Editorial

When A Hyphen Matters: Reflections on Disability and Language

Megan A. Conway, Ph.D.
RDS Editor-In-Chief

A colleague recently sent out an email titled, "Respect for My Community" in which he chastised a local service organization for distributing t-shirts that he believes misspelled the word "Deaf-Blind" (with hyphen) as "DeafBlind" (without hyphen). "Would YOU accept a T-shirt that said 'dEAF' [with improper capitalization] or 'Ward of Hearing' [with spelling errors]?" he wrote, "Would YOU be proud to wear a T-shirt showing the public the WRONG spelling of YOUR community?" His point is well taken. He is proud of his identity as a Deaf-Blind person. He fought long and hard for recognition of language that would describe his unique disability in a way that also reflects his identity. For many Deaf-Blind people, the hyphen is important because it signifies that "Deaf-Blind" is its own unique identity that is different from that of Deaf or Blind people. The capitalization of "D" and "B" are also important, because they signify cultural identity just as a capital "D" signifies Deaf cultural identity (as opposed to a lower case "d" which is understood to represent medical aspects of deafness).

Here is the difficulty though - one person's identity as a hyphenated Deaf-Blind person does not reflect everyone's identity. I personally am a deafblind (no hyphen) kind of gal. Some of this preference is aesthetic. I just like the way "deafblind" feels. It feels like one, clean, smooth word. For me, the hyphen medicalizes the word. And I am not alone. Outside of the United States, the term "deafblind" has long been preferred, and it is catching on in the U.S. DeafBlind Citizens in Action (of which I am proud to be a member of the Board of Directors) uses the term "deafblind" (without a hyphen) to describe its membership. Even the American Association of the DeafBlind, once the champion of "Deaf-Blind" (with a hyphen), seems to have recently dropped it. According to one DeafBlind person, when asked about whether or not a hyphen is preferred:

"It is definitely DeafBlind... one word, capital D and capital B and NO hyphen. It is true that it's always been hyphenated in the past. When the word DeafBlind is hyphenated, it usually indicates that it is a problem and that it needs a solution. As you know, DeafBlind people don't have problems that need solutions.... we have a language and culture! What we need and deserve is a community of people who will learn and respect our ways."

I personally do not identify with use of the capitol "D" and "B" because I have never quite seen myself as a part of a "culture" related to Deafness, Blindness, or DeafBlindness. This is mostly etiological - Although I am "legally" deafblind I do have some vision and hearing and use speech to communicate. I consider myself to have some degree of

membership in all of these communities, they are my people. But for me, capitalization does not matter.

This conversation about hyphens and capitalizations will, if it has not done so already, eventually put you into a deep coma. Who cares? Why are we arguing about grammar when there is so much good work that needs to be done to support Deaf-Blind/deafblind/DeafBlind/D/deaf and B/blind people in the community? Well, the answer is that it does matter and it does not matter. We do need to recognize that a hyphen can matter. And then we do need to move on.

Language matters because language has the power to shape societal perceptions, and language also reflects societal perceptions. Those who used to be called "crippled", "imbeciles", "deaf and dumb", and "retards" know how such language impacted how other people treated them and how they perceived themselves. "The Handicapped" fought long and hard for the word "disabled" because it feels more respectful and because "disabled" has become a signifier of identity and community membership that was claimed by disabled people themselves. But there is nothing to say that "disabled" will be a preferred term forever, nor that it is the preferred term for everyone who might be identified as such by others. Some people do not like the word "disabled" because they feel that it does not describe them. Similarly, at one time some members of the Deaf-Blind community decided that "Deaf-Blind" best described that community. But others then, and others now, do not agree.

Now for the moving on. The issue of language always comes up in my Disability Studies courses because students want to use language respectfully, but they sometimes just don't know how. "Is it o.k. to say 'handicapped'? What about 'handicapable'? Anything is o.k. so long as I put the person first, right?" To this later question I want to say, "Oh yeah, sure, if you call me a 'person who is an imbecile' that will be just fine" (but I don't, because I am the wise professor). What I DO tell my students, and what I say to you is, "Respect the person by respecting how they identify themselves." If you see yourself as Deaf-Blind, and it matters to you that I use a hyphen when I refer to you as Deaf-Blind, I will call you Deaf-Blind.

That's all very nice miss Pollyanna, but what do we do when we need to reach a consensus about the name of our organization, or how our disability is cited in the law, or how other people should refer to our community? In my opinion we do our best to ensure that the language that we use reflects the preferences of a majority of our community, the rest of us grin and bear it, and we move on to helping each other make our lives better.

Though it is too bad we can't all be like my grandfather who always said, "You can call me anything you want - just don't call me late for dinner."

Page 3

Research Article

"Friends Give Meaning to Life:" Reframing Friendship for Individuals with Autism Who Type to Communicate

Jessica K. Bacon, PhD
Montclair State University
Fernanda Orsati, PhD
Hussman Institute for Autism
Scott Floyd
Scott's Sensory Shop
Hesham Khater
Institute on Communication and Inclusion

Abstract: We, two able-bodied authors and two authors with autism, use a disability studies framework to understand our experiences of friendship. Taken from a series of recorded conversations over the course of a year, this project describes the development, maintenance, and complications related to our experiences with friendship, including: reframing of friendships, respect for communication, facilitator roles and support, interdependence and reciprocity, and permanency in relationships.

Keywords: Friendships, Communication, Disability Studies

We, the authors of this paper, are four friends. Two of us have autism and use facilitated communication (FC) and two of us are able-bodied. After spending time together over several years, we realized that the development of our relationships has been exciting, fun, frustrating, and complex. Friendship is generally difficult to define and its development is particularly unique for individuals who have autism and type to communicate. We have documented conversations between the authors about experiences with friendship. In this paper, we lay out the tenets of disability studies before documenting and critically analyzing the extant literature base about friendships, disability and autism. We then briefly discuss the process of writing this paper, we introduce ourselves as authors, and reveal the key insights and themes that came out of the conversations we had over several years.

As disability studies (DS) scholars, we assert that, "Disability is a social phenomenon" (Taylor, 2006, p. xiii). Taylor (2006) explained that adopting a DS perspective allows us to understand that:

> "Human beings differ in many ways. Variations according to ability do not need to be valued negatively or wrapped in stereotypes and stigma. Disability is not viewed as a condition to be cured but rather as a difference to be accepted and accommodated."

We believe there is no standard or "right" way people establish friendships. Further, we reject medical a pathological views of disability (Oliver, 1990) where it is assumed that

disability is a deficit or medicalized problem. Disability is often pathologized and differences in human interaction and sociality are viewed through deficit paradigms, which often become medicalized by professionals. Ableist perspectives (Hehir, 2002) problematically devalue disability and mark able-bodiedness as preferable, which may reify power dynamics within relationships.

Through adopting a DS perspective, we reconceptualized the concept of friendships as one that develops through interdependence, courage and support. Under such a perspective, individuals with disabilities are able to take risks, confront consequences, and take responsibility for their own acts—redefining ability, parameters of "normal" relationships and stigma (Jacobs, 2002). Jacobs (2002) asserts that when an individual is provided with choice, he or she will take increased responsibility. Jacobs called for a trans-disability understanding because, "Through increased communication, interdependence and reciprocity, there is a potential goldmine of shared experiences that future generations of disabled people will be able to utilize" (p. 12).

Condeluci (2014) notes that interdependence is a powerful concept built from mutual respect, which "implies an interconnection, or an interrelationship between two entities" (p. 8). Condeluci (2014) adds that all people are different, but through a framework of interdependence, differences are valued and all parties are empowered. Wendell (2006) asserts that:

> "Dependence on the help of others is humiliating in a society which prizes independence…There are disabled people who will always need a lot of help from other individuals just to survive … In addition, some disabled people spend tremendous energy being independent... If our culture valued interdependence more highly, they could use that energy for more satisfying activities" (p. 252).

Wendell's points have material consequences for how relationships are built and viewed in our society. In this paper, we call for a move away from a paradigm that casts people with disabilities as either independent or dependent and we strive for interdependence that focuses on individuals' capacities, stresses relationships, and is driven by people with disabilities. To begin, we describe the literature base related to Facilitated Communication (FC), disability, autism, and friendship, which often reify ableist perspectives.

Literature Review

We begin by describing FC, as both Scott and Hesham use FC as their primary means of communication. FC is a means of typed communication in which an individual with limited verbal speech is able to express ideas and thoughts (Crossley & Remington-Gurney, 1992). Individuals, who type to communicate, or use FC, rely on trained facilitators who provide physical, emotional, and social support to the typist (Crossley, 1994). Many FC users who once required intensive physical support to communicate ultimately demonstrate the ability to type with no or limited physical touch (Biklen & Burke, 2006; Rubin et al., 2001;

Wurzburg, 2004) and others read aloud their text during and after typing (Broderick & Kasa-Hendrickson, 2001; Kasa-Hendrickson, Broderick & Hanson, 2009).

Using FC has promoted inclusion in K-12 education (Ashby, 2012), higher-education (Ashby & Causton-Theoharis, 2012) and social and familial relationships (Biklen, 2005). FC has been documented through research and personal accounts to have positive impact on people's' lives in many areas, particularly by being perceived as smart, competent and part of society (Biklen, 2005; Mukhopadhyay, 2008; Rubin, et. al. 2001; Savarese, 2007).

Unfortunately, the literature base on FC has been steeped in controversy since it was introduced in the US as a form of communication for many non-verbal individuals with autism and cerebral palsy. Largely, the DS community has stood by FC as a legitimate form of communication and has defended the authenticity of the stories of those who use FC to communicate, despite ongoing controversy about the method. Transcending this debate, we (Scott and Hesham) offer proof in our daily lives that our way of communicating is authentic and is, in many ways, a building block for our ability to develop friendships. At the same time, our experiences in interacting with others are, at times, negatively impacted by the larger debate and assumptions made about the legitimacy of FC.

A limited literature base on friendships for people with developmental disabilities is available (Emerson & McVilly, 2004; Watt, Johnson & Virji-Babul, 2010) and none that we found directly described friendships for people who use FC. Unfortunately, most existing literature has constructed individuals with disabilities as incapable of developing meaningful friendships (Taylor, Asher & Williams, 1987) often because they are considered unable to understand others emotional needs (Abery & Fahnstock, 1994). Other extant research has emphasized support through family relationships (Biklen, 2005; Berube, 1996), friendships that develop with support staff (French & Swain, 2001) or through programmed activities (Jobling, Moni & Nolan, 2000).

When specifically looking at literature on autism and friendship, predominate perspectives have been pathological. The American Psychological Association (2004) explains that autism spectrum disorders are characterized by atypical interaction styles including deficits in the ability to appropriately use non-verbal behaviors, an inability to maintain developmentally appropriate peer relationships and lack of social and emotional reciprocity. People with autism are often considered unable to take the perspective of others or understand that the beliefs and desires of others are different from their own (Frith & Happe, 1994). Baron-Cohen, Leslie, and Frith (1985) asked, "Does the autistic child have theory of mind?" (p.37). This question began to dominate subsequent deficit-based literature describing people with autism as lacking such skills.

These deficit approaches to autism offer a limited way of viewing what it means to be a person with autism, and do not adequately take into account the perspectives of people with autism. DS scholarship, relying on personal accounts about autism, friendship and disability

has painted more humanistic perspectives. Howard, Cohn, and Orsmond (2006) conducted a case study of a young man with autism named "Tom." The authors found that Tom valued friendship in his life and often had help from his family in facilitating opportunities for friendship. Rosetti (2011) conducted a qualitative ethnography focusing on students with and without disabilities (including several students who were labeled as autistic) who developed reciprocal peer relationships in school. Rosetti (2011) found that youth undertook complex negotiating in order to interact and support one another and they did so outside of any formal school arrangements through "meaningful connections, shared humor, and friendship work" (p. 31). Thomas (2007) clarified that individuals with disabilities have been unfairly cast as dependent, resulting in inadequate understandings of their social networks. Bogdan and Taylor (1989) defended ideas of reciprocity and humanness in relationships for people considered to have severe disabilities. Lutfiyya (1991) explained that it was the human service field that held people back from developing natural and long-term friendships. Likewise, Van der Klift and Kunc (1994) clarified how formalized buddy systems and friendships circles hindered natural relationships and perpetuated a helper/ helpee framework, where the child with the disability was always being "helped."

In this paper, we work beyond deficit conceptions of disability that dominate the literature and reject the strong stigma often associated with autism, FC and the authentic ability to form friendships and socialize. Instead, we share narratives that reveal complicated, caring, and compassionate friendships that may not follow "normal" or "traditional" trajectories of friendship, but are, however, no less real, important or long-lasting. We also fill a gap in the literature by highlighting the connections between access to communication through FC and friendship development.

Process

The four authors' of this paper have known each other for varying lengths of time and met in a range of capacities. Eventually, we all found ourselves socializing and working together at the Institute on Communication and Inclusion at Syracuse University where we began to interact regularly as a group. We quickly realized that many of our conversations became focused around our experiences with making and maintaining relationships. We decided to embark on a collaborative process of documenting, analyzing and writing about our experiences. We consider the process we undertook to be a collaborative inquiry that offered insight regarding the topic of friendship development through our own experiences.

We held group discussions for approximately two hours per week, over the course of two semesters, totaling approximately 20 sessions. We recorded the conversations when appropriate (some responses were too personal to share publicly) through the communication devices used by Scott and Hesham. Fernanda and Jessica communicated verbally, while Scott and Hesham used FC to type their thoughts. During discussions, Jessica facilitated for Scott and Fernanda for Hesham.

The questions addressed in this article through analysis of group discussions, are the following: (a) How do we (Scott and Hesham) understand friendship in relation to autism and using FC?; (b) How does our role as facilitator's (Jessica and Fernanda) impact friendship building?; (c) How do our friendships correlate with or differ from ideas of care or support?; (d) How is the dependency aspect of supported typing managed? And, ultimately (e) Can we rethink friendship for people who type to communicate?

Once information was gathered, we collectively analyzed the recorded conversations and identified areas that came up repeatedly in conversations. Jessica and Fernanda used qualitative thematic analysis procedures to identify key themes, which were then brought back to joint project meetings and discussed with Scott and Hesham. We looked to our guiding questions and attempted to shed light on the aforementioned inquiries. Each of us also wrote a short bio, which provides an introduction to how we view FC in relation to friendship. Writing up the research findings occurred in a similar fashion and all authors collectively checked the text as sections were written.

Authors' Narratives

Hesham

I am Hesham, not just someone that knows how to communicate through typing but loving fun guy. I'm some[one], a joker guy that started typing [to] voice my lively ideas. My mind is [an] easy thinking place for treasured ideas. I have used FC since I was very young, but it did not [always] bring me friends. I have had friend-like people, but never a real friend until my time [in college].

If people could see into my heart, what would they see? They would see the worn down years of frustration… Not knowing about autism was a huge part of it. FC is how I interact with people; this tool is my life. It gives me the ability to speak my mind when I have no voice. You have no idea what this does for me. It gives me the opportunity to feel accepted in society. I have never felt this happy being able to be free from being a prisoner within myself.

Scott

My name is Scott. I like to do cool things like hanging out with friends and going to the park. When I was three years old, I began to type at Jowonio school. I learned to type with some of the teachers there and I remember it being so hard to get the concentration to get any words out. I just remember having to get up a lot to move around. I was excited though to have a way to get out my thoughts… [and] I do remember having to hit because could not say what I better needed. When I first started typing I felt new to the world because I could say what I was thinking and feeling. I kept at it because I wanted to be able to talk and prove I am a smart guy. I had some good years in school; mind you I never was really doing much typing.

I got to meet some good friends in school that also cared about me too. It was nice to

have some friends who were not in special ed. Finally I found my way out of school, someone my mom knew helped me find the OnCampus program at [Syracuse University]… It was a program where I could take college classes. I got to type with TA's [teaching assistants], friends, and one professor. During OnCampus I was able to participate in classes for the first time. It was great to have all the college kids see how smart I really am.

Jessica

I was introduced to the world of FC early in my doctoral program at Syracuse University. My first year as a doctoral student, I was assigned to work with the OnCampus program, an inclusive post-secondary opportunity for transition-aged high school students. During that year, I met Scott and soon we began to spend time together each week.

Before learning to communicate with Scott through FC, it was often difficult when we were out engaging in activities. I could often tell that Scott would become frustrated with me because he wanted to change the activity, or tell me something about my actions. Once we began to successfully type together, Scott and I had fewer miscommunications and our friendship was able to develop in a more meaningful and reciprocal way. During the following four years, Scott and I spent time together weekly. I was excited when we also expanded our friendship to share our thoughts and experiences with Fernanda and Hesham. The friendships I have created with all of the co-authors have been influential to me personally and academically.

Fernanda

I was a psychologist in Brazil, working with neuropsychological assessment in multidisciplinary teams when I heard about individuals who were typing to communicate. I visited Syracuse and met incredible people that before being able to type were deemed incompetent, and that changed my life. I moved to the U.S. and started my Ph.D. in Special Education at the same time that I started to learn FC and how to support individuals to communicate. I met Hesham in 2009 and we began to meet weekly then.

Our meetings involved a lot of time practicing typing, talking about various subjects from politics to relationships, or even just time hanging out. In one of the first times we met, Hesham told me to be calmer, and from that point on I knew we were connected. We built a great relationship over the years that changed not just my profession, but also my understanding of humanity.

Themes

In this section the authors described their conceptualizations and impressions about various aspects of friendships and relationships that were most important to them.

What is Friendship?

All four authors described how friendship was a vital part of their lives. Jessica and Fernanda identified the importance of having a community of friends as they worked through processes of graduate school. Similarly, Scott and Hesham noted the importance of friendship

during school and now as they have transitioned from school into the adult world of work and volunteering.

According to Scott, "I am just like everyone; I need friends to make life not so lonely or dull. Friends give meaning to life." Scott believed that in order to feel connected to the world, having friends was extremely important. Scott explained that it was important to have "ties to your feeling good friends. It is important to finding common interests. It's better because then you have more food for really good thoughts." Scott felt that he needed to connect with others through common bonds and interests. Scott also added that friendship for him:

> "Means someone who as it my side week after week. I know sometimes it's really a true relationship [when they go] the extra mile to type with me, looking to really get to know me as a one of a kind person. I want to add that really true friends come around week after week for years."

Jessica agreed with Scott's statement, "For me friends have been vital to my development of who I am as a person. When developing a friendship with Scott, it was really important to spend time together consistently so that we could trust each other enough to productively type and learn to have a reciprocal friendship."

Hesham similarly felt that friends were important. He explained; "Having friends is the greatest gift I have to honor in the good life I have. Nothing is more rewarding than great friends around us." Fernanda noted that in her process of moving to another country the new friends she made were responsible for "providing meaning to my life or to make it a 'good life' as Hesham explains."

Friendship in the lives of all four authors was extremely relevant and important. People with autism are often described as uninterested in making and maintaining social relationships (Bauminger & Kasari, 2000), but the sentiments of the authors showed a new perspective. For Scott and Hesham access to a reliable means of communication improved their ability to engage meaningful exchanges with others. We were able to privilege the structured weekly meeting time, and it mimicked other social gatherings when people come together each week to engage in scheduled activity.

Respect for Communication

Having respect for their way of communicating was vitally important to both Scott and Hesham. Communication through FC was their means for expressing aspects of their personalities. Both Scott and Hesham indicated that those they develop relationships with should respect, honor, and learn about their method of communication. Dishonoring FC often led to a breakdown of the potential for friendship and relationships were more difficult to build when they weren't able to share thoughts through FC. Similarly, Fernanda and Jessica noted that learning to understand and respect the process of FC took time and was not without challenges, but in the end was worthwhile. Fernanda also felt that because English was her

second language she needed similar validations of her language, her accent, her mistakes, and her cultural differences from friends. "When an individual understands who I am and where I am coming from, I am able to truly connect and be myself," she noted.

Scott repeatedly described how important it was for good friends to learn and respect FC. For instance, Scott stated that he felt "…lucky to have friends who are taking time to be my friend. I see so many people come and go out of my life, so friends who stick around to even learn my way of communication are rare, but so beautiful. When it happens it makes the lost chances, glimmers of the past, kind of like shooting stars."

Scott also emphasized that it was important for his friends to type with him because otherwise "they miss most of who I am and I don't get to dearly share my best qualities and smart insights, so then I am forced to go along everything they want, silently forced." At a later date, Scott reiterated that:

> "I [usually] just have to use my actions to get across my great needs. Like when I get upset, I yell what the person is saying. But if they typed with me, we could talk it out. So then there is more miscommunication that [is] not good for our friendships. I just think that a friendship goes two ways. I hear what they have to say all day long, so it's only fair to get to share my ideas too. I have so many things only friends who type with me finally get to hear."

For Scott, typing was an integral part of who he was, and it was a way for him to communicate his thoughts, wishes, and needs.

Jessica commented that it was undeniable that Scott regularly communicated with those around him, both verbally and non-verbally through his actions and interactions with others and the world:

> "Without typing, I was not always certain that I was correctly interpreting Scott. As I got to know Scott better, I began to better understand what certain actions, movements, and vocalizations meant, however it was much more useful to follow up with a typed conversation so that I was confident that I was not unfairly misinterpreting him. When I did hastily decide to interpret without asking for typed information, there was more potential for a breakdown of our communication. It became clear that Scott would become upset when he was misunderstood."

FC provided a deeper window for others into knowing Scott and who he was, and he felt that it was vital that his true friends could understand him as a complex, intelligent, and interesting person.

Hesham made similar comments in relation to the importance of his friends communicating with him through FC. Hesham explained that, "Friendship is great people that understand my way of communication and think that I have [a]lot to offer." For Hesham,

typing was not necessarily a prerequisite for developing a friendship. Hesham noted that he has friends with and without disabilities "that get me, but don't type with me." However, like Scott, Hesham explained the richness of a relationship and potential misinterpretations that can occur when his friends do not use FC with him:

> "I treat people politely, hoping the same to me. I resent [those] who don't fairly treat me respectfully, not to say hatefully. Respect [does] not yet satisfy results in tantrums that [are] jittery gestures, joking inside photographic hopes for communication. I see facilitated communication as a way out for my joking inside. Facilitators are language developers in a silent body. They bring out the inside knowledge."

Hesham further explained his take on the process of developing friendships:

> "Typing has to come with time; that is the first step. Having to understand me is just the beginning. The next step is recognizing me as exciting person, to get to know me. Then we have to spend time together, poorly structured, to yield more things in common. Then we can be friends."

> "For Hesham, friendship was a complex process that developed in different ways with different people. Although for Hesham typing may not be have been a requirement to developing a friendship, it was clear that typing provided an element which lead to deeper understandings. Fernanda understood Hesham's needs. "I knew that some days Hesham just wanted to hang out as friends, and walk around campus or in a park, or read an article in the newspaper." Fernanda added that:

> "This process that Hesham describes was very important for our friendship. We were able to plan activities and practice some skills together. However, we also had moments of less structure and more fun. Because I was able to support him through typing I saw this exciting and competent person he is, in every moment we were together. He was always able to make choices and provide input to all activities."

As noted by Jacobs (2002) it is through communication that individuals can build relationships that are interdependent and reciprocal. In order to be reciprocally committed to one another, both parties need to be able to make choices and communicate such information (Jacobs, 2002). Thus, for all of us, respecting Hesham and Scott's typed and non-verbal communication were key elements to friendship. Once Jessica and Fernanda learned to slow down, wait for answers, not anticipate but flow with the rhythm of the conversations, and understand the need for mutual decision-making, we began to establish connections that were conducive to friendship building.

Roles and Support for Communication

Scott and Hesham felt that at times it was difficult to effectively create friendships when typing with a third-party. Scott noted that:

"Those other guys my age who also have autism are also my friends. It's just different how we communicate. We always have to type with others around, so we can't always be as honest about what we share since we don't want to hurt anyone's feelings."

He also explained, "Secrets are tough when you are leaving out the facilitator." Similarly, Hesham described his feelings on this matter: "I like tying knots in friendships with people that type too… [But] when jokes don't belong to the facilitator it's hard to share." Scott and Hesham were both aware that the presence of the facilitator impacted their conversations they had with each other or other third parties. Having the facilitator always present, in every conversation certainly changed the dynamics of conversations and relationship development.

Fernanda and Jessica also struggled with how to respond or interact when they were facilitating conversations between Scott and Hesham, or with others. Jessica commented that sometimes it is:

"…Difficult to understand or know how my actions, my mood, or my general presence impacted Scott's conversations, particularly when he was talking with others. I try to support him without interjection, however Scott, being a very thoughtful and sensitive person, likely adjusted his comments with my presence in mind."

Similarly, Fernanda explained that:

"Feeling like the third or even the fourth wheel because you are supporting the communication of someone is complicated. As Hesham always comments 'sometimes the conversation is not of the facilitator's business.' This point makes me reflect on my role as a facilitator and on how much the facilitator should keep private about sensitive information. This changes the dynamic of relationships and friendships completely."

All four authors agreed that using FC provided the opportunity for the exchange of deep intimate ideas, thoughts, and details about our lives and feelings, which was a unique contribution of typing as a means of communication among friends. Jessica and Fernanda learned to consider how their presence impacted conversations, which was important so that Scott and Hesham were able to build authentic relationships with people who do not facilitate with them.

Interdependence and Reciprocity

As noted in the literature review, an important topic that the authors considered was related to mutual and interdependent support we gave and received from friends (i.e. Rosetti, 2011). Related to this, we live in a society that emphasizes independence and many individuals with disabilities spend a lot of energy in trying to be independent, rather spending

time and energy partaking in more satisfying activities (Wendell 2006). Furthermore, people with disabilities are often cast as only having dependent relationships with able-bodied individuals.

Thus, the four of us discussed how we all supported each other in different ways and were interdependent. Comprehending the myriad ways we all make use of support was a key to reframing what relationships meant. Scott explained the importance of having interdependent relationships and the problems he saw with the societal over-emphasis on independence:

"I think that is it tough sometimes to be pressured to be really independent. I think that everyone thinks I should do things alone; sometimes I need your help, but sometimes people do things for me that I don't need help with. I totally need help with reminders to do kind actions, like doing chores. I can't go to new places without someone meeting my needs to take it slow or [giving me] more time to not be scared of the new place. My friends are understanding… [and] my concentration needs support by friends who push me a lot, but not too much."

Scott elaborated that his friends care "to keep me safe. I sometimes have to rely on my friends to just be sure I don't walk into cars. I also need support to talk to others so I can make friends who will know I am smart." Jessica also explained:

"It took time to learn how to support Scott in a way that balanced his deserved independence with his safety and wellbeing. At the same time, it was important that as our relationship grew, Scott too began to understand and adapt to my needs. When I had needs such as running an errand for an assignment, or just venting the stress of academic work, Scott would understand and willingly support me."

Scott made it clear that he needed support from his friends in order to stay safe, to communicate, and to remember certain things like chores. At the same time, Scott was adamant that he could accomplish many things that too often others perceived him as incapable of.

Scott also felt that his contribution to his close friendships were important; "when it's real, I can support them too or give back by believing in them… or being there when they seem down. So being in a [friendship is a] two way street." Jessica also attested to Scott's contribution to their friendship; "often I would get lost in the car on the way to various outings. Scott was always patient and would sit back and enjoy the music on the radio in order to calm me as I frantically attempted to find the correct destination." Of these incidents, Scott explained he has "learned to be a good friend back. I have to wait good amounts of time to go places [with Jessica]. Not sure why, not sure how, but we always get lost. It usually is worth it though, we always have fun when we get there."

Hesham also expressed the importance of the interdependent nature of his friendships in relation to how he felt others interpreted his behavior. He explained that he sometimes felt:

"Trapped in behaviors that make me hide even more. Having nothing to do makes me trapped on choices that are not… leading to notably good life. Maybe knowing that I'm going to meet people that make me feel good about myself is more motivating."

Hesham explained that he was motivated to control his behaviors, such as jumping around or using loud vocalizations, that were linked to his disability when he was around people that made him feel good about who he was. Hesham went on to explain how he:

"Thinks inside this unreasonable body. None of the joy I experience inside translates to people around me… [that's why sometimes] it's hard to say joker like you [Fernanda] who doesn't get scared of me. [It's] too lonely when people are scared of my 'killing' [uncontrolled] behaviors."

Hesham revealed the support and understanding he needed from friends who were able to value his outward behaviors. Fernanda responded to this claim saying:

"I learned to understand Hesham's moods without reading his facial expressions, but listening to his breath, or observing his hand movements. Hesham also learned to read my anxiety and so many times he not just called me on it, but reassured that I was going to do well, particularly during stressful times of the Ph.D. or life away from my family."

Hesham also explained that "real friends take important solid steps, going the ride to places I've not been. [I] always think nuanced sadness [is] really carved [in the] reality of depending so much on others." Hesham also noted that he is "very dependent in many ways… [and] I will intuitively always be, but people are dependent in tying nods, hiding uncomfortable ways they are dependent as well." Here, Hesham illuminated how we are all interdependent, but some of us can hide it. Fernanda expanded upon the ideas of interdependence; "Hesham and all other friends helped me learn how to live in a different culture. I needed support on how to install cable TV, how to seal a letter, or to edit school papers. All individuals are interdependent. We need to be sensitive and open to learn from each other's strengths. I hope I supported and taught my friends in different ways as much as they supported me."

All individuals have different levels of needs and supports in daily life. Throughout our friendships, we were all able to recognize ways we were supporting each other while being supported. Friendships are about exchange, thus all four authors became aware of each other's needs and strengths; redefining normative conceptualizations of friendship including supporting each other's physical needs, being more sensitive to subtle signs, and providing authentic honesty. Interdependence encapsulates the complexity of the directions of support that are available within relationships amongst friends.

Permanency in Relationships

We all described conflicted feelings about building relationships with people who come in and out of our lives. Fernanda and Jessica have both recently relocated geographically, and Jessica noted, "it is difficult to rebuild new friends and relationships when life's paths require a change." However, the circumstances for Scott and Hesham are unique, as they have had friends and companions transition in and out of their lives since they began to receive services as young children. For instance, Scott explained that:

> "A friend means someone who… each week… has a good way of interacting, so that I am fully sure that they forget about the money or school credit for being around me. Only it gets hard sometimes to know what the really down reason is that someone is truly my friend."

On another occasion, Scott similarly explained that it was important for him to have friends who believed that the relationship meant, "More to them than a biweekly paycheck. Having friends go like the wind is hard, but some stick around and I just know it's for more than for sad biweekly salary. I am more important than for money." Jessica often struggled with the fact that for much of the time she spent with Scott, she was in fact monetarily compensated. She explained that she often felt guilt, particularly as her friendship with Scott developed. "Scott would sign my timesheets, each week, he knew that I was paid. I tried to convince myself that the paid time I spent with him was in fact quality time. However, I struggled with the idea that I would not get similarly compensated to spend time with other friends."

Also, when discussing how the service system impacted his perception of relationships Hesham postulated that for "people that get hired to hangout, [it] is really tricky, due to knowing respect through payment yields liking me after." When Hesham knew his friends were paid it was a, "tough fact to face. [I] don't want to face the truth, [it is] easy to fake hope. Other fans [friends] easily fade, [they] quit on me." Fernanda was never paid to support Hesham, which was a purposeful decision:

> "I wanted the freedom of a relationship, and not the structure of a job. As in a friendship I talked about myself, and sometimes even prioritized my needs, despite the fact we always kept his communication support in the center. I was a student, and some extra money would have helped a lot, but I decided it would be best to keep an informal friendship centered on his communication needs."

Both Hesham and Scott discussed the difficulty of people coming and going out of their lives and the confusion it caused when identifying the true reasons people became their friends. Simultaneously, they both felt they were able to decipher when those around them were truly friends and truly respected them as people. Interestingly, when discussing permanency of relationships, both Scott and Hesham described their mothers as unwaveringly permanent and important people in their lives. They explained this importance, while

simultaneously expressing desire to expand and create other friendships and relationships. The relationship developed between the four authors suppressed part of this need.

Discussion

We have offered insight into the development of friendships for young individuals transitioning into the world of working, graduate school, volunteering, and socializing with friends and family. This period was a complex time for all authors and friends were essential during this period of life. We feel that our experiences and conversations result in several important implications related to accessing communication, considering interdependence, and redefining permanency and services. While highlighting the implications, we also note that they may not be broadly generalizable as they are based on the sole experiences of the four authors of this paper.

The possibility of typing to communicate and accessing FC was described as extremely important to both Scott and Hesham. Typing was their way to communicate their innermost thoughts and feelings, it was an important tool for them when creating and maintaining friendships (Biklen, 2005; Mukhopadhyay, 2008; Rubin, et. al. 2001; Savarese, 2007). FC allowed others to understand and appreciate that they had much to contribute to conversations. As Jacobs (2002) stated, by communicating, we are able to make choices and as a consequence be engaged in life tasks, build self-esteem and inner confidence and benefit from the ontological security emanating from friendships. Because Scott and Hesham were able to use typed communication to make choices and advocate for themselves, as well as share their thoughts on life, politics and desires, they were able to further their development towards relationships with friends and family.

Also, Scott and Hesham described at length the need to feel that they were part of interdependent relationships. Scott and Hesham noted their unique support needs and they understood that they must rely on friends and family to fulfill those needs. However, it was also important for them to describe what they give to their relationships. This important concept of interdependence helps us understand the experience of friendships and autism beyond a deficit perspective. We redefined what was normal amongst friends, and went beyond traditional roles of support and friends. Our narratives challenge predominant deficit-based understandings of how people with disabilities form relationships (Thomas, 2007), particularly for people with autism (Frith & Happe, 1994; Baron-Cohen, Leslie & Frith, 1985).

Both Scott and Hesham, as all four authors have done during different points of their lives, questioned the motives of why people are in their lives. Unique to the experiences of Scott and Hesham, the lines between paid support and friends were sometimes fuzzy, leaving it difficult to decipher whether the person was there for a job, or because they were truly friends. The most mutual relationships were developed when Scott and Hesham had natural opportunities to interact with others or when services and supports were individualized and

allowed for flexible one-on-one time, and where power differentials were mitigated. DS literature documents that natural supports are more likely in a society where inclusive education and inclusive/community living arrangements are prioritized. We recommend more emphasis on such arrangements, where all people are empowered to live within the community (i.e. Condeluci, 2014) without having to worry about hiring and scheduling support for all moments of the day. Both Scott and Hesham relied on paid support during nearly all of the time that they were not otherwise supported by family members.

Also, both Scott and Hesham discussed the difficulty they experienced when individuals with whom they have built relationships leave their work positions. This is not an uncommon experience, as disability services have extremely high turnover rates; approximately 50% per year leave due to low wages and poor working conditions (U.S. Department of Health and Human Services, 2006). Thus, we recommend that emphasis be placed on valuing professionals who support people with disabilities and working towards lower turnover rates and that training focus on understanding interdependence as a framework for support.

At the same time, it is important that more inclusive social experiences be available where support is natural, so that people with autism can meet others and socialize without being dependent upon programming from the social service industry. Grade schools and institutions of higher education should emphasize inclusive opportunities for individuals with and without disabilities. More opportunities for inclusive volunteering and employment as people with disabilities transition into adult life are also recommended so that pathways can be created to build relationships in natural settings.

Conclusion

The four authors have traveled on an important and at times emotionally difficult journey together. We have all grown in our own understanding of what friendships and support mean for our lives. We feel that the words of the authors paint a complex picture of what it is like to develop a friendship for individuals who use FC, and for those who support them. This work is important as it shows the commitment Scott and Hesham have to making and maintaining friendships. Through adopting a DS perspective, we were able to refute ideas promulgated in psychological literature that people with autism are unable to develop meaningful relationships or understand the perspective of others (American Psychological Association, 2004), or that independence should be a primary life goal (Wendell, 2006).

Instead, the exchanges exemplified in this paper reframe the standard conceptualizations of friendship for individuals who type to communicate. Support to friends' physical needs, more sensitivity to subtle signs, honesty, and the impact of the third person (facilitator) in the relationship were all characteristics that configured our friendship. Moments amongst friends ranged from structured activities, to hanging out in silence, to extensive typed conversations. Present in any friendship, but regularly forgotten in

relationships with individuals with disabilities who use alternative means to communicate are respect and validation of means of communication, as well as choice provision and support for individuals' needs, while holding equal footing in decision making. Thus, Hesham and Scott expressed their desire to be heard, to be taken seriously and contribute to relationships.

Scott and Hesham advocated for themselves and for the expansion of our understandings of what friendships are to improve the social participation of all individuals in society. Through courage and mutual support we took risks, confronted consequences, and took responsibility to redefine "normal" in friendships. In closing both Scott and Hesham offered final sentiments to the readers. Scott explains to other autistic readers that it is important to "love yourself enough to take on the challenge [of learning FC], just stick with the autistic pride in us all." And Hesham left with explaining that he was "glad to be with respectful folks… I'm more happy than when I came in… I'm very glad to be a friend to you."

Jessica Bacon, Ph.D. is an Assistant Professor in the Early Childhood, Elementary and Literacy Education Department at Montclair State University. Her research interests include disability studies, self and parent advocacy, inclusive education, and standards-based reform in special education. Dr. Bacon has integrated her research and service commitments by working closely with community members who are parent-advocates, self-advocates, teachers, and students with disabilities.

Fernanda Orsati, Ph.D. is an Associate Clinical Researcher at the Hussman Institute for Autism in Maryland. She works in developing research and supports around behavior and communication for individuals with autism. She is interested in effective practices for the inclusion of students with disabilities in general education, the construction of behavior and intersections with race, culture and socioeconomics, access to communication for all, advocacy and parent advocacy, and dynamic assessment.

Scott Floyd is the owner of a small business called Scott's Sensory Shop. Scott is a graduate of Syracuse City School District's OnCampus program at Syracuse University. He volunteers around his community including at a local food pantry. Scott is a frequent contributor to the MyTimes Newsletter, sponsored by Advocates Incorporated and is a member of a local self-advocacy group.

Hesham Khater is a self-advocate with autism that types to communicate. After graduating Nottingham High School in Syracuse, NY he enrolled in the On Campus Program at Syracuse University where he took university classes including a Law and Disability course. He is now involved with the Institute on Communication and Inclusion at Syracuse University and volunteers in his community.

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Research Article

Self-Determination in Social Context: A Social Cognitive Approach

Jason Matthew Naranjo, PhD
University of Washington Bothell
Luke Duesbery, PhD
San Diego State University

Abstract: There is growing support for situating understandings of self-determination for students with disabilities in social and cultural contexts. However, exploration and expansion of theory is needed to illuminate the complexities of self-determination in the process of academic and career development, particularly for students from culturally diverse backgrounds. In an attempt to create this understanding we propose the use of social cognitive career theory because this theory of career and academic development accounts for both personal background and identity variables (e.g., disability, gender, and culture) and intrapersonal cognitive variables (e.g., coping-efficacy, self-efficacy) (Lent, Brown, & Hackett, 1994). Whereas self-determination theory in special education is primarily concerned with cognitive variables.

Keywords: Culture, Self-Determination, Transition

Students with high-incidence disabilities (HID) represent the largest group of individuals with disabilities in K-12 U.S. public schools. Recent data suggest that this group makes up between 70% and 89% of all students in special education (U.S. Department of Education, 2015). Historically the research literature in special education has defined HID as being comprised of students who have been identified with learning disabilities (LD), emotional and/or behavioral disorders (E/BD), and mild intellectual disabilities (MID) (Hallahan & Kauffman, 1977; Saborine, Cullinan, Osborne, & Brock, 2005; Sabornie, Evans, & Cullinan, 2006). The growth in recent years of the number of students identified with high-functioning autism, attention deficit hyperactivity disorder, (often covered under the other health impairment category), and speech and language impairments has led some researchers to expand the HID grouping to include these impairments (Gage, Lierheimer, & Goran, 2012). Beginning in the late 1970's researchers asserted that differences within HID were not meaningful grounds for instruction based on disability category and educational placement (Hallahan & Kauffman, 1977). There is controversy concerning the educational support of this population as a homogenous group of learners (Fuchs, Fuchs, & Stecker, 2010). However, evidence suggests that although differences in cognitive, academic, and behavioral performance exist within HID, academic and social development can be supported by a noncategorical approach to special education (Gage et al, 2012). This approach emphasizes academic and social inclusion and specially designed instruction in least restrictive environments based on individual student need rather than on administrative disability labels (Gage et al, 2012). This means that although students are still identified under

one of the 13 IDEA categories, depending on state policy and school culture they may receive services in a non-categorical or cross-categorical manner

Issues of overrepresentation and misidentification are unfortunately part and parcel of HID, particularly for students with LD, MID, and E/BD (Donovan & Cross, 2002). This raises serious concerns regarding long-standing systemic bias in general and special education. Research demonstrates that children and youth from lower socioeconomic backgrounds, those of color, males, and English language learners are overrepresented in the HID group (Sullivan & Bal, 2013; Sullivan, 2011). Said differently, some children and youth because of their gender, socioeconomic status and or cultural and linguistic background are labeled with HID not because of impairments that they are born with but rather because of cultural bias within the educational system (Artiles, Kozleski, Trent, Osher, & Ortiz, 2010). Impairments associated with HID are part of the lived experience of some learners from culturally and linguistically diverse backgrounds; however far greater numbers of these students are identified with HID than is otherwise reasonable to expect in the population because of the subjective/ judgmental nature of student's learning difficulties (Kilinger et al., 2005). Placed in the context of school-to-community transition issues of overrepresentation and student self-determination become significant due to the strong potential for marginalization and diminished long-term adult outcomes.

Situating theoretical and practical understandings of self-determination for students with HID from CLD backgrounds in social context is necessary for bringing to light the multifaceted process of academic and career development during the transition from school-to-community. This study engages a social cognitive approach and explores and expands theoretical understandings of self-determination in social context. In this study we conceptualize self-determination in alignment with the work of Saleeby (2014) and define self-determination as the promotion of? rights, empowerment and social justice for individuals with disabilities in social context. The social cognitive approach theorizes that the combination of the social environment (e.g., discrimination in the labor market) and individual cognitive variables (e.g. perception of barriers to employment and coping efficacy) influence career and academic development.

Literature Review

Special Education Placements and Prevalence

60% of students with disabilities in the U.S. spend 80% or more of the school day in the general education classrooms. Receiving the majority of their education in the general education curriculum (U.S. Department of Education, National Center for Education Statistics, 2016). Students with HID spend the greatest proportion of their school day inside general classes when compared to peers with other types of disability (U.S. Department of Education, National Center for Education Statistics, 2016). Examining national trends in special education placement from 1990-2007, McLeskey, Landers, Williamson, and Hoppey

(2012) found significantly greater numbers of students with HID being included in general education settings while at the same time their placements in more restrictive placements (e.g. pullout, separate class or separate school) diminished. The work of McLeskey et al. (2012) shows that when compared to elementary students, secondary students experience greater changes in placements toward more inclusive learning environments. However, even though progress toward more inclusive learning environments has been made in general, secondary students still experience more restrictive placements than their elementary counterparts (McLeskey et al., 2012).

Although largely included in general education classes, it is also apparent that students with HID encounter both academic and social-emotional barriers to school success. For example, students with HID encounter learning difficulties that lead to diminished longitudinal growth in core academic areas (e.g. reading and mathematics) (Wei, Lenz, & Blackorby, 2012; Wei, Blackorby, & Schiller, 2011). In addition, some students with HID experience emotional and behavioral difficulties that result in negative peer and student teacher relationships (Murray & Pianta, 2007; Murray & Greenburg, 2006). The barriers to academic learning and social-emotional adjustment encountered by these students should not be attributed primarily to deficit understandings of student ability. Rather, these challenges should be placed in social and political context and the complex interactions between the person, environmental affordances, and behavior should be accounted for so that broader understandings of disability and educational outcomes are possible (Baglieri, Valle, Connor, & Gallagher, 2010). These considerations should carefully include treatment of social class, language, and student culture.

Post-School Employment and Higher Education Outcomes

Labor market participation and success means more than just getting a job. Students with disabilities, and particularly those from CLD backgrounds in the transition from school-to-community are marginally positioned in academic, economic, and social opportunity structures (Trainor, Lindstrom, Simon-Burroughs, Martin, & Sorrells, 2008). This marginalization of students with disabilities occurs at the intersection of power, social class, race, and gender (Liasidou, 2013), and results in material deprivation, socio-political exclusion, and disempowerment (Gleeson, 2004; Liasidou, 2013). The post-school attainments of students with disabilities reflect barriers to full inclusion in academic, economic, and social opportunity structures for people with disabilities (Lindstrom, Kahn, & Lindsey, 2013).

To provide maximal access to long-term economic and social wellbeing for students with disabilities employment must provide living wages and a career development pathway (Lindstrom et al., 2013). The employment outcomes experienced by youth with HID suggest that although they are getting a start, the type of start that they are getting may compromise long-term economic stability and career advancement (Morningstar, Trainor, & Murray, 2015; Rowjewski, Lee & Gregg, 2014). The most frequently held jobs after exit from school for

youth with HID are those in the service industry in low-level positions (Morningstar et al., 2015). In these positions only half (50.2%) receive paid leave, few have employer provided health insurance (44%), and only one-third (33.8%) receive retirement benefits (Morningstar et al., 2015). Examining the employment outcomes of youth with and without HID two years following school completion, Rojewski et al. (2014) found that students with disabilities were less likely to be employed and less likely to be working full-time when compared to their non-disabled peers. The lack of opportunity for well paid employment with the potential for advancement adversely impacts students with disabilities from CLD backgrounds (Fabian, 2007). Barriers in the opportunity structure of the labor market such as discrimination and lack of experience create impediments to early career development for students with disabilities (Lindstrom et al., 2013). Further these issues are exacerbated by limited aspirations and barriers to higher education and training (Lindstrom et al., 2013).

Higher education confers a host of economic and social benefits that increase access to opportunity structures within society (Oreopoulos & Petronijevic, 2013). Continued academic development via higher education is a post-school pathway that is taken by few students with disabilities (Lindstrom et al, 2013). Studying a nationally representative sample, Morningstar et al. (2015) reported that in the first two-to-five years following high school less than half (47.5%) of youth with HID had ever attended higher education. Those who had attended postsecondary education chose to do so at 2-year or community colleges (37.6%) and professional/technical schools (29.3%). Fewer than 15% of youth with HID attend 4-year college or university (Morningstar et al., 2015).

Transition Planning

Meaningful transition plans create the foundation for transition education and in part establish the trajectory for post-school outcomes for youth with disabilities (Halpern, 1994; Trainor, Morningstar, & Murray, 2015). Federal Indicator 13 (I-13) establishes minimum transition planning requirements under IDEA (National Technical Assistance Center on Transition [NTACT], 2016). According to I-13 transition plans must identify appropriate post-school goals that are updated annually in the areas of education, employment, and when necessary independent living. Evidence that post-school goals are based on an age appropriate transition assessment and that transition services in the IEP will reasonably enable a student to meet their goals is also required. In alignment with assessment and transition services, I-13 also requires that a course of study be identified so that students may be better able to meet their post-school goals. Next, the transition plan must include IEP goals that are aligned with transition service needs. Evidence must be provided that students have been invited to engage in the transition planning process, and when appropriate community based agencies (e.g., vocational rehabilitation) are also to be invited to participate (NTACT, 2016). The extent to which transition plans are constructed to meet these requirements varies widely with some schools and districts creating plans that adhere to federal policy guidelines and others are working toward improved implementation (Landmark & Zhang, 2012).

Self-Determination

Transition plans can meet federal compliance mandates and still fall short of supporting students in the transition process particularly if plans are created for students instead of by them and with them and their families (Cobb & Alwell, 2009; deFur, 2003). The transition research literature suggests that self-determination beliefs and actions play an important role in shaping both transition planning experiences and post-school outcomes for students with disabilities (Test et al., 2009; Trainor, 2005. Self-determination has been defined as:

> "… A combination of skills, knowledge, and beliefs that enable a person to engage in goal directed, self-regulated, autonomous behavior. An understanding of one's strengths and limitations together with a belief in oneself as capable and effective are essential to self-determination. When acting on the basis of these skills and attitudes, individuals have greater ability to take control of their lives and assume the role of successful adults" (Filed, Martin, Miller, Ward, & Wehmeyer, p. 2, 1998).

As part of the transition planning process and in alignment with federal planning requirements, student self-determination knowledge and skills are often assessed. The rationale for the assessment of student self-determination is that, if teachers and transition service providers can accurately identify a student's strengths and areas of need in the area of self-determination through the use of an age appropriate transition assessment then they will be able to work with the student to formulate a transition plan that provides robust supports and services that are aligned with a student's post-school goals. These assessments typically do not address the role that a student's identity plays in the formation and enactment of self-determination nor do these measures assess how individuals view the social context in relation to the self in the process of academic and career development.

Although emerging evidence points to the importance of self-determination for students with HID (Test et al., 2009), this construct has also been critiqued for misaligning with the self-determination beliefs and actions of students from CLD backgrounds (Leake & Boone, 2007; Leake & Skouge, 2012; Saleeby, 2014). Critiques of self-determination recognize the importance of empowerment, rights, and agency for people with disabilities yet point out that the construct may not adequately encompass and agency expectations and actions of individuals from CLD backgrounds (Saleeby, 2014). According to Leake and Skouge (2012) the values of autonomy and independence that the concept of self-determination is grounded in are largely the values of American majority culture. This view of autonomy and individuality may misalign with conceptualizations of the self in interdependent relationships that are valued by some individuals from CLD backgrounds (Leake & Skouge, 2012). The dominant conceptualization of self-determination set forth by Field et al. (1998) in its current application is limited by not fully accounting for affordances made by social environments (Leake, 2012).

The challenge for both research and practice in the area of school-to-community transition is to build on the evidence that suggests that self-determination is an important factor in processes of academic and career development and expand conceptual understandings of the self in relation to others and the social environment so that research and educational practice is culturally responsive and socially contextualized.

In an attempt to create this understanding we propose the use of Social Cognitive Career Theory because this theory of career and academic development accounts for both personal background and identity variables (e.g., disability, gender, and culture) and intrapersonal cognitive variables (e.g., coping-efficacy, self-efficacy) (Lent, Brown, & Hackett, 1994). Whereas self-determination theory in special education is primarily concerned with cognitive variables.

Social Cognitive Career Theory

The use of social cognitive career theory holds promise as a novel cross-disciplinary tool for research and practice for understanding academic and career development processes during transition from school to community for students with disabilities from CLD backgrounds. Social cognitive career theory (Lent et al., 1994) finds its roots in the field of vocational psychology and conceptualizes the process of career and academic development as the formation and enactment of self-efficacy beliefs and outcome expectations in reciprocal relation to personal background (e.g, ethnicity, disability, gender, socioeconomic status), behavior, and environmental affordances. Said differently, as agents, people both are shaped by and shape social environments and therein make career choices and act accordingly. In this way social cognitive career theory frames the process of career and academic development in a social constructivist manner (Lent et al., 1994). In doing so, the theory prioritizes the role that the interaction between the person and their environment play in shaping academic and career development processes and outcomes (Lent et al., 1994).

Research suggests that both perceived and objective barriers in the social environment inhibit academic and career development (Lent, Brown, & Hackett, 1999). Perceived barriers can include perceptions of opportunity in the job market and objective barrier can be created by factors such as lack of quality educational opportunities and lack of material support for continued education and training. Cognitive personal variables (e.g., coping-efficacy) moderate the extent to which barriers influence career related goals and choices (Lent, et al., 1999). For example, if a young adult with a disability who is also a person from a CLD background perceives that a potential employer will discriminate against them based on their identity(s), she may not apply for a given position. Therefore, the individual perceives that the barrier to employment is too great and does not believe that she can successfully overcome it. As a result she may choose a less advantageous option.

Evidence from the study of the relationship between perceived barriers and coping efficacy in the context of career and academic development among marginalized populations

suggests that individuals who perceive greater barriers to their career and academic development have corresponding lower levels of coping efficacy (Luzzo & McWhirter, 2001; McWhirter, 1997). However there has been limited application of social cognitive career theory study of how students with disabilities from CLD backgrounds perceive and cope with academic and career related barriers (Dutta et al., 2015).

The purpose of this study is to apply social cognitive career theory in the development of a measure of perceived barriers to academic and career development and associated levels of coping efficacy for transition age students with HID from CLD backgrounds. In so doing our aim is to expand theoretical conceptualizations of self-determination through the use of social cognitive career theory to better understand the academic and career related perceptions of students with HID from CLD backgrounds. Our research question is, "Is there an underlying theoretical structure that relates ethnicity, disability, perceived barriers, and coping efficacy in the process of academic and career development for students with HID from CLD backgrounds?"

Method

Sample

Seventy students participated in this study (male n = 59, female n = 11). The mean age of participants was 19.2 years (SD = 1.0). The vast majority (96%) of student in the study were from CLD backgrounds. When asked to indicate their own ethnicity, 44% chose Hispanic or Latino, 31% Black or African American, 4% white, 4% Asian, and 17% indicated multi-racial. All (100%) of the students were identified as having HID; 74% with Specific Learning Disabilities, 10% with Emotional or Behavioral Disabilities, 7% with Other Health Impairments, and 4% with an Autism Spectrum Disorder. Data was missing for 4% of students.

The sample was chosen purposefully from students with CLD backgrounds with HID who were enrolled in a school-to-community transition program for individuals ages 18 to 22 in a large urban school district in southern California. This study was reviewed and approved by the Institutional Review Board at San Diego State University. All participants signed informed consent documents prior to participation in the study. Students were asked to complete the study measure in a single sitting during individual meetings with their special education teacher. Accommodations were made for those individuals who struggled with reading. Specifically, teachers read the items on the measure aloud to students, when necessary.

Measurement

This measure was developed in alignment with the social constructivist theoretical position of social cognitive career theory and was based on the work of Luzzo and McWhirter (2001). Luzzo and McWhirter (2001) sought to identify how individuals from marginalized

backgrounds perceived and coped with barriers to academic and career development. Given our interest in applying the measure with students from CLD background with HID, we elected to change several items on the original measure to make items more theoretically relevant. Specifically, we altered items within the barriers and coping scales to focus on disability rather than gender. Given that the measure was administered to sample of students predominantly from CLD backgrounds, we elected to retain items in the scales that addressed perceptions related to ethnic discrimination. The measure can be broadly divided into two groups of items, those pertaining to barriers to career and academic development, and those pertaining to coping efficacy (see Table 1 for a full listing of items) In addition, consistent with the work of Morningstar et al. (2015) we added an item to the scales that dealt with access to healthcare/insurance benefits.

Data Analysis

Our purpose was to develop and refine an instrument to measure perceived barriers and levels of coping efficacy in the process of school-to-community transition for students from CLD background with HID. Thus, in this study we chose to conduct an exploratory factor analysis (EFA) to reveal the underlying theoretical structure of variables measure by the instrument. In addition to the EFA, reliabilities were calculated with the field standard Cronbach's Alpha for each dimension of the refined instrument and overall (Cronbach, 1951).

Results

We first present descriptive statistics from the sample, then results from the exploratory factor analysis, and follow with the reporting of internal consistency reliability coefficients.

Descriptive Statistics

In general, participants indicated a high level of agreement to items on the ten-item Barriers to Academic and Career Development scale (M = 3.6, SD = 1.4). Items were presented on a 5-point Likert scale from strongly agree (1) to strongly disagree (5). Higher scores on this scale indicate higher perceived barriers. Of particular note, on average students indicated they perceived, "people's attitudes about my disability are currently a barrier to my educational goals" (M = 4.0, SD = 1.2). In contrast, participants indicated a relatively moderate level of confidence on the 16-item Coping Efficacy Scale (M = 2.5, SD = 1.5). Items were presented on a 5-point Likert scale from highly confident (1) to not at all confident (5). Higher scores on this scale indicate a that participants perceived that they would experience more difficulty but would be able to cope with difficulty overcoming perceived barriers. On average, students indicated the most confidence in overcoming finding, "work that provides adequate health care benefits" (M = 2.2, SD =1.2), and in "overcoming discrimination due to ethnicity" (M = 2.2, SD = 1.5). On average, students indicate the least amount of confidence in their ability to overcome barriers associated with, "lack of support

from friends" (M = 2.6, SD = 1.5). In this sample, students perceived significant barriers, but were moderately confident they could overcome them. Item mean and standard deviations for the sample are presented in Table 1.

Table 1 *Item Means and Standard Deviations for Perceived Barriers & Coping Scales*

	M	*SD*
Barriers to Career and Academic Development (10 items)[a]		
I*n my future career I will probably…*		
…be treated differently because of my ethnicity.	3.7	1.5
…have a harder time getting hired than people of a different ethnicity.	3.5	1.4
…lack support from friends to pursue educational goals.	3.8	1.2
…my disability is currently a barrier to my educational goals.	3.6	1.4
People's attitudes about my disability are currently a barrier to my educational goals.	4.0	1.2
Lack of support from my *significant other* to pursue education is a barrier to my goals.	3.9	1.2
My desire to have children is currently a barrier to my educational goals.	3.6	1.4
Relationship concerns are currently a barrier to my educational goals.	3.8	1.3
Having to work while I go to school is currently a barrier to my educational goals.	3.1	1.6
Lack of role models or mentors is currently a barrier to my educational goals.	3.5	1.5
Coping Efficacy (16 items)[b]		
I can overcome…		
…discrimination due to my ethnicity.	2.2	1.5
…discrimination due to my disability.	2.4	1.5
…negative comments about my ethnicity (insults, jokes).	2.4	1.5
…negative comments about my disability (insults, jokes).	2.4	1.5
…difficulty finding work that provides adequate health care benefits.	2.2	1.2
…family problems…	2.4	1.4
…not being smart enough...	2.3	1.4
…negative family attitudes about college...	2.3	1.4
…not being prepared enough...	2.5	1.5
…not knowing how to study well...	2.4	1.4
…not having enough confidence...	2.4	1.4
…lack of support from friends...	2.6	1.5
…people's attitudes about my disability...	2.4	1.5
…my desire to have children...	2.5	1.5
…relationship concerns...	2.5	1.4
…lack of role models or mentors...	2.4	1.4

Note a: Five-point Likert scale from strongly agree (1) to strongly disagree (5)

Note b: Five-point Likert scale from highly confident (1) to not at all confident (5)

Factor Structure

Principal axis factoring (PAF) using direct oblimin rotation was conducted to explore the dimensionality of the instrument. Individual items with extraction values less than 0.20 were removed from the analysis (Byrne, 2001). A conservative approach was used to generate the factor solution, including only factors with eigenvalues greater than two (Byrne, 2001). The variance accounted for by the solution, the variance accounted for by each individual factor, and the interpretability of the factors were all evaluated to determine the initial plausibility of the factor structure. To further confirm the factor structure a parallel analysis was used (Ladesma & Valero-Mora, 2007).

The PFA of the instrument suggested that a two-factor solution best explained the data. The variance explained by the solution was 50.1%, and the two factors individually accounted for 31.9%, 18.2%, respectively. In addition, parallel analysis indicated that a two-factor solution best represented the data when eigenvalues from the target data set were compared to eigenvalues from randomly generated data: (a) Factor 1: 8.30 vs. 2.58; and (b) Factor 2: 4.72 vs. 2.31. Using the pattern matrix for interpretation, ten observed variables loaded on the first Factor (values ranged from .53 to .82); sixteen observed variables loaded on the second Factor (values ranged from .55 to .84). The correlation between the two factors was -.12. Factor loading for each item are provided in Table 2.

Table 2 *Item Weights – Principal Axis Factoring*[a]

	Coping	Barriers
Barriers to Academic and Career Development		
I*n my future career I will probably…*		
…be treated differently because of my ethnicity.	-.001	.496
…have a harder time getting hired than people of a different ethnicity.	.000	.524
…lack support from friends to pursue educational goals.	-.067	.663
…my disability is currently a barrier to my educational goals.	-.067	.328
Barriers to Academic and Career Development (continued)		
People's attitudes about my disability are currently a barrier to my educational goals.	-.090	.637
Lack of support from my *significant other* to pursue education is a barrier to my goals.	-.011	.702
My desire to have children is currently a barrier to my educational goals.	.156	.811
Relationship concerns are currently a barrier to my educational goals.	.175	.817
Having to work while I go to school is currently a barrier to my educational goals.	.036	.602
Lack of role models or mentors is currently a barrier to my educational goals.	-.038	.663

Coping Efficacy		
I can overcome…		
…discrimination due to my ethnicity.	.836	.073
…discrimination due to my disability.	.648	-.157
…negative comments about my ethnicity (insults, jokes).	.576	-.301
…negative comments about my disability (insults, jokes).	.647	-.165
…difficulty finding work that provides adequate health care benefits.	.554	.068
…family problems...	.581	.057
…not being smart enough...	.724	.086
…negative family attitudes about college...	.726	-.094
…not being prepared enough...	.751	.064
…not knowing how to study well...	.627	.135
…not having enough confidence...	.661	-.129
…lack of support from friends...	.731	-.030
…people's attitudes about my disability...	.759	-.094
…my desire to have children...	.669	.107
…relationship concerns...	.691	-.056
…lack of role models or mentors...	.765	.141

Note a. Rotation Method: Oblimin with Kaiser Normalization.

Internal Consistency Reliability

For the 10-item Barriers subscale, internal reliability was high ($\alpha = 0.87$). For the 16-item Coping Efficacy subscale reliability was very high ($\alpha = 0.93$). Overall reliability for the 26-item instrument was high ($\alpha = 0.87$). Coefficients indicated a high degree of internal consistency, indicating that the measure is accurately gauging the identified theoretical constructs.

Discussion

The purpose of this study was to explore how students with HID from CLD backgrounds perceived barriers and coping in the process of academic and career development. We grounded our work in social cognitive career theory to better understand how personal background variables (e.g. disability status, ethnicity) and personal cognitive variables (coping efficacy) influence perceptions of academic and career development in social context. We sought to expand the conceptualization of self-determination to focus attention on the social construction of efficacy beliefs. In so doing, our goal is to move the disability-transition research toward a view that situates the development of efficacy beliefs (self-determination) and the enactment of those beliefs in social context. In the sections that follow we discuss the of our findings, the importance of our results, limitations, and implications for research and practice.

The research question addressed by this study was: Is there an underlying theoretical structure that relates ethnicity, disability, perceived barriers, and coping- efficacy in the process of academic and career development for students with HID from CLD backgrounds? Our findings suggest that salient markers of identity (e.g., ethnicity and disability) theoretically relate to the perception of barriers and the social construction of coping-efficacy beliefs and that social cognitive career theory is a useful theoretical framework for understanding the process of career and academic development for students with HID from CLD backgrounds.

Leake (2012) notes that self-determination beliefs and actions are situated in and informed by social context. We found that students with HID from CLD backgrounds perceived that the opportunity structure of the social environment presented barriers related to discrimination based on their ethnicity and disability status. More specifically, on average, participants perceived that people's attitudes about their disability were a significant barrier to their educational goals. Participants also noted that they believed that they would be treated differently because of their ethnicity and they would have a harder time getting hired than people of a different ethnicity. They viewed these as serious barriers to achieving their academic and career goals. Although participants were moderately sure that they could cope with these barriers, these finding are important because they demonstrate the theoretical connection between identity, coping-efficacy, and the social environment for students with HID from CLD backgrounds. Further, these results support and extend the work of Lindsay (2011) and Lindstrom et al. (2013) that suggest that barriers such as discrimination in the labor market impede the career development of transition age youth with disabilities.

Supportive social relationships have been found to be predictive of improved post-school educational and employment outcomes for students with disabilities (Test et al., 2009). Using cross-cultural research as an analytic lens, Leake (2012) persuasively argued that self-determination occurs in social context and that interdependent social relationships produce social capital that is required for self-determination. Our findings show that concerns about relational supports and perceived barriers to the attainment of educational goals occur in social context. In addition, the perceptions of relational barriers were conceptually connected to coping efficacy. In other words, if significant barriers were perceived due to the lack of relational support then individuals had corresponding lower levels of coping efficacy. This finding supports the notion that interdependent social relationships yield the social capital needed for self-determination and that in the absence of social capital self-determination may be diminished. Consistent with the ideas of interdependent social relationships and social capital, we also found that participants perceived that the lack of role models/mentors posed barriers to the attainment of educational goals and that coping with this barrier was thought to be moderately difficult.

Limitations

Our results demonstrate that social cognitive career theory is a useful theoretical

framework for understanding how students with HID from CLD backgrounds view themselves in relation to the social environment in the process of academic and career development. Although our findings provide evidence for the social construction of perceived barriers and coping-efficacy beliefs in the context of school-to-community transition, consideration should be given to the limitations of our work. First, we recognize that our sample was chosen purposefully and was relatively small in size. There is much debate in the methodological literature concerning adequacy of sample size when using EFA (Beavers et al., 2013). The primary issue raised is that small sample sizes invite sampling error that can undermine the stability of the factor solutions and compromise the validity of results (Beavers et al., 2013). However, given that the purpose of this work was to explore the theoretical structure among markers of identity and coping-efficacy we believe that the sample selected illuminates the complex theoretical structure that was observed. We encourage inquiry in subsequent studies that utilize the measure that we have developed to drawn on larger samples whenever practically possible.

The use of EFA as an analytic tool presents limitations. The goal of EFA is to explore an underlying factor structure and the relationship between theoretically related variables. This approach requires researchers to make subjective methodological decisions concerning the grouping of items (in this case items on a measure) into statistically and theoretically meaningful categories. To address this issue we took a conservative approach to generating a factor solution that included only factors with eigenvalues greater than two (Byrne, 2001). Although our approach was inline with best practices, there is the possibility that decisions that were made using EFA were unintentionally influenced by our biases. However the two-factor solution that was generated mapped onto the barriers and coping efficacy constructs specified in the social cognitive career theory literature with high levels of statistical reliability. This leads us to believe that the methods selected were appropriate given the theoretical context. The next section discusses the results and implications and is organized around our research question.

Directions for Future Research

Although our findings suggest that social cognitive career theory is a sound theoretical structure for understanding perceived barrier and coping efficacy in social context, this line of inquiry should be extended in a number of important ways. First, given the phenomenological nature of the perception of barriers and coping, future research should take a mixed methods approach to the study of social cognitive career theory involving students with HID from CLD backgrounds. For example, through the use of measures such as the one developed in this study quantitative data could be generated to further specify how barriers are perceived by groups of students with HID from different ethnic backgrounds (e.g., white, African American, Latino), and or different socioeconomic backgrounds or places (e.g., urban, rural, suburban). In depth grounded theory work should also be conducted through the use of qualitative methods to gather rich data to reveal how social cognitive career theory

relates to the lived experiences of students with HID from CLD backgrounds. Coupled with these approaches, well planned longitudinal studies tying perceptions of barriers and coping-efficacy with long-term academic and career outcomes are warranted. The combination of both qualitative and quantitative inquiry has the potential to illuminate the complex processes of academic and career development for this population of students.

Practically our findings suggest that a measure such as the one developed in this study, once further refined through Confirmatory Factor Analytic procedures with larger sample could be used by teachers and vocational counselors to better support students in the process of transition from school to work and higher education.

Conclusions

Transition involves a multi-dimensional planning process; one component of this process should be to identify barriers to successful academic and career development. Another component should be to identify how these barriers present themselves in social context and how students cope with such barriers. In this study, we demonstrated that these two dimensions, while related, are distinct. A strong two-factor structure emerged from our analyses, and this factor structure is well aligned to research related to the perception of barriers and coping efficacy in the process of career and academic development (Lent et al.,1999). We further demonstrated these dimensions can be measured among transition age students with HID from CLD backgrounds. We believe that the resulting information can be used to expand theoretical conceptualizations of self-determination and possibly facilitate more effective transition planning. Each subscale in the instrument had high internal reliability, suggesting the items within each subscale were highly theoretically related. In addition, overall reliability was high enough to suggest the instrument might be used for decision-making purposes, such as those in the transition assessment process.

We strongly believe that both researchers and practitioners require an instrument like the one developed here, to better align goals with student needs, and eventually lead to improved employment and educational outcomes for students with HID from CLD backgrounds.

Jason Matthew Naranjo Assistant Professor Special Education School of Educational Studies.

Luke Duesbery Associate Professor Teacher Education School of Teacher Education

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Creative Works

On Speaking and Not Speaking: Autism, Friendship, Interdependency

Sonya Freeman Loftis, PhD
Morehouse College

This collection of autobiographical fragments explores the subject of autistic voice. Juxtaposing moments when autistic communication is recognized and understood with moments in which it isn't, this work of creative nonfiction examines ideological tensions between independence and interdependency, the potential lines (or lack of lines) separating friendship and support, and some of the inevitable problems that are created when one person speaks for another. The piece also explores the dangers that may arise when social systems and authority figures fail to recognize autistic voices.

On Speaking and Not Speaking: Autism, Friendship, Interdependency

1

I am 12 years old, riding the school bus. "Where are you from?" the girl sitting next to me asks. When I tell her that "I have lived here in town all of my life," she is amazed. Although we have been in the same class all year, she has never heard me speak before. She had assumed that I could not speak English.

2

I am 16 years old, having a meltdown. All I know is that I can't communicate, that I have become chaos and entropy. I lie on the floor of my bedroom and scream for hours. I cover my ears so that I won't hear the sound of my own screaming.

3

I am 22 years old, working on a Ph.D. at the University of Georgia. I can't navigate the crowded, noisy streets downtown by myself, but my friends often take me. "Do you want sour cream?" The restaurant is even more crowded and noisy than the perfectly unnavigable street, the line behind me steadily building. My friend, Jess, chews at her bottom lip, uncertain of what to do. The majority of the time, I speak just fine. Except when I don't. So my friend is having a dilemma. Should she order for me? Should she give me more time? She would never dare to speak for another—to trample on someone else's subjectivity. But the problem we are having is practical as well as philosophical: I do want sour cream, even if I can't ask for it. I wish Jess would speak for me. The crowd at my back builds precariously. The silence lengthens.

4

I am 27 years old, a professor of English on my way to a professional conference. The senior shouting officer of the TSA (my friend Lisa says that the TSA in Atlanta have officers employed explicitly for shouting) is doing his best work at maximum volume. He can't tell that I'm autistic, and he can't figure out why yelling "move to the left" isn't helping me move to the left. Actually, I'm not moving at all: I'm standing helplessly still in a sea of moving people. I can't understand why this man is yelling at me nor understand what he is yelling about. Lisa, hesitant to touch me, is also trying to get me to move to the left. But my body isn't doing what it's told.

"You can't separate us." Lisa is trying to stay calm in the chaos that is airport security. "I'm her assistant. You won't be able to communicate with her without me."

"What number are you?" she asks later as we get on the plane. No response. Long pause. "What number are you?" she types on her phone. The ability to type, unlike the fleeting ability to speak, rarely leaves me: I type "9." Lisa breathes deeply and calmly, while I sit beside her, my face in my hands. On our 1-10 scale, a 10 is a full-blown meltdown. You can't have a meltdown on a plane, I think to myself. You can't have a meltdown on a plane. THERE IS NO PLACE TO HAVE A MELTDOWN ON A PLANE. "Security thought you were deaf," Lisa says later, when it has passed.

5

I am pregnant, six months along. "It won't hurt you," the doctor says in an attempt to be reassuring. I can't say anything in response. I have yet to realize that the most complicated part of my very complicated pregnancy will be my inability to communicate with my doctors. I want to say, "I feel like I'm dying."

Later, the doctors discover that I am, in fact, dying. So is the baby. They need to do an emergency C-section. I can't answer basic questions—can't make any noise at all. When they cut me open, my husband says anxiously, "Shouldn't you check to see if she can feel that?" My whole body trembles. "If she could feel that, she would be screaming right now," the doctor says confidently.

6

I am never singular, never alone. This duality confuses people. Who is this person with her? What is this person's role? At the Comparative Drama Conference, my friend Steph is mistaken for my lover. ("You make an adorable couple," a conference-goer says to her during my presentation, "You must be so proud—she's so articulate!") At the Modern Language Association, Lisa is mistaken for my graduate student. When Lisa explains that she is my support person, the chair of my disability studies panel asks, "So you are helping her travel? How does that work?"

At the Society for Disability Studies conference, people aren't quite sure how to work conversationally with my support person. I am glad that people are talking to me, but I am

sorry that they are ignoring my friend. Even in disability circles, independence remains an alluring ideology. We want to regard independence as the end goal—the sign of adulthood, the mark of arrival. We want to believe that independence is possible for everyone. I recognize the dilemma: to engage my support person in conversation may seem to overlook me in my autistic silence, may seem in some way to fail to acknowledge my disabled humanity. But Steph is a brilliant gal. Like all of my friends who help me travel, she doesn't get paid for her work.

My autism specialist is surprised to hear that my friends travel with me to conferences, that they have made my career possible. She is surprised to find that they take me to doctor's appointments and help me to get my hair cut. She fails to recognize that our relationships are complex and symbiotic, that I also give. This makes Lisa and Steph angry. "You have good friends," Lisa says, "because you are a good friend." My autism specialist seems to assume that I am a burden rather than a friend. Sometimes I worry that she is right.

7

I am 31 years old, having a meltdown. I lie on the bathroom floor and scream. My husband lies down on the floor beside me, just far enough away so that I know he isn't trying to touch me. He lies there without speaking, a silent solidarity in the lines of his body. He waits. He smiles. He is patient. In our 11 years of marriage, it is the most romantic thing that he has ever done for me.

8

I am 33 years old, and I need to have surgery. The hospital cannot decide whether to treat me as a child or as an adult. Angry conversations are held in front of me about my legal status. "She is an adult, and she can speak," the ultrasound technician says, "Legally, she *must* speak for herself." But I can't speak for myself at the moment, so I cover my ears with my hands and scream.

The hospital says that they cannot allow a support person in the recovery room. "If she has a meltdown, I can't guarantee that they won't use restraints," the hospital administrator says. In the weeks leading up to the surgery, I lie awake in bed at night and imagine the restraints. I know that I may not be able to communicate with the nurses and that they may not look closely at my medical records. "We should write the word AUTISM on your arm with a Sharpie," my friend Allison says. I imagine inscribing my body with my disability label as the ultimate act of both acceptance and defiance.

The doctors give me so many anxiety drugs that I don't remember the surgery at all. In the weeks that follow, I'm so grateful that I can't remember. But my friend Alice is angry. "There shouldn't be things you don't want to remember," she says. I understand Alice but do not agree with her. Alice imagines a world in which the medical system accommodates and cares

for people like me. Such a world is a theoretical possibility, I know, but it isn't the one I have lived in. For my part, I am glad that the drugs have erased the sound of my screaming.

9

"What kind of ice cream do you want?" The man behind the counter can tell that there is something "wrong" with me. My friend Ann, whom I met on the floor during circle time in Kindergarten, is sizing me up with her knowing eye: after twenty-eight years of friendship, she knows intimately what an incipient meltdown looks like. It is too crowded in here. Much too crowded. "She wants strawberry," Ann says with false confidence. She slams the palm of her hand down on the wooden bar in front of us. "Definitely the strawberry." And I am glad to have the strawberry ice cream, glad that Ann hustles me into a quiet seat in a hurry, so very grateful to have had Ann to speak for me all of these years. It is dangerous and beautiful and bittersweet, this speaking for me. After all, if someone doesn't speak for you, you don't get any ice cream at all—but I wish I could tell her that I wanted cookies and cream.

Sonya Freeman Loftis: Associate professor of English at Morehouse College. She is the author of two monographs: Shakespeare's Surrogates (Palgrave Macmillan, 2013) and Imagining Autism (Indiana University Press, 2015). Her work on drama and disability has appeared in journals and collections such as The Disability Studies Reader, 5th edition, Disability Studies Quarterly, Shakespeare Bulletin, and The South Atlantic Review.

Creative Works

Finding Becky: How Disability Erasure in Play Reflects and Influences Reality

Karin Hitselberger

The original version of this article was published on Claiming Crip (www.claimingcrip.com) under the title, Finding Becky: The Evolution of Barbie And the Importance of Representation

Abstract: This blog post examines the personal impact of disability representation in children's toys, and explores how the story of a two decade old, discontinued, disabled doll mirrors the experiences of disabled people in society today.

Keywords: Toys, Representation, Popular Culture

I'm a big fan of nostalgia. I love things like Throwback Thursday and Flashback Friday. I love almost anything that brings back good memories, especially fond memories of my childhood. Whether it's watching classic Disney movies and Nickelodeon shows on Netflix, picking up an old favorite snack when I happen to see it at the store after a particularly rough day, or giggling with my sister or my friends over the numerous Internet articles and quizzes extolling the virtues of 90s kids, I definitely enjoy the occasional blast from the past.

So, you can imagine how excited I was when my mom decided to surprise me with some 90s Barbie dolls to decorate my office, but these weren't just any Barbie dolls. My mom got me three different versions of Becky, the wheelchair-using friend of Barbie, an absolute favorite from my childhood.

My first exposure to Becky was Christmas of 1996 when my sister, all my cousins, and I received the doll as a Christmas present from my mother. I remember everybody loved her. She wasn't a "special" toy somehow reserved only for disabled girls. Anyone could play with Becky, and they did. I remember my friends loved that doll because unlike most Barbie dolls her legs were bendable so that she could sit in her wheelchair. Everyone loved her, but she was special to me.

Problematic or not, Barbie dolls matter because they often reflect the hopes and dreams of the little girls who play with them. That's why Barbie can simultaneously be an astronaut, a teacher, a movie star, a doctor, an Olympian, and a scientist, just to name a few. Barbie often reflects for little girls who they are and what they want to be when they grow up, which is why I was so excited to see the recent release of Barbie dolls that reflect a larger range of body types and skin tones, and it is why I treasured my Becky doll as a little girl. It is why I wish she still existed.

Becky mattered because she showed everyone that a wheelchair was nothing to be

afraid of, and it didn't prevent you from having a life just like everybody else. Becky was a school photographer, a cheerleading coach, and even a Paralympian. Becky was part of Barbie's world, even if it wasn't made for her. The original version of Becky had to be redesigned because of technical difficulties and not being able to fit into the elevator of the dream house. Eventually, she was discontinued.

There has never been an official statement as to why Mattel stopped making Becky; in fact, it is incredibly difficult to find any official information on Becky at all. However, the prevailing theory seems to be that Becky was discontinued because she didn't fit into Barbie's world, and it was easier to get rid of her than to change everything else.

Whether or not this is the true reason, Becky's departure matters, because the truth is Becky didn't fit into Barbie's world, and there hasn't been a Barbie in a wheelchair since. It matters because Becky's discontinuance reflects how we are often taught to think about disability, in terms of fixing people rather than society. It matters because it echoes a way of thinking that suggests people are problematic when they are different, instead of a realization that it is impossible to have a world where everyone is the same.

Becky's absence matters. Her redesign matters. Her presence mattered. All of it matters, because representation matters. It is important for disabled toys to exist because it reinforces the idea that disabled people are a natural part of the world, just like everybody else. Their absence in fantasy worlds teaches as much as their presence. Becky mattered because she was there, she did not have a passive role, she was a friend, an active part of Barbie's world. Becky matters because she was shown as someone with hopes, dreams, and aspirations. Becky matters because she was thrust into a world that was quite literally not designed for someone like her.

Becky matters because I am Becky and when I was seven years old seeing a doll that looked like me was the most powerful thing in the world. Becky matters because representation in toys and mainstream media is so important because it shows that disability is nothing to hide or be afraid of. Becky matters because of the dream house. Becky matters because, instead of trying to fix disability, we should be trying to live in a world that is accessible to all people, no matter who they are.

Representation in toys is so important, but in order for it to make a difference, it has to be real. Having a doll in a wheelchair sends a great message to disabled and nondisabled children alike, but if that doll cannot fully participate in the fantasy society it is a part of, it just reinforces the message that disabled people are different and that disability is problematic.

If you have a doll like Becky in a wheelchair, but you have to take her out of the wheelchair to really be able to play with her in the dream house or the Barbie car, it continually sends the message that Becky's wheelchair is the problem. It promotes the idea that if we were able to get rid of her wheelchair Becky would be able to fit into Barbie's

world.

Becky matters because we need to stop being afraid to redesign the dream house. We still live in a world where so many people feel like Becky in their everyday lives, the girl who is excluded because she does not fit into the dream house. I know I do. I constantly get the message that I am the problem, because I do not fit. Disability is so often thought of as "my problem" and "my responsibility".

Instead of creating an inclusive society where disability does not have to mean sitting out of life, so many people are focused on eradicating disability altogether. I will admit that I am ambivalent about whether or not I would cure my disability if I had the opportunity, but I will also say that I would rather have equality than a cure every single day of the week.

I am not a problem that needs to be fixed. I cannot and do not need to get rid of my wheelchair to fit into this world. Instead, I need to work on fighting for a world that understands that disability is just part of our natural diversity, and we need to create an environment that is accessible to all people.

I live in a world that regularly ignores my existence without even realizing it. I live in a world where finding truly accessible housing is about as common as finding a magical pink unicorn. I live in a world where staying at home in my parents' house and never really going anywhere is still consistently offered as an acceptable solution to inaccessibility. I live in a world where my very existence is still seen as a problem. I live in a world where so many people's perspective on the ultimate solution to inaccessibility is to get rid of disability altogether.

It may seem like it is just a toy, but the dream house matters. The dream house matters because real accessibility is not optional it is essential. The dream house matters because we need to change the dream house! We need to realize that accessibility is possible, and instead of trying to change people to fit into our world, we need to change the world. The dream house matters because Becky was not the problem, the inaccessible environment was. I want to live in a world where we fight to change the dream house, instead of trying to change the people in it.

Photo Description: Photos of three Barbies: Share a Smile Becky, Paralympic Champion Becky, and Becky, I'm the

School Photographer.

Karin Hitselberger is an internationally known and award-winning blogger who focuses on the intersection of popular culture and disability. She blogs at www.claimingcrip.com and she is deeply interested in how representations of disability in media and popular culture influence the psychosocial well-being of disabled people. Hitselberger received her BS Communication Studies and BS Religious Studies, University of Miami PG Dip. Disability Studies, University of Leeds.

Best Practices

Sports and Disability: Enhanced Health, Self-Efficacy, and Social Inclusion Through Athletic Participation

Tayo Moss, MS
Michigan State University
Trenton J. Landon, PhD
Utah State University
Allison Fleming, PhD
Penn State University

Abstract: Sports and recreational participation have demonstrated health and social benefits. However, persons with disabilities are typically not provided the same opportunities as people without disabilities. This article discusses the benefits of sports and recreation, and the barriers that have existed for persons with disabilities. The purpose is to demonstrate the need for rehabilitation counselors to consider the utility of physical activity as a way to enhance health, self-efficacy, and community inclusion. Recommendations are presented for rehabilitation counselor advocacy for improved participation in sport and recreational pursuits by persons with disabilities.

Keywords: disability, social inclusion, rehabilitation counseling

There are over one billion persons with disabilities around the globe (World Health Organization & World Bank, 2011) and an estimated 53 million in the United States (Center for Disease Control & Prevention, 2015). Disability has been a permanent part of human history, and the number of people with disabilities increases with the aging global population, as the result of congenital conditions, and accidents or injury causing physical limitations (Larkin, Alston, Middleton, & Wilson, 2003; Smart, 2016). However, it has been suggested that people with disabilities have never been allowed to be ordinary citizens, and represent a disenfranchised minority group (Smart, 2016). Negative attitudes towards people with disabilities persist (Wilson & Scior, 2014), and this may stem in part from the historical propensity to view people with disabilities from the Biomedical Model of disability, which focuses on the anatomy and physiology of a person. Alternative models of disability developed over time, with the recommendation of the World Health Organization's International Classification of Functioning (ICF) as an appropriate framework for quality of life measurement and assessment for rehabilitation professionals (Chan, Tarvydas, Blalock, Strauser, & Atkins, 2009; Fleming, Fairweather, & Leahy, 2012). The purpose of this article is to demonstrate the need for rehabilitation counselors to consider the utility of physical activity as a way to enhance health, self-efficacy, and community inclusion. In turn, enhancing these aspects may have a positive impact on overall quality of life.

Efforts to address the needs of people with disabilities has led to legislative protections and specific services designed to increase the quality of life of people with disabilities. Rehabilitation counselors are tasked with assisting people with disabilities in meeting

personal goals, securing employment, and addressing independent living needs (Commission on Rehabilitation Counselor Certification – CRCC, 2015). While facilitating employment has been the historical emphasis, recent research has suggested rehabilitation counselors should also attend to more subjective components of QOL (Fleming et al., 2013). Quality of life can be "explained as a combination of function, difficulty with work and daily living activities, community participation, and environmental support" (Fleming et al., 2013, p. 21).

Rehabilitation counselors have a long history of advocating for people with disabilities, particularly in those areas where there is a lack of opportunity and full participation. One area where people with disabilities have been excluded is sports and athletic recreation. People with disabilities generally show lower levels of participation in sports and athletic recreation than their peers (Anderson & Heyne, 2010; Kroll, Kehn, Ho, & Groah, 2007; Murphy & Carbone, 2008). While there are opportunities for sports participation (e.g., Paralympics, Special Olympics, adaptive sports), event participation with these organizations is based on the type of disability. The Special Olympics represents over 4 million participating athletes with intellectual disabilities hailing from over 169 countries (Special Olympics, 2016). When considered in light of the almost 200 million people with an intellectual disability (Special Olympics, 2016), this represents an extremely small portion of athletic participation by persons with intellectual disabilities. Participation rates of people with disabilities in athletics and recreational pursuits are influenced by a variety of factors, including poor concept of self (Scarpa, 2011), lack of support services (Foley, Harvey, Chun, & Kim, 2008), low self-efficacy (Dixon-Ibarra & Driver, 2013), and accessibility issues resulting from health and disability status (Burns & Graefe, 2007; Murphy & Carbone, 2008). Sports participation and increased physical activity is not a traditional service provided directly by a rehabilitation counselor. However, gym memberships can be included in a plan for employment as an appropriate service for some rehabilitation service recipients. Rehabilitation counselors have an obligation to attend to the personal, social, and psychological goals of people with disabilities (Rehabilitation Counseling Consortium, 2005), not just employment. Rehabilitation counselors can better meet this obligation by advocating for inclusive physical activity and sporting opportunities.

Health Benefits of Physical Activity for People with Disabilities

The World Health Organization (WHO) defines health as "a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity" (WHO, 2002). Previously, disability began where and when health ended; once persons were considered disabled, they were placed in a different health category (WHO, 2002). Thus, people with disabilities were often perceived as having ill or poor health and many definitions of "good" health center on the absence of pathology. This means that the presence of any "deformity" or "deficit" may result in the individual being considered unhealthy. Such views are based predominantly in the medical model of disability, where having a disability is viewed from a pathologizing, objectifying, and categorizing framework (Smart & Smart,

2006). When viewed from this model, people with disabilities are often perceived as having ill or poor health, which can lead to a host of negative social sanctions including social exclusion, being ostracized, and marginalized.

Regular physical activity enhances the health of people with disabilities, such as improved cardiovascular and muscle fitness, mental health, and increased ability to do daily tasks e.g., dressing, eating, hygiene (Dixon-Ibarra & Driver, 2013). Other benefits include the increase of muscle mass, increased range of motion, reduction of stress, increased self-efficacy, and increased confidence. Benefits can be further categorized into physical, mental, and emotional gains. Health benefits for people with disabilities can have a significant impact on how they view themselves. Streber, Peters, and Pfeifer, (2016) asserted that physical activity may diminish some physical limitations associated with the long-lasting effects of a disability or chronic illness. Physical activity over an extended period may reduce some symptomatology of chronic illness or disability, thus reducing the severity (Foley et al., 2008; Streber et al., 2016). However, many people with disabilities do not participate in regular physical activity (Anderson & Heyne, 2010; Kroll et al., 2007).

Social and Emotional Benefits of Physical Activity and Sports

One reason for the lack of participation in physical exercise by individuals with disabilities is low self-efficacy (Dixon-Ibarra & Driver, 2013). Bandura (1977, 1997) defined self-efficacy as one's beliefs in their capabilities to execute an action to obtain a certain outcome. An individual with greater self-efficacy will pursue greater challenges and strive for higher goals. In contrast, an individual's self-efficacy may decrease if they experience negative psychological states such as pain, fatigue, and anxiety (Middleton, Tran, & Craig, 2007). Self-efficacy has been found to be an important factor influencing health for people with disabilities in diverse areas including improvement in rehabilitation after a stroke (Robinson-Smith, Johnston, & Allen, 2000), and stuttering cessation (Craig, 1998).

The construct of self-efficacy has been heavily employed in sports to understand how performance can be related to self-confidence. The Disabled Sports USA (DSUSA) program conducted a survey in 2009 with their member participants, the majority of whom are veterans with acquired physical disabilities. They found an overwhelming majority of DSUSA members felt physical activity significantly improved their QOL, and that physical activity helped them secure employment, be given greater responsibilities in the work setting, and provided opportunities for raises when compared to the general population of adults with disabilities (DSUSA, 2009). Thus, a reasonable solution to increase self-efficacy in the populace with a disability, is to participate and engage in sports, leisure, or recreation activities. These benefits include increased health and fitness, longer lifespan, greater mental and social well-being, increased self-esteem and socialization, and decreased stress (Kristen, Patriksson, & Fridlund, 2002; Kristen, Patriksson, & Fridlund, 2003; Martin, 2006). Sports can also be a gateway for providing social support (e.g., teammates, coaches, athletic staff) to

the disability community.

A social support system involves close individuals who provide emotional support and resources in times of need (Pines & Aronson, 1988; Wright & Fogler, 2017), and often this support system is comprised of the family, primary caregivers, and a few relationships with individuals without disabilities (Lippold & Burns, 2009). For individuals with disabilities, these networks are often smaller than individuals without disabilities. Sports can provide a responsive and supportive social environment, which can stimulate confidence and growth for people with disabilities. Participation in extracurricular, leisure and fitness based activities by college males has led to feelings of empowerment and enhanced perceptions of personal accomplishment and social inclusion (Blinde & Taub, 1999). Participation in these types of activities not only has benefits in the classroom, but across the individual's lifespan (Astin, 1999).

In recent years, general physical education (GPE) programs in the United States have incorporated disability sports to their physical education curriculum (Davis, Rocco-Dillon, & Grenier, 2012; Grenier & Kearns, 2012). Sports such as wheelchair basketball and sitting volleyball can provide unique skills for able bodied students as well as deliver an influential message regarding how difficult it can be for an athlete with a disability. Grenier and Kearns (2012) implemented a disability sport program for a southern New England school, which enrolls 400 students from kindergarten through the fifth grade. The authors sought to first educate these students on the Paralympic Games, and to also understand how participation in a disability sport could alter students' perceptions of classmates with disabilities. Four disability sports were introduced to the students over a five-week period: wheelchair basketball, goalball, sitting volleyball, and sledge hockey. Students were asked to report what they learned and how they felt about playing the sport at the conclusion of the activity. The results found that including a disability sport in GPE programs may be a plausible avenue for reducing the stigma linked with having a disability (Krahe & Altwasser, 2006). This example provides a model for more schools within the United States to incorporate inclusive physical education programs. However, the careful planning, appropriate design and implementation of the such disability simulations is imperative (Burgstahler & Doe, 2004). While simulation exercises have the ability to engage learners and foster discourse about people with disabilities (French, 1994; Kiger, 1992), unintentional and long lasting negative attitudes towards people with disabilities have resulted from simulation exercises (Burgstahler & Doe, 2004).

Sport as a Model of Social Inclusion

Social inclusion has been defined as "societal acceptance of people with disabilities within school, work, and community settings" (Walker et al., 2011, p. 15). Social inclusion is impacted by subjective societal attitudes towards people with disabilities (Simplican, Leader, Kosciulek, & Leahy 2015) and is a key element in the overall well-being of people with disabilities (Buntinx & Schalack, 2010; Simplican, et al., 2015). Social inclusion is also a

primary element and focus of the United Nations Convention on the Rights of Persons with Disabilities (Quinn & Doyle, 2012; Simplican, et al., 2015). Other pieces of legislation here in the United States have also sought to increase community access and community involvement of people with disabilities by removing socially constructed barriers to integration (e.g., Public Law No: 93-112, the Rehabilitation Act Amendments of 1973 [P.L. 93-112], Americans with Disabilities Act of 1990 [P.L. 101-336]). Yet, social isolation or social exclusion remains a pervasive issue for individuals with intellectual and developmental disabilities (Bigby, 2008; Forrester-Jones et al., 2006; Milner & Kelly, 2009; Robertson et al., 2001; Simplican, et al., 2015).

The United States is a sporting-crazed nation (Abdel-Shehid, 2002). This love affair with sports positions athletes to take on important cultural, social, and political roles and has provided opportunities for sporting figures to transcend boundaries and push for social inclusion through the promotion and creation of equal-status relationships (Davis et al., 2012). Jackie Robinson was the first man of color to play professional baseball in the modern major leagues, breaking the culture barrier by introducing racial integration of sports into American society (Mann, 1951). Jesse Owens, another prominent athlete of color for the United States, triumphed in Hitler's Berlin, winning multiple gold medals in the 1936 Olympic Games (Frost, 2014). Drawing from both national and international fame, profound charisma and dedication to faith, Muhammad Ali protested a variety of established laws and systematic repression of African-Americans (Abdel-Shehid, 2002). More recently, former President Barack Obama and Raul Castro used baseball to break down the barriers of the past relationship between the United States and Cuba, with President Obama suggesting, it was "sports that can bring the American and Cuban people closer together" (Korte, 2016). These examples demonstrate how sports and athletes can transcend social boundaries and help foster social change, providing a model for people with disabilities.

People with disabilities have sought access to sports based on the perception that sports can serve as an equalizer, and a means for gaining acceptance (Devine, 2013; DePauw & Gavron, 1995). Several professional athletes with disabilities have become successful in the mainstream world of sports. Kickboxer and amputee, Baxter Humby remains the only kickboxer to ever win a world title with one hand. James Abbot played major league baseball for ten years despite being born without a right hand. Humby, Abbot and other athletes with disabilities have opened doors for marginalized groups by increasing the awareness of athletes with disabilities. Increased awareness has helped to establish accessible sporting facilities and organized sport programs for people with disabilities (DePauw & Gavron, 1995). In addition to sports participation, physical activity has been found to reduce the marginalization of people with disabilities (DePauw & Gavron, 1995).

Physical activity assists in improving inclusion for people with disabilities by altering the societal stigmas about people with disabilities and shifting internal perceptions of how people with disabilities feel about themselves (United Nations, n.d.). Emotional and psychological benefits, social benefits, and community and societal benefits have all been

suggested as outcomes of people with disabilities pursuing and engaging in physical activity (Anderson & Heyne, 2010). There is something about physical activity, and sport in particular, that has provided a platform for individuals seeking greater social inclusion and social justice.

Barriers to Participation

Research has found that people with disabilities are less physically active compared to the general population (Heath & Fentem, 1997). Inactive lifestyles of people with disabilities often contribute and lead to higher risks of mortality, as well as various chronic diseases such as coronary artery disease, diabetes, colon cancer, and osteoporosis. Participation in sports may improve the lifestyles of people with disabilities and increase their physical activity. A physically active lifestyle, including sport participation could also have a positive effect on the risk of coronary artery disease, diabetes mellitus type 2, high blood pressure, obesity, depression, diminished self-concept, and dependence upon others (Durstine et al., 2000). Participation in sport related physical activities (e.g., swimming, fitness exercises) have been found to keep people with disabilities fairly active during treatment (van der Ploeg van der Beek, van der Woude, & van Mechelen, 2004). People tend to become physically inactive after their rehabilitation period due to rehabilitation centers not providing enough effort to keep former patients active (van der Ploeg et al., 2004). There is a desperate need to provide recommendations to assist people with disabilities on how to self-initiate daily physical activities outside of rehabilitation treatment, such as an involvement with sports.

While the arguments for physical activity and participation in sports increasing individual health, self-efficacy, and social inclusion are compelling, there is another aspect to this relationship. For some individuals, having a disability negatively impacts their sense of self (Toombs, 1994). Research has found that people with disabilities may have lower self-efficacy due to internal or external barriers. Internal barriers involve different types of pain or fatigue, inadequate physical functioning, psychological uncertainty, and susceptibility to psychological grief. External barriers relate to attitudes of society (e.g., stereotyping) and environmental obstacles, such as poor building designs (e.g., steps and no ramp, Barlow & Harrison, 1996). Personal factors, such as personality, social support networks, and age of disability onset may exacerbate or reduce the impact of barriers experienced on an individual (Blake & Rust, 2002). When combined, such barriers lead to participation rates of people with disabilities in regular exercise or sporting pursuits as low as seven percent (Lohrey, 2015).

Individuals with physical disabilities reported the main reasons for the lack of physical activity were: environmental barriers, insufficient social support, pain, physical limitations and negative beliefs about exercise benefits (Aguiar et al., 2017; Dixon-Ibarra & Driver, 2013; Nosek et al., 2006). Kerstin, Gabriele, and Richard (2006) examined self-efficacy for individuals with spinal cord injuries. They found that previous performance accomplishments increased self-efficacy, due in part to a recall of past positive physical activity experiences. Understanding the different antecedents of efficacy (e.g., vicarious experiences, past

performances) will assist practitioners in establishing a framework for increasing self-efficacy.

Waring and Mason (2010) found that in order to encourage participation in sports by typically underrepresented groups (e.g., women, ethnic minorities, individuals with disabilities), a targeted outreach, focusing on these specific populations is necessary. While the idyllic and aspirational line from Field of Dreams (Frankish & Robinson, 1989) positively suggests, "If you build it, they will come," reality is far different. Encouraging marginalized groups to participate fully in sports requires the recognition of and targeted efforts to overcome environmental and social barriers that might otherwise limit participation. Targeted efforts can range from being inclusive in recruiting efforts (e.g., targeting all marginalized groups) to ensuring that the facility is welcoming to people with disabilities. In the United Kingdom, Waring and Mason (2010) specifically noted adapting sport and recreational facilities to meet the needs of people with disabilities prior to the facility opening their doors to the public is one way to promote inclusion. People with disabilities felt the four-court sports hall, the changing facilities, and the fitness studio had been designed with them in mind, and accommodations or adaptations were not an afterthought. Over a relatively short amount of time, the overall percentage of patrons with disabilities raised to 29% of the facility membership. This approach to fostering inclusion demonstrates the need for considerable effort to attract targeted individuals and to overcome existing and significant barriers to inclusion. This approach also requires dedicated human resources collaborating with agencies possessing the experience and knowledge of working with marginalized groups.

Exclusion

There have been many calls for inclusive approaches to foster greater participation rates of individuals with disabilities in sporting programs (Anderson, Wozencroft, & Bedini, 2008; United Nations, 2007). The need for advocacy and inclusion arises out of a reality rife with exclusion. Table 1 outlines four types of social inclusion/exclusion as suggested by Bailey (2005).

Table 1. *Types of Inclusion/Exclusion*

Spatial	Social inclusion relates to proximity and the closing of social and economic distances.
Relational	Social inclusion is defined in terms of a sense of belonging and acceptance.
Functional	Social inclusion relates to the enhancement of knowledge, skills, and understanding.
Power	Social inclusion assumes a change in the locus of control.

Bailey (2005). Used with permission (R. Bailey, personal communication June 2, 2017).

While exclusion can take many forms, exclusion is essentially present when an individual or group experiences a lack of access to power, knowledge, services, facilities, choice, and opportunity (Bailey, 2005). Historical aspects of social inclusion have focused primarily on poverty and ways to raise income levels of deprived citizens; more contemporary definitions focus on enabling and empowering individuals to fully participate in society and improve life opportunities through enhanced social experiences (Waring & Mason, 2010). In addition to the many health benefits previously outlined, sport is generally recognized as one medium for providing social activities where a range of social experiences occur and participants develop a variety of life skills (United Nations, 2007; Waring & Mason, 2010). Sport also offers a unique way of addressing Relational Exclusion and Power Exclusion by shifting the decision to participate more fully to the individual with a disability (increasing their power) and fostering social relationships (increased sense of belonging and acceptance).

Improving Participation by Increasing Contact and Information

There is place for inclusion and participation for people with disabilities in athletics. "Individual and group-based benefits from social inclusion hinge upon broader changes in the attitudes and behaviors of society" (Simplican et al., 2015, p. 22). In discussing societal rehabilitation, or efforts to reduce the general public's prejudicial attitudes towards people with disabilities, Anthony (1972) suggested a two-part process: contact and information. Contact with people with disabilities, moderated with information about the individual and their specific disability type was essential in order to foster a favorable impact on persons without disabilities and change attitudes and beliefs. Abbott and McConkey (2006) found providing the community with information on the individual and their disability was one component of overcoming social exclusion. Research has shown contact with people with disabilities to have a positive effect on societal attitudes, thus increasing social inclusion can lead to decreased levels of negative attitudes in society (Sharma, Forlin, Loreman, & Earle, 2006). However, mere contact with people with disabilities does not always lead to an increase in positive societal attitudes about people with disabilities (Alghazho, Dodeen, & Algaryouti, 2003). The effectiveness of the contact with people with disabilities in positively impacting social inclusion hinged on the quality of contact (McManus, Feyes, & Saucier, 2011), and contact alone, where information about the individual on a personal level or knowledge about the disability is not increased, can serve to reinforce negative stereotypes (Siperstein, Norins, & Mahler, 2007).

Recommendations for Rehabilitation Practitioners

Given the findings by the DSUSA (2009) relative to athletic participation, work related gains, and QOL in general, rehabilitation counselors may better assist the individuals they work with by helping them seek out and participate in athletic and recreation based pursuits. While employment is definitely an ideal aspiration and can be measured objectively, employment by itself is not a complete indicator of social inclusion and overall QOL. The

International Classification of Functioning, Disability, and Health (ICF) has been recommended as a model for service provision appropriate to rehabilitation counseling (Chan et al., 2009), and the ICF's attenuation to the subjective components of health and wellness will help rehabilitation counselors in all settings attend to their ethical obligations of respecting human rights and dignity, acting to alleviate personal distress and suffering, and advocating for the fair and adequate provision of all services (CRCC, Preamble, 2017). This requires the consideration of subjective measures of QOL, of which physical activity is one.

Further, while the participation in a sporting team or event helps to foster social relationships and is supported through legislation, institutional barriers, environmental barriers and social barriers exist and limit participation in sports for people with disabilities. By attending to this lack of inclusion, rehabilitation counselors, administrators, and educators adhere to their ethical obligation of advocacy. Section C.1.a of the Code of Professional Ethics for Rehabilitation Counselors states, "In direct service with clients, rehabilitation counselors address attitudinal barriers, including stereotyping and discrimination, toward individuals with disabilities. They increase their own awareness and sensitivity to individual with disabilities" (CRCC, 2017, p. 10).

Many counselors must document a comprehensive needs and skill assessment. This assessment is meant to justify how the rehabilitation plan addresses the needs of the individual being served. Comprehensive needs assessments often focus primarily on vocational match to the individual's skill set. These assessments could be expanded to holistically address the needs of the individual by using the CBR-Matrix (depicted in Table 2) as a way to develop plans for employment that address social, recreational, and vocational needs of the client (United Nations International Children's Education Fund – UNICEF, 2013).

Table 2. *WHO Community-Based Rehabilitation (CBR) Matrix*

<table>
<tr><td colspan="5" align="center">CBR Matrix</td></tr>
<tr><td>*Health*</td><td>*Education*</td><td>*Livelihood*</td><td>*Social*</td><td>*Empowerment*</td></tr>
<tr><td>Promotion</td><td>Early Childhood</td><td>Skills Development</td><td>Personal Assistance</td><td>Advocacy and Communication</td></tr>
<tr><td>Prevention</td><td>Primary</td><td>Self-Employment</td><td>Relationships Marriage & Family</td><td>Community Mobilization</td></tr>
<tr><td>Medical Care</td><td>Secondary & Higher</td><td>Wage Employment</td><td>Culture & Arts</td><td>Political Participation</td></tr>
<tr><td>Rehabilitation</td><td>Non-Formal</td><td>Financial Services</td><td>Recreation, Leisure & Sports</td><td>Self-Help Groups</td></tr>
</table>

Assistive Devices	Lifelong Learning	Social Protection	Justice	Recreation, Leisure & Sports

Source: United Nations International Children's Education Fund (2013). Used with permission (World Health Organization, personal communication, June 23, 2017)

The CBR-Matrix was originally designed for countries serving people with disabilities with little or no rehabilitation service infrastructure. However, it is it an ideal framework for use by rehabilitation professionals everywhere as it emphasises the empowerment and inclusion of people with disabilities in decision-making across all activities of daily living, and was designed based on an ultimate goal of reducing poverty.

To help encourage physical activity in people with disabilities outside of rehabilitative settings, expansion of adaptive sporting leagues should be considered (e.g., wheelchair basketball, cycling, racing). Participation in these physically adaptive programs may foster social inclusion and even promote a sense of empowerment due to being around individuals who also have some sort of disability. DSUSA is an example of an adaptive sports program that assists over 60,000 youth and adults with disabilities. Involvement with their program assists participants with developing independence, confidence, and fitness. This program provides over 30 sports throughout 100 community chapters in 37 different states nationwide. Research has found that it is possible to obtain a long-lasting improvement in physical activity participation by using physical activity promotion programs, with tailored counseling sessions (van der Ploeg et al., 2004).

Future Research

Research into the link between participation in sports and employment outcomes for people with disabilities will provide insight into how success in one area of the WHO's Community Rehabilitation Matrix might overlap into success in other areas. The WHO suggests the domains are interrelated and the overall health of an individual is benefited when all domains and areas within the domains are addressed. Attending to the sports, leisure, and recreation area of the Social and Empowerment domains would in theory have a positive impact on the Livelihood domain and its areas focusing on employment. Such an approach will begin to better attend to the objective and subjective domains of overall QOL as outlined by the ICF. Qualitative research could examine this relationship more closely and gain insight into the participants' perceptions on the impact of increased participation in athletics, recreation, and leisure on satisfaction and improvement in vocational pursuits. In order to increase effectiveness of practice and strengthen inclusion and overall advocacy of people with disabilities in sports and recreational activities, future research should:

- Help to build a framework of evidence-based practice linking subjective and objective measures of QOL.

- Offer insight into the direct impact of sports and recreational activities on vocational pursuits.
- And serve as a reference for rehabilitation counselors to utilize in the development of comprehensive needs assessments and corresponding plans for employment.

Future research may also involve surveying athletes with disabilities in established programs (e.g., Paralympics, Special Olympics, World Dwarf Games) to better understand how sport participation can foster social inclusion. Qualitative and quantitative research could examine what participation in sporting events has done for improving self-efficacy and confidence in these athletes, as well as perceived contributions to their overall QOL. The relationship between sport participation, self-efficacy, and employment may also be explored. Such research will further build the evidence based rationale for rehabilitation counselors to more closely examine the utility of sporting participation in service delivery, particularly in relationship to building social networks and social support for people with disabilities. Additionally, qualitative research might examine volunteers with these associations to better understand concepts related to social inclusion, motivation to volunteer, and societal benefits from the volunteers' perspectives.

Summary

As the late Nelson Mandela stated in his speech for the World Refugee Day in 2006, "Sport speaks to people in a language they can understand" (Curatolo, 2014). Sports have been a great avenue for creating an environment that provides opportunities for all human beings regardless of race, religion, age, physical ability or economic background (Curatolo, 2014). For individuals who are vulnerable, sports can serve as a positive alternative place to go and feel physically or emotionally safe (Curatolo, 2014). In the late 1800s, Sweden used gymnastics as a means of therapy for people with disabilities (Sherrill, 2004). Since this time, there have been more than 17 high-profile international games for people with disabilities that have assisted in fostering social inclusion, including the Deaflympics (for athletes with hearing impairments) the Paralympics (for athletes with physical disabilities), and the Special Olympics (for athletes with intellectual/developmental disabilities; DePauw & Gavron, 2005). These Olympic games are motivating and empowering, and the participating athletes represent a diverse array of disability types.

While opportunities for athletic participation and recreation have been provided, they are often centered in exclusionary principles. These policies and recreational guidelines are typically constructed by well-intended, able-bodied individuals, who often possess a limited understanding of how to accommodate, and occasionally have no intent of including people with disabilities on any level (likely stemming from misunderstanding of disability and unconscious discrimination). Seeking to remove those environmental and social barriers that presently impede the full inclusion of people with disabilities will help increase overall health, levels of self-efficacy, and community inclusion of people with disabilities. Enhancing these aspects may have a positive impact on the overall QOL and sense of community not just

people with disabilities but people without disabilities as well.

Tayo Moss, M.S. Tayo is a doctoral student in the Department of Kinesiology at Michigan State University. His core interests include motivational implications of diversity within group contexts, and social inclusion for persons with disabilities.

Trenton J. Landon, Ph.D., CRC. Dr. Landon is an assistant professor in the rehabilitation counseling program at Utah State University. His core interests include clinical supervision, and professional development of counselors, and social inclusion for persons with disabilities. He can be reached by email at trent.landon@usu.edu.

Allison R. Fleming, Ph.D. Dr.Fleming received her PhD in Rehabilitation Counselor Education from Michigan State University. She is currently an assistant professor in the Department of Educational Psychology, Counseling, and Special Education at Pennsylvania State University. Her research interests include strength based and environmental contributors to successful education and vocational outcomes for individuals with disabilities. She can be reached by email at apf5208@psu.edu.

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Page 71