

Islands of Loneliness: Exploring Social Interaction Through the Autobiographies of Individuals With Autism

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Abstract

Assumptions of difficulties with social interaction, or lack of interest in social interaction, are central to many definitions and conventional understandings of autism. However, many individuals with autism describe a strong craving social interaction. This article uses autobiographical accounts written by individuals who identified as autistic as a source of qualitative research data and specifically explores the ways these texts address issues of social relationships. Using narrative inquiry, the authors explored how individuals with autism described their own notions of and experiences with social interaction. This article discusses the broad themes of (a) the desire to have connections and (b) navigation through the world of people. Last, implications for the education of individuals with autism are considered.

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I will make my way back groping from the world where I am
beside myself
I am always discovering ways I have looked for islands
Whose shores I guess at
I would be lying
If I were to describe loneliness
As if it were something I wanted
Loneliness is my enemy
And I will fight the good fight against it. (Sellin, 1995, p. 217)

Many individuals who are labeled *autistic* experience social interactions differently than “neurotypical people” (people without autism). There is a pervasive belief among educators and other professionals in the field of autism that individuals with autism prefer or choose to be alone. In 1943, Leo Kanner used ideas about deficits in social interaction to first define the term *autism*. For example, he described one of the students in his study as, “Happiest when he was alone...oblivious to everything around him.” The word *autism* is derived from the Latin word *auto*, referring to the self. Asperger (1944) stated, “The autist is only himself, and is not an active member of a greater organism which he is influenced by and which he influences constantly” (p. 38). These perceptions have persisted in more recent literature, with terms and descriptions of individuals with autism that

include “happy obliviousness” (Church, Alisanski, & Amanullah, 1999), “lacking awareness of others” (Chamberlain, Kasari, & Rotheram-Fuller, 2006), and “socially avoidant” (Edelson, 2008). Other researchers have located the difficulty in deficits in social cognition (Bauminger, Shulman, & Agam, 2003).

Many individuals with autism reject these perceptions and suggest that, although interaction can be difficult, they long for social connection and are acutely aware of their own social isolation. In the previous quotation, Birger Sellin, a man with autism, wrote of loneliness as an enemy; social interaction and friendship were things he desperately sought. Through his words, and the voices of others with autism, we begin to examine the meaning of autism in the social lives of those who experience it. From that perspective, this study sought to address the following research questions: (a) What do people with *autism spectrum* labels who write autobiographies report about their interest and desires around social interactions? (b) How do people with autism spectrum labels narrate their own experiences with social interaction?

The definition of *autism* includes a section on “abnormal functioning” in the area of social

interaction. The following selection is taken from the definition of autism in the *Diagnostic and Statistical Manual of Mental Disorders (DSM-IV-TR; American Psychiatric Association, 2000)*, the standard classification manual used by mental health professionals in the United States:

A qualitative impairment in social interaction, communication, and restricted, repetitive, and stereotyped patterns of behavior, interests and activities. Delays or abnormal functioning in at least one of the following areas, with onset prior to age 3 years: 1) social interaction, 2) language, or 3) symbolic or imaginative play. (p. 607)

Delayed, impaired, abnormal—these are words often used in the field to define autism and to describe its manifestation in the day-to-day lives of individuals so labeled. However, many individuals with autism reject these descriptions and prefer to define their own experiences through autobiographical writing (Barron & Barron, 1992; Blackman, 1999; Grandin & Scariano, 1986; Mukhopadhyay, 2000; Sellin, 1995; Tammet, 1995; Williams, 1992).

Throughout this article, the word *expert* is reserved for those who live with autism. It might be easy to assume that the experts whose words were the basis for this study were atypical of most on the autistic spectrum. However, the seven authors presented here represent the whole range of the spectrum, from individuals who are highly verbal and whose competence or intelligence has never been questioned to those who do not speak and have been labeled “mentally retarded.” We put the term “mentally retarded” in quotes because we consider this to be a socially constructed concept, rather than an objective category. Although several of the authors in this study were given that label, we do not feel it is a useful construct to apply to anyone.

We use the term *autism* to represent this whole range, including those who refer to themselves as having Asperger syndrome. We do not differentiate between the experts’ labels in any way, as we embrace the notion that they are all authors, all experts on their experience of autism. Furthermore, we believe that the words of the authors are so central to this work that we did not change unconventional punctuation and spelling to ensure we communicate what they actually wrote.

We recognize that all autobiographical narratives are representations of reality and are filtered through the memories and experiences of individuals. We were guided by the sentiment of Biklen (2005) as he wrote about his own use of autobiographical accounts in research.

I do not assume that the perspectives of a person classified as autistic are especially “authentic,” for this person, like anyone, lives in the world, is affected by available ideas and language, and is not any more context-free than the next person. The fact that an account is personal and based on lived experience does not make it “true” in the sense of being objective (i.e., not subjective) or wholly divorced from “public” understanding. (p. 5)

Therefore, although we recognize that all narrative is impacted by the dominant ideas of the time and represents only one person’s experience, those experiences are still the most important perspective on the understanding of autism.

In this article we do not attempt to claim a universal truth about autism or describe any “grand narratives” of the autistic experience. These authors do not speak for all people with autism, and we recognize that there is wide variation among individuals with this label and alternative perspectives on social interaction undoubtedly exist. However, these texts provide a window into the individual experience of autism for these experts, from which we can draw conclusions and raise additional questions in an effort to open the door for greater opportunity and social engagement.

Three aspects of this article make it distinct from the growing body of literature on autism. First, this research focused on autobiography as the narration of the individual and their experience of social relationships. Second, we examined how to support the development of social interactions. Therefore, this research was done not just to understand more about autism but to inform educators and parents about how to help foster social relationships. With greater understanding of practices that are most helpful, educators and parents become better equipped to support the social engagement of individuals with autism. Third, this study incorporated the perspectives of individuals with autism who used augmentative and alternative methods of communication. Two of the authors used facilitated communication and 1 used the rapid prompting method. *Facilitated communication* is an alternative means of expression for people who cannot speak, or whose speech is highly limited, and who cannot point reliably. A trained facilitator provides physical and emotional support to enable a person with limited verbal communication to type their thoughts and ideas. *Rapid prompting* is a method in which communicative responses are elicited through intensive verbal, auditory, visual, and tactile prompts.

Although we recognize the controversy over authorship that has arisen in response to these alternative methods (Bebko, Perry, & Bryson, 1996; Crews et al., 1995; Klewe, 1993; Shane & Kearns, 1994; Wheeler, Jacobson, Paglieri, & Schwartz, 1993), other researchers, using a range of testing situations and methods, have successfully demonstrated authorship of individuals who use facilitated communication (Broderick & Kasa-Hendrickson, 2001; Calculator & Singer, 1992; Cardinal, Hanson, & Wakeham, 1996; Janzen-Wilde, Duchan, & Higgenbotham, 1995; Niemi & Karna-Lin, 2002; Rubin et al., 2001; Sheehan & Matuozzi 1996; Weiss, Wagner, & Bauman, 1996). In addition, an increasing number of people are demonstrating independence with facilitated communication—typing without physical support (Biklen, 2005; Mukhopadhyay, 2000; Rubin et al., 2001) or speaking aloud as they type (Broderick & Kasa-Hendrickson, 2001). The decision to include authors who used alternative forms of communication was purposeful, because it provides access to the voices of those both with and without speech.

Method

This study was grounded in qualitative inquiry (Bogdan & Biklen, 2001; Denzin & Lincoln, 2000) by examining “meaning-making” (Pauly, 1991) of individuals with autism and their own experiences and beliefs about social interaction. By specifically using narrative inquiry (Clandinin, 2007; Clandinin & Connelly, 2000), we reviewed autobiographies of individuals labeled autistic and used their written words as data to help us understand the experience of social interaction. This article is not merely a summation of these works or a presentation of the words of these authors. Instead, in this study, we treated these important texts as data, similar to the data garnered through personal interviews or life histories. Narrative researchers have argued that the story of human experience is a central unit of analysis and worthy of investigation (Clandinin, 2007). Narrative inquiry fits within the umbrella of qualitative research in that it demands “attention to methods for analyzing and understanding stories lived and told” (Clandinin, 2007). This research project, and in particular the text selection, was deeply influenced by the work of Kluth and Chandler-Olcott (2005). As they selected autobiographical texts to determine literacy lessons for educators, we selected from a similar

pool to determine how individuals described their own experiences with social interaction.

Text Selection

Of the 20 autobiographies we considered, we chose those that (a) were written by individuals with autism and not family or friends, (b) had a focus on childhood experiences, (c) had more than eight passages dedicated to a description of experiences with social interaction, and (d) represented the wide communication range of people with autism, including individuals who do not speak. Of the 20 we reviewed, the following autobiographies met our criteria for analysis. See Table 1 for a description of those texts and their authors.

Data Analysis

The 20 works were analyzed and coded by the three researchers using both deductive and inductive analyses (Strauss & Corbin, 1998). We began by deductively coding the autobiographical texts according to the two research questions. We looked for passages and data examples that addressed the two overarching research questions. Then, proceeding inductively, we used open, also known as line-by-line, coding and axial coding to further refine our analysis (Strauss & Corbin, 1998). Rather than beginning with a preconceived notion of what we would find and then looking for evidence to prove or disprove our theories, we used the texts as data to reconceptualize constructions of the role of social interactions in the lives of individuals with autism. We identified and shared potential codes, collapsing, combining, and refining as needed until we had a set of mutually agreed on codes to use in analyzing all of the autobiographies.

In addition, to ensure accuracy of representation, this article was sent to each of the authors of the autobiographies. Each expert was asked to read the work and provide correction or suggestions for accuracy. To date, 4 of the 7 authors have responded and minor additions were made to address their original meaning. The overarching themes that emerged across texts are presented as findings in the following section.

Results

Our initial findings suggested that researchers have much to learn about social interaction of individuals with autism. Although it undoubtedly

Table 1 Information About Authors and Autobiographical Texts

Author	Gender	Country of origin	Method of communication	Autobiographical text
Sean Barron	M	United States	Speech	Barron, J., & Barron, S. (1992). <i>There's a boy in here</i> . New York: Simon & Schuster.
Lucy Blackman	F	Australia	Facilitated communication	Blackman, L. (1999). <i>Lucy's story: Autism and other adventures</i> . Redcliffe, Queensland, Australia: Book in Hand.
Temple Grandin	F	United States	Speech	Grandin, T., & Scariano, M. (1986). <i>Emergence: Labeled autistic</i> . Novato, CA: Arena Press.
Tito Mukhopadhyay	M	India	Rapid prompting method	Mukhopadhyay, T. R. (2000). <i>Beyond the silence: My life, the world and autism</i> . London: National Autistic Society.
Birger Sellin	M	Germany	Facilitated communication	Sellin, B. (1995). <i>I don't want to be inside me anymore</i> . New York: Basic Books.
Daniel Tammet	M	United States	Speech	Tammet, D. (2006). <i>Born on a blue day: Inside the extraordinary mind of an autistic savant</i> . New York: Free Press.
Donna Williams	F	Australia	Speech	Williams, D. (1992). <i>Nobody nowhere: The extraordinary biography of an autistic</i> . Garden City, NY: DoubleDay.

Note. *There's a Boy in Here* is co-authored by Sean Barron and his mother Judy. However, we only used the portions of the text written by Sean.

comes as no surprise to those who have worked closely with people who have autism, this research indicated that individuals with autism are interested in friendships and relationships. The evidence presented in these autobiographies disagrees with the common conception that these individuals

prefer to be alone. Our research findings are organized using the two main themes of (a) desiring connections and (b) navigating the world of people. This first theme of desiring connections is used to situate and highlight the importance of this work. The second theme is used because these

authors provided insight into the impact of these differences on the development of social interactions and friendships. A discussion of educational implications and directions for additional research conclude this article.

Desiring Connections

There is a common misconception that individuals with autism prefer to be alone and do not notice others. Grandin (1986) wrote, “To say that an autistic child has absolutely no response to people is a misconception.” The strongest findings in this study supported Grandin’s sentiment. Birger Sellin (1995) wrote about the pervasive nature of his loneliness.

how come I always have so many lonely hours I am lonely everywhere how come
it is always so difficult to say anything on a subject
like about my loneliness the whole story of often does no
good even does harm because i
get really really lonely. (p. 90)

He felt this loneliness as so oppressive and overbearing that death was preferable.

thats why i often wish i was dead
because im alone in my loneliness. (p. 50)

Sellin further described the feeling of loneliness. He wrote,

its like being buried
alive the loneliness of an autistic is like a great clod of
earth weighing down the soul. (p. 84)

This awareness of isolation and longing for social interaction and friendship were also described by authors who identified as having Asperger syndrome. Daniel Tammet, for example, wrote about being very aware of this isolation. “People with Asperger’s syndrome do want to make friends but find it difficult to do so. The keen sense of isolation was something I felt very deeply and was very painful for me” (Tammet, 2006, p. 78). He was particularly aware of his lack of friendship in the quiet hours of the night.

I was gradually becoming more and more aware of my loneliness and began to long for a friend. All my classmates had at least one and most had several. I would spend hours at night awake in bed looking up at the ceiling and imagining what it might be like to be friends with somebody. (Tammet, 2006, p. 74)

These examples support the idea that people with autism want to be with others and suggest that these experts are acutely aware of their own social

situations and how others perceive them. They understand, feel, and experience loneliness in ways that do not differ from anyone else. Like all human beings, these individuals desired friendship, interaction, and belonging. The ways that they experienced and navigated the social terrain, however, were quite unique. Some of the general challenges that people we interviewed faced while in “the world of people” (Grandin, 1986, p. 19) were intense.

Navigating the World of People

The autobiographies from our interviews were rich with examples of difficulty navigating the neurotypical world. Several subthemes emerged under this larger theme. These included (a) the need for predictability, (b) communication and social disorientation, (c) unconventional responses to sensory information, (d) intense interests and the work of being social, and (e) turning within: imagination as a substitute for interaction. For most people, communication, interests, sensory information, and imagination are used as vehicles to help people socialize with others and understand the world. However, our authors described these vehicles as unreliable at best and, at worst, nonfunctional.

The need for predictability. These experts’ general accounts of learning about people and the unpredictability of others were similar across narratives. These individuals appreciated predictability and a willingness on the part of other people to enter into the interaction. For Sean Barron, the unpredictability of others made him feel insecure.

People bothered me. I didn’t know what they were for or what they would do to me. They were not always the same and I had no security with them at all. Even a person who was always nice to me might be different sometimes. Things didn’t fit together to me with people. (Barron & Barron, 1992, p. 20)

Similarly, Birger Sellin wrote of going into the world and not understanding the ways of others. He described making wrong assumptions when he was with others.

a real lonely person judges wrong when he goes out among people he simply doesn’t understand their ways a lonely person is a real solitary strong loner longs secretly for the important company of the other steely cowards. (Sellin, 1995, p. 90)

Throughout many of these narratives, the individuals made assumptions about others that

were unconventional or even counterproductive. For example, Donna Williams wrote about having trouble knowing how to interact or make friends. At one point in the book, she stated, “I did not know how to make friends, so I would stand there calling this girl every four-letter word I knew.” When this friend caught her and was about to beat her up, she asked her why Williams was tormenting her. She stated, “I wanted to be your friend” (Williams, 1992, p. 32).

Communication and social disorientation. The second theme that emerged under the navigation of the social world was unconventional communication. It is imperative to have a reliable means of communication available if people are to interact with others. However, many individuals in this study experienced difficulty with communication. Some students with autism use few or no spoken words. Many individuals are increasingly finding communicative success through using facilitated typing, independent typing, assistive technology, and picture exchange systems (Biklen, 1990; Kluth, 2005).

Each of the experts used communication differently. Some spoke, some typed, and some used facilitated communication. What follows are some of the experts own explanations of their relationship to the world through communication. Sellin, a man who uses facilitated communication, described communication as way to bring people to life but also as a means for replacing what he called “social disorientation.”

talking is something very important to me it is a device for making dead people come alive again and for crazy lonely people it replaces their social disorientation. (Sellin, 1995, p. 74)

He also wrote about how he sees language as a link between people.

i love language more than anything
it links people
a language gives us dignity and individuality
i am not without language. (p. 154)

Birger asserted that he is not a person without language. He is clearly an intelligent person with complex language. Lucy Blackman wrote about her own language and the need for others to be able to accurately interpret her language. When thinking back to her childhood, she described her mother’s ability to pick up the subtleties in her body language and make meaning from them.

Successful “social” contact depended on someone else interpreting my own signals. Some of my attempts at communication were fairly conventional, as when I put my arms up toward a person with my hands stretched up because I desperately needed to be picked up or lifted over an obstacle. However Jay [Lucy’s mother] noted that if I turned my hands outward when I put my arms up, I was asking for a boost for a somersault, rather than some help climbing up. If she interpreted wrongly, things could get very noisy. (Blackman, 1999, p. 11)

Tammet narrated his schooling experience and the attempts others made to communicate with him. He struggled to make meaning from the social context of speech and had difficulty managing social expectations.

Sometimes other children in the class would try and talk to me. I say “try” because it was difficult for me to interact with them. For one thing, I did not know what to do or say. I almost always looked down at the floor as I spoke and did not think to try to make eye contact. If I did look up, I would look at another person’s mouth as it moved while they were speaking. Sometimes a teacher speaking to me would ask me to look him in the eye. Then I would bring my head up and look at him, but it took a lot of willpower and felt strange and uncomfortable. When I talked to someone it was often long, unbroken sequence of words. The idea of pausing or of taking turns in a conversation did not occur to me. (Tammet, 2006, pp. 74–75)

Tammet also wrote quite extensively about the systems that he used and the visualizations he created for himself to make sense of other peoples’ emotions. He used his own strengths and interests as a way to code for and understand more obscure concepts.

Numbers are my first language, one I often think and feel in. Emotions can be hard for me to understand or know how to react to, so I often use numbers to help me. If a friend says they feel sad or depressed, I picture myself sitting in the dark hollowness of the number 6 to help me experience the same sort of feelings and understand it. ...By doing this, numbers actually help me get closer to understanding other people. (Tammet, 2006, p. 7)

Social interaction requires the use of a commonly understood communication system, and it requires navigating a great deal of sensory information at once. For many individuals with autism, integrating those sensory systems can be quite challenging.

Unconventional responses to social sensory information. Another tool that people use to navigate their social contexts is sensory information. It is such a powerful tool that when defining *autism*, Temple Grandin (1986) stated that the sensory system is what causes the difficulty in social interaction.

Autism is a defect in the systems which process incoming sensory information causing the child to over-react to some stimuli and under-react to others. The autistic child often withdraws for her environment and the people in it to block out an onslaught of incoming stimulation. (Grandin & Scariano, 1986, p. 9)

This description rings true in the words of several experts. Specifically, sound is a very common challenge for people identified as autistic. For example, Tito Mukhopadhyay wrote about his mother arranging for him to have play dates, but the sensory information was overwhelming at times. "Every evening they came home and played, while the boy tried [referring to himself in the third person] to hide. What a noisy group! He was already disturbed by voices. He tried to flap away the sound with even greater frequency" (Mukhopadhyay, 2000, p. 11).

Similarly, sensitivity to touch was a reoccurring theme in these authors' autobiographies. The ways that individuals experienced touch, and at times feared it, was considered a barrier to interaction with others. For example, Daniel Tammet shared a time in school when his fear of touch stood in the way of participation in games.

When the time came to play social games, such as musical chairs, I refused to join in. I was frightened by the thought of the other children touching me as they shoved one another for one of the remaining seats. No amount of gentle persuasion by the supervisors would work. (Tammet, 2006, p. 20)

Although touch was something that these experts craved, having some control or predictability over that experience was important.

I craved tender touching. I ached to be loved-hugged. At the same time I withdrew from over-touch as from my overweight, overly affectionate, "marshmallow" aunt. There is a balance in teaching the autistic child the joy of touch and panicking the autistic child with the fear of engulfment. (Grandin & Scariano, 1986, p. 28)

Purposeful touch needed to be controlled with certain rules or standards. Donna Williams would not tolerate physical bodily touch, but would touch other children's hair. She stated, "Touching other children's hair was the only friendly physical contact I would make" (Williams, 1992, p. 9).

Williams wrote of the challenges faced when she had difficulty with touch and nearness of people. Those difficulties were compounded by the ways others misinterpreted her reactions and responded to her. "I had problems with people coming near me. I would flinch and move away. My father blamed my mother...My older brother

became more fed up with me, called me a spastic. I mirrored his obscene impersonations. Slap. I learned not to respond at all" (Williams, 1992, p. 19). This pattern of difficulty in handling the incoming sensory stimuli, leading to frustration and additional recrimination, highlights the difficulties several of these experts experienced.

Intense interests and the work of being social. When many people socialize, common interests are used as a vehicle for starting conversations and maintaining relationships. One theme throughout these autobiographies was having intense interests that differed from others. To be clear, the existence of these intense interests did not reduce the drive for connection but instead may have necessitated greater flexibility on the part of the peer. For example, Lucy Blackman, a young woman who uses facilitated communication, described her experiences typing with others. She stated,

I had no desire to gossip and bitch, and had no real interest in any of the things they thought were important. Sometimes typing with someone who expected me to like the things that the others had hankered after, I would express a longing for dresses, or to go to rock concerts or to have a boyfriend. However invariably when that person tried to keep the common interest going, I floundered into non-compliance. None of this was in any way as desirable as learning how to do school work in a way that would show I was bright. (Blackman, 1999, p. 10)

Blackman wrote that she desired interaction that could help her learn to demonstrate her competence. Perhaps she felt that communication was too precious to spend on less important topics. Individuals who use facilitated communication often describe the time and concerted effort it takes to use this method, which are due to the challenges posed by motor-planning differences.

Tammet (2006) shared that he was at times confused over why others were focused on such uninteresting topics. He wrote about listening to his brother's and sister's friends, "I would sit by the window overlooking the garden and listen to them playing. I could not understand why they weren't talking to each other about really interesting things, like coins or chestnuts or numbers or ladybirds" (Tammet, 2006, p. 74).

In addition, these experts considered social interaction with individuals who often did not share the same interests to be a lot of work. Sean Barron and Temple Grandin reported a great deal of stress and anxiety involved with social interaction. Grandin (1986) wrote,

Nerve attacks, complete with pounding heart, dry mouth, sweaty palms, and twitching legs, had the symptoms of “stage fright.” At puberty I was desperate for relief from the “stage fright” nerves. I alternated between erratic, impulsive behavior and withdrawal into my inner world where stimulation could be avoided. I even avoided going on class trips because they made me feel anxious. (Grandin & Scariano, p. 70)

Barron’s narrative demonstrates “the work of being social” quite clearly. To develop a sense of humor, he memorized the television show *Gilligan’s Island* as an actor would memorize lines in a play. However, his attempts at humor did not have the effect on his peers that he anticipated.

Every day I arrived home, rushed in, and turned on the show. I’d take the scene or two that I thought were the most hilarious and play them over and over in my head. I would try to capture each nuance and then imitate it. When the actors said or did something funny, they always got laughs. Therefore, I concluded, if I did the same things, I’d get the same results.

The next day I had even more material to make the other students laugh. I wanted to win them over to me. However, my attempts at humor seemed to annoy them more than anything else. They reacted with irritation and I got increasingly angry and embarrassed. My anger extended to the actors on the show as well. “They drew laughter, dammit – so why can’t I!!!” (Barron & Barron, 1992, p. 180)

In another poignant example of the effort it takes to try to engage in conversation in natural ways, Barron wrote about wanting to prove his competence and engage in conversations like others. He wrote,

I had a driving need to ask questions about the states because I could not talk the way “normal” people talked, nor could I take part in their conversations, since I didn’t understand them. Everyone else talked effortlessly, their conversations flowing as smoothly as a creek, and I felt very inferior, shut out, less important. I had to compensate for what was lacking, and what better way than to show people that I knew all fifty states, their positions on the map, the shapes of each one? I needed to show everybody how smart I really was, and by asking the questions, I was doing just that. I never asked, “What states have you been to?: but rather, “Have you been to Montana?” so that I could show them I knew all the states. (Barron & Barron, 1992, p. 203)

The intense work that these individuals undertook to attempt to make and sustain connections with others is complex and demonstrates both knowledge of these differences and a need to connect. Unfortunately, these differences lead to difficulties connecting or maintaining connections with others. At other times, these unique interests lead to real connections and friendships. For some of the experts in this study, these difficulties in

maintaining outward social connections further lead to a development of friendship substitutes.

Turning within: Imagination as a substitute for friendship. Another tool that is often used to help children navigate social play is imagination. The responses these individuals had to difficulties connecting to the world were similar to what would be expected of anyone (e.g., anger, shutting off, withdrawing). However, an interesting theme that emerged was the use of imagination or turning inward as escape from the demands of social interaction and as a replacement for intense social deprivation.

A lonely person is always replacing important experiences of poor humanity on this earth by constantly talking mostly in his lonely mind. (Sellin, 1995, p. 102)

Williams, Tammet, Grandin, and Sellin, quoted above, all wrote about imaginary friends. Donna Williams wrote,

People were forever saying that I had no friends. In fact my world was full of them. They were far more magical, reliable, predictable, and real than other children, and they came with guarantees. It was a world of my own creation where I didn’t need to control myself or the objects, animals, and nature, which were simply being in my presence. I had two other friends who did not belong to this physical world: the wisps, and a pair of green eyes named Willie that hid under my bed. (Williams, 1992, p. 9)

As a child Grandin seemed to use her imagination not as a way to have friends but as a way to defend herself against those who teased her, or as an enjoyable escape. She wrote about some of the characters in her imaginative stories.

By the time I was eleven years old, I had increased my cast of characters, and Alfred Costello was often in my made-up stories. Alfred, a real person, was in my class at school and he teased me all the time. He made fun of the way I talked, tripped me when I walked down the aisle, and called me names like “dummy” or “weirdo.” ...Alfred was a mischievous character in real life and a nasty villain in my made-up stories. In my stories Alfred threw garbage around the school grounds or stuck his tongue out at the teacher. And I laughed as I told the story out loud to myself. And when, in my stories, Alfred got caught, I laughed and laughed and laughed. (Grandin & Scariano, 1986, p. 32)

Mukhopadhyay (2000) described his relationship with his own shadow as a young boy. It was a predictable companion during the day, but at night the shadow went away and the pain of separation from his shadow was very real. He wrote, “Nights were terrible! He searched everywhere for his shadow. He flapped to call it, there was nothing but the darkness. He cried for it betrayed by the friend.” (Mukhopadhyay, 2000, p. 5)

These examples of imagination and invented companions illustrate once again the complicated nature of social interaction for many of the experts in this study. Social interaction was something each expert longed for and, at times, feared. These authors described differences in their ways of relating to the world, which impacted their development of social relationships. In the Discussion section, we consider the implications of these desires and challenges for those that seek to support individuals with autism as they navigate the complex world of social interaction.

Discussion and Implications

The implications of this study for educators are relatively straightforward. The more we understand how individuals with autism both want and need social interaction, interpret sensory information, communicate, escape from interaction, and so forth, the better equipped we will be to create classrooms that include learners with autism so that they can reach their full academic and social potential.

The classroom is composed of a web of interpersonal interactions. These interactions occur between students and teachers continuously throughout the school day. The benefits of social interaction in the classroom have been well documented by educational theorists for decades. Researchers have demonstrated that learning itself is an interpersonal act (Vygotsky, 1978). There is a clear link between interaction and achievement (Johnson, 1981; Johnson & Johnson, 1981; Marr, 1997). There is also a good deal of empirical evidence to suggest that peer interaction and self-esteem are intricately connected (Maslow, 1970). Research supports the notion that personal identity and feelings of confidence and worth are developed through interactions with peer groups (Branthwaite, 1985). The benefits of social interaction in schools cannot be discounted for any student, particularly for individuals with autism. The major implications addressed below are (a) disinterest not being the issue, (b) the necessary first step of having inclusive education, and (c) the high importance of positive attitudes and adequate supports.

Disinterest Is Not the Issue

The first implication in this work comes in realizing that it is not disinterest that separates

people with autism from others; it is, instead, difficulty navigating the world of people. Unconventional ways of seeing, hearing, interpreting touch, interpreting social cues, and knowing how to act in a social world make interaction much more complex. In realizing that it is not generally a choice, disinterest, or a preference to be alone, we must begin to look closely at educational opportunities for social interactions.

Inclusive Education: A Necessary First Step

The pervasive sentiment that individuals with autism prefer to be alone and lack social interaction skills can lead to placement in segregated classrooms with only other students with disabilities, further diminishing the opportunities for developing peer relationships. Danger exists in these misconceptions because when educators believe students choose to play, be, or learn alone, they tend to create isolated experiences for them. This is commonly used as a rationale to segregate or separate students with autism from their peers without disabilities—they do not notice anyway. This could not be further from the truth. Throughout these autobiographies, these experts were placed in segregated settings with others who could not communicate well and, therefore, had even fewer opportunities for interaction. Each individual who was educated in a setting for people with autism or other disabilities spoke of the setting as a repository for those who were unwanted or cast away and they certainly noticed. The threat of segregation was also pervasive for these individuals. William's mother threatened to send her away to an institution. Fear of going to "that place" was a negative motivator for her. Sellin wrote about not being educated in the general education classroom, the pain it caused him, and how segregation caused his "undesirable behavior."

It pains when people avoid us and the schools refuse to take us. I have lived it and felt that every day there may be others like me who are facing the social rejection like me. I must make the point clear that it is not lack of social understanding, which causes the weird behavior, but it is lack of getting to use oneself in the socially acceptable way, which causes the weird or undesirable behaviour. (Sellin, 1995, p. 57)

Placements in settings that were rich with interaction were found to be preferable. Of the autobiographies under review, the experts who were in inclusive settings were much more likely to develop complex social skills and have the

opportunities to develop friendships. Tammet spoke about the blessing of being immersed in the world.

Their presence did ultimately have a very positive influence on me, however: it forced me to gradually develop my social skills. Having people constantly around me helped me cope better with noise and change. I also began to learn how to interact with other children. (Tammet, 2006, p. 54)

As Tammet suggested, children are not going to learn to live, work, and play in an inclusive community unless they are consistently immersed in that community. Children do not learn to communicate or behave in a room with others who do not also know how to communicate or behave. Children will not develop friendships or relationships with other students without disabilities if they are not together in the same room, learning and playing side by side. Placing a child in an inclusive setting is a necessary but not sufficient first step.

Attitudes and Supports Necessary

Grandin wrote about the attitudes that teachers and parents need so that students with autism can grow to reach their own potential. These attitudes and beliefs include balancing high expectations with understanding and acceptance. “Deep, constant caring, understanding, acceptance, appropriately high expectations, and support and encouragement for which is best in him will provide a base, from which he can grow to his own potential” (Grandin & Scariano, 1986, p. 7). The notion of emotional support was a clear sentiment by the authors. When the experts wrote about relationships, they used words like “trustworthy, kind, accepting, and supportive” to describe their friends. Therefore, as educators we must create educational atmospheres where teachers, paraprofessionals, and peers are accepting and kind and believe that all individuals are deserving of friendships. Last, we must provide appropriate supports.

We cannot merely place students in inclusive classrooms, provide emotionally supportive environments, and hope for the best. In many cases, educators need to provide different kinds of inclusive supports and help students mitigate their own social context. Within each of these works, the authors reported needing someone to help them navigate the social terrain. In all seven of the cases in which responsibility was left up to the individual or to the parents to accomplish this, it was not

sufficient. This article points to the teachers’ role in helping students with autism navigate the social terrain of the classroom, the playground, the hallways, and so forth. These kinds of supports include helping students understand social situations, taking others’ perspectives into account, and learning how to make friends, enter a game, or take turns socially. Providing accurate information for peers regarding unconventional behaviors and reactions to sensory information may be a key to social support. In addition, this work implies that educators must create classrooms that are responsive to the specific sensory needs and sensitivities of their students. This may involve altering the physical environment, materials, and design of instruction to make the classroom a more comfortable place for students with autism.

These texts send another clear message. All students need access to a reliable method of communication if they are to engage with others. From the perspective of the educator, this means recognizing, supporting, and seeking alternative methods of communication as well as modeling respectful interactions for other students in the classroom. Students cannot engage in meaningful social relationships without some means of communication.

These experts suggest that attention to social interaction and friendship is imperative. Educators need to see facilitating social interaction as part of their responsibility. Teachers and support staff cannot assume that interactions and friendships will naturally develop. The work of being social should not be undertaken alone. It is not the individual with autism who alone needs to engage in friendship work, but it is the responsibility of all educators and students to develop communities that support the social belonging of all.

Limitations

Despite the results of this study, future research can improve and expand on the present investigation in several ways. First, our results came from a small sample of seven autobiographical texts. Although in some ways this small sample allowed us to read deeply for meaning, it would be beneficial to replicate this study with more autobiographical data.

Second, the data collected in this study were limited to the written and edited works of the authors. The text and data are static, and the

researchers could not go back to the text to confirm the data or ask additional questions. Therefore, misinterpretation of the data is possible. To mitigate this limitation, this article, in manuscript form, was sent by e-mail to each of the authors of the autobiographies and four of the seven responded with comments and suggestions.

Although we recognize that all narrative writing is a construction of one's interpretation of experience, the third limitation stems from the time frame in which these autobiographies were written. Five of the seven authors wrote autobiographies as adults. Therefore, these stories and reflections were limited to memory, whereas the others were written during adolescence when these events were more recent.

Future Research

To shed light on certain aspects of social relationships and answer certain research questions, this research generated more questions. First, in examining the relationships and friendships, what social supports, expectations, or contexts were necessary to develop these relationships? Second, we will continue to use this data source to get information on several other topics, including effective and ineffective responses to unconventional behavior and the use of adult supports. Last, we would like to examine the autobiographies for examples of friendships and relationships to determine what made them successful and what made them possible. This line of research will undoubtedly take us on a long journey.

Conclusion

In light of the above research, educators need to take a more active part in determining educational placements that foster belonging and inclusion with peers. In addition, educators need to create inclusive educational opportunities and environments that will help students with autism to more easily navigate the social terrain, taking into account differences in the ways that some students navigate the world. With this new knowledge, we can no longer stand idly by and watch students who appear lonely and disconnected. Instead, we need to stand beside our students who, like Birger Sellin, see "loneliness as a constant enemy." As educators we need to collectively join in the good fight against loneliness.

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