## REVIEW OF DISABILITY STUDIES: AN INTERNATIONAL JOURNAL

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# **Editorial**

## **Inclusion and the Gifts of Art**

Maria T. Timberlake RDS Associate Editor for Creative Works

On an early spring day in March 2015, I received the gift of song at the Museum of Fine Arts in Boston Massachusetts. The gift was offered as part of Sonic Blossom, an exhibit created by internationally acclaimed artist Lee Mingwei<sup>i</sup>. The concept is that an opera singer wanders in the galleries and approaches random visitors asking, "May I give you the gift of song?" If the museum go-er accepts, they take the prepared seat in the gallery and the song is sung. In the photo below I am receiving the gift of song from Abby Krawson<sup>ii</sup>.



Figure 1 Photograph of the author receiving the gift of song from Abby Krawson

Mingwei refers to the song as "a transformative gift" and I can attest to the magical nature of this art. I was deeply affected by the beauty and intimacy of sitting in a majestic space and for a few minutes, being the singular focus of the singer and the song. Three months later, I was back in Boston on a sunny June afternoon to host Mingwei's Living Room exhibit at the Isabella Stewart Gardner Museum. The exhibit invites the guest host to select objects of their own, with personal or aesthetic significance and bring them into the museum. The host then shares her or his artifacts, telling the stories and engaging visitors in dialogues about the items. I received another unforgettable gift by being the "artist" for a day.



Figure 2 Photograph of the author hosting Mingwei's Living Room exhibit

Both of these experiences immersed my academic researcher-teacher self into a world of imagination, color, texture, music, and history. While Mingwei's art is not about disability per se, his works are about human connection, paying sincere attention to others, and dissolving barriers between strangers. Mingwei's work has been described as "a way to engage interaction and nurture participation" and these themes resonate deeply because I came to disability studies via inclusive education. For me, inclusion has always been an intuitive response to other human beings and cannot be reduced to an educational philosophy or placement decision based on evaluation results and classroom variables. Many disabled individuals, family members, advocates, and scholars have written eloquently about inclusion and the principles of openness and acceptance. I have been delighted to discover an individual who gives expression to the spirit of inclusion in visual and performance art.

The gifts I received at these exhibits continue to accrue and readers of RDS who have been inspired by music, literature or visual arts may understand the significance. Absorbing Mingwei's art and reflecting on his unabashed desire to connect with his fellow human beings persuaded me to be more explicit about connection and love in my research and teaching. Mingwei has mended clothes and cooked meals for strangers in his performance exhibits. I saw how he dissolves barriers, deliberately reverses roles and undoes everyday structures of power and authority with beauty and gentleness. This vision of social barriers and social positions as

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malleable is vital to creating an inclusive world. Without any professional claim to the disability field, Lee Mingwei illustrated a counternarrative to the need for separation and I am still thinking about his honesty in seeking connection and his confidence in offering his time and service to strangers. Many educators have been conditioned to assess and evaluate people before offering participation but Mingwei did not stop to determine whether I possessed the prerequisite skills to be involved nor did he need to be assured that I would "benefit" in some practical way from being included.

The gifts of art I received strengthened my conviction that creative works and scholarly papers are a unique and vital combination here at RDS. One artist's inclusive spirit provided me with an extraordinary experience that I treasure, and a deep thinking about my work that has remained long after the song was sung. If you know of an artist that you believe our readers might appreciate, consider crafting your own story. Or perhaps you have art to share? We publish visual images of paintings and sculpture, drawings and photographs as well as poetry and short story. Please join me and the editorial team here at RDS in bringing more gifts of art to our international readership.

<sup>1</sup> Lee Mingwei, Artist <a href="http://www.leemingwei.com/artist.php">http://www.leemingwei.com/artist.php</a>

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<sup>&</sup>lt;sup>2</sup> Abigail R. Krawson, Soprano <a href="http://www.operabby.com/html/">http://www.operabby.com/html/</a>

<sup>&</sup>lt;sup>3</sup> http://www.leemingwei.com/projects.php <sup>4</sup> Gross, J. R. & Hyde, L. (2000). *Lee Mingwei: The living room.* Published by the Trustees of the Isabella Stewart Gardner Museum. Two Palace Road Boston, MA 02115.

# **Research Articles**

# Rethinking Disability and Inclusive Education: A Teacher Study Group

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**Abstract:** This qualitative study explored the outcomes of five teachers' engagement in a study group, the content of which was based in the radical/critical tradition of counter-narratives and social change, and which explicitly aimed to explore institutionalized ableism and the role of educators in the systematic segregation of students with disabilities in schools. The findings indicate that teachers experienced significant and meaningful shifts in their thinking about the constructed meanings of disability in society, the nature of disability oppression, and the implications of inclusive education in democratic societies.

**Key Words:** disability studies in education, teacher education, ableism

### Introduction

In 1975, Public Law 94-142 granted children with disabilities in the US access to a public education previously denied to them, setting in motion a global debate on educational practices pertaining to this group of students and influencing policy changes in many countries (Winter & O'Raw, 2010). This landmark legislation, which today goes by the name of Individuals with Disabilities Education Act (IDEA, 2004), was rooted in a civil rights perspective and a vision for the integration of children with disabilities in schools and society (Hale, 2013; Odom, 2002, Ong-Dean, 2009) Despite the progressive and emancipatory spirit which originally guided these laws (Hale, 2013), today students with disabilities remain a marginalized group, their education entrenched in ideologies of *separate but equal*. In the decades following the passing of these laws, special education has emerged as an increasingly separate system of education rooted in a set of assumptions about the distinctness of its teaching practices as well as about the children it serves (Connor & Ferri, 2007).

In academic discourses there is an increasing focus on educating students with disabilities inclusively and there exists a growing body of research which points to numerous benefits of this practice (Cole, Waldron, & Majd, 2004; Downing, Spencer & Cavallaro, 2004, Fisher & Meyer, 2002, Freeman & Akin, 2000; Rea, Mclaughlin, & Walther-Thomas, 2002). However, ability-based grouping is prevalent in public schools in the U.S., with large numbers of students with disabilities educated in partially or fully segregated learning environments. Currently, national statistics indicate that approximately 33% of all preschool children with disabilities and approximately 52% of all children with disabilities between ages 6 and 21 are educated predominantly (at least 80% of the school day) in general education classrooms (U.S. Department of Education, 2009). In New Jersey (the state wherein this study was conducted), only 46.6% of children receiving special education services are being educated inclusively, i.e. in a setting in which they spent 80% or more of their day alongside nondisabled peers. These numbers are even more troubling when we disaggregate them by disability classification; for

instance, for students labeled as having "autism" only 23.7% are educated inclusively (spend 80% or more of their day alongside nondisabled peers); for those regarded as having "multiple" disabilities, that percentage drops to 15.1%, and for those regarded as "intellectually disabled," it drops still further to 5.2% (The Technical Assistance and Dissemination Network).

The widespread practice of ability-based segregation of students with disabilities perpetuates stigma, leads to low expectations and a watered down curriculum, and renders children with disabilities a marginalized group within schools (Gabel & Connor, 2009). From another perspective it is worth noting that even when students with disabilities are educated inclusively, they tend to be socially isolated, have few reciprocal friendships and are often at the margins of their classroom communities (Guralnick, Neville, Hammond, & Connor, 2007; Odom, 2002). Teachers may not be trained to take an active role in facilitating social interactions between children with and without disabilities (Buysse, Goldman & Skinner, 2003) and may not feel prepared to address the fears and prejudice of nondisabled children; indeed some view self-contained classrooms as "safe havens" in which children with disabilities are insulated from rejection or bullying (Lalvani, 2013). Thus despite the original emancipatory intent of IDEA to increase educational access and equity for all children, it may be fair to say that it has failed to fulfill its promise (Hale, 2013). Today, almost four decades later, the building of truly inclusive classroom communities remains an elusive goal in many schools, and special education has established itself as a parallel system of education based on the unquestioned premise of "separate but equal" for *some* children.

# **Institutionally Sanctioned Ableism**

Problematic issues in the education of students with disabilities are situated in dominant assumptions which are, at their core, deeply ableist in nature. The term ableism refers to negative or prejudicial attitudes toward people with disabilities (Linton, 1998), or a societal devaluing of this group of individuals based on "beliefs that some ways of being are superior to others" (Baglieri & Shapiro, 2012, p. 222). Ableist attitudes are implicit in cultural master narratives that center on notions of disability as undisputed tragedy, and on beliefs about people with disabilities as suffering, deserving of sympathy, or needing to be "fixed" (Linton, 1998; Shapiro, 1993). When applied in educational contexts, ableism manifests as a focus on the "normalization" of school children (Baker, 2002), i.e. efforts to remediate children with disabilities so that they may learn or behave in the same ways as nondisabled students (Hehir, 2005). In dominant educational discourses rooted in ableist assumptions about which children can be educated inclusively, placement in a general education classroom is understood as based on children's abilities rather than as a fundamental right of all children to access their neighborhood schools, their natural community of peers, and the general education curricula (Slee, 2001; Valle & Conner, 2010). As such, special education remains entrenched in medical model perspectives which position disability as deficit or as limitations to overcome. Despite operating from a deficit- based model however, few teachers locate deficits in institutional structures and educational practices; rooted in notions of the *otherness* of students with disabilities, the practice of ability- based segregation is institutionally upheld and seldom problematized by teachers (Lalvani, 2013). Focusing solely on biological impairments, traditional special education locates the source of the "problems" related to disability within

individual bodies, leaving structural and attitudinal barriers unexamined, and thus absolving society of any complicity in negative outcomes for individuals with disabilities (Byrom, 2004; Connor & Ferri, 2007)

In contrast, a growing body of disability studies scholarship posits that the experience of disability is not merely a natural outgrowth of impairments, but rather the "product of social and political processes" (Linton, 1998, p. 72). Drawing from a constructivist epistemological paradigm, critical disability studies (DS) petitions us to retract our collective gaze from individuals' impairments, and to focus it instead on cultural and institutional practices which contribute to the systematic oppression of disabled people (Hahn, 1997; Linton, 1998). Drawing from this perspective, disability studies in education (DSE) scholars argue that problematic issues in the education of students with disabilities are rooted in ableism, and that inclusive education is better understood as linked to issues of democratic principles, civil rights, and social justice (Ainscow, Booth, & Dyson, 2006; Ballard, 2003; Slee, 2001; Ware, 2003). This is *not* to suggest that inclusive education is about the mere physical placement of students with disabilities in general education classrooms while ignoring their impairments and learning needs; rather, within a DSE framework, inclusive education is understood as an educational practice wherein teachers take account of differences in abilities and functioning, and are responsive to the learning needs of diverse students through fundamentally altered pedagogical strategies. Indeed, as noted earlier, there is evidence that when done in this way, inclusive education is effective and associated with academic and developmental gains for students with a wide range of needs for support (Cole, Waldron, & Majd, 2004; Fisher & Meyer, 2002, Rea, Mclaughlin, & Walther-Thomas, 2002).

# The Silence Around the Topic of Disability in K-12 Curricula

Today, people with disabilities comprise the nation's largest minority group and one that continues to face discrimination, oppression, and marginalization (Shapiro, 1993). Although there is a growing acknowledgement in social justice- based multicultural education of the need to directly confront issues connected to discrimination and prejudice (Nieto, 2013; Nieto & Bode, 2011) by infusing anti-bias (e.g., anti-racist, anti-sexist, etc.) curricula in K-12 schools, anti-ableist curricula are not typically included. Indeed it is remarkable that the topic of disability is often excluded in educational discourses on diversity and in multicultural curricula. In particular, there is a silence in schools around the topic of disability oppression, both in historical and contemporary contexts.

A growing body of critical scholarship which frames disability as a constructed category on par with race, class and gender (e.g. Kudlick, 2003), explicates that what unites these groups is the shared experiences of stigma, oppression, and marginalization (Gordon & Rosenblum, 2001). However, in social justice education there is little or no acknowledgement of the existence of ableism and its impact on students, schools, and society. As such, the ability-based segregation of students with disabilities in schools remains largely unexamined by educators. If the topic of disability is addressed in schools at all, it is usually done as isolated activities which are conducted during a designated "disability awareness" day/week and generally take the form of watered down and decontextualized information, presentations of "famous" people with

disabilities, and disability "simulations" which aim to help children "put themselves in a disabled person's shoes" (Lalvani & Broderick, 2013). Although such efforts may certainly be well intentioned, they have been long condemned by disability rights activists who argue that these activities perpetuate paternalistic notions about disability and reinforce feelings of fear or pity among the nondisabled (Brew-Parrish, 1997; Connor & Bejoin, 2007; Valle & Connor, 2010). Additionally these activities are problematic because they equate disability with impairment, thus leaving the issues of *disablement*, i.e. cultural and institutional attitudes and practices which present barriers to full access and acceptance for individuals with disabilities, unexamined (Valle & Connor, 2010).

Framed within a CDT lens, the study described here sought to examine any shifts in the thinking of teachers who engaged in a teacher study group, the content of which was based in the radical/critical tradition of transformative pedagogies, counter-narratives, and social change (Friere, 1970; Giroux, 2011), and which explicitly aimed to confront cultural and institutionalized ableism and to explore the role of educators, in the marginalization of students with disabilities in schools. Consistent with Nieto and Bode's (2011) assertion that multicultural education should intentionally confront all forms of injustice, this project was based on a stance that if we are to prepare teachers to teach inclusively, they need to position disability oppression alongside other forms of injustice and to challenge ableism in addition to other forms of prejudice in educational systems, discourses, and practice (Lalvani & Broderick, 2013).

Ballard (2003) states that it is only when we prepare teachers to be "thoughtfully critical of the society in which they live" by calling into question the exclusion of some members of society, that they are able to create truly democratic learning communities in which all students are valued members. Similarly, Slee (2001) asserts that if we are to create inclusive schools, it is important to provide teachers with the tools needed to critically examine institutional policies and practices, to identify personal complicity in systematic exclusion, and to redefine what needs to change. Grounded conceptually in these perspectives, the teacher study group discussed in this paper aimed to create a space for teachers to rethink dominant discourses and practices pertaining to the education of students with disabilities and to work toward establishing inclusive teaching practices and classroom communities.

## Methodology

## Participants and Recruitment

Five teachers (four general education teachers and one special education teacher) from two public elementary schools within the same school district participated in this study group facilitated by the author. The author is not employed by the schools and has no professional role within the school district; the project was initiated by the author and offered as a professional development opportunity for teachers. In order to establish the study group, the author met with the principals of the schools and discussed the aims and scope of the project. The principals subsequently invited teachers at their respective schools to participate, describing the project as an opportunity for teachers to engage in a semi-structured study group facilitated by a teacher educator. Five teachers responded to the invitation and volunteered to participate. The group

met weekly during after- school hours to discuss critical issues in disability studies and inclusive education. The discussions were focused on specific topics each week, which included (but were not limited to): cultural and personal attitudes towards disability; ability-based segregation, the intersections of race, social class, and disability; disability culture; power, privilege and ableism; language and oppression; and barriers to teaching inclusively. Prior to each session, teachers completed readings selected by the author from CDT and DSE literature (e.g. Connor & Ferri, 2007; Linton, 1998; Shapiro, 1993; Valle & Connor, 2010). The objectives of the study group were for members to: (1) Engage in critical thinking about the socioculturally situated meanings of disability, (2) Examine personal and cultural beliefs and attitudes towards individuals with disabilities and understand how these impact our work as educators, (3) Identify institutionalized discourses and practices which sanction ability-based segregation of students with disabilities in schools, (4) Problematize the omission of the topic of disability in K-12 curricula and in discourses on social justice education, and (5) Generate strategies to create inclusive classrooms and school communities.

Teachers engaged in weekly "journaling" throughout the duration of the study group. In their journals, reflecting on aspects of the readings and discussions which they found to be most compelling, they aimed to make connections to their own experiences, beliefs, and teaching practices. Through their journaling they also documented any shifts in thinking and interrogated their previously held assumptions. At the culmination of the study group each teacher generated ideas and a proposal to effect change in their own classrooms and schools.

# Data Collection and Analysis

Data for this study derive from the journal entries completed by the teachers throughout their participation in the study group. A discourse analysis of their written reflections was conducted, using qualitative research techniques (Bogdan & Biklen 2007). Teachers' written reflections were reviewed thoroughly and all patterns and commonalities in their perceptions were initially recorded. Following this, codes were identified based upon frequency and consistency of particular perspectives or interpretations that existed across the data. This method is consistent with the Emergent Themes Approach (ETA), which is described by Glaser and Strauss (1967) as a method for analyzing data in which conceptual themes emerge from the data rather than the other way around. The numerous codes that were identified were then organized under more abstract stratifications or coding categories; each category containing a cluster of codes that pertained to the broader conceptual theme. This is consistent with the technique of identifying open and axial coding (Strauss & Corbin, 1998). Once the codes and organizing categories were identified, each teacher's written reflections were coded. All of the data analysis was done by the author.

## **Findings**

The data indicate that each teacher in the study group experienced significant and meaningful shifts in thinking with regard to the ways in which they conceptualized disability and approached issues related to the education of students with disabilities. Raising critical questions and concerns through their writing, teachers also demonstrated new understandings about educational equity and the ways in which the goals of social justice education (SJE) can inform

their practices. The findings discussed here represent an analysis of the commonalties noted in teacher's written responses, and are organized under three thematic categories of conceptual shifts which teachers believed they had experienced.

# Problematizing special education practices

# Questioning Ability-Based Segregation

Teachers in the group discussed their shifting interpretations of the practice of educating children with disabilities in separate learning environments and began to question dominant assumptions about its benefits. At the outset of the group, as indicated in data from journal entries completed during the first week, none of the teachers problematized ability- based segregation and all had considered it necessary for some students with disabilities, for example: those who struggle academically, are significantly delayed developmentally, or present challenging behaviors. For example, in her first journal entry one teacher wrote:

"I think the biggest challenge is when the student is significantly below grade level – they need direct instruction. Sometimes the pull- out classroom is less distracting for them ... Students who are significantly below do better in a pull –out."

Journal reflections completed during the commencing weeks of the study group highlight teachers' dramatically altered views about this practice. For instance, they now expressed beliefs that children are sometimes placed in self-contained learning environments as a result of prejudice, unwillingness on the part of professionals to teach students with disabilities, or a teacher's lack of knowledge about how to differentiate instruction. Their comments indicate that in discussing the removal of some children from general education classrooms, whereas in the beginning of the group, they had focused on *impairments*, locating the "problem" in individual minds and bodies, toward the end of the group, they focused on *disablement*; locating the "problem" in institutional structures and practices, and in a failure of educators to support all children in inclusive learning environments. For instance, in discussing the removal of some students from general education classrooms, the same teacher several weeks later wrote:

"I think it's the way the school handles it, and the way the teacher handles it, and how the system is handling the kids. There are so many roadblocks and people aren't even aware of the roadblocks ... I think people just want to say: 'well, it's the child's disability' - but it's not like we've actually taught the child."

Additionally, teachers in the group began to note discrepancies between institutional discourses on inclusion and the ways in which it is practiced, particularly as they pertain to students with severe or intellectual disabilities or those labeled with autism. For instance, two teachers commented that only "certain kinds of children with disabilities" are usually educated inclusively even within schools which are regarded as "inclusive" and that they were beginning to question why this may be the case. Whereas at the outset of the group these teachers had expressed beliefs about disability classifications or the severity of a child's disability as determining whether or not a child could be placed in a general education classroom, during the

course of the study group they began to problematize disability labels, expressing new beliefs that these are sometimes used to exclude children or to deny them access to general education classrooms. For instance one teacher wrote:

"In our group this week, I questioned: Where are the kids who are more severely disabled? What types of kids do we see in inclusive classrooms? You don't get a variety of disabilities ... We must have other kids with disabilities in the district. Where do those kids go? How are we helping them? I've had many different kinds of disabilities in my class, but there were other kids who just weren't there, and I wonder, who determines what's the cut-off? It's really interesting...I'm thinking about it differently, like, who is deciding who is being included and who is not?"

# Questioning "Expert" Knowledge

As seen in the comments above, teachers began to ask critical questions about educational decision making and planning for children with disabilities. Additionally, rethinking dominant "knowledge," some began to question the implicit ideologies which guide special education practices as well as professionals' judgments often positioned as objective truths. For instance, one teacher wrote:

"Who has the right to say who should be in special education? Who really defines what special education is? ... People make assumptions based on some general rule. And noone tells you why; they just say this is how it should be."

Their reflections point to their increasing focus on the ways in which decisions about special education and inclusive education are situated in sociopolitical contexts. Whereas at the outset of the group, they had expressed beliefs that the "experts" in special education make decisions about programming and placement based on children's levels of impairments, they later began to question "expert" knowledge and to ask critical questions about how or why so many students with disabilities end up in separate schools or classrooms. Thus, during the course of the study group teachers gained a heightened awareness of inequalities in schools and the ways in which professional judgments, cloaked in "scientific knowledge," are inextricably linked with issues of power and control. For example, one teacher stated:

"I always trusted the experts in special education ... You know, like, I'm not qualified and this is the qualified area at play. I knew something was wrong, but I had this belief that this is what the kids needed. I am just becoming aware that maybe that's not what it is – maybe it's just that we need to adjust."

# Redefining Disability

### From Biological Reality to Sociopolitical Construct

The data indicate that the teachers in this group experienced transformations in the ways in which they understood disability; moving away from dominant conceptualizations of

disability as deficits in physical or cognitive functioning, they began to understand the experience of disability as situated in sociopolitical contexts. In their journaling during the first week, teachers focused predominantly on deficits or biological limitations. For instance one teacher wrote that disability is "a condition that impacts a person's physical, mental, social, emotional or educational abilities" and another described it as "an impairment that impacts your daily life." Additionally at the outset of the group, teachers understood disability to be a fixed and universal category, and in discussing factors which influence outcomes for students with disabilities, they focused largely on impairments. As such, they located disability within individual minds and bodies; in their initial writings, there was little to suggest that they took into account sociopolitical environments and systemic barriers which also influence outcomes for students with disabilities.

The data revealed that over the course of the study group, the meanings which teachers ascribed to the phenomenon of disability began to shift. Their journal entries completed toward the end of the group point to their understanding of disability as situated in the expectations and values in a given society and in culturally defined parameters of normative functioning. Additionally teachers began to understand the ways in which disability labels rely on the subjective interpretations of those in positions of power and control. For instance, one teacher questioned: "Who gets to decide what's the norm - what's acceptable and what's not - who is determining that?" Their writings highlight their understanding of the fluid nature of disability labels and of the socioculturally constructed meaning of disability. This is seen, for example, in this teacher's comments:

"What is/was an impairment or a disability might be controversial or questionable in a different time, place, or society ... What role does society play? Society gives the guidelines of what is a meaningful life, and perhaps those who do not fit the guidelines are thought to be meaningless lives?"

One teacher discussed what she believed to be her transformed understanding of disability as a form of human diversity, or as an identity marker not unlike the constructed categories of gender, race or ethnicity. She also discussed her understanding of people with disabilities as members of a minority group. This following excerpt from her writing sheds light on her own awareness of the ways in which her conceptualizations of disability were shifting:

"It's almost like the curtain has been drawn ... Before, I never really thought about disability as a community of people, and I never really classified them in a cultural way in my mind."

Shifting the Gaze: From Impairment to Ableism

Over the course of the study group, teachers became increasingly focused on examining ableist ideologies and nondisabled privilege. Their writings indicate an emerging awareness about the negative attitudes which exist in society toward people with disabilities. For instance, one teacher reflected on her heightened awareness of the ways in which people with disabilities are "being segregated, looked at differently and treated differently," and another teacher

commented that she believed people with disabilities are devalued because in society "people have a fear of disabilities." Additionally, one teacher discussed her views about the more covert ways in which disability is negatively positioned, problematizing the assumptions of otherness implicit in the admiration which society confers on those individuals with disabilities who have "overcome" their disabilities and are therefore considered to be "heroes." An excerpt from her journal is below:

"I've just become aware that people with viewing people with disabilities as inspirational/heroes or as superhuman is a form of discrimination as well ... Putting people with disabilities on display, akin to heroes, it's like the age-old slight of calling a black person articulate. In our praise/amazement is our bigotry."

Similarly other teachers made connections between ableism and other forms of oppression, and compared people with disabilities to members of other historically marginalized groups. For instance, discussing her own shifts in thinking as a result of participating in the study group, one teacher wrote:

"I never before thought about people with disabilities as a segment of the population that's been discriminated against, or as a group of people who have been advocating for change. I'm not sure what to make of it yet."

In addition to cultural ableism, teachers also shifted their gaze to institutional practices rooted in ableist ideologies. When discussing inclusive education, they began to focus less on children's inherent dis/abilities which they had previously believed would prevent them from participating in general education classrooms, and more on problematic institutional practices which define normalcy in narrow ways and deny children access to their civil right to belong. For instance, one teacher wrote:

"Removing kids from classes – I don't think people see it as discriminatory practice, and I'm starting to see it as discrimination. And discrimination doesn't always mean you're bad or evil; it just means you have this preconceived idea and you're drawing a line across this kid ... There's a bigger issue here - our communities are segregated. And we're ignoring our self-contained rooms where it's segregated. It's like, separate but equal, but not quite! That's what makes me uncomfortable ... I didn't want to make people feel bad at our last meeting, but I meant what I said. It doesn't sound good, but we're basically discriminating. We're segregating."

Whereas at the outset of the group teachers had expressed that certain disabilities and behaviors presented barriers to some children's being educated inclusively, they now expressed beliefs that ableist attitudes and practices presented barriers for the full acceptance and achievement of children with disabilities in schools. This shift in teachers' thinking, i.e. from a focus on impairment to a focus on disablement in the context of schooling suggest that these teachers understandings about *what needs to change*, was fundamentally transformed.

### Redefining Teachers' Role in Inclusivity

# Interrogating Personal Complicity in Institutional Ableism

The data indicate that teachers in the group became increasingly more focused on examining personal complicity in negative outcomes for students with disabilities in schools. In their journals they critiqued their own previously held assumptions and personal biases, and questioned whether their own teaching practices were truly inclusive. Teachers who had initially expressed support for ability-based segregation for some students with disabilities now began to problematize not only the institutional sanctioning of this practice, but also their own role in perpetuating it vis-à-vis their failure to question the removal or exclusion of some children from their classrooms. Additionally they raised critical questions about whether the "problem" may lie in teachers' unwillingness to differentiate instruction or lack of training in creating accommodations and modifications for individual students; as such, they began to reflect on the ways in which their own teaching practices may be contributing to the difficulties experienced by some children. This is seen in the following excerpt from one teacher's journal:

"When we first started, I always felt that pull- out was best for the students that were really struggling ... Now, my first thought is - what have we done to support this child at school? Have we done everything? ... What are we doing to change to help make progress? ... I think the biggest shift in my thinking is - how can I adapt this curriculum to meet the child's needs? It has pushed me as a teacher, challenged me to work with the regular teacher to make it happen so that kids can be part of the class and be successful."

In their written reflections, two teachers in the group discussed their discomfort at exploring their own ableist assumptions; however, their discomfort did not stop them from engaging in critical self-reflection. The following excerpt from one of these teachers' writings reveals her engagement in deep thinking about her previously held beliefs about children who present behavioral challenges. Placing the onus on herself, she discusses her altered beliefs that if she is to teach inclusively, she must examine her personal biases and responses to children with behavioral challenges:

"It's really about examining ourselves ... quite honestly, it's uncomfortable cause then you think – wait, I obviously have some stereotypes or misconceptions about this ... As a kid I remember that room full of "bad kids" - because it centered a lot on behavior. I believed it was because of some kind of negative behavior ... And then when I became a teacher, again – it was this room full of "bad kids"... But the behavior's not really an excuse for having them there - I have to pop that bubble in my head that they're in a self-contained classroom because of their behavior."

### Positioning Self as Agent of Change

In addition to examining personal biases and attitudes with regard to students with disabilities, the teachers in this group began to view their role and responsibility as educators in very different ways; positioning themselves as agentic, they discussed the changes they were

beginning to make in their own practices. As such, their writings indicate that their shifting perspectives were manifesting as "adjustments" in their expectations of students as well as in the ways in which they delivered instruction in their classrooms. For instance one teacher stated:

"My shift is just becoming aware that perhaps it's that we need to adjust ... There are adjustments I am trying to make. It's hard. I've been trying to change the way I approach certain behaviors and how I teach ... It's made me think differently about my own teaching, my own perceptions on what's acceptable and what's not acceptable, what I expect and don't expect in a classroom. It's kind of made me think differently about not just special education, but education as a whole."

Similarly other teachers in the group expressed their altered beliefs that in order to teach inclusively, they need to identify aspects of their own teaching which need to change and be willing to make these changes in their practices. As one teacher stated:

"You have to be willing to challenge each other and think reflectively about -is this what's best for me or is this what's best for my students? And then think about - how do we make it work?"

In their final journal reflections, teachers expressed their interest in continuing to work toward greater inclusivity at their schools. Their writings at the conclusion of the group point to their heightened commitment to teaching inclusively and to their beliefs about the importance of working with other professionals to collectively develop strategies for change. For instance, one teacher *wrote*:

"I believe our school needs to come up with strategies of how we should work together to create a curriculum to meet the needs of all students ... I believe this is something that will take a lot of work, so we should be brainstorming now on how to prepare for this ... I think as teachers we need to ask ourselves —"what can I do to adjust my instruction so they can access this work?" I think teachers have to start thinking. It's up to us to recognize that if we create an inclusive environment, I think this is going to make us better teachers because we're going to have to figure out how to adapt our curriculum."

To this end, the teacher quoted below discussed the need to create a "safe" space to keep the conversation on inclusive education ongoing at her school site and to have a community of support for teachers invested in inclusive teaching:

"It's important to explore that discomfort in a safe place, I don't think most people are willing to explore discomfort in a large group. You need to feel support ... Having a group like this makes you feel like you're not standing alone ... Knowing that I'm not alone makes me more willing to take a risk."

At the culmination of the study group each teacher generated ideas and proposals for changes they hoped to effect at their schools. These included: creating a resource guide on instructional accommodations and modifications for a variety of K-5 lessons for use by all

teachers at the school; developing a workshop for teachers on the use of children's literature to teach children about disability, differences, and acceptance; developing an information session aimed at helping parents understand the benefits of inclusive education and learn strategies to support their children in inclusive learning environments; and developing a curriculum aimed at exploring identity and human differences through interactive video gaming technology and the creating of virtual "avatars." Teachers discussed their plans to fully develop and implement these projects during the next academic school year. Although at the conclusion of the study group these projects were in the formative stages and had yet to be implemented, the generating of these ideas and proposals may be taken as an indication of the specific ways in which transformations in teachers' conceptualizations of disability and their heightened awareness of disablement can potentially lead to systematic change in practices in schools.

### Discussion

The findings of this study point to the positive impact on teachers of participating in a discussion-based study group conceptually grounded in radical, constructivist paradigms and informed by critical disability studies scholarship. The teachers who participated experienced significant and meaningful shifts in their thinking about the constructed meanings of disability in society and the nature of disability oppression. Moving away from medical model based perspectives on disability as biologically defined or as limitations to overcome, they developed a conceptual understanding of disability as a sociopolitical construct and an awareness of the ways in which decisions pertaining to the education of students with disabilities are linked with issues of power and privilege. Resonant of the seminal work of Tomlinson (1982) who invited teachers to explore their own knowledge of disability and disablement, the teachers who participated in this study group developed the dispositions needed to disrupt dominant discourses on disability and to question ableist practices which lend institutional support to the marginalization of students with disabilities in schools. In exploring a range of misconceptions they had previously held about inclusive education and in interrogating their personal biases, these teachers perceived their belief systems to be transformed.

Giroux explains that critical self-reflection is an important aspect of social justice education, and that educators have an obligation not only to scrutinize public institutions but also to deeply interrogate their own role and complicity in the oppression of individuals or groups (Guilherme, 2006). These data indicate that in addition to problematizing institutional discourses and practices, the teachers in this study engaged deeply in critical self-reflection, identifying personal attitudes, beliefs, and practices which may contribute to the systematic segregation of students with disabilities at their school district. Examining what Giroux and McLaren (1986) refer to as *counter knowledge*, these teachers developed an understanding of inclusive education as a precondition for democratic societies (Bernstein, 1996) and as fundamentally linked to civil rights (Ballard, 2003; Slee, 2001).

According to Ayers (1988), critical teaching requires that teachers develop not only the dispositions but also *practices* which strive for social justice. The simultaneous nurturing of inclusive attitudes and practices among teachers is a key element in the inclusion debate. For inclusive education to be effective, transformations in thinking will not be enough; teachers also

need to develop pedagogies that are responsive to the needs of each student. To this end, these data suggest that the transformations which teachers believed they had experienced in their thinking were indeed informing their practices; teachers believed that their changed perceptions were instrumental in leading them to explore inclusive teaching strategies. Additionally, they generated proposals to effect changes at their school sites with regard to greater inclusivity for all students. Although their proposed projects were in the conceptualization stages when the group ended, teachers' discussions of these projects, which they intended to implement during the upcoming school year, may be interpreted with optimism; they indicate that participation in a critical study group, grounded in a DS framework, can empower teachers to view themselves as agents of change and to seek ways to develop inclusive pedagogies.

These findings have implications for teacher education. They suggest that if we are to effectively prepare teachers for inclusive practices, they need to gain an understanding of the socioculturally constructed nature of disability and of inclusive education as a practice related to democracy, equitable societies, and social justice (Ballard, 2003, Bernstein, 1996; Slee, 2001; Ware, 2003). Consistent with Campbell's (2009) invitation to invert the traditional approach to disability and to shift our collective gaze to the "production, operation, and maintenance of ableism" (p. 4), this study is a call for teacher educators to prepare all teacher candidates to recognize and name ableist ideology at work in institutional policies and everyday school practices, and to make connections between social justice education and the need to confront *all* forms of segregation. The development of inclusive pedagogy, which should be an ultimate goal in teacher education, should be conceptually rooted in an understanding of the situated nature of disability and the nature of prejudice and oppression.

Although this study involved a small group of teachers and was therefore limited in its scope, those who participated in this project experienced significant and meaningful shifts in their thinking in a relatively brief duration of time. As such, these data support the need for critical pedagogies in teacher education and more opportunities for teachers to engage in professional development experiences that are transformative and empowering. Many scholars have argued for using a CDT lens in preparing teachers (Connor & Ferri, 2007) and for more engagement in critical dialogues in which "disability becomes entangled with other forms of oppression and revolutionary responses" (Goodley, 2013, p. 631). This study suggests that teacher education can benefit from coursework firmly grounded in a CDT framework which provides teachers with the tools to recognize and disrupt ableist discourses and practices in schools, engages them in a dialogue about their own complicity as educators in the continued marginalization of many students, and empowers them to position themselves as agents of change.

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# **E-Mentoring Across National Boundaries**

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**Abstract**: Computer-based mentorship, or e-mentorship, is a beneficial mentoring technique that promotes independence and self-efficacy among the individuals being mentored, with and without a disability<sup>1</sup> (McDonald, Balcazar & Keys, 2005; Smith, 2008; Stumbo et al., 2010). E-mentorship increases and broadens the individual's communication and social skills and increases knowledge about overcoming community participation barriers. It also increases the visibility of individuals with disabilities by integrating them with the non-disabled, and allowing both sides to share views and experiences. Before introducing face-to-face programs, introducing an e-mentoring program will help build and empower youth<sup>2</sup> with disabilities in one country by using an existing mentor group based in a different country and the active resources of a traditional mentorship program committed to these activities. E-mentoring has the potential to expand mentorship programs from more economically developed western industrialized countries (such as UK or USA) to developing countries: across boundaries.

**Keywords**: technology, mentoring, youth with disabilities

#### Introduction

In this paper I want to explain why expanding mentorship programs in countries like the United States of America to developing societies, like some South and Central American countries, could complement or even enhance the development of youth with disabilities.

## What is Mentorship?

The idea of mentorship can be traced back to ancient Greece. In *The Odyssey*, Odysseus, before he left Ithaca for the Trojan War, entrusted the education of his son, Telemachus, to an old friend named Mentor (Acomb, 2013). From this story the English language adopted the word "mentor", which is defined as a counselor, supporter, and overseer of an individual's development (Thomas, 2001; Bierema & Merriam, 2002; Mezias & Scandura, 2005; Acomb, 2013). In this example, Telemachus, the object of Mentor's efforts, is referred to as the mentee or protégé (Burgstahler & Cronheim, 2001).

In our society, education is critical to the development of the individual - it improves the chances for him or her to secure employment and fit into society. Entrusting someone with this guidance, a mentor, is extremely beneficial for both the mentor and the protégé. Mentorship, or the role developed during the interaction between mentor and protégé, is described in the literature as encompassing a wide variety of activities: counseling, role-modeling, guiding and networking (Acomb, 2013; Burgstahler & Cronheim, 2001).

# Types and Benefits

The traditional definition of mentoring describes a hierarchical relationship between a senior and junior members of the same organization (Mezias & Scandura, 2005), but in a more generic sense, mentorship is a relationship that develops between two individuals: a mentor and protégé. As such, as Burgstahler and Cronheim (2001) indicate, it can develop in many different ways, depending on the context. Mentorship relationships can be formal or informal, categorized by the type of "connection," or social/racial/cultural bond between the mentor and his/her protégé, and molded by the social context of the relationship. For example, work-related relationships are more formal in nature and consequently generate more formal types of mentorship programs, but sometimes relationships are developed in a more spontaneous way, therefore leading to more informal connections (Mezias & Scandura, 2005). As such, formal connections may lead to informal ones. Therefore both types may be combined in a program.

Acomb states that some mentorship relationships are informal and unstructured (Acomb, 2013, p. 125), since they are driven by the personality of both individuals. Buchanan (2005) lists different types of relationships: student to student, educator to student, or professional to student, in a mentor-protégé structure. As these relationships can be informal, they can be formal and structured too (Mezias & Scandura, 2005), as those defined in a computer based programs. These connections, or the channels of communication between all members, can develop either as hierarchically defined directional and vertical communications, or as layer defined horizontal ones. Regardless of the type, these relationships develop in an emotional context which is also defined by diversity - marked by cultural, social, age, and gender categories and experiential trends (Buchanan, 2005).

Many of these categories, such as gender, define relationships. Darling, Bogat, Cavell, Murphy and Sanchez (2006) affirm that boys and girls construct their interpersonal relationships in mentorship groups either with mentors or other protégés in two different types: instrumental for boys and psychosocial for girls. The instrumental type is more active and goal-setting oriented, and the psychosocial type is more emotional or personality-development oriented. Beyond gender stereotypes, both of these exemplify types of relationships that should be considered when creating connections in a formal structured program or when monitoring and orienting emerging connections in a more informal one.

Another structure that may emerge is a peer to peer relationship, where communication flows in a more horizontal manner, and mentors share their experiences and approaches to different situations, expanding their emotional and social connections.

Regardless of the relationship layout and mentorship type, both individuals benefit from these relationships. As in other social relationships, such as immediate family (grandparents, parents, and siblings) or close friendships, and not just for individuals with disabilities, both individuals play fundamental roles (Burgstahler, 1997). In these relationships both mentors and protégés provide information, counsel, and guidance when appropriate, which flows in both

directions, and doing so form a bond of dependency and "belonging" (Burgstahler & Cronheim, 2001s).

For mentors, besides the inherent benefits of a social relationship, the benefits also include the encouragement to set goals for another individual, and the chance to share and prove different strategies and set more personal challenges, in the case of computer based mentoring, like Disabilities, Opportunities, Interworking and Technology (DOIT) (for more on the DOIT project see the section in this article, "Using Existing E-mentoring Communities for Protégés with Disabilities"), particularly around communication skills and outreach efforts (Burgstahler & Cronheim, 2001). For protégés, the biggest benefit is access to role models.

In summary, in a computer based context, benefits include the possibility of broadening his/her mentor and protégé network, providing access to experience and advice, and the opportunity to develop technological and communications skills. These translate into a social network expansion effect.

These benefits of mentoring increase by adding cross-cultural diversity to the mentoring context as in programs across boundaries (Groce, 2004). In the organizational context of mentorship, Cox and Blake (1991) argue that the cross-cultural diversity characteristic of a workgroup increases creativity, problem solving, and adaptability by exposing it to more competition and diverse socio-cultural scenarios. This is true for non-organizational types of mentorship programs as well.

### Mentoring and Disability

As stressed by the United Nation Children's Emergency Fund (UNICEF) (2007) in the editorial of their *Innocenti Digest* No. 13, mentoring can be a valuable tool to enrich young people with disabilities while they prepare for adult life. According to this article, most young people with disabilities across the world are often not provided with enough development possibilities early in their life. They often lack opportunities such as primary and secondary education, or life-skills and vocational training that are more easily available to other young people. This oversight and their higher propensity for abuse is stressed by the fact that young people with disabilities are often ignored or dismissed (UNICEF, 2007, p. vii). Mentoring is a tool to address some of the rights for youth with disabilities, described in the United Nations 1989 Convention on the Rights of the Child (UNCRC), such as upholding child nondiscrimination policies, accommodating to the best interest of the child, procuring child survival and development, and respecting the views of the child (UNICEF, 2007). Another state-defined treaty is the United Nation's Convention on the Rights of Persons with Disabilities (UNCRPD), which embraces similar principles as the UNCRC but with a broader scope. But although it has no explicit mention of adolescents as a specific category, according to Kett (2012) young people with disabilities played a significant role in the drafting of the Convention. Their needs and interests are incorporated in the Convention because it spells out the needs/issues of skill development and education of all people with disabilities.

### **Statistics**

Just based on the numbers indicated below I argue the value of mentorship programs for young people with disabilities, both as supportive or alternate avenues to conventional educational programs, primarily in developing countries. Stumbo et al. (2010) state that approximately 3 million individuals between 5 and 15 years old and 24 million individuals ages 16 to 64 years experience disability in the United States. Globally, though estimating the number of young adults that live with a disability worldwide is complex (Filmer, 2008), it is estimated at roughly 180 million. Based on UNICEF projections, this number grows every year (Groce, 2004). For example, in Italy in a ten year span the number of young people with and without disabilities enrolled in primary schools rose from 2.5 million to 7.6 million, while the number of teachers increased from 38,000 to 90,000 (UNICEF, 2007, p. 29). Considering this scenario, as a realistic progression in any society for adolescents with disabilities, and noting Spencer's (2006) estimate that 2.5 million adults serve as volunteer mentors to young people in the United States, I believe increasing mentorship (rather than formally enlisting more educators) can be a means of addressing this student-teacher gap.

If we project these numbers to the developing world, we count that about 80%, or 180 million, of these young individuals live in developing countries (Groce, 2004), and additionally, as Groce (2004) states, they live among the poorest and most marginalized populations in these countries. Therefore any educational program targeting developing countries, where disability can be associated with poverty and low schooling attainment for youth (Filmer, 2008), must consider the economic limitations or restrictions for young people with disabilities. A crossnational venture might address some of these limitations, because of the resources and infrastructure available in more western industrialized economies.

Therefore any mentoring program that targets youth with disabilities can leverage socially pre-defined education structures, like those of tutoring or home schooling programs and ultimately make those structures more accessible and relevant (McDonald et al., 2005). By achieving this, some of these programs can reach out to segregated young people with disabilities, who experience limited access to education (Burgstahler,1997) because of social and physical diversity, evidenced though accessibility barriers. Therefore, mentoring programs must embrace social diversity by actively engaging youth and mentors with a variety of forms of disability, as well as other categories of sociocultural diversity (UNICEF, 2007). As they increase the social and vocational dimensions for young people, they broaden the number of teacher and student networks and providing more opportunities for education, coaching and social support (Mezias & Scandura, 2005). Mentoring for young people with disabilities not only may bridge these social barriers but also reach beyond the more conventional education channels which shadow the gaps generated in a young adult's life by these limitations.

Transitions in the individual's development, from school to different types of professional or vocational employment, require structures, often socially defined, to support the change process (Stumbo et al., 2010). Institutions like schools, clubs, gyms and even friends, family, and non related adult mentors serve this purpose. Scholars, such as McDonald, Keys, and Balcazar

(2007) and also statements from the UNCIEF (2007) agree that these support networks may be scarce for young people with disabilities. Therefore, the most critical function for mentoring programs oriented towards young people with disabilities are to ease any anxieties that arise during these transitions, improve the individual's social competence, improve his or her disability-related skill set and increase their motivation to succeed (Stumbo et al., 2010).

# Adolescent Development

Research by Spencer (2006) supports the idea that young people's relationships with non-parental adults, for example mentors, promote adolescent development. For young people with and without disabilities, this development is determined by the child to adult transitions mentioned before, where these non-parental role models promote success. For this reason, in countries such as the United States, many mentorship programs specifically targeted at youth with disabilities share a common goal: to facilitate successful transitions (Stumbo et al., 2010).

Commonly, young adults go through these stages with institutional support, from the corresponding schools, colleges, or places of employment, and during the transition phases between these, with support from family, peers and other role models. These transition supporters acting as formal or informal mentors provide guidance and information that individuals require while traversing a transition. Darling et al. (2006) characterize these transitions as cognitive and contextual, defined by the cognitive development stage of the individual and the socio-cultural context. And they define them as phases determined by the normative changes in family and school, individual's biological changes, and social changes like adaptive parent-child dynamics and increased exposure of the young adult to peers.

Due to social stereotypes, lack of social visibility and accessibility issues, the transition from childhood to adulthood for adolescents with disabilities is more challenging because of limited access to information on health and sexuality, and overall vocational life skills which create developmental barriers (UNICEF, 2007). Groce (2004) affirms that for adolescents with disabilities these barriers are accentuated by social factors such as prejudice, isolation and discrimination.

Mentorship focused on protégés with disabilities, and computer based programs specifically, may undermine these barriers by reducing the stigma associated with disabilities first by widening the mentoring peer-to-peer networks, second by pairing mentors without disabilities and protégés with disabilities. Third, it does so by publishing more information on the definition and types of disability and how to interact with individuals with disabilities; as McDonald et al. (2005) concluded, stigma or social stereotypes are driven by misinformation. These three actions will increase social visibility of youth with disabilities, and due to these, exposure to information and will eventually reshape the relationships between these young individuals and family members, friends, peers and other members of their society. They will also counteract prejudice and discrimination by increasing the adolescent's peer exposure engaging them in more social activities (Burgstahler, 1997).

To summarize, adolescents with disabilities experience more social and physical exclusion (McDonald et al., 2005). I argue that a cause and effect of this exclusion is the degree of visibility of the individual with a disability in society. On one hand if the individual is not visible it is difficult to integrate him/her into society; in other words he/she is denied opportunities for economic, social and human development. On the other hand, no awareness is raised in the non-disabled population about the needs and existence of the disabled one, if this individual is not included in social, economic or political activities, or involved in the decision-making process for activities not necessarily related to disability.

# Disability and Developing Societies

When crossing boundaries these programs must address belief systems indigenous to the targeted developing countries, and be aware of misjudgments due to culturally-racist assumptions or statements (Sheldon, 2005). By involving source and target societies, this process must be considered in a global context (Sheldon, 2005). Mentorship programs which are implemented successfully in more economically developed societies can and should disseminate the concept that disability is a social issue and while reaching across boundaries, project a social-model view of disabilities into a global context, to developing societies. As mentioned, mentorship programs achieve these through social network expansion and information availability as part of their education outreach programs. It is necessary for mentorship programs, regardless of the political or economic repercussions when crossing boundaries, to understand that education is a critical social issue and include it in their agendas. As Nelson Mandela said, "education is the most powerful weapon which you can use to change the world."

Currently there are already programs for labor-skills education implemented in developing countries (Groce, 2004) by non-governmental organizations (NGOs) of western origin (Sheldon, 2005). In Barbados and Cambodia, programs were implemented for young individuals with disabilities, to teach them job skills, providing not only job-specific vocational training (Kett, 2012) but also social interaction training (Groce, 2004). To ease their penetration when crossing boundaries, mentorship programs can learn from these local implementations about outreach mechanisms, networking, and social/cultural biases. In other words, mentorship programs formulated and implemented in more economically developed countries expand into developing societies by following guidelines and processes established by local grass-root programs and by understanding local stereotypes. As an example, the prejudice that individuals with disabilities must be hidden (Sheldon, 2005) can make implementing social programs in developing countries for youth with disabilities more difficult.

# Developing a Cross-National Mentorship Program

### **Cultural Considerations**

Social stereotyping revolves around differences in gender, race, culture, and social status. These social expressions can be barriers to the development of a mentorship program. Besides the definitions or aspects of disability mentioned in the section in this article, "Mentoring and Disability," the UNICEF (2007) also states that disability is a condition in which physical or

social barriers affect an individual in such a way that he or she cannot take part in community life. A mentorship program must develop within an environment that considers these barriers or differences not as challenges, but as opportunities to acknowledge and elaborate on the differences between mentors and protégés. In this context, it is especially important to consider that the members' self image and their success with relationships are polarized by two distinct concepts: race and ethnicity (Darling et al., 2006). But when crossing boundaries physical barriers are not just uncovered by disability but also by the individual's social and cultural background, which might translate then into additional barriers. As Hill, Song, and West (2009) establish, through their research on Web Learning Environments, the cultural, gender and ethnic differences of mentors and protégés alike impact the student's learning experience and the way they interact with peers, friends and family members. Differences which Darling et al. (2006) indicate, can have profound effects on the fit of protégés in mentoring programs.

To develop a mentorship program across national boundaries the cultural contexts and individual's cultural perspectives must be considered, for example those defined by different world-views, such as collectivism and individualism. Darling et al. (2006) established that cultures which embrace collectivism, such as Asian, Latino and African, prefer mentorship programs that focus on in-group mentoring, either with multiple mentors and/or protégés, whereas European American youth value one-to-one relationships.

Besides the cultural differences, mentorship programs must also acknowledge differences in gender. It is essential to keep in mind that both boys and girls have two distinct social identities (Darling et al., 2006), and this difference determines how youth relate with others and with themselves. For example, girls' relationships are characterized by more emotional closeness, especially during adolescence, so girls are more likely than boys to anchor their relationships in emotional connections. This difference defines the psychosocial, the individual's psychological development in and with his or her social context, and the outcome of the mentoring relationship (see Rivas-Drake et al. (2014) for more about psychosocial effects on adolescent development). Gender shapes interpersonal relationships, and also when it combines with the individual's racial and ethnic identities it positively correlates with self-esteem and self concepts (Rivas-Drake et al., 2014). This is true particularly in peer-to-peer relationships, in which the adolescents are empowered as they see themselves as role models (Burgstahler & Cronheim, 2001).

As is true for other social dimensions, disability alters gender expectations (McDonald et al., 2005); or, as Filmer (2008) concludes, disability interacts with both economical and social characteristics. Social expectations and stereotypes, such as those around gender, undermine the individual's identity and his/her relationships. For men, disability detracts from reaching the definition of masculinity, and for women, disability interferes with their fit in that of femininity (McDonald et al., 2007). For example, female protégés are at a higher risk of discrimination (Groce, 2004), therefore a mentorship program must try to align the mentor-protégé goals with their social identities, considering girls and boys may need different types of relationships (Darling et al., 2006).

Nevertheless, and as Acomb (2013) argues, a mentorship program must seek to surpass both physical and social barriers instead of just trying to avoid them. He also suggests that a successful program must develop a wide network of mentors, across gender, race, culture, and physical differences in order to address each individual's identity issues. Besides the benefit of finding identity similarities through individual's classification variety, exposing protégés to varied mentor-protégé or a peer-to-peer networks, may also help dismantle some stereotypes and myths, for instance, that the experience of disability is easier for the opposite gender (McDonald, Balcazar & Keys, 2007).

Therefore mentorship programs designed to function across nations will manage groups of mentors and protégés, both with and without disabilities that have different social and cultural backgrounds. Then, these programs must establish a broad cross-cultural framework that targets a varied population while it evaluates them through different social and cultural expectations, eventually enforcing rights to education, employment and social participation of young people with disabilities in their society (Groce, 2004).

# Computer-Based Communication (CMC)

Computer mediated mentorship programs, or e-mentoring, are traditional mentorship programs, as those described above, that express and maintain the relationships of mentors and protégés through computer based technologies, primarily electronic mailing, instant messaging, and computer conferencing. Therefore they are also referred to as computer mediated communication (CMC) programs (Bierema & Merriam, 2002). Scholars such as Burgstahler (1997), Burgstahler and Cronheim (2001), Bierema and Merriam (2002) and Kim and Bonk (2006), believe that e-mentoring can enhance the mentoring process especially when targeting youth with disabilities, but research in this area is still sparse. The rationale of this approach to mentoring, is clarified by Burgstahler and Crawford (2007) who conclude that computer mediated communications may ease social isolation by generating peer and mentor networks that offer similar friendship ties and development as face-to-face relationships, and by affecting positively the self-esteem of adolescents with disabilities. This also empowers these individuals as it builds their computer skills and promotes the exchange of information.

In order to surpass the social and physical barriers existing for individuals with disabilities in their environments, computer-based mentorship programs can embrace some of the following five qualities: establish vertical and horizontal communication channels, establish a wide range of available and interconnected social resources, focus on computer skill development, embrace computer based communication, and establish transition support mechanisms.

First, develop and make available one-to-one, peer-to-peer, and in-group relationships, accommodating individualistic or collectivistic social perspectives. Second, define a wider social resources network for the protégé, providing a connection with more mentors and peer protégés to choose from, connecting them through one-to-one messaging, electronic mailing avenues, peer-to-peer conferencing, or forum-like applications. This is fundamental, as Acomb (2013) argued, for developing cross-gender/cross-racial relationships.

Third, focus on computer skill development, which by itself not only enhances the protégés working capabilities, but in some cases also helps overcome physical barriers by "minimizing distances" between mentors and protégés. The communication gaps can be reduced by not requiring the individuals' mobilization), or by suppressing the need for individuals with disabilities to require human interpreters to communicate by providing access to software readers, translators or magnifiers. This will enhance communication, as this adolescent with disabilities with access to similar technologies states. "I like electronic communication because I don't need an interpreter on the Internet or my TTY" (Burgstahler, 1997, p. 7), he says, adding, "This type of communication kinda hides what type of disability you got" (Burgstahler, 1997, p. 7).

Fourth, simplify communication by embracing computer mediated communications, and subsequently acknowledging that text-based computer-mediated communication can alleviate social inhibitions (Smith, Scielzo, Yarbrough & Rosopa, 2006) by positively affecting communications and boosting adolescent's with disabilities self-esteem (Burgstahler & Cronheim, 2001). Computer mediated communication can be easily supervised by the mentors to mitigate issues as those pointed out by Kim and Bonk (2006) and Smith (2006). Additionally, they argue that one of the disadvantages of a completely electronic means of communication is the lack of emotional meaning and social cues attributed to gender and/or status or any other type of non-verbal cues. This is something mentors must pay attention to because as it makes communication more transparent, but it also may allow misunderstandings.

And lastly, computer-based mentorship programs provide support to protégés through the adolescent transitions, just as regular organizational mentorship programs provide protégés with greater connectivity during their movement through three expatriate stages: departure, expatriation, and repatriation (Mezias & Scandura, 2005). This motion is similar to what an adolescent may experience during development transitions such as from college to work, or when gaining social independence.

Using Existing E-mentoring Communities for Protégés with Disabilities

DOIT is a university based e-mentorship national program for individuals with disabilities (Burgstahler & Crawford, 2007). It successfully enforces the five qualities listed in the previous section of the article by using and providing access to assistive technology (Carlson & Ehrlich, 2005). It combines in-person mentoring with computer based relationships (Bierema & Merrriam, 2002), by creating a social network fueled by vertical and horizontal relationships, such as one-on-one, or one-to-many, or many-to-many hierarchies and peer collaborations (Stumbo et al., 2010). DOIT performs an effective outreach to individuals with disabilities, and is a source of information on disability dissemination (Burgstahler & Cronheim, 2001).

If it were to cross boundaries, this program could reuse its current mentor team to connect with protégés in developing countries, thus exposing its mentors and reducing some the costs of trying to implement an e-mentoring program targeted to youth with disabilities in a developing country. This would help to avoid additional costs because resources and accessibility are more limited in these areas (Filmer, 2008). Because it embraces computer-based communication, it

can foster the spread and local growth of mentoring programs as it inspires the local development of in-person mentoring relationships in developing societies. By extending their mentor coverage and implementing computer-mediated communications these programs can not only connect mentors in one country with protégés in another, but also promote mentor crosstraining as well as information exchange and dissemination (Stumbo et al., 2010). By incorporating these elements in its agenda, the mentoring program is actively re-shaping their mentors as it embraces new cultures, and establishes computer connections with youth with disabilities, by leveraging online technologies (Singh, 2010), and becoming "boundaryless". After stating these and considering arguments from scholars such as Bierema and Merriam (2002), Stumbo et al. (2010) and Burgstahler and Cronheim (2001) in this topic, I argue that DOIT exemplifies a reasonable program to move across boundaries.

# Mentoring Across National Boundaries

By extending a well-defined e-mentorship program to developing societies, we can ease social isolation and foster the development of academic, work-related and social skills (Kett, 2012). E-mentorship programs already have surpassed one boundary - a fixed location. An e-mentorship program may connect mentors and protégés regardless of their physical location by means of computer networks, making them a good channel to expand a mentorship program across national boundaries.

Burgstahler and Crawford (2007) argue that once a mentor-protégé connection is established, e-mentoring is an appealing option for a mentoring program, as it can translate and maintain this connection or communication despite many accessibility issues that may arise. The lack of connectivity is the main barrier I see for promoting this expansion to developing countries. However, the cost and feasibility issues associated to this can be solved by the leveraging of local developing community based initiatives like: the Projimo project in Mexico, or the KAMPI organization in the Philippines, which combine local support programs with international funding (UNICEF, 2007). Although these programs are intended for the production of low-cost aids (like low-cost wheelchairs) in developing countries to address mobility issues, we can target programs such as the One Laptop Per Child (OLPC) initiative, to develop a low-cost computer network, and provide young protégés the access to computers required to establish an e-mentoring program. The OLPC project generates laptops designed for youth in developing countries at a cost of \$199 USD (for more information on this initiative go to <a href="http://laptop.org/en/laptop/">http://laptop.org/en/laptop/</a>).

Today social service non profits rely mostly on traditional sources of funding, donations and grants that may not be appropriate to address these costs for resources to build computer networks with the expansion of mentorship programs (Dees, 1998). An alternative is to target more self-sustaining funding, relying on the youth with disabilities families' income (Park, Turnbull & Turnbull , 2002). They can accomplish this by also incorporating volunteer work, adaptive equipment supplier discounts (Dees, 1998), and micro loan operations, as those described by Mersland (2005). These will create funding for the programs allowing protégés with disabilities in developing countries to reach their mentors.

The role of translating the rights stated by the United Nation's Conventions into practice is a responsibility of the countries ratifying the Convention. These can be accomplished in the developing societies by following a combined approach for establishing a mentoring program. First, they should leverage resources from mentoring organizations in more economically developed countries, and second perform the implementation and reap the benefits for protégés in developing countries. As Kett (2012) states, these programs must be enforced in the target society by the local government, service providers, private sector, and non-governmental organizations (NGOs). For example, in countries like Kenya, Sierra Leone, Sri Lanka, and China, in which, despite their current social and economic development progress gaining momentum, their social policies on disability are still being developed. Nonetheless the governments and other parties have redefined federal laws and policies to accommodate citizens with disabilities (Kett, 2012). Changes have led to the development of programs such as the 'Livelihood Opportunities for Disabled Youth' in Kenya, a welfare support program targeted to families of individuals with disabilities, and skill training for adolescents (Kett, 2012).

#### Conclusions

Other ongoing initiatives, like the Y-Care International (the international arm of the Young Men's Christian Association [YMCA]) actually set a program's definitions in one country or context and implementation in another (Kett, 2012). Its success suggests that this model can be applied for expanding mentorship programs across boundaries. Of course there are still constraints facing protégés with disabilities in developing countries, but relocating and subsequently implementing programs, like mentorship ones, can be an effective means to implement initiatives to improve their quality of life.

Some of the ideas discussed in this article, such as computer mediated communications, the United Nation's Convention on the Rights of People with Disabilities, and developing societies' cultural, social and economic makeup, structure guidelines for developing e-mentoring across national boundaries. The implementation strategy can be outlined and prioritized as follows:

- 1. Find a successful mentoring program in an economically developed country, ideally one that has an e-mentoring or wants to deploy it.
- 2. Choose a developing country with a youth-with-disabilities population that can access the Internet.
- 3. Define an appropriate financial strategy to establish a viable computer network between mentors and protégés or supply the selected group of protégés with laptops (like with the OLPC program) that can connect to the Internet. Choose a foundation or institution focused on youth with disabilities in the developing country to gather the protégé team.
- 4. Pair mentors from one country with protégés from the other.
- 5. Train the protégés on the concept of peer-to-peer mentoring and the use CMC technologies and of the e-mentoring program.
- 6. Launch the program, monitoring the progress with regular group meetings of protégés and mentors.

7. Use these meetings to educate and reduce cultural/social barriers.

By bridging countries, or ignoring boundaries in the global context of disability, not-for-profit organizations, such as those mentioned before, leverage resources from more economically developed societies for use by individuals with disabilities in developing societies to achieve the social goals defined by global entities like the United Nations. Mentoring organizations can learn from this, and by following these steps and ultimately pairing individuals across countries ratify Sign's (2010) precept that we work better together.

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#### **Endnotes**

Here on identified also as protégés

The United Nation defined "youth" as individuals between the ages of 19 and 24

## "I'm Not Sure I Even Know": Therapists' Tentative Constructions of Autism

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**Abstract:** Autism has historically been constructed within and through biomedical discourses and practices. Therapeutic interventions have focused on "treating" and "curing" the individual diagnosed with autism, with therapists positioned as the "experts." In this paper, we report findings from a discourse analysis informed by discursive psychology of eight interviews with therapists of children with autism labels. While the therapists were frequently positioned as "experts" with presumed "stocks of knowledge," they were reluctant to definitively name autism as something with clearly defined characteristics, thereby making evident the shifting nature of knowledge surrounding what autism "really is." We discuss implications for practitioners and others, as well as point to the importance of engaging in social constructionist studies of the discourses surrounding autism.

**Keywords:** discursive psychology, discourse analysis, constructs of autism

#### Introduction

Like most developmental disorders, autism has often been positioned as a disorder to be named and understood by professionals, often presumed to be the "experts." Most definitions of autism describe it as being a biological fact comprised of a triad of deficits, which include: (1) impaired social interaction, (2) lack of or limited imagination, and (3) delayed and/or limited communication (Frith, 1989). The disorder is typically diagnosed when qualitative impairments in an individual's ability to engage in social interactions and communicate are noted, alongside stereotypical behaviors (American Psychiatric Association, 2010). Even though the notion of autism was first discussed by Kanner in 1943 and Asperger in 1944, the biological "facts" that surround autism are often presumed to exist outside of the disciplinary knowledge that has made an autism diagnosis possible. In contrast, some scholars have suggested that the early constructions of autism are situated within and out of certain disciplinary practices and discourses (Nadesan, 2005), particularly the discourses of medicine, education, and childhood psychiatry. As Foucault (1972) noted, discourses within the broader social process act to legitimate certain versions of the world, privileging and maintaining a given truth about the world/subject. The discourses surrounding autism have also been tightly coupled with the professionalization of its treatment, with ideas related to how autism should be "fixed" resulting in the development of particular interventions and professionalization of interactions (Donnellan, Hill, & Leary, 2010). Yet, to date, little research has examined how professionals go about making sense of what autism means at the level of discourse.

Thus, in this paper, we share findings from a study focused on how therapists at a pediatric clinic constructed fluid meanings of autism in the context of a research interview. More

specifically, we report on findings generated from a discourse analysis informed by discursive psychology (Potter & Wetherell, 1987) of eight interviews with therapists of children with autism labels. As we analyzed the data, we were struck by the patterns and variations in how the therapists defined autism, and thus decided to focus a line of analysis on these definitions in order to better understand them. Further, in the larger data set, the participating parents frequently positioned the therapists as "experts" and presumed that they had "stocks of knowledge" that non-experts did not possess (Lester, 2012). Taking this into account, this study attended to the ways in which the therapists made relevant and talked about the construct of autism. We illustrate here how the therapists were reluctant to definitively name autism as something with clearly defined characteristics. Rather, the therapists negotiated the complexities and ambiguities of the social category of autism, making evident the shifting, fluid nature of knowledge surrounding what autism "really is." First, however, we briefly discuss how autism has been historically constructed and made real in and through broader discourses and institutional practices. Further, we highlight how interventions designed for people with autism labels have been positioned as a practice for "fixing" and "correcting" symptomology.

#### The Discursive Construction of Autism and Its Treatment

Situated within the public and professional discourses surrounding a "deviant" or "abnormal" child, as well as discourses around normative developmental patterns (Piaget, 1924/1928), Kanner's (1943/1985) seminal article described 11 children who displayed what he believed was a "unique" syndrome (p. 41). Since Kanner's seminal publication, there has been prolific work around autism; however, it was not until 1980 that the American Psychiatric Association incorporated the criteria for the diagnosis of autism within the *Diagnostic Statistical Manual of Mental Disorders* (DSM) (American Psychiatric Association, 1980). Since that time, autism has remained in the diagnostic manual, with expansive changes to the criteria being made over the last few decades.

The prevalence of autism is unclear, particularly with the recent changes to and the publication of the DSM-5 (2013), which has functioned to redefine its diagnostic criteria. However, it has been estimated that one in 88 children born in the United States will be diagnosed with autism (CDC, 2012), and approximately 540,000 people have been diagnosed with autism in the United Kingdom, with one fifth identified as children (Knapp et al., 2007). Researchers suggest that the scientific taxonomies used to diagnose autism remain in flux (Rosenberg et al., 2009). Not surprisingly, then, there exists great controversy and inconsistency regarding the diagnosis of autism. For instance, Mayes and Calhoun (2004) reported a lack of evidence for the DSM's assertion that Asperger's was distinct from the autistic disorder. Further, Sanders (2009) suggested that Asperger's and an autistic disorder are not qualitatively distinct, but are instead "different quantitative manifestations of the same disorder" (p. 1560). With the recent revisions of the DSM, many autism-related diagnoses, including Asperger's syndrome, are now included within a single diagnosis of autism spectrum disorders.

Despite these ongoing debates, autism remains a common topic in the media (e.g., Trilling and Massin, 2010, *ABC* television series "Parenthood"), and the most prolifically researched childhood mental health disorder (Wolff, 2004). The vast majority of the research

related to autism has focused on identifying the etiology, neurological differences, genetic markers, and appropriate treatment for those with autism. More importantly, the majority of the research has assumed that the "experts" who work with people with autism labels know (or at least should know) what it means to be labeled autistic, and how to "treat" and "remedy" the presumed condition (Biklen et al., 2005; Glynne-Owen, 2010). Some researchers have even argued that professionals working with children with autism labels should have an understanding of what autism really is and how to address the needs of diagnosed individuals (Cascella & Colella, 2004).

In many ways, knowing what autism is has been implicitly related to the ability to effectively treat autism. How does one treat what one cannot define? This very question is played out in the diagnostic manuals within which symptomology is outlined in a very detailed way. Yet, clinical practice has long been described as a subjective process (Karim, Cook, & O'Reilly, 2012), one whereby particular norms may or may not be imposed on the identity of another. In fact, a common characteristic of autism interventions has been the focus on changing people with autism labels to fit within the norm (Brownlow, 2010). Such interventions have rested upon assumptions related to the normal-abnormal binary, with the professionalization of the "interactions with people with autism" often being bound within interpretations of "what happens in terms of simple, binary views of behavior (i.e., good/bad or positive/negative)" (Donnellan et al., 2010, p. 2). Accordingly, particular professions have defined the bounds between normal and abnormal behavior and thereby generated practices around how to make "normal" or "treat" those constructed as falling outside the expected. As Becker (1963) suggested it is "social groups" that "create deviance by making the rules whose infraction constitutes deviance, and by applying those rules to particular people and labeling them as outsiders" (p. 9).

Yet, while biomedical discourses have shaped how autism has been defined and treated, some individuals diagnosed with autism have resisted the pathologizing of their bodies, positioning society as the disabling entity (Oliver, 1996) and disability as a social construct (Gilson & DePoy, 2000). One such group, the Aspies, which includes individuals diagnosed with Apserger's, have advocated for viewing autism spectrum disorders in relation to its positive qualities (Bagatell, 2007). In an ethnographic study of adults diagnosed with Asperger's, Rosqvist (2012) found that many of her participants expressed ambivalence towards those interventions used to treat them, as they viewed such interventions as requiring them to "be someone other than who they are" (p. 5). Rosqvist suggested that interventions should be informed by the neurodiversity movement, and thereby conceptualized in relation to positive understandings of autism.

Along with the assumption that professionals "know" what autism is and how to treat it, has come the notion that there are "recognizable stocks of knowledge that are made manifest and 'visible' through specialized and technical vocabularies" (Housley & Fitzgerald, 2002, p. 74), with certain social categories (e.g. therapists) owning these stocks of knowledge, while others do not. Discursive research has shown that the relationship between expert and commonsense explanations is often ambiguous (Gilbert & Mulkay, 1984; Horton-Salway, 2004). Rather than a generalized, concrete knowledge base, expertise is, instead, locally produced in the process of

building up one's account. As such, in this study, we sought to unpack how therapists, the presumed "experts," made sense of the varied constructions of autism.

## Theoretical and Methodological Perspectives

While some research within the field of disability studies has emphasized the socially constructed nature of disabilities (Corker & French, 1999; Oliver, 1990) and the voices and perspectives of people with autism (e.g., Rubin et al., 2001; Mukhopadhyay, 2008; Savarese, 2007), relatively fewer studies have specifically attended to the situated, discursive ways in which caretakers of children with autism labels perform and make relevant their own understandings and representations of autism. As such, with a commitment to insider perspectives, we took up a social constructionist orientation to discourse theory and analysis, situating this study within a discursive psychology framework (Potter & Wetherell, 1987). As a broad framework, discursive psychology is underpinned by social constructionism and attends to how "psychology" and "reality" are produced, dealt with and made relevant by participants in and through interaction (Hepburn & Wiggins, 2005, p. 595). Like Osteen (2008), we do not deny the bodily realities of impairment. However, in lieu of assuming bodily (physiological) or psychological states to be an underlying explanation for why people act as they do, discursive psychology views physiological states, such as autism, to be constructs which are situated and made real in discursive practices.

How facts are constructed at the level of discourse is of particular interest in discursive psychology (Potter, 1996), and we considered in our analysis how therapists went about constructing their accounts of autism as factual or not. Factual claims often function to construct credible accounts that may be difficult to challenge. Specifically, when describing a position, people, including therapists and other professionals, rhetorically organize their descriptions to make their accounts seem believable to others and not easily challenged. In doing so, the speaker, orienting to the possibility that their description may be dismissed or discredited, often discursively works to undermine alternative explanations (Billig, 1996; Potter, 1996). Constructions, then, are often built in ways that counter possible alternative explanations. Such constructions are built to provide "norm-oriented accounts and justification for" actions and beliefs (Edwards, 1997, p. 9). Such factual claims often function to disguise personal interests, and are presented as "just telling it how it is" (Edwards & Potter, 1992, p. 3). As such, a discursive psychology orientation to fact construction does not treat a participant's account as a way of discovering their internal experiences, but rather views the account as actively constructing a version of the world. Thus, as we attended carefully to the ways in which the therapists talked about the meanings of autism, we presumed those meanings were always contingent, negotiable, and made visible in discourse.

#### Methodology

We situated our discourse study within discursive psychology (Potter & Wetherell, 1987), also drawing upon conversation analysis (Sacks, 1992) and critical orientations to disability (Thomas, 1999). Drawing from a larger ethnography of the everyday practices of children with autism labels and their parents and therapists (Lester, 2011), this study focused

more specifically on the ways in which therapists went upon negotiating, at the level of discourse, meaning(s) of autism. The research question of focus was: How do therapists discursively construct the meaning(s) of autism?

#### Site and Participant Description

Prior to conducting the study, we acquired Institutional Review Board approval. After approval, the first author traveled to the research site, The Green Room (self-selected pseudonym). The Green Room was a pediatric clinic located in a mid-sized city in the midwestern region of the United States, and served approximately 80 families of children with developmental disabilities in a bi-state area. The clinic offered individual occupational, physical, and speech therapy, as well as group social skills therapy and sibling support programs.

Upon arrival at The Green Room, the first author worked closely with the directors of the clinic to identify and contact parents whose child (1) had a diagnostic label of autism, and (2) participated in at least one of the clinic's therapeutic activities, ranging from group social activities to speech therapy to occupational and physical therapy. A total of 12 children clinically diagnosed with autism spectrum disorders and 14 parents (11 mothers and 3 fathers) agreed to participate in the larger study.

The directors identified the therapists and clinic staff who worked with the participating children/families and invited them to participate in the study. Through purposeful sampling, the first author recruited the participation of three speech and language pathologist (two of whom were also the directors of the clinic), two occupational therapists, one physical therapist, one teacher/social group facilitator, and one medical secretary/sibling support group facilitator. The occupational therapists, speech and language pathologists, and physical therapists held master's degrees. The teacher/social group facilitator held a bachelor's degree. The therapists all had varying levels of clinical experience, ranging from ten years to less than a year. Table 1 provides a summary of the participating therapists' and clinic staff's demographic information, including the number of years they had been at the research site. All of the participants selected pseudonyms that were used to maintain their anonymity. From here on, we refer to all participants as "therapists."

Table 1. Participating Therapists' Demographic Information.

Pseudonym	Professional Title	Total Years at the Site
Bria	Occupational Therapist	4
Drew	Speech Pathologist/Clinical Director	4
Jennifer	Speech Pathologist	2
Megan	Speech Pathologist/Clinical Director	4
Michelle	Teacher/Autism Specialist	4

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Patricia	Physical Therapist	1
Samantha	Medical Secretary/Sibling Support	1/2
Seth	Occupational Therapist	1/2

#### **Data Sources**

The interview data from the eight therapists was the primary data used for this analysis. The interview data was part of a larger corpus of data that included 14 interviews with the parents of children with a clinical diagnosis of autism, 175-hours of audio and video data (e.g. from group and individual therapy sessions and waiting room conversations), 650 pages of field notes made during observations at the clinic, audio recordings of two meetings with the participants focused on discussing the findings, a corpus of e-mail correspondence with the therapists, and artifacts/documents that were used within the therapy sessions. This larger data set informed the analytical understandings we report here.

The first author, who collected all of the data, interviewed the participating therapists at The Green Room. The interviews ranged from 10 minutes to 42 minutes, averaging 22 minutes. The interviewer followed a semi-structured interview protocol (Appendix A), with the bulk of the time spent on exploring meanings of autism. Throughout, we did not assume that the therapists were trained or taught to conceptualize autism in a similar way. Rather, we presumed that the therapists would likely vary in how they talked about autism, as discourse is variable and functions to construct multiple social realities (Potter & Wetherell, 1987); we were interested in examining this (potential) variability. Further, even though the therapists were aware that they were invited to participate in the study because they worked with children with autism labels, we did not assume that the therapists necessarily took up "expert" identities; rather, this is what we hoped to explore at the level of discourse. We recognized that "identity inscription of any kind," whether by academics, therapists or parents, is "occasioned by some interactional or institutional circumstance" (Rapley, Kiernan, & Antaki, 1998, p. 825). As such, during the course of the interviews, the first author only used the word "autism" after the therapists made it relevant in their talk. Indeed, all of the therapists spoke of autism at some point during their interview at which point the interviewer asked: "When you say autism, what does that mean to you?"

#### Data Analysis

During the data analysis process, we took an interpretive and emergent approach to data analysis. More specifically, we conducted a discourse analysis from a discursive psychology perspective (Edwards & Potter, 1993), drawing upon conversation analysis (Sacks, 1992) and poststructural understandings of discourse (Derrida, 1981; Foucault, 1971). We sought to move our analysis between the micro-level of the conversation (interview talk) and macro-level discourses (e.g., what is culturally "known" about autism), while remaining committed to staying close to what the participants made evident in their talk.

Similar to other discourse studies (see Lester, 2012), we carried out six phases of data analysis, including: (1) repeated listening; (2) transcription and creation of modified Jeffersonian transcripts; (3) intensive reading and re-listening of the synchronized transcripts; (4) selection, identification, organization, and analysis of patterns across the discourse segments; (5) generation of explanations/interpretations; and, (6) reflexive and transparent sharing of findings. Transana, a computer application often used for discourse analysis and the creation of Jeffersonian transcripts (Fassnacht & Woods, 2005), was used for transcribing the audio and video data. Beyond the transcription process, we used ATLAS.ti 6 (Muhr, 2004), a computer-assisted qualitative data analysis software package, to organize and systematize the analysis process, primarily using the coding, memoing, and other annotating features. ATLAS.ti has been used in discourse analysis studies of talk (e.g., Lester & Paulus, 2014), and described as a tool that can be used to support the micro-level analysis typical of discourse analysis informed by conversation analysis (Lester, in press; Paulus & Lester, 2013).

Throughout the analysis, we took multiple measures to attend to the authenticity of our claims (Antaki et al., 2003). First, with the participants' discourse surrounding autism being understood as having shifting meanings, we intentionally sought out alternative cases and explanations. We also attended to inconsistencies and diversity in the participants' talk (Potter, 2004). Second, the first author shared these findings with the participating therapists and the parents. Seven of the eight participating therapists and one parent shared their responses to these findings over several weeks and even months, sending the first author emails, calling by phone, or sharing via face-to-face gatherings. We share some of these responses within the findings section, illustrating the ways in which they build upon the initial impressions generated in the early stages of the analysis process. Finally, in lieu of simply reporting our interpretation of the data and pointing to an excerpt to illustrate a particular point, we demonstrate how a given excerpt of the data has been analyzed and thus how our interpretations were reached (Wood & Kroger, 2000). Jeffersonian symbols included in the excerpts are in Appendix B.

## **Findings**

Overall, we noted that rather than working up a factual account of a "true" technical and/or medical definition of autism, the therapists positioned their definition of autism as tentative and still unfolding. While all of the participants named some of the characteristics often associated with autism (e.g., social challenges), they never constructed autism as something that could be fully known. Rather they produced a meaning of autism that was contingent and difficult, if not impossible, to define. We found that all of the participating therapists mitigated their own knowledge claims when constructing the meaning(s) of autism, frequently highlighting the variation and "spectrum" of autism, while displaying reluctance to define autism conclusively. We highlight below three representative excerpts that illustrate how the therapists went about building and even mitigating their own expert status on the "facts" surrounding autism. Then, we offer a discussion around how the participants, including one participating parent, responded to this study's findings.

## The "Spectrumed" Conundrum

In Excerpt 1, Drew, a speech and language pathologist, constructed autism in relation to a "spectrum," evoking an image of autism referring to more than one thing.

#### Excerpt 1

- 1 Jessica: when you say autism what are you referring to what do you mean
- 2 Drew: like my definition=
- 3 Jessica: =mm [hm
- 4 Drew: mm] (.1) I think er (.2) it's so spectrumed out that it's hard now to like define
- 5 it in actual words >I think for me< it's it's essentially and I don't even really like
- 6 the word disorder because that kind of indicates that at some point there was order
- 7 and I don't think for them that that there was so I think like a total mm (.1)
- 8 unavailability of processing=
- 9 Jessica: =mm hm=
- 10 Drew: =so they're not processing (.) language or social language or nonverbal
- 11 language or even really kind of the relationship component [um
- 12 Jessica: mm hm]
- 13 Drew: and (.2) so I guess that's kind of you know from the super high functioning
- 14 who (.2) don't get that there's like a social you know ramifications and perspective
- 15 taking they don't process that information um and not that they don't that the brain
- 16 doesn't actually process but like for them they just don't (.2) they just don't get it
- 17 Jessica: mm hm
- 18 Drew: to like super low functioning where really (.) um words in general aren't super
- 19 meaningful [so
- 20 Jessica: mm hm]
- 21 Drew: I guess for me that's kind of what I (.) think of

Here Drew evoked "spectrum" as her first response to being asked to define autism (line 4). She stated, "I think er (.2) it's so spectrumed out that it's hard now to like define it in actual words," emphasizing that the spectrum itself makes it hard to define what it is "in actual words" – as opposed to just knowing it when you see or experience it. At present, autism is constructed in the medical literature and popular media outlets as a spectrum, with this particular term being one of the primary ways to talk about autism. In the case of Drew, such a focus perhaps functioned to justify her claim that it is "hard now to like define it" (lines 4-5), as it encompasses a variety of symptoms.

Drew then engaged in several false starts/self-repair, with ">I think for me< it's it's it's essentially" (line 5) before defining it as what it is *not* – a disorder. False starts often function to mark something as a source of trouble (Lamerichs, 2003). In this case, perhaps the trouble is in defining autism. After these false starts/self-repair, Drew described what autism is not, revealing in this way what it is: "I don't even really like the word disorder because that kind of indicates that at some point there was order and I don't think for them that that there was". She went on to define autism as a processing problem (repeating a variation of "processing" four times), though with hedges and mitigating devices such as, "so I think like a total mm (.1) unavailability of

processing=" (lines 7-8). Mitigating devices often function to display hesitancy and uncertainty around what is being shared (Pomerantz, 1984). Here, Drew restated that "they," that is people with autism labels, are not processing language, social or nonverbal cues. As such, Drew coupled the meaning of autism with common characteristics that are frequently listed in diagnostic manuals (e.g., social language challenges). Drew went on to say, "or even really kind of the relationship component" (line 11), positioning an understanding of human relationships as even more basic than language processing, neither of which the person with autism presumably "gets" or "has." She then distinguished between the "super high functioning" person with autism, who "just don't get it," and the "super low functioning" person with autism, for whom "words in general aren't super meaningful" (lines 13-16). Drew ended her definition with a mitigating sentence, "I guess for me that's kind of what I (.) think of (.) when I think of it." The words "I guess" perhaps functions to again point to the tentative and contingent ways in which Drew constructed the meaning of autism.

We noted in Drew's talk a contrast being made between the "types" of autism, which is common in talk surrounding the meanings of autism (Lester & Paulus, 2012). Historically, the very term "high functioning" has become code for an individual who is perceived as being highly verbal and more accomplished than those labeled "low functioning." Further, as Osteen noted (2008), even within the autism community there is a rift between those individuals labeled "high functioning" and those identified as "low functioning" (p. 6), particularly as much of the popularized writing around autism position "higher functioning" individuals as being a step forward or even more desirable. Such individuals (e.g. Temple Grandin) are often described as savants and/or worthy of public attention, gaining a great deal of media attention and becoming the "voice" of and even dominating representations of autism. Some recent literature has begun to question and critique this assumption, illustrating the slippery nature of naming an individual "high" versus "low" functioning and presuming that verbalness equates to success or intellectual potential (Biklen et al., 2005). For instance, Rosetti et al. (2008) conducted a study exploring the actions and/or performances of individuals labeled with autism during communication "training" sessions. All of their participants typed to communicate. The researchers suggested that the participants in their study performed agency through their nonverbal actions, with these nonverbal and presumably "low functioning" actions frequently misinterpreted by non-autistic professionals as moments of incompetence or purposeless behavior. Nonetheless, the discourse of our times continues to position autism as that which is experienced in extremes, resulting in "low" and "high" functioning forms (Osteen, 2008).

## The (Im)possibility of Defining

In Excerpt Two, Bria, an occupational therapist, responds to the question, "When you say autism, what does that mean to you?" by providing an account for why she no longer knows what it means when someone says autism. Bria's response was particularly intriguing, as she took up the idea that autism is not definable.

## Excerpt Two

- 1 Bria: Um I think < I've (.1) grown to almost >have such a broad definition of autism
- 2 that I >don't even have one anymore< um and I'm not even sure I know=

- 3 *Jessica*: =mm hm=
- 4 Bria: = specifically what I would call autism anymore because to me it's such a
- 5 spectrum like if someone says oh well this child has autism like I don't think that
- 6 that necessarily >means <u>any</u>thing to me < anymore because I it because it could
- 7 mean so many things=
- 8 Jessica: =mm=
- 9 Bria: =it could mean that they just have some sort of social problems or have a little
- 10 bit of um the Asperger type traits or it could be someone who is totally nonverbal or
- 11 <u>absolutely</u> anywhere in between=
- 12 *Jessica*: =Mm hm=
- 13 Bria: =So (3) I don't know I think it's at this point so defined that it's undefined

Bria began by stating that she has "grown" to have a "broad definition of autism." So broad, in fact, that she no longer knows how to define autism. Her use of the word "grown" implies that in the past she had a more absolute and narrow definition of autism (lines 1-2); yet, as time has passed and with more experience, she has grown to orient to autism as an indefinable entity. Bria claimed not to know what to "specifically" call autism and then moved to account for her inability to answer the question. While many of the parents in the larger study located the meaning of autism in their individual, day-to-day experiences (Lester & Paulus, 2012), Bria did not. She positioned autism as a "spectrum," like the majority of the participating therapists, with multiple meanings and degrees of seriousness (lines 5-7).

Bria's choice of the word "spectrum" emphasized her focus on the idea that what comes to be named autism includes a wide range of possibilities (lines 4-5) – so many possibilities that they are difficult, if not impossible, to delineate. She then moved to name what autism "could mean," naming "social problems," "Asperger type traits," and "someone who is totally nonverbal" as possibilities (lines 9-10). This naming worked to construct a boundary of sorts around what "could" count as autism, with her choice of the word "could" leaving open the possibility that other meanings are possible. In other words, autism does not have one unitary definition. She further complicated the meaning of autism by stating that its meaning could be located "absolutely anywhere in between." By defining autism, she claimed, it remains "undefined" (lines 11-13), positioning autism as a floating signifier.

## The "Troubles" with Defining

In Excerpt 3, Jennifer, a speech and language pathologist, displayed "trouble" in her talk, hesitating when asked to talk about the meaning(s) of autism. This "trouble" or difficulty in making sense of the meaning(s) of autism was displayed through a variety of conversational features (e.g., laughter).

## **Excerpt Three**

- 1 Jessica: so how (.) for you then what what is autism
- 2 Jennifer: U:h (laughs) (2) [smacks lips together] (2) °autism° what is autism (4)
- 3 [smacks lips together] (6) I I really think of it as like a brain based developmental (.)
- 4 disorder I [guess

- 5 Jessica: mm hm]
- 6 Jennifer: um (. 3) with those those three things that I said [before
- 7 *Jessica*: mm hm]
- 8 Jennifer: the social needs and the communication needs and then the behav- and the
- 9 stereotypic behavioral needs um (3) something that really doesn't have a cure but
- 10 something that can really be managed (.)
- 11 Jessica: hm (.)
- 12 *Jennifer*: it's different for every kid↑ (.) I think I think of the spectrum whenever I
- 13 think of it there's some kids that you might see on the street and you'd never
- 14 know
- 15 Jessica: mm hm

In Excerpt Three, Jennifer did not respond immediately with an official definition of autism; rather, she hesitated through the use of "uh", laughter, lip smacking, repeating the question, and a self-repair ("I – I") in line 3. This hesitation pointed to trouble in the talk – specifically the troubles that are part of defining a construct that is "slippery" or "difficult" to unequivocally make "real". Her use of "really", in her statement "I really think of it", implied a contradiction between what she should think and what she "really" does think, or what she used to think, and what she currently thinks, perhaps similar to Bria's use of "I've grown almost to have" in Excerpt Two. She used pauses and phrases such as "I guess", as she names her definition "brain based developmental (pause) disorder I guess", making visible the uncertainty or hesitancy around offering an "official" definition.

Bria then used a three part list to complement the definition "with those, those three things that I said before", defining autism in terms of the needs of the person with autism (social, communication and "stereotypic" behavioral needs) (lines 8-9). Three part lists are often used to establish the completeness of a claim (Heritage & Greatbatch, 1986). Further, the list that she provided mirrors the official diagnostic criteria that are used in the DSM to diagnose autism. Yet, Jennifer did not solely construct autism with medicalized language or according to the official diagnostic criteria; instead, she positioned autism in relation to "needs" (line 8). Needs are something that can be met, and she chose to define autism in terms of needs rather than other kinds of static linguistic, physical, or emotional symptoms. Perhaps this functions to highlight Jennifer's membership category as a therapist – an individual who is asked to meet needs through intervention. She acknowledged that autism is "something that really doesn't have a cure", yet it is "something that can really be managed" (lines 9-10).

She, similar to the other therapists interviewed, in line 11 highlighted "it's different for every kid" – emphasizing the uniqueness of children diagnosed with autism, thereby evoking the notion of the "spectrum" as opposed to what could be seen as the same syndrome or symptoms across those with the diagnosis. She closed by saying that in some "kids" you would never know that they had autism just by looking at them, highlighting that the spectrum includes not only physical manifestations but other more "hidden" symptoms as well. This notion of hidden symptoms raises the possibility that when you cannot see something, its very truth or existence is potentially called into question.

#### Participant Responses to the Varied Constructions of Autism

The participating therapists and parents were all invited to respond to the analysis presented above, with seven of the eight therapists offering responses in the form of emails and face-to-face interactions and one parent offering a response during a face-to-face meeting. While the therapists, in response to the findings presented above, reiterated the ways in which the meanings of autism were untenable, again positioning its very meaning as always shifting and unfolding, Maria, the participating parent, stated the she was "surprised that the therapists spoke about autism as they did. I'd expect therapists, not really the parents, to have a more concrete definition." Maria pointed to Excerpt Two as she spoke, the excerpt in which Bria constructed autism as indefinable. Maria continued by stating, "I like how open-minded the therapists are, but I'm just surprised that they didn't state a more concrete definition of autism since they are therapists." Maria also offered her own definition of autism, stating that: "Autism is a sensory thing that then looks like a child behaving badly but they are really just having a sensory issue that probably makes it hard for them to communicate."

Maria's response highlighted the presumed distinction between lay and expert knowledge, with particular social categories (e.g., therapists) positioned as holding some knowledge that others do not hold (Housley & Fitzgerald, 2002). Yet, as discourse studies continue to highlight, the distinction between expert and lay knowledge remains ambiguous (Horton-Salway, 2004). While we did not orient to Maria's response as indicating that our interpretations were "right" or "wrong" (Tracy, 2010), we viewed her response as further highlighting the variable ways in which autism is made "real" in talk, as well as making evident how "experts" are positioned as people who should know what autism "really" is.

#### **Discussion and Conclusions**

We suggest that much of the therapists' talk in the interview data reinforces the idea put forth by many disability studies scholars (Altman, 2001; Biklen et al., 2005, Osteen, 2008) who argue that autism, as a disability category, is a floating signifier (Foucault, 1972; Laclau & Mouffe, 1985), itself void of meaning and thus open to receiving multiple and at times conflicting meanings. To say that autism is a discursive category recognizes that attempts to locate definitive differences between who is autistic and who is not autistic is a difficult and perhaps untenable task. Certainly, the therapists' talk pointed to just that — autism, as a floating signifier, does not rest at any level of static meaning, but performs instead a play of signifiers (Barthes, 1973). In therapeutic and clinical practices more generally, this is further complicated by the lack of definitive diagnostic assessments and the subjective approach to determining whether an individual qualifies as autistic (Karim, Cook, & O'Reilly, 2012). Nonetheless, there has been a recent drive to increase the sensitivity of psychiatric diagnoses (Frances & Nardo, 2013), resulting in a broadening of diagnostic criteria and fears that as a result "the pool of 'normality'" will "[shrink] to a mere puddle" (Wykes & Callard, 2010: 302).

While autism, like other diagnostic categories dependent upon subjective assessment processes, is often portrayed in the media and other contexts as a well-defined disorder that can be definitively diagnosed and treated by experts, our study questions these assumptions. Rather,

as noted in our findings, the categories themselves are fluid in nature with the "experts" reluctant to define what counts and what does not count as an "autistic identity". That all of the therapists in our study mitigated their own knowledge claims highlights the variation and "spectrum-ed" nature of autism. Further, the therapists' reluctance to define autism in any strong, definitive way, other than naming some symptoms, may provide additional evidence for the socially and culturally-mediated nature of autism. That is, even the community of practitioners ostensibly trained to "fix" the disorder, are reluctant to define it in a concrete way. Similar to Timimi Gardner, and McCabe (2011), the very value of a label of autism is perhaps questioned here, which itself is bound within the cultural, discursive, and economic practices that define it (Lester & O'Reilly, in press).

These findings offer insights to practitioners, parents of children with autism, and the public at large, to better understand the somewhat subjective nature of diagnostic categories such as autism and the associated treatments. That there is fluidity in how autism is described by the experts (in this case, therapists) should lead us to be more cautious in our own descriptions, as well as in our treatments, particularly in that treatments are commonly linked to diagnostic categories. Rather than being driven by diagnostic labels or visibility-based interventions, supportive treatments can and should be driven by the specific needs of the person (e.g. linguistic needs). Timimi, Gardner, and McCabe (2011) suggested that the "task of good clinical services is to take each individual and their family's narratives into account and find creative possibilities for change" (p. 3). Indeed, autism as a construct is fluid, shifting and complex (Lester & Paulus, 2012), while simultaneously resulting in the emergence of bodily needs and interventions (Lester & O'Reilly, in press).

Finally, as Nadesan suggested, the significance of a study that examines the social construction of autism "extends beyond 'autism' as a distinct disorder to include the ideas and practices whereby we constitute everyday life and social institutions, including the processes that will ultimately produce the opportunities for personhood in the early twenty-first century" (Nadesan, 2005, p. 3). This study's findings provide opportunities to reimagine other identities for individuals labeled with autism, while pointing to the layered and contingent nature of the construct of autism. Dominant discourses surrounding autism have often presented a monolithic version of people labeled autistic, frequently situating the meaning of autism within a medicalized and deficit-oriented framework. Broderick and Ne'eman (2008), like other scholars, have called for counter-discourses and narratives offering cultural critiques of medicalized notions of autism, thereby producing alternative possibilities for making sense of embodied differences. We suggest that the findings from this study offer new possibilities for making sense of the contingent meanings of autism, the process of being named autistic, and the very act of interpreting differences.

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# Appendix A Therapist Semi-structured Interview Protocol

- 1. What things might you want someone to know about the children you work with?
- 2. Describe your role at the clinic.
- 3. Describe each of the participating children.
- 4. What kinds of things do you do in the group therapy sessions?

## Appendix B Transcription Conventions

The transcription conventions utilized were developed by Jefferson (2004) and adapted for this research study.

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- ↑ Upward arrows represent marked rise in pitch.
- ↓ Downward arrows represent a downward shift in pitch.
- = Equal signs at the end of a speaker's utterance and at the start of the next utterance represent the absence of a discernible gap.
- <u>e</u> Underlining represents a sound or word(s) uttered with added emphasis.
- [] Extended square brackets mark overlap between utterances.
- (7) Numbers in parentheses indicate pauses timed to the nearest second. A period with no number following (.) indicates a pause which is hearable, yet too short to measure.

# Is There Room in the Inn? Towards Incorporating People with Disability in Tourism Planning

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Abstract: Despite the fact that tourism is as much a social right to people with disabilities as it is for so-called able-bodied people, the former group received little focus worldwide until very recently. Little emphasis has been given to ensuring that people with disabilities have access to tourism facilities despite the fact that they now constitute a substantial market for tourism operators globally. While Zimbabwe's tourism fortunes are moving in a positive direction, where is the person with disabilities? Has anyone considered them in terms of economic as well as physical access to tourism products? This research endeavoured to explore the state of affairs in Zimbabwe's tourism sector where accessibility is concerned. The researcher modified the Scandic's accessibility questionnaire and used it as a checklist for accessibility of hotels and lodges. Zimbabwe Tourism Authority, the Ministry of Tourism and Hospitality Industry and organisations that represent people with disabilities, were also consulted in the survey. While economic policies are being crafted to bring the country back to its feet, little is being done in providing access to tourism by people with disabilities.

Key Words: travel, accessibility, Zimbabwe

#### Introduction

Access to tourism and recreation is a constitutional right as prescribed in the United Nations Convention on the Rights of Persons with Disabilities (UN, 2006). Just like anybody else in society, people with disabilities are entitled to entertainment, recreation and tourism, among other things. Prevailing western social norms and values recognise travel and recreation as a right (Yates, 2007) and the contribution of tourism to the well-being of disabled people is well known in the developed world (Yau, McKercher, & Packer, 2004). Studies have suggested that travel companies have a social responsibility to meet the needs of disabled people since travel has been identified as an important aspect of the quality of life of disabled people (Kinney & Coyle, 1992; Prost, 1992). It is however very unfortunate that in many countries, people with disabilities suffer discrimination, segregation and social exclusion (Darcy, 1998; Burnett & Bender-Baker, 2001).

Providing opportunities and access for people with disabilities is not only an ethical issue, but also a business opportunity for operators in the tourism sector just like it is for any other sector (United Nations, 2009; APEC, 2003). In fact, the social model of disability argues that people with disabilities do not like to be treated as recipients of charity but as equals with the socialled "able-bodied," thus they are willing to pay as much for their holidays as their able-bodied counterparts (Oliver, 2006). Furthermore, people with disabilities are not the weaker species, who should engage in more docile and passive tourism; they are also interested in partaking in challenging forms of tourism, especially outdoor adventure. According to Zeller (2008) and Jaquette (2005), people with disabilities feel much more satisfied when they visit natural areas

and at times they engage in more challenging wilderness activities than the able-bodied do. The latter could support the notion that it makes business sense to make tourism accessible to people with disabilities.

## Disability and Aging

One cannot complete a discussion on disability and accessibility without talking about aging. The world over, the number of people with disabilities has been on the rise in recent years and this increase has been mainly attributed to ageing and other health related factors (Darcy, 2002; Turco *et al.*, 1998; Yau *et al.*, 2004). Research has shown that there is a very positive correlation between ageing and disability (WHO, 2007). While this is true, Mann (2005) argues that older persons with impairments may not necessarily be disabled if they find ways of adapting to that impairment. In most cases, however, the majority of these elderly people do not have a way of compensating for their impairments, thus becoming disabled.

The world over, the number of aged people is expected to increase tremendously by 2050 and the greatest increase is expected in developing countries, especially Asia. This may, perhaps, be attributed to improvements in the general standards of living in these countries. 16.7% of Americans were 60 years and above in 2005 and by 2050, the number is expected to increase to around 26%. In 2005, Chinese aged 60 and above represented 10.9% of the Chinese population, a percentage which is expected to rise to 31% by 2050. The Japanese are expected to register the largest growth from 26.3% to 41.7% (Eurostat, 2005; Dobriansky, 2007). These patterns only show how important disability tourism is and is likely to become in the future.

#### Economic Significance of the Disability Market to Tourism

The number of people with disabilities is estimated to be between 600 million to 859 million worldwide (APEC, 2003; United Nations, 2009; Vantton, 2002). These numbers represent a significant part of the population, 10 to 19% (Bull *et al.*, 2003; Huh & Singh, 2007). This is also reflected in national statistics where disabled people make up a significant portion of their population. For instance, in 2007, the US Census Bureau reported over 21% of its population as disabled people. This was approximately 54 million people (US Department of Commerce, 2007).

It would not be an exaggeration to argue that the disabled population has become a significant consumer market (Darcy, Cameron & Pegg, 2010; Buhalis, 2005; Darcy, 2002). According to research by Lipp and Laurel (2007), American adults with disabilities spend an average of \$13.6 billion US dollars on tourism each year. This research further revealed that these people made 32 million trips in 2002 and spent \$4.2 billion on hotels, \$3.3 billion on airline tickets and \$2.7 billion on food and beverages while they were travelling (Harris Interactive Research, 2005). This was also supported by Parker & Carter (2004), Rains, (2007) and the UNESCAP (2007) who emphasized that creating accessible tourist destinations is not about charity but about serious economic gains.

In the United Kingdom, the same study has shown that 10 million adults with disabilities can spend about 80 billion pounds on tourism per year. In Canada, economically active disabled

people are able to spend 25 billion Canadian dollars for travelling (Lipp & Laurel 2007). A study by Dwyer and Darcy (2011) revealed that the overall expenditure by tourists with disabilities in the United Kingdom from 2003 to 2004 was close to \$12 billion US dollars. This is quite a massive expenditure and enough cause for a more conscious decision to take disability tourism seriously. The Commonwealth Department of Industry, Tourism and Resources (CDITR, 2003) identified disabled and senior populations as an emerging market which can sustain the tourism industry. Tourism Australia has responded by establishing disability tourism as a niche (Tourism Australia, 2005).

In the East and South Asia Pacific (ESAP) region, people with disabilities and older people are becoming a growing group of consumers of travel, sport, and other leisure-oriented products and services (ESAP, 2000). The share of the aged people in developed countries is said to have been on the increase with baby boomers coming of age and representing a very lucrative market for travel and tourism. The developing world is following suit as health facilities and medications improve (ESAP, 2000). The UN projects that by 2025, about 14% of the ESAP region's total population will be over 60 years and the region will be expected to house over 50% of the world's aged population. By 2041, about 23% of Canadians will also be over age 65 (Horgan-Jones & Ringaert, 2004).

Research has revealed some very important characteristics of the tourist with disabilities. People with disabilities stay longer at a destination than their able-bodied counterparts, they spend more money per day and usually demand more services. Another important attribute of this growing market is that they travel in low season to avoid crowds (Burnett & Baker, 2001; Denman & Clerkson, 1991; Ray & Ryder, 2003, Van Hon, 2001). This is particularly important when one considers the fact that the tourism and hospitality industry is highly seasonal and that getting patronage during off-season is a "blessing." Moreover, once one captures this niche, there is likelihood that the friends, family members and associates of tourists with disabilities are also captured (Darcy & Buhalis, 2010).

The interesting thing is that these people do not only have the will but they also have the disposable income to enable them to travel (Smith, 2011, Australian Hotel Association, 1998; Bennet & Bender-Baker, 2011; Darcy, 2000, 2002, 2008). The assumption of these researchers is, perhaps, that the situation in Europe and America applies to all parts of the world, yet there are variations in economic, socio-cultural and legal frameworks in each part of the world. In this regard, Africa needs tailor-made policy frameworks for sustainability. The following questions need to be answered in regards to Zimbabwe: Are there enough facilities to enable people with disabilities to travel? Do these facilities meet the expectations of tourists with disabilities? Is Zimbabwe accessible to these people?

## Disability in Zimbabwe

Although no reliable statistics exist, there are an estimated 1.5 million people with disabilities in Zimbabwe. If this is true, it means that over 10% of the total population is disabled (Choruma, 2007). These people suffer a great deal from exclusion and social magnetization. According to Mr. Magweva, the technical adviser of the National Association of Societies for the

Care of the Handicapped (NASCOH), Zimbabwe was losing 25% of its GDP through the exclusion of disabled people. He estimates the loss to be around \$200 million US dollars per year. It is the researcher's assumption that the tourism industry has a stake in the above mentioned figure and action has to be taken.

According to Khupe (2010), the authorities in Zimbabwe have done virtually nothing to alleviate the plight of disabled people. Apart from enacting the Disability People Act in 1992, all that the people have been given are empty promises and nobody really seems to care. The government has also shown their position regarding people with disabilities by allocating very little funds towards people with disabilities in each year's budget. Has the tourism industry done anything at all to cater to disabled people in Zimbabwe? Are there any disability-friendly policies and strategies in the tourism industry in Zimbabwe? Are the tourism and hospitality operators doing something about the accessibility of their establishments for people with disabilities?

With the ongoing economic downturn globally, tourism destinations need to "think outside the box" to utilize niche markets. One such market is that of people with disabilities, (Eichhorn & Buhalis, 2007). This market has however remained unsung. Despite the increasing disability market, most countries in the developing world and tourism service providers have still not recognized the importance of harnessing the market (ESAP, 2000).

Currently, Zimbabwe receives the majority of its international visitors from Europe (8%), the US (3%) and Asia (3%) (ZTA, 2013). The arrivals from these markets actually grew significantly in the first quarter of 2013 with Europe increasing by 84%, Asia 76% and America 5%. It is by no coincidence that these source markets also have the largest numbers of people with disabilities with a high demand for tourism. Unfortunately no statistics exist regarding tourists with disabilities in Zimbabwe to date, nor is there any published work on disability tourism in Zimbabwe. This probably is enough evidence to prove that this segment has not received enough attention and most likely, not much has been done to cater to it. It is clear from the literature that very little has been written on disability and tourism in Africa, let alone Zimbabwe.

#### Materials and Methods

## Research Design

The researcher adopted an exploratory design for this study. Robson (2002) argues than an exploratory study is an important way of finding out what is transpiring, seeking new insights and asking questions to assess phenomena in a new perspective. True, research to do with disability tourism has been conducted and published in other countries, especially in the developed world, but very little was done in Africa, and Zimbabwe in particular. Further, researchers have concentrated on "people with disabilities" and "tourism" as stand-alone subjects. This research looked at disability tourism as a composite concept. The fact that such research is quite new in Zimbabwe and that disability tourism is still in its infancy as a concept, points to an exploratory design as appropriate.

## Research Population

The research population was made up of registered tourism operators in Zimbabwe's premier tourist destination, Victoria Falls. These include hotels/lodges, travel agencies, tour operators and cruise operators in the resort town. Victoria Falls was used as a mirror of Zimbabwe's tourism sector because it is the epicentre of tourism activities in Zimbabwe and is undoubtedly the most popular destination in the country. Further, almost every tourist facility is found in the town. The Zimbabwe Tourism Authority and the Ministry of Tourism and Hospitality Industry as well as organizations that represent people with disabilities were also part of the research population. A comprehensive list of all operators in Victoria Falls (by category was supplied by the Zimbabwe Tourism Authority (ZTA). A total of 8 hotels, 9 lodges, 39 tour operators, and 11 boat cruise operators constituted the population.

## Sampling

Respondents in this research were selected by use of a combination of sampling techniques. For hotels in Victoria Falls, a census was used. All the 8 registered hotels and 9 lodges were used in the research. This was done because the number of hotels is not too high, hence it was feasible to visit them all. Secondly, the hotels and lodges in Victoria Falls are spread across the different star ratings, ranging from 1 to 5 stars and for lodges from standard to luxury. This meant that at least every star category in the country is represented. At each hotel/lodge, the front office manager was the targeted respondent. In situations where there was a maintenance manager, he/she would also be a respondent. For other operators, simple random sampling was used to identify and select the organizations included in the research. The researcher obtained a list of all registered tour operators and boat cruise operators from the Zimbabwe Tourism Authority (ZTA) and randomly picked 15 tour operators, and 10 cruise boat operators, which represented at least one-third of the total population. The researcher targeted the marketing manager and the operations manager of tour operating companies, or at least one of them. The sampling was purely judgemental, where only key informants were chosen. This sampling technique ensured that only the needed information was collected, saving on cost and time.

The Director of Research and Standards was selected from ZTA while the Principal Tourism Officer was chosen from the Ministry of Tourism and Hospitality Industry. As already alluded to, these were also chosen on the basis of their positions and expertise in the subject under study. Two umbrella bodies that represent societies of people with disabilities were used in this survey. The National Association of Societies for the Care of the Handicapped (NASCOH), a national body representing 53 disability organizations and the Federation of Disabled Persons of Zimbabwe (FODPZ). For the NASCOH, the executive director was purposively selected while for the FODPZ, the organization's spokesperson was chosen as a respondent. The researcher also targeted the executive director of Women with Disabilities Coalition, an organization which represent the needs and rights of women with disabilities exclusively. This was quite useful in ensuring that everyone is represented and an accurate interpretation of their

varying needs is made. The variety of respondents made the findings of this research more reliable and valid.

**Data Collection Procedure** 

Data for the survey was collected using three different yet complementary primary data collection techniques. These are interviews, questionnaires and observations. In-depth interviews were held with the Director of Research and Standards at ZTA, the Principal Tourism Officer in the ministry, tour operators, cruise boat operators, travel agents as well as the representatives from the disability organisations. Appointments were made in advance and face to face interviews were conducted.

The researcher adopted and modified the Scandic's questionnaire and administered it to all front office and maintenance managers in the hotels. The questionnaire has 68 (modified from 107 questions) dichotomous questions which are used to assess the accessibility of hotels. The Scandic hotel group has made a name in accessibility standards globally (Rains, 2010; ENAT, 2011) and is considered as a benchmark for hotel accessibility. The instrument helps in checking the availability of disability-friendly facilities, from the parking bay to the hotel bedroom and kitchen. In other words, the questionnaire checks for accessibility in every section of the hotel. This instrument provided great insights in constructing a questionnaire that would help in establishing the level of accessibility of hotels and lodges in Zimbabwe's Victoria Falls area. The drop and pick method was used in this research where the questionnaires were dropped and collected two days later. This method afforded the respondents more time to fill in the questionnaire resulting in a higher response rate. Since the questions were dichotomous, very little time was needed to fill it in.

To complement the above mentioned procedure, personal observations were also made. An observation checklist, similar to the modified questionnaire was used. Without interfering with employee duties, the researcher made the observations at all the hotels and cruise boats visited.

Document analysis was also done to complement the findings from the survey. Policy documents from the Ministry of Tourism and Hospitality Industry as well as those from the Zimbabwe Tourism Authority were interrogated. The researcher managed to get a copy of the draft national tourism policy from the Ministry of Tourism and Hospitality Industry and thoroughly scrutinised it with the aim of identifying the position of the policy makers regarding persons with disabilities and the implications thereof. The ZTA Strategic plans for both international and domestic tourism were also analysed.

## Results and Discussion

Data collected for the research was analysed both qualitatively and quantitatively. Qualitative data was analysed using content analysis where responses were categorised according to the questions on the questionnaire. All responses whose contents related to a certain question were grouped together and meaningful conclusions were made. Quantitative data was analysed using descriptive statistics in the form of percentages.

Accessibility of Hotels to People with Disabilities

A four page questionnaire (Modified Scandic questionnaire), made up of 68 questions was used to collect data from the hotels. The 68 items on the questionnaire were condensed to only seven categories for data analysis. These seven are summarised in table 1 below:

Table 1: Accessible	Accommodation	in	Victoria	Falls.	Zimbabwe

Area	Accommodation with	Accommodation without
Accessible parking and entrance	12	5
Accessible reception area	10	7
Accessible bedrooms	5	12
Easy access to bedrooms	4	13
(elevators or lifts, ramps, etc.)		
Accessible Restrooms/Toilets	5	12
Accessible showers/bathrooms	1	16
Accessible restaurants	11	6

Using the modified Scandic's questionnaire, the research revealed that only 30% of the registered hotels and lodges in Victoria Falls have accessible accommodation. The nature of the accommodation is such that only one or two rooms are accessible in a hotel that has more than 150 rooms. The majority of the respondents cited that their accommodation facilities do not have rooms designed specifically for people with disabilities. Of the hotels that had accessible rooms, access to those rooms is a nightmare. Observations revealed that some of the accommodation's facilities still use staircases and no ramps are provided. A person with mobility impairment would require assistance to get to the room. The majority of the accommodation's facilities do not have elevators and those with elevators do not have a sound system indicating the level reached in a storey building.

While 70% of hotels and lodges in Victoria Falls have wide parking areas for people with disabilities close to the main entrance, responses on the questionnaire exposed that there were thresholds at the front door entrance. This makes it very difficult for persons using wheelchairs to enter. According to the Scandic accessibility standard, a benchmark against which most hotel accessibility is set, is that doors, especially the front door, does not have a threshold, or has a very low threshold which allows those using wheelchairs and walking aids to enter without difficulty (Centre for Universal Design, 2009; Rains, 2004).

In 10 to 20% of the accommodation facilities, the concept of universal accessibility seems not to have been adequately understood. Some think that their facilities are accessible simply because there are ramps for wheelchair users and wide corridors. Their understanding of disability is limited to limited mobility while other dimensions of disabilities are ignored. These include: visual, hearing, mental and sensory disabilities, to mention just a few (DEO, 2005; Buhalis, 2005). It is evident from the responses that up to 90% of the hotels do not have facilities for people with hearing or visual impairments. As for tourists with mental and sensory disabilities, nothing is available in Victoria Falls. They are, as Choruma (2007) puts it, "The

forgotten tribe." The research yielded that only 3 to 5 star hotels in Victoria Falls have accessible rooms although the accessibility is not absolute. Bathrooms still remain relatively inaccessible in most of these hotels. This is evidenced by the fact that 95% of these hotels do not have shower chairs and thermostatic mixers as required by best practices in hotel accessibility (Sawyer & Bright, 2006).

#### Accessibility of Cruise Boats in Victoria Falls

The Victoria Falls resort is home to a number of cruise boats which utilize the Zambezi River for their cruises. Observations showed that the cruise boats are almost identical in their interior. All the cruise boats observed had no wheelchair access since there were steps at the entrances and no ramps were provided. Upon enquiring on how people with disabilities can utilize these cruise boats, the researcher learned that wheelchairs were literally lifted into the boats by staff on board. Other visitors with various impairments were assisted into the cruise boats since there are no grab bars. None of the cruise boats had designated sitting areas for people with disabilities. Such persons have to opt to sit on their wheelchairs or on the ordinary seats despite their disabilities.

Within the cruise boats, very small restrooms are available, only accessible by steps, since they are located in a deck lower than the sitting deck. For wheelchair users, there is double trouble when trying to access these toilets. First, they have to be lifted from their wheelchairs since the chair cannot fit into the restroom. Secondly, they have to endure the steps down to the restrooms. It is, however, important to note something positive about the cruise boats; there is a very short distance from the parking area to the cruise boat. There are also slip resistant surfaces to the boat and special menus are served to those with special dietary requirements. These positives are however outweighed by the factors already discussed.

Of the travel intermediaries interviewed, all agreed that the destination is not yet ready to accommodate people with disabilities. Tour operators echoed that they would love to promote packages for people with disabilities but there are very limited facilities available for such a niche. The same sentiments were echoed by travel agencies who lamented that the products they sell on behalf of the principals, still fall short in terms of accessibility for people with disabilities.

## The Views of Organizations That Represent People with Disabilities

Organizations that represent people with disabilities, in unison, are crying out that people with disabilities are not prioritized in Zimbabwe. The respondents agree that unlike women and girls, their song is falling on deaf ears, no matter how loud they sing it. They argue that policy makers and parliamentarians only talk of people with disabilities when it is benefitting to them and nothing is done afterwards. According to one respondent, the reluctance of authorities responsible for people with disabilities is shown by the unavailability of statistics on people with disabilities in Zimbabwe. Statistics on people with HIV, AIDS and of the unemployed are readily available, but very little is available concerning people with disabilities. There is, however, an estimated 1.5 million people with disabilities in Zimbabwe, which is more than a 10% of the

total population (Choruma, 2007). This could be a gross underestimation since many children with disabilities are hidden from the public and are left out of most research.

People with disabilities, according to their representatives, are still stigmatised and discriminated against. They are relegated to the position of beggars since they are perceived to be economically unproductive and lazy. This is unlike the situation in western countries where people with disabilities are an economic niche to reckon with (Lipp & Laurel, 2007; Dwyer & Darcy, 2011). The representative organizations argue that the fact that very little money is allocated to this group of people in the national budget each year, is enough evidence that government and other responsible authorities have little interest in them.

Commenting on policies to do with people with disabilities, organizations that represent people with disabilities (i.e. NASCOH, FODAZ & Women with Disabilities Support Organisation) pointed out that there is no disability policy in Zimbabwe. All that is available is the Disabled Persons Act of 1992 as amended in 1996. They argue that despite the fact that disability is the second fastest growing "industry" after HIV and AIDS, no policy has been put in place for it. These organizations further pointed out that the Disabled Persons Act of 1992 was biased towards people with physical mobility disabilities leaving out the other dimensions of disability. The Act is just too general, they say.

People with disabilities believe that even the new constitution of Zimbabwe does not fully address their needs. According to their representatives, the new constitution does not commit state resources to assist people with disabilities. Further, they argue that the fact that the new constitution gives provision for only two people to represent people with disabilities in the upper house of assembly is incommensurate with the spirit of emancipating them. Moreover, the constitution does not spell out whether these two Senators should be people with disabilities or not. The research also revealed that people with disabilities feel they were not fully consulted in the constitution-making process and that the draft constitution was not drafted in disability-friendly language, especially for those with visual impairments and the illiterate-which constitute the majority of this population segment (Choruma, 2007). They argued that generally people with disabilities are rarely consulted in policy issues. Mandipa (2013), however, argues that the new constitution is disability-friendly, citing that it clearly spells out that discrimination on the basis of disabilities in this regard.

## People with Disabilities and Tourism

The study exposed that, to a larger extent, people with disabilities do not travel for leisure. One disability advocate actually believes that people with disabilities do not travel at all. Reasons for not travelling for leisure and/or business are as follows: first and foremost, they are the poorest in society and secondly, they are not given an opportunity to acquire education, especially in rural areas. These people are also segregated and discriminated against when it comes to employment. If they are employed at all, they are not given the opportunity to occupy leadership or managerial positions. This is supported by findings by Khupe (2012) whose research revealed that people with disabilities are given menial jobs, even by organizations that

purport to represent their needs. All these factors determine the disposable income that people with disabilities have at the end of the day, which in turn determines their propensity to travel (Chikuta, Njerekai & Nkomazana, 2013).

People with disabilities are "disabled" from travelling by the nature and state of tourism facilities in Zimbabwe. The few disabled persons that have the requisite disposable income rarely visit tourist establishments because there is virtually no transport that is disability-friendly. The "so-called" tourist coaches available have little space for people with disabilities. Local tour operators have not gone to the extent of purchasing disability-friendly vehicles. Some of the coaches have entrance barriers at the door and some do not have seats designed specifically for people with conditions like muscular dystrophy. This is, perhaps, because the disability market has not shown any potential in Zimbabwe. According to Darcy (2002), many operators feel it is not worthwhile to purchase or reengineer a vehicle only to accommodate one or two disabled persons who come only once or twice a year. What these operators do not realize is the fact that globally, people with disabilities have become a market to reckon with and the fact that most Zimbabweans with disabilities are poor does not mean that inbound tourists with disabilities are also poor. Further, people with disabilities argue that travelling is very expensive for them. This is mainly because they have to travel with their aids/assistants, in most cases, and this doubles the cost of transport. At times, having a wheelchair or any assistive device is an additional charge on the coach, bus or plane.

Apart from transport, people with disabilities are worried about the inaccessibility of the hotels themselves. One executive director of a disability organization, who is also disabled, lamented that the cost of travelling and utilizing tourist facilities is very expensive, just like it is for transport. Instead of paying for one (like in the case of able-bodied persons) people with disabilities pay for at least two people in the hotel. While it is an advantage for the hotelier or accommodation provider, it is a prohibiting factor for people with disabilities.

As revealed by the Scandic questionnaire, people with disabilities concurred that most hotel rooms in Zimbabwe are not yet disability-friendly. They argued that the bath places, toilets and some beds are not fit for use by persons with some types of impairments. One respondent pointed out that sometimes the restaurant setup is not accessible by people with limited mobility and those with visual disabilities. At times food is served in a buffet style which might not be accessible to some disabled persons.

The attitude of hotel staff was highlighted to be another hindrance to travel by people with disabilities. Respondents pointed out that while some hotel employees are very friendly, others are really a problem. They seem to be ignorant of what disability is all about and they view people with disabilities as aid-seekers and beggars: "...They think their toilet will be messed up. Just because one has a disability does not mean one is not able to use toilets. Sometimes you are given a lot of food as though you have never been to a hotel. They want to teach you how to order your menu and want to make you look stupid in front of other visitors," said one of the disabled respondents who has been to hotels on several occasions.

All the organizations that represent people with disabilities are in agreement that more needs to be done to make our tourism industry more accessible to disabled tourists. The improvements suggested include: provision of ramps, elevators, accessible toilets and showers. They also recommend that all facilities have signage in large print as well as in braille to cater for the visually impaired. Hearing loops must be provided for those with a hearing impairment. Their suggestions are in line with the concept of universal design and the best practices as entailed in the Scandic Accessibility Standards (Rains, 2004, 2007). Attitudes of able bodied employees should be changed if Zimbabwe is going to be accessible to tourists with disabilities.

The Policy Position on Disability Tourism in Zimbabwe

The government of Zimbabwe, through the Ministry of Tourism and Hospitality Industry and the Zimbabwe Tourism Authority believes people with disabilities are catered to in policy documents. According to the Principal Tourism Officer in the Ministry of Tourism and Hospitality Industry, the draft tourism policy has incorporated people with disabilities. Section 5.10 of the draft tourism policy, which is sub-headed "Role of the physically handicapped" has the following points:

- The Government will ensure that all major tourism destinations/products will be provided with facilities that are user-friendly to persons with disabilities.
- The Government will promote the mainstreaming of people with disabilities to participate in mainstream tourism activities.

A thorough interrogation of the policy revealed that only these two statements were mentioned in the draft policy regarding persons with disabilities. In the first instance, the heading already sidelines other forms of disabilities by categorically pointing out physically handicapped people. According to the Disabled Persons Act of 1992, as amended in 1996, persons with disabilities include but are not limited to the physically handicapped. Buhalis (2007) concurs with this definition and pointed out that disabilities can be sensory, hearing, visual and mental. From this analysis, one can conclude that people with disabilities are not even understood at the policy making level.

The draft policy talks of *major* tourism destinations/products, leaving out the minor ones. At policy level, one would expect that all destinations be mandated to be disability-friendly. Provisions can be made for the smaller destinations to do it step by step. Leaving these minor destinations and products out gives a loophole for many to escape this noble and economically worthy cause. The ministry argues that people with disabilities are catered to as far as it is concerned. What remains is for the ZTA to ensure that policy is implemented properly. It argues that the detailed specifications are the baby of the tourism authority.

Zimbabwe Tourism Authority and Disability Tourism

ZTA is mandated with enforcing the specific industry requirements as prescribed in the tourism policy. To date, due to the absence of an operational tourism policy, ZTA is being guided by the Statutory Instrument (SI) 128 of 2005 (Grading and Standards Regulations) and

Statutory Instrument 106 of 1996 (Declaration and Requirements for Registration). Section 5 of the 3<sup>rd</sup> schedule of SI 128 0f 2005, provides that accommodation facilities should have ramps to enhance access to all areas of the hotel, lodge, motel or any other accommodation facility. It also provides that all hotels with three star grading and above must have at least two rooms for people with disabilities while those with two stars and below should have at least one room for disabled persons.

SI 106 of 1996 provides that, as a requirement for registration, all accommodation facilities should have at least one properly working and well maintained cubicle toilet to cater for people with disabilities. The two statutory instruments sound quite pro-disability from a distance. A closer look at these instruments show that SI128 of 2005 is only concerned with people with mobility disabilities, specifically wheelchair users. Nothing is mentioned about the other dimensions of disability. SI 106 of 1996 has too simple of requirements when it comes to access for people with disabilities. It does not specify what the toilet should contain in contrast to the Scandic's standard which stipulates the position of the toilet seat, the grab bars and where toilet paper should be placed. At the end of the day, one can conclude that the provisions in the statutory instruments are too general and many establishments can do the minimum and get away with it.

The Zimbabwe Tourism Authority came up with its national tourism and marketing strategy, whose way is to map the way forward in terms of tourism development in the next couple of years. One would expect that issues to do with people with disabilities would be topical in such a strategic document, but again, no mention is made of this market niche, hence no strategy has been put in place for them. Even the domestic strategy does not make any provisions for people with disabilities. Perhaps the salient message being communicated is: there is no room for people with disabilities in the national tourism strategy.

#### Conclusion

While it is known that people with disabilities are rightfully entitled to tourism and leisure facilities in Zimbabwe, it is clear that the issue of priority needs attention. Despite the fact that Zimbabwe, like many other countries, ratified the United Nations Convention on the Rights of People with Disabilities in September 2013, it is still very clear that, from policy-making to implementation, the country's tourism industry still lags behind when it comes to providing access to people with disabilities. It seems that the industry, like other industries, still believes that people with disabilities are an insignificant sector in the economy; hence there is no need for stretching scarce resources to try and provide for an economically unproductive and poor market. This is, however, a very mistaken notion, as long as we are still living in a global village. While disabled persons in Zimbabwe may not be economically empowered, other countries, especially in Zimbabwe's primary markets, are finding the disability market very viable. The ministry of Tourism and Hospitality Industry and ZTA should work towards universal accessibility and universal design to ensure that all players in the tourism industry join the accessibility bandwagon. As of now, there is no room for people with disabilities in the tourism and hospitality industry in Zimbabwe.

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## **MULTIMEDIA REVIEW**

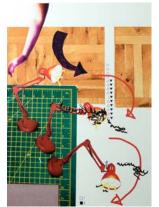
## **Kate Mahony's Awakening (of Things)**

By Alexandra Kadlec

Kate Mahony is working stuff out—with the help of a pink pillow, desk lamp, and plastic bucket. In conversation, this is how the artist describes her performance for <u>Art of the Lived Experiment</u>, a disability arts exhibition that premiered at <u>DaDaFest International</u> 2014 in Liverpool, England and made its inaugural and only U.S. appearance in Grand Rapids, Michigan last April.

In a corner gallery space within the Urban Institute for Contemporary Arts, Mahony employs these and other household objects curiously. She puts them over her head, ties them to her leg, props them on her shoulder, and drags them across the concrete floor. Eventually, the objects become characters in their own right, burdening and obstructing the artist, transforming her into what she has proclaimed a "domestic monster."

While these actions may seem puzzling at first, they are not altogether unpredictable throughout the performance. Mahony is following a set of how to's depicted on several bouncy bright vinyl collages stuck to the wall behind her, and the audience can easily see that. After the artist enacts each instruction, she takes a thick black marker to the collages liberally, leaving a new set of scribbles.





Figures 3 & 2 Collage series by Kate Mahoney for *Art of the Lived Experiment*. Courtesy Kendall College of Art and Design. Photo: Matt Gubancsik

Mahony acknowledges that her performance is bound to confuse, and she's okay with that. After all, she's trying to make sense of things, too. But digging deeper into the concept for this piece, and expanding the lens to Mahony's approach to the medium itself, yields enriching dialogue.

The themes driving *Art of the Lived Experiment* confront the inevitable process of change throughout our lives, and the ways we are required to adapt; in particular, how disability and its differencing affects our interactions with others, the world, and ourselves.

How the art and artists in *Art of the Lived Experiment* address the experience of disability is not immediately evident; and of course neither is disability itself, which may affect our minds or bodies (or both simultaneously). There is Katherine Sherwood's *Olympia* and *Maya*, odalisque figures that challenge ideals of feminine beauty, in one regard by incorporating scans of the artist's brain post-hemorrhage. Laura Swanson's *Uniforms*, a series of 4-foot-tall mannequins clad in various outfits, confronts the objectification of physical difference in a disquieting manner; as someone living with dwarfism, Swanson explores the theatrical spectacle of her body and its marginalization within society.

Similar to Sherwood and Swanson, Mahony's exploration of disability is undeniably personal. Diagnosed with a nonverbal learning disorder and dyslexia in 2012, the artist has been forging a practice through forms that involve the language of movement, absent of words. She likens her performances to creating in a live studio, which naturally invites a certain pressure of expectation and even fuels some awkwardness in her movements.

From 2011 to 2013, Mahony was part of the collective LUPA (Lock Up Performance Art), which she conceived with *Art of the Lived Experiment* curator Aaron Williamson. An artist-run performance platform, LUPA featured a rotating mix of performers in the spirit of experimentation, hosting monthly iterations in a non-descript garage in the Bethnal Green district of London.

Here was a space to try things out, without fear of failure or judgment. LUPA's performances were typically offbeat, often comical, sometimes outrageous. And its varied audiences became active participants, cheering, booing, audibly gasping at the scenes unfolding before them.

Mahony's performance for *Art of the Lived Experiment* carries a similar element of playfulness but with an undertone of deliberation. Her collage series was inspired by the *Mutus Liber*, a 17<sup>th</sup> century alchemical text containing a set of illustrations for manufacturing the Philosopher's Stone, a substance believed to turn base metals into gold.



Figure 4 Photograph of the Mutus Liber

The collages present a modern-day twist on the indecipherable text; they confront everyday objects from new angles, but without a clear sense of purpose in the context of art. The objects

depicted have become disassociated from their conventional functions, visually manipulated and manipulating within the performance.

Mahony describes the making of the ephemeral collages—which must be torn off the wall and recreated—as a process of "walking backwards through [her] own work." She had to make sense the accompanying performance from a visual, tangible angle first. And yet having concrete instructions was no guarantee of how exactly her movements would unfold from there.

Such an act is significant to the artist's practice. Averse to the idea of "fixed art", Mahony prefers to be challenged by works that must be recreated continuously, the kind that are never the same. In this sense, her performances demand vulnerability; in them, she cannot hide behind a clear or comfortable formula.

Although Mahony can never predict how people will react to her work, she admits to being surprised by the silence that enveloped her performance in Grand Rapids for *Art of the Lived Experiment*. (Personally, she finds the piece rather humorous.) But perhaps within the context of a disability arts exhibition there lies a certain hesitation on the part of the observer: of how to interpret, react, and respond.

These are choices we all have to make, in fact, on a daily basis, whether in regard to others or ourselves. Mahony has come to view her diagnoses not as limitations but rather "liberations"; she could suddenly claim her view of the world, and her perpetual search to understand it, as fully her own.

## **DISSERTATION ABSTRACTS**

- 1. Demyelinated: The workplace experience of women living with multiple sclerosis McCauley, J. R. ProQuest Dissertations & Theses, 2014. [PhD Dissertation] United States: Michigan: Capella University, 2014. Publication Number: 3631249.
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