's at stake in the lives of people with intellectual disability? Part I: The power of naming, defining, diagnosing, classifying, and planning supports. *Intellectual and Developmental Disabilities, 51*(2), 86–93.
- Schalock, R. L., Luckasson, R., & Shogren, K. (2007). The renaming of mental retardation: Understanding the change to the term intellectual disability. *Intellectual and Developmental Disabilities, 45*(2), 116–124.
- Shapiro, J. (1994). People First No pity: People with disabilities forging a new civil rights movement (pp. 184-210). New York: Random House LLC.
- Shoultz, B. & Williams, P. (1982). *We can speak for ourselves*. Indiana: Indiana University Press.
- Siebers, T. (2011). Introduction. In T. Siebers (Ed.), *Disability theory* (pp. 1-33). Michigan: The University of Michigan Press.

- Simons, K. (1992). 'Sticking up for yourself:' Self advocacy and people with learning difficulties. York: The Joseph Rowntree Foundation.
- Thomas, C. (1999). *Female forms: Experiencing and understanding disability*. Buckingham: Open University Press.
- U.S. Department of Health & Human Services. (2013, March 29). Intellectual and Developmental Disabilities. *NIH Research Portfolio Online Reporting Tools*. Retrieved from <http://report.nih.gov/nihfactsheets/ViewFactSheet.aspx?csid=100>
- Vernon, A. (1999). The dialects of multiple identities and the disabled people's movement. *Disability & Society*, 14(3), 385-398.
- Watson, W. (1996). Bad Samaritan: Very cognitively disabled people and the sociological sensibility, *International Journal of Critical Sociology*, 37(3-4), 321-251.
- Werner, S., Corrigan, P., Ditchman, N., & Sokol, K. (2011). Stigma and intellectual disability: A review of related measures and future directions. *Research in Developmental Disabilities*, 33(2), 748-765.