

Research Article

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

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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;

Wurzberg, 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 have been a requirement to developing a friendship, it was clear that typing provided an element which led 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."

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