Disqualified in the human race: a close reading of the autobiographies of individuals identified as autistic

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Much can be learned about the experience of autism by listening to the voices of individuals so labelled. They describe their understanding of competence, living in a culture where autism is considered deviant, deficient and outside the range of 'normal' human experience. This paper utilises autobiographical accounts written by individuals who identify as autistic as a source of qualitative research data and specifically explores the ways in which these texts address issues of competence. Using narrative inquiry, it explores how individuals with autism, both adults and adolescents, describe their own notions of competence and, further, the instructional practices that support their ability to demonstrate their competence.

Keywords: autism; autobiography; competence; inclusive education; inclusion; intelligence

Introduction

All the world was a busy place
And I was an idle kind
Disqualified in the human race
A different form of mind
(Mukhopadhyay 2000, 65)

Those words, written by Tito Mukhopadhyay, a young man with autism, provide a fitting introduction to this study about how individuals identified as autistic define themselves and their understanding of competence through their own narratives. He describes himself as 'disqualified in the human race' by virtue of his 'different form of mind'. We look to autobiographical accounts as a way to speak back to the deficit based and medicalised constructions of autism so prevalent in the professional discourse. Many definitions of autism include a component of abnormal functioning. 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 USA:

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.

Contained within that brief description are the words 'impairment', 'restricted', 'delayed', and 'abnormal'. All of these terms imply not only difference from the norm, but

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also deviance. These words and the clinical definition from whence they came clearly mark autism as something that is outside the range of typical human existence, something undesirable.

However, for this study we looked not to those professional descriptions of the experience of autism and instead turned to personal accounts written by individuals who live with this label every day. Therefore, in this paper the term 'expert' will be reserved for those who live with the label. In this way, we move the experience of autism from the margins to the center as we examine how individuals identified as having autism describe that experience through writing. For this paper, we are especially interested in their understandings of competence and how they narrate their experiences in this area. We leave the often unconventional spelling, punctuation and form used by the authors in order to ensure authenticity. While this may impact the readability of the data passages, the centrality of the experts' writing was vitally important to this work.

The unique aspects of this study that set it apart from other literature on autism include first a focus on the individuals as a unit of analysis and secondly a consideration of instructional practices that support the development of individuals as competent learners. These authors have much to share about their own experiences and we trust that the data gleaned from these texts will prove instructive to educators as they design educational experiences that support the full and active participation of children on the autism spectrum.

Making sense of competence: the cultural meaning of 'smart'

When discussing the cultural meanings of 'smart', we should first consider widely held definitions of the term 'competence'. Competence has been defined as 'the knowledge that enables a person to speak and understand a language' (http://www.m-w.com; accessed March 10, 2007). Competence, according to this definition, refers to understanding, performance and spoken language. It is important to recognise that constructions of 'smartness' assume more than simply technical competence and performance. There is also an expectation of cultural familiarity and ability to comply with those culturally constructed norms.

Clinical definitions have assumed that a very large percentage of individuals with autism also experience differences in cognitive functioning, placing them in the mentally retarded range (Biklen 2005). Early definitions of autism by Leo Kanner (1943) claim that approximately 'one-third have severe to moderate learning difficulties'. More recent literature places that number even higher, in the range of 75% (Maurice, Green, and Luce 1996; Rapin 1997). According to the National Mental Health Association, 'About 7 in every 10 children and adolescents with autism also have mental retardation or other problems with their brain function or structure' (National Mental Health Association 2006). Despite the fact that more and more autobiographies written by individuals labelled as having autism have emerged that challenge this statistic, the conflation of autism and mental retardation remains deeply entrenched (Kasa-Hendrickson 2005).

The authors of this paper argue that mental retardation is not a useful construct to describe people with autism, or anyone for that matter. We further contend that considering the ways individuals labelled autistic describe notions of competence is far more potent and productive than describing these assumed deficiencies because it leads to a discussion of valued supports, rather than simply areas of perceived weakness. Notions of retardation and competence are not fixed ideas or absolute truths (Bogdan and Taylor 1994; Hayman 1998; Kliewer 1998). Rather, they are based on cultural norms and are perpetuated through language, media, institutions, etc. For example, in Western culture, eye contact is considered a sign of respect and understanding in conversation. Lack of eye contact can be seen

as a marker of autism. Conversely, in many Eastern cultures, eye contact between children and adults is a sign of disrespect, and therefore is not described as a manifestation of autism.

However, while all of these concepts are socially constructed (Biklen and Duchan 1994; Bogdan and Taylor 1976, 1994; Kliewer 1998; Goode 1992; Hayman 1998; Linton 1998; Barnes, Oliver and Barton 2002), the material consequences of those constructions are real and long-lasting. For example, many students have been denied access to typical classrooms and rich curricula on the basis of perceived notions of incompetence (Biklen 1992; Kliewer 1998; Kliewer and Biklen 2001; Rubin et al. 2001). Understanding how individuals with these labels make sense of their own competence in relation to these cultural norms will add to the educational literature on autism.

Theoretical framework and research questions

> how come academics know specially good stuff without having to do anything in life themselves does an academic know how sciences affect socalled simple people who are all the same. (Sellin 1995, 125)

Birger Sellin raises a provocative question that provides an apt introduction to this discussion of methodology. He seems to be challenging academics and professionals in the disability field to question whom should be defining an understanding of autism. Perhaps, he is calling for a re-centering of research that values the contribution of people with disabilities.

This study is grounded in qualitative inquiry (Bogdan and Biklen 2001; Denzin and Lincoln 2000), specifically narrative inquiry (Clandinin 2007; Clandinin and Connelly 2000). We borrow from Jankowski and Wester's (1991) notion of *verstehen*, which 'refers to an understanding of the meaning that people ascribe to their social situation and activities' (44–45) through textual analysis. Others have used narrative inquiry in a similar fashion to understand the experience of autism (Chandler-Olcott and Kluth 2006; Kluth and Chandler-Olcott 2005; Biklen 2005) and that work has laid the foundation for this current study. Narrative researchers argue that the story of human experience is a central unit of analysis and worthy of investigation (Clandinin 2007). This form of inquiry fits within the larger body of qualitative research in that it demands 'attention to methods for analysing and understanding stories lived and told' (Clandinin 2007). For this study, we reviewed autobiographies of individuals who have the label of autism and used their written words as data, similar to that gathered through personal interviews or life histories, to help us understand the construction of competence. Our work draws especially on Kluth and Chandler-Olcott (2005) and their use of autobiographical analysis to explore notions of literacy development for children and adolescents with autism. We are selecting from a similar pool of autobiographies to determine what individuals believe about their own competencies. We used the following research questions as guides:

- What do people with autism spectrum labels who write autobiographies report about their own understanding of competency and what that means in their daily lives?
- What instructional practices support individuals with autism spectrum labels in their development of a belief in their own competency?

Text selection

Text selection began by initially reviewing 20 full-length autobiographies written by adults or adolescents with autism. We then narrowed our data set using the following selection

criteria. First, we looked for texts that had more than eight passages dedicated to a description of competence, intelligence or smartness. Secondly, as we were interested in educational implications we looked for those that focused on the childhood and adolescent years. Finally, we selected narratives that represented a wide communication range, including individuals who do not speak and who use alternative or augmentative communication systems. We applied the selection criterion and the following seven autobiographies were analysed in depth: Barron and Barron (2002); Blackman (1999); Grandin and Scariano (1986); Mukhopadhyay (2000); Sellin (1995); Tammet (2006); and Williams (1992).

Data analysis

Those seven texts were read independently by both authors and then closely analysed and coded using both deductive and inductive analysis (Strauss and Corbin 1998). First, we read and deductively coded two texts independently, looking for passages that addressed the overarching research questions and taking notes in the margins on possible codes. Those potential codes were then shared, collapsed, combined and refined until we arrived at a mutually agreed upon set of codes to use in analysing all of the remaining autobiographies. The analysis then proceeded inductively, using axial and open coding (Strauss and Corbin 1998). Once we completed the reading and coding of all texts we pulled out the text passages that fit each code and organised them into a chart with the following headings: title of book, page number, data passage, and code. We then sorted the data by code to identify those that were prevalent in multiple books. With the data organised in this manner, we identified overarching themes that cut across books. The findings are presented in the following section.

Findings

Several key themes emerged from the data. The first theme of problematic performance explores the complicated interaction of knowing and doing for many of the experts in this study. In the second section, the burden of proof, we describe the experts' frustration at the ways in which they were defined and constructed as incompetent by others and the work required to 'appear smart' in light of societal expectations of normative performance. Thirdly, drawing on the experiences of the experts, we discuss how to create contexts for competence, particularly in instructional settings.

Problematic performance: knowing versus doing

Traditional constructions of competence, particularly those based on the construct of intelligence or aptitude rely on measuring a person's ability to perform certain tasks. In other words, rather than assessing understanding or awareness what they are actually testing is performance – the ability to do something or perform in a particular way. For many of the individuals in this study, this was a common problem. Consider the example of Mukhopadhyay when his mother took him to see a specialist in the field of disability:

> Time was running out and the parents took the boy to a special therapist. He [the therapist] was a bit impatient to handle a two years eleven months old boy and declared after ten minutes observation that he was sorry that the boy was mentally retarded. (Mukhopadhyay 2000, 10)

After ten minutes, Mukhopadhyay was labelled 'retarded'. It is impossible to discuss constructions of competence and intelligence without addressing the role of assessment and clinical judgment (Biklen 1988) in that process. When psychologists and other educational professionals assign labels of autism or 'mental retardation' they do it by evaluating performance on given standardised measures. As was the case for Mukhopadhyay above, this was often the result of very brief 'examinations' based on outward measures of performance.

   This was also the case for Sean Barron, who described his troubling experience with a psychologist:

> He told me to do things. He wanted me to draw a house – a square with a triangle for a roof. I heard what he said, but I didn't understand that the square and the triangle should be connected. I drew them separately, He said I hadn't done it the way he asked, so I got frustrated and gave up trying. (Barron and Barron 2002, 53–4)

Barron was able to draw the square and the triangle. He could have even put them together into a house if he had understood that was the expectation. However, his failure to comply with the examiner's expectations led to a presumption of incompetence. Rather than relying on the local understanding (Kliewer and Biklen 2001) of parents and caregivers, the experts in this study were assessed and labelled by 'professionals' operating from an etic, or outsider, perspective (Goode 1992).

   Many of the autobiographies describe the individual as fully aware of what they were being asked to do, but unable to perform in the desired way, thus leading to the assumption that they did not understand. Reframing this as an issue of performance, rather than ability, brings a new perspective to the understanding of competence. In other words, it was not that they did not understand the task; instead they were not able to *perform* the task. Several factors can impact the ability to convey understanding through bodily performance. The following section will explore issues of movement, speech, and sensory processing related to performance.

Movement and motor planning

For some people on the autism spectrum, this difficulty with performance can be attributed in part to difficulties with praxis, or motor planning. For individuals with dyspraxia, it can be difficult for them to enact their desired intention, through movement or speech. Several experts differentiated between awareness and performance, or knowing and doing. For example:

> My readers should not be guided by the idea that the boy had no 'awareness' of the things that happened around him.
>
> The main difficulty was that the boy was losing control over his body. A sense of denying its existence was so strong, that he could not respond to a situation the way it should have been done. (Mukhopadhyay 2000, 17)

Mukhopadhyay, similar to others in this study, described being aware of the world around him, cognisant of and interested in his surroundings. However, differences in motor control and bodily awareness made acting on those intentions very difficult. Movement difficulties can manifest themselves in difficulties initiating actions, continuing actions or

transitioning between activities (Donnellan and Leary 1995). Dyspraxia can also impact speech, as will be evident in the following section.

Speech

Related to difficulties with motor planning and movement, three of the experts, Mukhopadhyay, Lucy Blackman and Sellin, did not use speech as their primary means of communication and instead used alternative communication systems such as Rapid Prompting Method[1] or Facilitated Communication.[2] For some individuals identified as autistic, verbal speech is difficult. Unfortunately, speech is often intricately linked with constructions of competence. Going back to the initial definitions of competence presented earlier in this paper, speech is considered central to an understanding of competence. However, these individuals called that assumption into question:

> nonsensical knowall birger is pleased
> to be known all over the world
> lack of speech is not the same as lock of intelligence a
> speech inhibition can have various internal functions
> Bringing peace inside you
> i mean without certain knowledge of the theories known
> to no one theories from the depths of the autistic world
> you cant explain speech or get a grip on it
> it is a great problem because we need support while
> writing
> i have no idea why that should be so.
> (Sellin 1995, 199)

Sellin argues that he does not know why speech is so difficult, but that differences in verbal communication should never be construed as lack of intelligence. Others in this study echoed that message.

Complications with speech and performance were at issue even for authors who did not use alternative forms of communication. Several of the experts describe an awareness that their use of spoken language was not conventional, that they were not always able to convey in words the ideas they had in their heads. This inability to convey through speech or bodily performance led to constructions of incompetence and inability. In the following quote, Temple Grandin describes an experience in school where her teacher asked her to complete a phonetics workbook page:

> Mrs. Clark gave us each workbooks with pictures. On one page there was a box, a suitcase, a birdbath, a chair, a telephone and a bicycle. Mrs. Clark said, 'Mark the pictures that began with 'b'.' I marked the suitcase because I thought it was a box. I skipped the picture of the bird and birdbath. They were in the middle of a garden and I thought 'g' was the key sound for them. But I couldn't speak well enough to explain to Mrs. Clark why I had or had not marked certain pictures. I understood the concept of the b sound, and I had a logical reason for every mark I made. Frustration raged within me and I wanted to hit or kick to release the feeling. (Grandin and Scariano 1986, 25)

She knew the sounds that each of the pictured words began with. Her words demonstrate an understanding not only of the sound–symbol relationship, but also the meaning of the words themselves. However, she was unable to explain her logical choices through speech and was thus presumed to be unable to differentiate the sounds. Again, bodily performance could not accurately convey her awareness and understanding in the way expected by the

teacher. Difficulties with performance can also be attributed to differences in sensory processing.

Sensory processing

Many of the experts described difficulties in regulating sensory information, further complicating performance. These sensory differences can mean being over-reactive to some stimuli and under-reactive to others. For example, Williams struggled with managing the onslaught of sensory information:

> Anything I took in had to be deciphered as though it had to pass through some sort of complicated checkpoint procedure. Sometimes people would have to repeat a particular sentence several times for me, as I would hear it in bits, and the way my mind segmented their sentence into words left me with a strange and sometimes unintelligible message. (Williams 1992, 69)

In a later work, *Exposure anxiety – the invisible cage* (2003), Williams aptly describes the connection between sensory processing and constructions of competence:

> The non-autistic person is able to keep up with that rate of incoming information not because they are cleverer than people with autism or Asperger Syndrome, but because in filtering information they take in less information, so they have more time to process it. (Williams 2003, 67)

For Williams, difficulties with sensory processing should never be confused with lack of cleverness or intellectual ability.

The burden of proof : the work of looking smart

> i am so disappointed because everyone doubts
> whether I write all this by myself the people in the school center said and I even
> heard some teacher in the socalled
> study room and there was a psychologist there too I was in
> the next room and I could hear everything.
> (Sellin 1995, 69)

For individuals labelled with autism, the question of competence looms large and the work to deal with the doubts of others is both frustrating and exhausting. The following section addresses the challenge and pressure of living under the cloud of presumptions of incompetence. The subthemes in this section include: (1) the language of incompetence, (2) the problem of low expectations, (3) living with the doubt, (4) meeting the burden of proof, and (5) the importance of trust and relationship.

Language of incompetence

One of the most compelling themes throughout the books was the experts' discussion of the language used to describe them. According to Williams:

> To them [her family], I was a nut, a retard, a spastic. I threw 'mentals,' and couldn't act normal. (Williams 1992, 11)

And later in the book:

> They had thought of a new name for me, I was now 'a blonk'. This meant that I was a moron. My brother would bring his face close up and announce, 'Wonk, wonk, blonk, blonk'. His proximity deeply disturbed me, but now so did his words. (Williams 1992, 53)

'Blonk', 'retard', 'moron', 'nut'. All of these words were used to describe and define Williams. Disability studies literature reminds us of the importance of language, including spoken language and interaction, writing and cultural artefacts. From a symbolic interactionist perspective, objects have no meaning outside of the ways in which we act on them. Therefore, it stands to reason that language plays a vital role in creating and recreating meaning – in this case, the meaning of competence and retardation. This includes formal, clinical language as well as the more informal language heard in casual conversation.

From a social constructionist position, the maintenance and furthering of the diagnosis and human condition called, 'mental retardation' relies on the words and actions of professionals and non-professionals. If Western civilization suddenly lost the vocabulary of mental retardation, including terms such as intelligence, normal, disability, and so on, the constructed reality of mental retardation would no longer continue in its present form (Danforth and Navarro 1998, 31).

What is so damaging from about these terms, aside from the stigmatising nature of the labels themselves, is that they not only reflect societal ideas of normalcy and deviance, but they also shape those ideas. 'Labels have a way of drawing our attention away from understanding the individual as a complex and competent person. Rather, what we see is reinterpreted within the stereotypes associated with a particular disability' (Kliewer and Biklen 1996, 91). Instead of seeing persons labelled autistic as complex, unique individuals, they are instead viewed by how well they do or do not conform to the cultural stereotype. Actions that may be seen as just part of their personality had they been an unlabeled person are inscribed with meaning when considered in relation to the label. Language both reflects and shapes the ways in which individuals with disabilities are constructed. Once someone is seen through a lens of retardation, the person behind the label becomes obscured, often leading to denial of opportunities and limited expectations.

The problem of low expectations

Many of the experts described frustration at the extremely low expectations to which they were subjected. For Sellin that meant being asked to do simple arithmetic when he was capable of so much more:

> i don't want to do sums because i am too big i am big and
> clever and handicapped
> i am a sad case …
> anyway i don't want to be handicapped.
> (Sellin 1995, 63)

Contrast the preceding passage, where Sellin describes his frustration at having to 'do sums', with the following, where he declares that all he really wants for Christmas is a good copy of Nietzsche. The juxtaposition of those two statements is striking:

> I have been thrown out of the institution again
> Because they all say i didn't know what I wanted
> Because yet again nothing new would be right
> Question: WHAT WOULD YOU LIKE FOR CHRISTMAS?

> I would like a good edition of crazy Nietzsche.
> (Sellin 1995, 211)

These contradictory constructions of Sellin illustrate the tension that existed in many of these autobiographical accounts. The experts were seen as and referred to as 'idiots' and 'retards' and given simple work to complete, while they were actually craving challenge and stimulation. The danger of these low expectations is that for several of these individuals they led to limited opportunities and denial of access to enriching curriculum.

Exposure to consistently low expectations and demeaning language were frequent occurrences for many of the experts in this study. These low expectations were often based on a presumption of incompetence, due to the difficulties that the experts had conforming to societal standards of 'normal' performance. The next section addresses the challenges of living with the doubt and the work it takes to maintain the appearance of 'smart' and 'normal' according to societal standards of performance.

Living with the doubt

Nearly all of the experts had to live with the knowledge that others in their lives doubted their competence and even doubted that the work they produced was genuine:

> I tried so hard to convince people that I was capable of their precious 'normality'. It was this that, so strongly against my own will, caused me to fight so hard for so little reward for the joyless achievement of remaining aware and responsive. (Williams 1992, 79)

For Williams, it was a battle to be seen as 'normal' – a battle with limited rewards. This concept of normal or the 'normate body' to use Garland Thomson's (1997, 8) vocabulary 'usefully designates the social figure through which people can represent themselves a human beings'. The normate represents what it means to be fully human without contingency. Normalcy is, however, a mythical state, a construction rather than a reality. However, as Williams describes, even if 'normal' is only a construction, it is a construction with real consequences – denial of opportunity, segregation, doubt of authorship.

For the experts who did not use speech as their primary means of communication, the question of competence was further complicated. For the experts in this study who did not rely on speech, one used the Rapid Prompting Method and two used Facilitated Communication. While there are increasing numbers of individuals who have demonstrated independence with Facilitated Communication – typing without physical support (Biklen 2005; Mukhopadhyay 2000; Rubin et al. 2001) or speaking aloud as they type (Broderick and Kasa-Hendrickson 2001), the controversy over authorship continues, undoubtedly fuelling the doubt and scrutiny described by the individuals in this study. The controversy over Facilitated Communication in the USA centred on the question of authorship. In other words, critics questioned who was actually doing the typing, the Facilitated Communication user or the person providing the physical and emotional support. The use of Facilitated Communication grew increasingly contentious as some Facilitated Communication users typed sensitive messages, including allegations of abuse. A number of studies have failed to validate authorship and have shown that a facilitator's physical support can influence the person's pointing (Bebko, Perry, and Bryson 1996; Crews et al. 1995; Klewe 1993; Shane and Kearns 1994; Wheeler et al. 1993). However, other studies using a range of testing situations and methods of documentation have successfully demonstrated authorship on the part of the person who uses Facilitated Communication (Broderick and Kasa-Hendrickson 2001;

Calculator and Singer 1992; Cardinal, Hanson, and Wakeham 1996; Janzen-Wilde, Duchan, and Higgenbotham 1995; Niemi and Karna-Lin 2002; Rubin et al. 2001; Sheehan and Matuozzi 1996; Weiss, Wagner, and Bauman 1996).

Mukhopadhyay, who uses the Rapid Prompting Method, describes the scepticism that clouded his successes. 'Some, yes, said they were impressed. But there were others who were a bit skeptical as to "how a boy who can't talk, can calculate and communicate"' (Mukhopadhyay 2000, 23). For Mukhopadhyay, Blackman, and Sellin, challenges to their systems of communication became challenges to their own competence, placing the burden of proof squarely on their shoulders.

Baffled and exhausted: meeting the burden of proof

As the previous sections describe, living under the shadow of suspicion was very difficult for the experts. However, their efforts to mitigate that doubt and to prove themselves to others should not be overlooked. Even for the individuals who did speak, the burden of proof was ever present. Barron describes his awareness of the indicators of intelligence and the effort he made to meet those cultural expectations.

> I became aware that people used language to communicate with one another, but I didn't know how this was done. I got the idea that big words were a sign of intelligence. So, to make myself smarter, I decided to read the *Random House Dictionary.* It was the biggest one we had. That day, after school, I started reading with the first definition. Every day I read as much as I could, concentrating as hard as possible. Nearly eight weeks later I finished the dictionary. I felt a sense of power, and I was eager to have people hear me use these words! I didn't know how to use them in context, I realized years later. But when I was fifteen I thought I could just substitute a big word for a small one and everyone would say, 'Boy is he smart!' When my plan failed I was baffled and hurt. At first I was angry with everyone, but then I know what it really meant: I still didn't have a clue as to how people talked to one another. (Barron and Barron 2002, 197)

Barron was aware that demonstrating a command of the English language was a marker of intelligence and he desperately wanted to be seen as smart. So, he memorised the dictionary to prove his intelligence to those who doubted him. Barron also memorised the locations and shapes of all 50 states as well as the call letters for radio stations all over the country as a way to demonstrate his intelligence. However, this unconventional knowledge was not acknowledged or valued by the people he so desperately wanted to impress. He was instead seen as strange.

For Sellin, the work of showing what he knows takes a physical as well as emotional toll.

> i want everyone to
> know that autistic children aren't stupid the way people
> often think im not a real person without the writing
> because it's the only means of expression i have and it's the
> only way of showing how i think and i do it too but its
> still very difficult i find it very exhausting.
> (Sellin 1995, 57)

Difficult, exhausting – those are the words Sellin uses to describe his efforts at meeting the burden of proof. In other writings he expresses his frustration that no one recognises how much energy it takes to perform in ways that meet societal expectation. 'nobody asks how difficult it is'. For these experts, the work of proving themselves to others was exhausting, a battle for dignity and recognition.

The importance of trust and relationship

For individuals presumed to be retarded, the stakes for performance are very, very high. However, the stress and anxiety of performance was alleviated for some of the authors when the people who supported them believed in their abilities. According to Mukhopadhyay:

> The boy [referring to himself in the third person] wondered about the different thoughts that the people had and behaved accordingly. For them, who trusted him, he was eager to communicate, but for those who were skeptics, he refused to co-operate. (Mukhopadhyay 2000, 23)

For Mukhopadhyay, belief and trust were essential components to performance. The last section of this paper describes the contexts for competence evidenced by the autobiographical accounts.

Creating contexts for competence

In this final section we outline several factors identified by the experts as supportive of their demonstration of competence. These factors include the importance of (1) presuming competence, (2) building on interests, (3) making it 'real' or concrete, (4) structure, and (5) inclusion. While several of the examples provided come from home environments, rather than schools and teachers, we extend their application to the classroom arena.

The presumption of competence

For some of the experts, the limiting descriptions and identities ascribed by those outside the family were counterbalanced by family members or teachers who believed in their abilities even in the absence of 'evidence'. Anne Donnellen, a researcher in the field of autism, describes this as making the least dangerous assumption, meaning that even in the absence of evidence, educators should adopt practices and policies that are least likely to limit potential. Mukhopadhyay writes about receiving the diagnosis of 'mental retardation' and his mother's refusal to accept this notion, instead operating on the least dangerous assumption about her son:

> It was a terrible thing to hear from a doctor in Calcutta that I was mentally retarded. And thank God that mother did not believe it after the initial shock because I had proved to her that I was not. (Mukhopadhyay 2000, 10)

Rather than relying on proof of competence before granting access to rich educational experiences, a presumption of competence approach 'implies that educators must assume students can and will change and, that through engagement with the world, will demonstrate complexities of thought and action that could not necessarily be anticipated' (Biklen and Burke 2006). Parents, however, are not the only ones who need to presume competence. Educators do as well:

> Mr. Reynolds (a dear teacher) never emphasized ability, but instead allowed me to show him what I was capable of, and he would tell me which things I did better than others. (Grandin and Scariano 1986, 38)

Those are the words of Grandin, talking about one of her teachers. Rather than starting from a presumption of inability, this teacher kept the door of possibility always open for Grandin to step through and share what she knew. Key to a presumption of competence is a focus on supporting student interests.

Building on interests

> If anybody wonders, 'how a dumb, mute boy learns anything' I shall tell them that 'anybody can learn anything'. I shall tell them that 'anybody can learn anything if one has the interest. More the interest, faster is the ability to learn'. (Mukhopadhyay 2000, 15)

Learning is possible, but the student needs to feel connected to the material and needs to be interested. Many of the texts described the importance of building on interests, even interests that seem unconventional. A hallmark of many definitions of autism is the idea of intense fascinations on particular topics. One common approach to the education of students with autism is to eradicate those specific interests in favour of those that seem more typical and to increase focus on the task at hand. These experts, however, advocate a very different approach. Rather than trying to eliminate those interests, they channel them into experiences for learning.

For Grandin, that meant encouraging a fascination with building and mechanics, particularly an interest in the 'squeeze machines', used in the handling of cattle. She writes:

> Mr. Carlock, was my salvation. Mr. Carlock didn't see any of the labels, just the underlying talents. Even the principal had doubts about my getting through tech school. But Mr. Carlock believed in building what was within the student. He channeled my fixations into constructive projects. He didn't try to draw me into his world but came instead into my world. (Grandin and Scariano 1986, 82)

Grandin has translated that intense interest into a successful career in animal husbandry that might never have been possible without the support of teachers who recognised her potential and supported her interests. In addition, she had teachers who made learning 'real' for her.

Making it 'real' or concrete

In addition to building on interests, several experts described the importance of making abstract concepts real and concrete. Returning to Grandin, she describes how she learned the concept of 'pi':

> The only thing I remember in math class was a hands-on demonstration of 'pi' – the formula for finding the area of a circle. I remember the teacher took a cardboard circle and wrapped a string around the circumference and showed the class it equaled three diameters with a little left over which worked out to 3.14. This was real to me. I saw it. I understood it. (Grandin and Scariano 1986, 56)

Mukhopadhyay also relates how his mother was able to teach him abstract games such as 'chase' by providing a concrete and real object to follow:

> The catch and chase game was also having a problem for the boy, as he could not chase anybody, though he enjoyed somebody chasing him and gave a running and dodging game to the other person who chased him. The difficulty was overcome, when his mother held a biscuit in her hand and taught the boy how to chase the 'person' by slowly fading the biscuit. (Mukhopadhyay 2000, 38)

Real objects helped them to make connections to abstract ideas. They also provided a visual cue that supported learning. Predictability and structure also supported learning.

Importance of structure

Many of the experts craved predictability and consistency and therefore reacted positively to structure and routine. The demands of performance were more easily handled when there were clear expectations and a sense of control. According to Barron:

> School was very soothing to me in a way. I immediately saw the structure of it, and that helped me feel I had some control. Since I could already tell time when I got there, I knew exactly wheat would happen when – and that had a calming effect on me. (Barron and Barron 2002, 83)

Difficulties with performance were mitigated when the experts knew what to expect and could count on people relating to them in reliable ways. While complete consistency is not possible, these experts describe the comfort that comes from structure. Conversely, open-ended situations were difficult:

> He was a lover of regulations. Walking on the road was easier than walking on the fields. He hated places that were full of freedom and got hyperactive. (Mukhopadhyay 2000)

Importance of inclusion

When discussing creating contexts for competence, the importance of school inclusion cannot be overlooked. The individuals whose works we studied experienced a mix of educational placements from fully inclusive classrooms to segregated schools and institutions. For individuals like Barron, Williams and Sellin, the threat and impact of segregation was significant. In the following passage, Sellin makes an impassioned and compelling argument for inclusion:

> but how can a person really know
> what a sensible person is
> how can a person know
> how things work
> if he is shut out of society.
> (Sellin 1995, 114)

How can someone demonstrate competence, how can they learn from others if they are shut away from society? Learning is a social process, in which people learn from each other and with each other. Therefore, learning cannot occur without interaction (Vygotsky 1978). Inclusion in typical classrooms with access to rich educational experiences is a necessary means to this end.

Future research

As we continue to learn from these accounts, several questions arise that we wish to explore through further research. First, how do individuals labelled autistic make sense of, and critically interrogate, concepts of intelligence and retardation. While many of the experts argued vehemently for recognition of their own intelligence, this current article does not address global notions of retardation. In other words, while many individuals labelled autistic deny retardation as a meaningful construct to define themselves, we wish to explore further how they make sense of this idea for others. According to these experts, is it the construct of retardation that is faulty or only the application? In addition, we wish to further develop the interaction of communication and behaviour with constructions of competence.

Conclusion

It is clear from this study that a consideration of competence must include more than simply looking at intelligence test scores and mental age equivalents. The experts in this study present a far more useful and compelling way of thinking about smartness and competence. They present themselves through their writing as unique individuals with much to contribute, who are very aware of the narrow ways in which they have often been constructed by others. Through this paper, we explored the issue of problematic performance as evidenced through differences in movement, sensory processing and speech. In addition, the experts in this study describe how they have been constructed as incompetent and the challenges of working under that threat of doubt. Finally, we discussed contexts and strategies that supported a demonstration of competence.

These autobiographies are powerful in that they interrupt dominant notions of disability-as-deficiency and force the reader to challenge assumptions about competence and participation. One of the strengths of this research is that it is a call to action for all educators to broaden conceptions of intelligence. Rather than seeing intelligence and competence as a fixed set of expectations regarding scores on IQ tests or performance on standardised measures, we need to recognise the socially constructed nature of ability and disability and recognise alternative notions of intelligence. As educators we need to rethink competence and broaden our conceptualisation of intelligence and 'normative' performance. We have to see creating inclusive contexts for competence as part of our job, perhaps our most important job. By recognising and valuing the 'different form[s] of mind' we will no longer disqualify people from this thing we call the human race.

Notes

1. Rapid Prompting is a method where communicative responses are elicited through intensive verbal, auditory, visual, and tactile prompts. However, it is considered to be different from Facilitated Communication.
2. Facilitated Communication is an alternative means of expression for people who cannot speak, or whose speech is highly limited (e.g., echoed, limited to one or a few word utterances), and who cannot point reliably. The method has been used as a means to communicate with individuals with severe disabilities, including persons with labels of 'mental retardation', autism, Down's syndrome, and other developmental disabilities.

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References

American Psychiatric Association. 2000. *Diagnostic and statistical manual of mental disorders: DSM-IV-TR.* Washington, DC: American Psychiatric Association.

Barnes, C., M. Oliver, and L. Barton, 2002. *Disability studies today.* Cambridge: Policy Press.

Barron, J., and S. Barron. 1992. *There's a boy in here.* New York, NY: Simon & Schuster.

Barron, J., and S. Barron. 2002. *There's a boy in here: Emerging from the bonds of autism.* Arlington, TX: Future Horizons.

Bebko, J., A. Perry, and S. Bryson. 1996. Multiple method validation study of facilitated communication: ii. Individual differences and subgroup results. *Journal of Autism and Developmental Disabilities* 26: 19–42.

Biklen, D. 1988. The myth of clinical judgment. *Journal of Social Issues* 44, no. 1: 127–40.

Biklen, D. 1992. *Schooling without labels.* Philadelphia, PA: Temple University Press.

Biklen, D. 2005. *Autism and the myth of the person alone.* New York, NY: New York University Press.

Biklen, D., and J. Burke. 2006. Presuming competence. *Equity and Excellence in Education* 39, no. 2: 166–75.

Biklen, D., and J. Duchan. 1994. '*I am intelligent.*': The social construction of mental Retardation. *Journal of the Association for Persons with Severe Disabilities* 19, no. 3: 173–84.

Blackman, L. 1999. *Lucy's story: Autism and other adventures.* Redcliffe, Qld: Book in Hand.

Bogdan, R., and S.K. Biklen. 1998. *Qualitative research for education: An introduction to theory and method.* Boston, MA: Allyn & Bacon.

Bogdan, R., and S. Taylor. 1976. The judged, not the judges: An insiders' view of mental retardation. *American Psychologist* 31, no. 1: 47–52.

Bogdan, R., and S. Taylor. 1994. *The social meaning of mental retardation: Two life stories.* New York, NY: Teacher's College Press.

Broderick, A., and C. Kasa-Hendrickson. 2001. 'Say just one word at first': The emergence of reliable speech in a student labeled with autism. *Journal of the Association for People with Severe Handicaps* 26: 13–24.

Calculator, S., and K. Singer. 1992. Preliminary validation of facilitated communication. *Topics in Language Disorders* 12: ix–xvi.

Cardinal, D.N., D. Hanson, and J. Wakeham. 1996. Investigation of authorship in facilitated communication. *Mental Retardation* 34: 231–42.

Chandler-Olcott, K., and P.M. Kluth. 2006. Mother's voice was the main source of learning: Parents' role in supporting the literacy development of students with autism. Paper presented at the Annual Meeting of the National Reading Conference in Los Angeles, CA, USA.

Clandinin, D.J. 2007. *Handbook of narrative inquiry: Mapping a methodology.* Thousand Oaks, CA: Sage.

Clandinin, D.J., and M. Connelly. 2000. *Narrative inquiry: Experience and story in qualitative research.* San Francisco, CA: Jossey-Bass.

Crews, W., E. Sanders, L. Hensley, Y. Johnson, S. Bonaventura, and R. Rhodes. 1995. An evaluation of facilitated communication in a group of nonverbal individuals with mental retardation. *Journal of Autism and Developmental Disorders* 25: 205–13.

Danforth, S., and V. Navarro. 1998. Speech acts: Sampling the social construction of mental retardation in everyday life. *Mental Retardation* 36: 31–43.

Denzin, N.K., and Y.S. Lincoln. 2000. *Handbook of qualitative research.* Rev. Ed. Thousand Oaks, CA: Sage.

Donnellan, A.M., and M.R. Leary. 1995. *Movement differences and diversity in autism and mental retardation.* Madison, WI: DRI Press.

Garland Thomson, P. 1997. *Extraordinary bodies.* New York, NY: Columbia University Press.

Goode, D. 1992. Who is Bobby? Ideology and method in discovery of a Down syndrome person's competence. In *Interpreting disability: A qualitative reader,* eds P.M. Ferguson, D.L. Ferguson, and S.J. Taylor (197–212). New York, NY: Teacher's College Press.

Grandin, T., and M. Scariano. 1986. *Emergence: Labeled autistic.* Navato, CA: Arena.

Hayman, R.L. 1998. *The smart culture: Society, intelligence and the law.* New York, NY: New York University Press.

Jankowski, N.W., and F. Wester. 1991. The qualitative tradition in social science enquiry: Contributions to mass communication research. In *A handbook of qualitative methodologies for mass communication research,* ed. K.B. Jensen and N.W. Jankowski, 44–74. London and New York: Routledge.

Janzen-Wilde, M., J. Duchan, and D. Higginbotham. 1995. Successful use of facilitated communication with an oral child. *Journal of Speech and Hearing Research* 38: 658–76.

Kanner, L. 1943. Autistic disturbances of affective contact. *Nervous Child* 2: 217–50.

Kasa-Hendrickson, C. 2005. There's no way this kid's retarded: Teachers' optimistic constructions of students' abilities. *International Journal of Inclusive Education* 9, no. 1: 55–69.

Klewe, L. 1993. Brief report: An empirical evaluation of spelling boards as a means of communication for the multihandicapped. *Journal of Autism and Developmental Disorders* 23: 559–66.

Kliewer, C. 1998. *Schooling children with Down syndrome: Toward an understanding of possibility.* New York, NY: Teacher's College Press.

Kliewer, C., and D. Biklen. 1996. Labelling: Who wants to be called retarded? In *Controversial issues confronting special education,* ed. S. Stainback and S. Stainback, 83–95. Boston: Allyn and Bacon.

Kliewer, C., and D. Biklen. 2001. 'School's not really a place for reading': A research synthesis of the literate lives of students with severe disabilities. *Journal of the Association for Persons with Severe Handicaps* 26: 1–12.

Kluth, P., and K. Chandler-Olcott. 2005. Never give up on a child: Literacy lessons from autobiographies written by people with autism. Paper presented at the meeting of the American Educational Research Association, April 2005, in Montreal, Quebec, Canada.

Linton, S. 1998. *Claiming disability: knowledge and identity.* New York, NY: New York University Press.

Maurice, C., G. Green, and S. Luce. 1996. *Behavioral intervention for young children with autism.* Austin, TX: PRO-ED.

Mukhopadhyay, T.R. 2000. *Beyond the silence: My life, the world and autism.* London: National Autistic Society.

National Mental Health Association. 2006. *Fact sheet on autism.* National Mental Health Association. http://www.sutistics.org/library/nopioneer.htm/.

Niemi, J., and E. Karna-Lin. 2002. Grammar and lexicon in facilitated communication: A linguistic authorship analysis of a Finnish case. *Mental Retardation* 40: 347–57.

Rapin, I. 1997. Autism. *New England Journal of Medicine* 337, no. 2: 97–104.

Rubin, S., D. Biklen, C. Kasa-Hendrickson, P. Kluth, D.N. Cardinal, and A. Broderick. 2001. Independence, participation, and the meaning of intellectual ability. *Disability and Society* 16: 415–29.

Sellin, B. 1995. *I don't want to be inside me anymore.* New York, NY: Basic.

Shane, H., and K. Kearns. 1994. An examination of the role of the facilitator in 'facilitated communication'. *American Journal of Speech–Language Pathology* 3: 48–54.

Sheehan, C., and R. Matuozzi. 1996. Investigation of the validity of facilitated communication through the disclosure of unknown information. *Mental Retardation* 34: 94–107.

Strauss, A., and J. Corbin. 1998. *Basics of qualitative research techniques and procedures for developing grounded theory.* 2nd ed. Newbury Park, CA: Sage.

Tammet, D. 2006. *Born on a blue day: Inside the extraordinary mind of an autistic savant.* New York, NY: Free Press.

Vygotsky, L.S. 1978. *Mind in society: The development of higher psychological process.* Cambridge, MA: Harvard University Press.

Weiss, M., S. Wagner, and M. Bauman. 1996. A validated case study of facilitated communication. *Mental Retardation* 34: 220–30.

Wheeler, D., J. Jacobson, R. Paglieri, and A. Schwartz. 1993. An experimental assessment of facilitated communication. *Mental Retardation* 31: 49–60.

Williams, D. 1992. *Nobody nowhere: The extraordinary biography of an autistic.* Garden City, NY: Double Day.

Williams, D. 2003. *Exposure anxiety – the invisible cage: An exploration of self protection responses in the autism spectrum and beyond.* London: Jessica Kingsley.