

Independence, Participation, and the Meaning of Intellectual Ability

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ABSTRACT *This article presents a non-speaking person's perspectives on independence and the implications of newfound communication abilities for her participation in the world and upon the meaning of intellectual ability. The person with the communication disability also has autism and, early in her life, was classified by school officials as 'severely retarded'. The narrative focuses especially on the concepts of independence, participation, and intellectual competence or intellectual performance, and their relationship to the concepts of democracy, freedom, and identity, all from a non-essentialist perspective. In addition, the article addresses practical questions about how, from her perspective, the non-speaking person developed the ability to communicate without physical support.*

Introduction

This article focuses on a non-speaking person's perspectives on independence and the implications of newfound communication abilities for her participation in the world and upon the meaning of intellectual ability.¹ The concepts of independence, participation and intellectual competence or intellectual performance of course cannot be understood apart from how they are interpreted and practiced, and how they relate to still other concepts, for example, democracy, action, freedom and identity. In this study, however, we are also focusing on independent action as a practical question. How does a person with autism come to be able to independently move a hand, to type a letter, to form a word and thus to articulate ideas? How does one develop strategies to make even the physical acts of expression possible? How do these relate to more general questions about disability identity and inclusion?

We entered into this study from a critical perspective. We wanted to explore the idea of participation or what Greene has referred to as freedom to create 'the kinds of conditions in which people can be themselves' (Greene, quoted in Kohli, 1998,

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p. 18). How does one come to participate in ever fuller, more complex ways? In part, our focus on participation was a technical one—how to move, how to point to communicate without physical support—but also a broader question of inclusion. Kohli, in an account of Greene’s notion of freedom, describes it this way:

For Greene, acting, choosing, and deciding are what make a person free: ‘The person choosing breaks the chain of causes and effects, of probabilities, in which he normally feels himself to be entangled. He breaks it in part by asking “Why?” by perceiving the habitual itself to be an obstacle to his growing, his pursuit of meaning, his interpreting and naming his world’. (p. 7)

Freedom, Greene says, ‘is the freedom to decide what sort of person you ought to be’ (quoted in Kohli, p. 18).

This seems to be similar to Bernstein’s idea of enhancement, of the opportunity and conditions to test and expand or cross boundaries:

Enhancement has to do with boundaries and experiencing boundaries as tension points between the past and possible futures. Enhancement is not simply the right to be *more* personally, *more* intellectually, *more* socially, *more* materially, it is the right to the means of critical understanding and to new possibilities. (Bernstein, 1996, p. 5)

We were interested in physical independence but also on the meaning of participatory independence in social and intellectual life.

We acknowledge that disability identity, like gender and race identity has been largely linked to particular, imposed, interpretations of the body. The nonspeaking body has been often equated with nonthinking (Borthwick & Crossley, 1999) or limited thinking (Brown, 1970). This was essentially the definition imposed upon the first author of this study, as school assessments were used to classify her as ‘severely retarded’.² This study and article are in part, therefore, about the body’s relation to performance, but also about the culture’s interpretation of the body and the person-with-a-disability’s construction of identity. In this way, the article approaches identity much as others have explored ethnicity, race and gender:

Ethnic and national identities operate in the lives of individuals by connecting them with some people, dividing them from others. Such identities are often deeply integral to a person’s sense of self, defining an ‘I’ by placing it against a background ‘we.’ ... Racial identities, like those along the dimensions of gender and sexuality, are defined in a peculiarly corporeal way: one’s identity as an African American is rooted in one’s embodiment as a black body. (Appiah & Gates, 1995, p. 4)

Like Thomson (1997), we recognise the body and particular representations of the body (e.g. independent action), together with other concepts such as mental retardation, learning difficulties and learning disabilities, and intellectual disability as ‘cultural constructs to be questioned (i.e. interrogated)’ (p. 21). Furthermore, we

agree with Thomson that 'all representation is political and comprise(s) the theoretical milieu in which ... (to) examine disability' (p. 21). In others words, 'the body as a cultural text ... is interpreted, inscribed with meaning—indeed *made*—within social relations.' This perspective, Thomson argues, is fundamentally democratic, 'denaturalizing disability's assumed inferiority, by casting it as difference rather than lack' (p. 22). In this study, a person with a communication disability speaks about this particular difference in relation to social and intellectual participation, and in so doing, moves us away from the usual, dominant discussion of a purely essentialist argument of the nonspeaking-person-trapped-in-a-disabled-body.

The Study

This study was conducted in a collaborative research style which involved correspondence and meetings back-and-forth between the principal researcher, Rubin, who is an Augmentative and Alternative Communication aide user (AAC user), and a group of collaborating researchers (henceforth referred to as the collaborating researchers). Rubin served as principal informant for the article and is its first author. She learned to communicate with facilitated communication (Crossley, 1994) and, subsequently, learned to type without physical support. Rubin has given addresses at numerous conferences and symposia and other venues including the California Autism Society of America (May 1997), the University of New Hampshire (June 1999), and the TASH International Conference (December 1998), where she gave a keynote address.

Data for the study include interviews between one of the collaborating researchers and Rubin, the AAC user, and observations of Rubin in her home and community contexts, including situations in which she gave speeches to professional audiences. The interviews were semi-structured and open-ended, and were designed to allow Rubin to talk about how she thinks about, understands, and pursues independent communication and independent living; the fc user's communication in the interviews was accomplished without any physical support as she typed. The observations were carried out in the tradition of participant observation (Taylor & Bogdan, 1984; Bogdan & Biklen, 1998). In addition, because of the slowness of communicating through typing, Rubin provided a selection of previously prepared essays and speeches that she felt would respond to some of the interview questions; this creates some choppiness to the flow of the interview-style presentation, but we think adds to the overall content. The collaborating researchers also viewed videotapes of Rubin, made of her in her college classrooms and of her giving a keynote address.

As a device of presentation, we have prepared our analysis of the topics—*achieving independence and its relationship to participation and to the meaning of intellectual ability*—in the form of an interview, constructed from all of the data sources (i.e. interviews, observations and essays/speeches). The collaborating researchers coded the data into theme areas and then constructed the interview format for the article to cover these themes. After coding the interviews and essays, again using qualitative research methods (see Bogdan & Biklen, 1998; Glaser & Strauss, 1967) the

collaborating researchers prepared a draft of the interview article, as well as a list of topical areas that they felt needed further elaboration or clarification from Rubin. As this information was provided, the collaborating researchers prepared second and third drafts, which were then reviewed and edited by the first author. The collaborators on the article went back-and-forth continuously to edit, revise and rewrite the article several times before submitting it for publication. Although there were no substantial disagreements among the research team about the content, Rubin, the AAC user and first author, had final say over the manuscript; for example, Rubin decided that the article should reproduce and contest the label ‘severely retarded’ that was imposed upon her in her school years.³

Speaking of Independence

Interviewer: You haven’t always been able to communicate with typing or pointing, and you typed for five years before beginning to type without physical support. Official records characterized you as performing at a 2-year-old level when your chronological age was actually 12 years old. What was it like before you had a way to let people know who you were inside?

Rubin: At the age of thirteen just before I was introduced to ... facilitated communication, my IQ was tested to be 24. Some people like me were so lost in a world of autism, that we did not hear what was being said. I heard people around me talking, but ... I did not process the meaning of those words. My bizarre and uncontrolled body movements also added to the belief that I was retarded. And perhaps I was. I honestly can say that I did not think for my first 13 years. I am not saying that all people with autism share this, but this was my experience.⁴

I was sadly assumed to be mentally retarded. No one made the distinction in real life if I was *labeled* mentally retarded or *was* mentally retarded.

Interviewer: So this wasn’t a question of being cured of retardation.

Rubin: No. I never would say I was cured. I am still very autistic. I am self abusive, echolalic, and obsessive/compulsive. I am definitely not cured (of autism). Was I mentally retarded before and cured of that? I don’t believe we know enough about the brain and the body to answer that. When I wasn’t able to communicate, I was not relating to the world. Was I retarded? Sadly I think I was because I wasn’t able to assert myself in any way. Actually I was a non-person. Everyone in my family and at school were great at including me socially, intellectually, culturally, and personally. I was mainstreamed for part of the day at school, I was sitting in regular classes, I was taken on all family vacations, to museums, and restaurants. I was always treated well, but I was still not asserting myself and was a passive receiver. It wasn’t until I was able to communicate that I became a part of society. Now I could actually participate in classes, be

a friend to people who wanted to extend friendship to me, actually enjoy cultural events such as concerts and museums, and assert my wishes as to where I want to go and what I want to do. I am now a person rather than a non-person.

Interviewer: So you weren't angry that psychologists assessed you as intellectually *disabled*?

Rubin: At the time I had no reaction because I was not aware. I certainly understand why I was assumed to be retarded. All my very awkward movements and all my nonsense sounds made me appear retarded. Perhaps I was. Voices floated over me when people spoke to me. I heard sounds but not words. It wasn't until I had a communication system that I was able to make sense out of the sounds. Assume killer autism was preventing me from connecting with the world.

Interviewer: A lot of people who have been classified as you were, with the impolite and prejudicial term 'retarded' now use facilitated communication, but few have progressed to the point you have of being able to type without any physical support. And as you know, there has been a large debate over whether those who do need physical support are indeed communicating or whether perhaps it is their facilitators who are communicating. Does the fact that you type without any physical support alter how you are perceived?

Rubin: As a person with autism I have very limited speech, and lack motor control governing my body movements. When I was in school autistic people like me were usually placed in separate schools or special day classes with other disabled students (and) were not allowed to learn academic subjects. Because of the way we move and our lack of speech we were assumed to be retarded. I was thought to be retarded (but) all this changed ... once I could type without support ... My very existence challenged beliefs about mental retardation. Able to type independently ... my presentations (at conferences) were acts of advocacy. Once someone had seen me, they were no longer able to assume mental retardation was present in people who looked like me. When people see me they are forced to admit that their assumptions about mental retardation are wrong.⁵

Interviewer: How did you actually get started communicating?

Rubin: When I was in the eighth grade, the school psychologist and speech therapist introduced me to facilitated communication. I was a terrible subject because of my behaviors, but my mom insisted I practice everyday at home and my teacher worked with me everyday at school. The speech therapist worked with my entire class at school because none of us had a working communication system. After a few months, I progressed from getting a few letters right, to words, then phrases, then sentences and paragraphs. By the spring I was typing well enough to go into a science

class. I was surprised that I knew a little arithmetic and could read and spell. This information was stored in my brain, but had been inaccessible.

Interviewer: You've talked before about how you decided to type independently. I wonder if you'd explain that again.

Rubin: I wanted to go to college and I knew there would always be a question about my intelligence as long as I needed physical support. Actually you said it. I decided to do it. I did it.

Interviewer: At that point, your facilitator would just hold your hair and so it seems there was a process of the facilitator putting a hand on your back or a hand on your leg, so a kind of process you went through; it was actually practicing.

Rubin: You are right. Fading did not mean independent typing.

Interviewer: Could you explain that? (Fading is a term facilitators often use to mean withdrawing physical support, for example from the hand or wrist to the elbow or shoulder and then to no physical support at all).

Rubin: The truth about fading is that fading allows independence but it doesn't assure independence.

Interviewer: Do you think that ... someone could go from having physical support at the wrist to independence in one step?

Rubin: Impossible.

Interviewer: So some amount of fading *is* required.

Rubin: Yes. However, I now can very easily fade from the wrist to independence when I first start typing with a new facilitator. Fading is no longer necessary, but I have been typing independently with many people for four years. Basically I decide when and with whom I will type independently.

Interviewer: What else do you feel is necessary?

Rubin: You have to be committed and decide to do it.

Interviewer: How did *you* do that?

Rubin: I decided I would do it when I was in San Diego. I was canceling my insecurity by being in a different environment than where I typed with support. My mom asked me a question and I began typing before she could touch me. Alice waits until a consumer tells her he wants to type independently. Basically I don't think it will work unless the FC user decides he wants to do it.

Interviewer: How exactly did you 'cancel' your insecurity?

Rubin: When I decided I wanted to be independent I ... waited until we

were in a different environment. I also chose San Diego sadly because there was a skeptic at that conference. Actually anger is a great motivator.

Interviewer: I notice that when you are typing you also speak with your voice, coming out with phrases like 'Netna netna' and 'go home go home go home birthday birthday'. Could you talk about that?

Rubin: My speech is still mostly echolalic but I am using more real speech. Still I sometimes say one thing and type another. But that is happening less. Typing is always what I want and speech is never what I want. When I use speech alone I sometimes mean what I say and other times I don't.

My awful echolalia is ... an example of movement of thought (problems). I say a word or sound and am unable to switch it off or change to a different sound. Obsessive compulsive behavior is also an example of a movement problem. I sadly get stuck with certain thoughts and actions. For example, when I say a sound I require someone to respond with a specific answering sound. I have taught the people around me how to respond.

I can control Echolalia when I am in class because I am cognitively engaged. When I type my echolalia disappears somewhat. Some people might use echolalia appropriately as a means of communication, but I never did. Since I started typing my spoken language has increased, although it is absolutely not enough for a conversation.

Interviewer: Would you talk about how and when you use independent typing?

Rubin: When I answer questions in class I do it independently when it is short answer. When I am meeting with my professors I type independently. When I am taking a test I type with support when questions are essay and independently when multiple choice. For term papers I type with support and only type independently when I need to clarify something. For math, I always needed support because it was hand-over-hand. (This refers to a practice she introduced to her parents and then at school, where she puts her hand on that of her communication partner, and as the partner holds a pencil, she guides the person in writing numbers; an alternative approach she uses is to point to multiple choice selections for math problems and then to have a communication partner record her responses).

I definitely use it (independence) when I am answering questions after a presentation. I also use it when I am communicating with people who are skeptics about FC. I use it almost all of the time when I type with my mom ... When we are writing presentations I need support.

I also use it when I am at home with Alice and Margaret (two support staff at her home) because they are very secure in their knowledge and experience with FC. I can actually type independently with most of my staff for

social typing, and only use physical support for long papers because independent typing is slow.

Sadly I can only use it for short answers with Shoba. When I type with Melody and Carol (a new facilitator for her) I need support. I will soon be able to type independently with Melody because she is feeling much more secure about FC. Carol is too new to judge. When I type with Jackie I can really do it independently but she still is unsure of herself and lightly touches my shoulder sometimes. I know she really doesn't have to but I haven't told her to stop the support. I don't want to make her nervous.

Interviewer: So the way you type with a person relates to the stage of your relationship with the person. It sounds as if you have quite a cadre of communication partners.

Rubin: Loneliness no longer is a part of my life. My support people ask me to spend time with them when they are not working. Mopping up their problems is my specialty. They respect my advice and enjoy being with me.

Interviewer: Does any particular technology make a big difference with independence for you?

Rubin: Technology is minor. The devices help, but a piece of paper with the letters on them would do. It is the method and the belief that we are intelligent that is important.

Interviewer: Does typing without any physical support affect your speed of typing or the content?

Rubin: Naturally I type slower without support. I actually type more accurately without support because I have to look at the keyboard all the time. I mean when I have support I look away throughout the time I am typing. As for content I am able to express myself better without support. I am freed from the interference by the facilitator. Facilitators can prevent me from typing my thoughts as long as we are needing a lot of support. I can type without facilitator influence if the touch is very light at my shoulder.

Interviewer: How typical is it that influence is a problem?

Rubin: Actually the person interferes each and every time that I type.

Facilitator: Okay. What do you mean by that? How do you make sure you end up typing your own thoughts?

Rubin: Actually I need, I really try very hard to overcome any influence when support is at my forearm. I actually like independent typing better.

Interviewer: When you do feel influenced, how do you go about overcoming it? What strategies do you have?

Rubin: Actually decidedly difficult. I actually force my finger to go where I want.

Interviewer: Could you talk a little about what tasks or activities are harder for you than others and under what circumstances?

Rubin: New environments are harder to type in. When I am at home I type easily. At school it is more difficult. The exception is when I am at conferences, I can type well in new environments and with new people around me. I don't know why. Actually new environments just are unsettling. I need to get more emotional support in new environments.

Interviewer: Could you explain what you mean by emotional support?

Rubin: Actually the kind of support I need depends on many factors and who is facilitating. When mom is the facilitator I get all the emotional support I need and I can type independently anywhere. In school (my mother is) ... not there so it is more difficult.

I think FC forces me to think. Speech (i.e., communication by typing) comes when thinking and movement work together.

Interviewer: You mention movement difficulties often. Are some movements easier or more difficult than others?

Rubin: All and each awful movement is difficult. The movement issue amazes many people because autistic children often are very agile climbing on roofs or walking on the back of a couch. However, this skill actually occurs without thinking. We have problems when we try to purposefully plan our movements. Sadly we cannot even move from one place to another when we want to. We compensate by going where a movement takes us and actually use our weird movements to get where we want to go. For example, when I want to move my hand around a keyboard I often touch my facilitator first and then go to the key I want. I just can't move my hand there sometimes without an intervening movement. Because of these movement problems we sometimes look retarded. For example, when someone asks me to do something, sometimes I can and other times I can't. I understand the request but I can't follow it. I absolutely will eventually be able to do it, but no one waits long enough.

Interviewer: Does physical independence affect the actual typing?

Rubin: Independence also helps with negating influence. Even when a facilitator gives minimal support at the shoulder or back, I can feel influence. Obviously I don't mean influencing which letter I hit, because that would be impossible with just a light touch on my back; however, the physical touch can influence my typing by having me know what the facilitator wants me to type. I can only verify what I am saying, not describe just how it happens. Being independent doesn't prevent this entirely, but it

makes me responsible for what I type. I can more easily reject the facilitator's awful interference with what I want to say⁶

Interviewer: How would you describe what independence means for your life?

Rubin: Actually FC can change a life. But a person is incomplete without independence. Independence begets respect and equality.

Interviewer: Is there anything else you want to say about independence?

Rubin: Supported living changed my life even more than college.⁷ I would not (have) been able to have friends without it. I wanted to move out of my parents' home when I went to college, so we bought me a house near campus. I have a roommate who also works as the FC specialist at Community Living Incorporated. She pays half the rent and utilities, but is reimbursed by community living. We get along absolutely famously most of the time. We are both adventurous and like to travel and are crazy about dancing. We go out either by ourselves or with friends, most of whom work at Community Living Inc., and always have a great time. I would like to get more involved with events at school and will now be able to do that because Leslie, a school support person, just graduated from the college last May and knows everyone on campus.

Conclusions

Three themes dominate this interview and these themes parallel Bernstein's (1996) conception of 'democracy and pedagogic rights' (p. 6). First, typing without any physical support is something that Rubin, like other AAC users, had to work toward for years, in her case over 5 years, with a combination of strategy (e.g. fading, beginning in a new setting) and personal motivation. Rubin explains that fading 'doesn't assure independence' even though it's a necessary step. In addition, and perhaps most important, she says, 'you have to be committed and decide to do it'. In this sense, accomplishing physically independent typing would seem to require ongoing dialogue between facilitators and FC users, leading to the point where the FC user decides to take a try. The support to develop physical skills associated with typing without physical support corresponds to the concepts of 'resources' provided to students 'with respect to *their needs and conditions of effective support*' (italics in original text, Bernstein, 1996, p. 8). While the technical skills of pointing and typing without physical support are not *all* that Rubin required to enjoy participation, they nevertheless were and are essential to participation.

Secondly, Rubin associates her progress in independence of all kinds, that is in typing as well as in living, with her desire to participate in the world around her. In moving to a new home, she could work on independent living. In attending college, she could participate in an academic curriculum and also work at developing collegial relationships and friendships with peers and instructors. Her participation in college and community living is in turn supported by a range of professionals, her

family and friends, and staff she hires to support her. Clearly, the participation would not be possible without a supportive family, a receptive/welcoming college community, and professionals to help make sure that the facilitators and other support staff she hires are trained to learn how to support her.

Of course, Rubin herself plays a major role in shaping the kinds of supports she receives. She designed and implemented a wide range of supports to accommodate her movement problems, obsessions and compulsions. She sometimes carries a plastic spoon with her in order to feel calm. When she feels she may have an 'outburst' she asks to be led away from people. An example of how she uses supports in her typing comes from one of the interviews conducted for this study. While one of the authors was asking her questions, Rubin took several breaks, stretched her body, and then returned to typing when her mother reminded her to.

Although he may never have had in mind the kind of circumstances and conditions we have described here, these *do* seem to constitute what Bernstein means when he refers to conditions for 'access' and 'acquisition'. There can be no effective education (i.e. access) without provision of supportive services to in turn allow for acquisition:

Acquisition requires effectively trained, committed, motivated *and* adequately salaried teachers with career prospects, sensible to the possibilities and contribution of *all* their pupils, operating in a *context* which provides the conditions for effective acquisition, and an education which enables reflection on what is to be acquired and how it is to be acquired. (Emphasis in original text, Bernstein, 1996, p. 8)

In keeping with the gendered nature of support and the inadequacy of societally provided supports even when they are expansive, Rubin was required to depend heavily on her mother for acquisition.

Other autobiographical accounts by people officially classified as autistic report similar gains *and* similarly supportive families, friends, and professional staff who were essential to the accomplishments. Grandin's first account (Grandin & Scariano, 1986) credits her devoted, innovative mother, caring and supportive relatives, and the chance to be mainstreamed with non-disabled students as crucial to her success. Grandin is described as being 'high functioning' autistic. Yet similarly, Blackman, a non-speaking person who at one time was classified as 'intellectually disabled' and was confined to special schools for people so labelled, has had experiences not unlike Grandin's. An AAC user now, able to type without any physical support, she began her communication with facilitation. She points to her devoted mother, a remarkable teacher/AAC specialist, and a college that was willing to admit her as crucial elements in her development (Blackman, 1999). Blackman, however, was known to be able to identify words—she had literacy skills—even before she learned to communicate by typing. Kochmeister (Biklen & Rice, 1999), on the other hand, was not known to have any literacy skills and in this respect more closely resembles the circumstances described in this article; she is an AAC user who types without support, but first learned to communicate with facilitation. Like Rubin, she now attends college. She points to her family, and especially her father,

as well as skilled communication specialists and an accepting college as key elements in her emergence into participation.

Thirdly, in finding a means to communicate, the first author began a process of transformation from a person who was in many ways cut off from the world—words flowed around her but she made no sense of them—and assessed and treated as having severe learning difficulties. Upon reflection, Rubin thinks of herself as possibly having been ‘retarded’, for without a means of communicating, she had stopped listening to or connecting with much of what went on around her. *With* a means of communicating, all this changed—communication was no ‘cure’ for autism, but at least with communication she could engage with the world in a much more dialogical way than had previously been allowed or been possible. She began to connect with others’ words, and eventually to participate not only in decisions about her school and living arrangements, but also in intellectual conversations, including this one.

In regard to the first author’s physical and intellectual *breaking through*, Rubin’s experiences and interpretations of her life seem to exemplify three concepts that Bernstein holds central to democracy and pedagogy, namely *confidence*, *participation*, and *inclusion*. As Bernstein argues, it is virtually impossible to act without experiencing a right to enhancement (comparable to Greene’s notion of pursuing freedom) and the *confidence* that attends it (Bernstein, 1996, pp. 6–7). Then in turn, the ability to act needs ‘the right to be included socially, intellectually, culturally and personally’ (Bernstein, 1996, p. 7). This right, he explains, is, however, ‘complex because to be “included” does not necessarily mean to be absorbed. Thus the right to be included may also require a right to be separate, to be autonomous’ (p. 7). In this case, autonomy is expressed in the personal, subjective interpretation of disability, where disability is not something to be escaped or denied, but to be understood and appreciated.

The other core concept of Bernstein’s that this interview evokes is participation. Bernstein’s idea about participation is:

(that it) is not only about discourse, about discussion, it is about practice, and a practice that must have *outcomes* ... the right to participate in procedures whereby order is constructed, maintained and changed. It is the right to participate in the construction, maintenance and transformation of order. Participation is the condition for *civic practice*, and operates at the level of politics. (Bernstein, 1996, p. 7)

In Rubin’s narrative account, participation includes having a stake and effect in redefining the notion of ability and diagnostic classifications associated with presumed ability or disability.

In retrospect, we might ask, can a non-speaking person ever be assumed intellectually unable or, as in this account, is it the environment that simply is not providing the necessary scaffolding or, in Bernstein’s terms, the conditions for access and acquisition for enhancement, for her to show the complexity within her? It may reflect an essentialist interpretation of disability that the normate world seized upon communication as the sign that Rubin should be granted a presumption of com-

petence. While some people around her found this redefinition of her competence reason to question the communication/intellectual competence nexus, the field as a whole clearly has not abandoned the essentialist notion that inability to demonstrate literacy equates with intellectual incompetence. Our view is that competence should always be presumed, with the burden upon teachers and others around the person to find ways of helping the person communicate. On this we align ourselves with McDonald, a person with cerebral palsy who herself was silenced until her teen years: 'Unless someone makes a jump by going outside the handicapped person's previous stage of communication, there is no way the speechless person can do so. Failure is no crime. Failure to give someone the benefit of the doubt is' (McDonald, in Crossley & McDonald, 1984, p. 76). In this regard, we are also reminded of the warning that Burton Blatt made about the construct of ability, and about the mistake in assuming an essentialist interpretation of disability. He used an example of another individual who once was thought of as incompetent, but then later, with a means to communicate, as very competent:

The mentally retarded (Blatt here refers to the construct 'the mentally retarded') are no more people than is the photograph a person. To understand this permits one to appreciate the beauty of a Helen Keller and to realize that—while she was not mentally retarded—before she was not mentally retarded, and before Anne Sullivan, she was mentally retarded (Eds. note: i.e. thought to be 'mentally retarded', at least within an essentialist frame). (Blatt, quoted in Taylor & Blatt, 1999, p. 79).

NOTES

- [1] In contrast to most other accounts of a controversial form of augmentative and alternative communication (AAC) called facilitated communication, that typically involves both physical and emotional support (see Crossley, 1994, 1997; Biklen & Cardinal, 1997), because this account describes the experiences of an individual who has learned to type without physical support, authorship of the words typed with facilitation is no longer contested. As Beukelman & Mirenda (1998) have noted, in regard to 'a small group of people around the world who began communicating through FC and are now able to type either independently or with minimal, hand-on-shoulder support ... There can be no doubt that, for them, FC 'worked', in that it opened the door to communication for the first time ... For them, the controversy has ended.'
- [2] The term mental retardation is still used widely in the USA, while other jurisdictions have long since abandoned this term in favor of 'intellectual disability' (Australia) and 'learning difficulties' or 'learning disabilities' (UK). In this article, we have reported on the term imposed on the first author, but subsequently dispense with the term mental retardation and refer instead to intellectual ability, recognising, of course, that the idea of intellectual ability is always socially constructed.
- [3] When we discussed this, Rubin commented, 'Why change the word mental retardation when we are described that way every day. The term doesn't matter. Sadly people mostly want to pretend they are being respectful by using a politically correct term, but it doesn't make any difference as long as they think we are not as smart as they are.'
- [4] When she was 7 years old she was assessed at a Mental Age of 2 years 11 months on the Stanford Binet, at 2 years 10 months on the Merrill Palmer Scale of Mental Tests, and 1 year 1 month on the socialisation domain of the Vineland Adaptive Behavior Scale. At age

9 years 11 months she was rated at 2 years 11 months on the Merrill Palmer Scale of Mental Tests, 2 years 6 months on the Peabody Picture Vocabulary Test-Revised (PPVT-R), and between 1 and 3 years on the motor skills, social and communication, personal living skills, community living skills portions of the Inventory for Client and Agency Planning (ICAP), and an overall assessment of 2 years 1 month in adaptive behaviour. At age 9 years 11 months her behaviour was described in a formal assessment as: 'self injurious behaviors, scratching arms, forehead', 'yelling/screaming ... becomes part of a cycle towards biting/pinching when angry, up to 10 times per day', 'Aggressive behaviour pinching, scratching others, biting adults ... behaviours function to communicate that she is angry or upset and allow for stress reduction. Susie may become angry if routine is altered or people in the routine are changed. May tantrum without identified reason.' 'Self isolation ... (She) will not interact with others unless prompted to do so even when children are within close proximity ... self stimulatory activities usually occur during self isolation ...' When tested at 12 years 10 months, just prior to learning to communicate with facilitation, the (individual) was assessed at 2 years 6 months on the Arthur Adaptation of the Leiter International Performance Scale, 1 year 4 months on the Developmental Test of Visual Motor Integration, 2 years 3 months on the Normative Adaptive Behavior Checklist, and 2 years 1 month on the broad independence rating of the Inventory for Client and Agency Planning.

- [5] Within the field of intellectual ability there is currently a debate going on concerning the relationship of communication impairments of people with developmental disabilities and findings or presumptions of incompetence. Jacobson *et al.* (1995) for example have argued, 'That there is a strong presumptive relationship, in general, between overt production and actual ability is a cornerstone of psychological assessment methodology, statistics, and psychometrics' (p. 757). In contrast to this position, Borthwick & Crossley (1999) question both the speech/retardation presumption *and* the social construct of intellectual ability itself: 'Any person dealing with a person diagnosed as mentally retarded (or intellectually impaired, or learning disabled) should specifically consider the possibility that the observed disability could be accounted for not by an all-encompassing general difference but by a more parsimonious assembly of particular symptoms—that 'mental retardation' [i.e. 'learning disability', 'learning difficulty' or 'intellectual disability'] may be, both in any given case and in its wider conceptualization, inadequate as an explanatory concept, undefinable as a scientific entity, and unhelpful as a clinical diagnosis' (paragraph 39). They argue further, 'Existing observations are similarly compatible with two directly contrary hypotheses—global mental-retardation-based language deficiency, and various combinations of specific and limited speech and executional impairments masking relatively intact language understanding or cognitive processing. We believe that the latter hypothesis involves fewer problems and offers the prospect of greater educational gains' (paragraph 40). See also, Smith (1999).
- [6] Marcus described interference similarly: 'I needed to find a way for (my facilitator) to support my typing without fouling my stream of thought ... the easiest thing to do was to find out from his touch what he anticipated I would type.' He further explained that trying to ignore this interference can be like 'trying to sing "O, Canada" when the band is playing "The Star Spangled Banner."' And overcoming it requires disciplined effort. 'Taking charge of my communication means giving up on the comforting feeling that somebody else is my leader and I am just a follower. Keeping in charge requires more self-confidence than I have sometimes. Despite these difficulties, it keeps getting easier' (Marcus & Shevin, 1997, pp. 124–125). Crossley described a similar phenomenon in the book *Speechless*, noting that even slight pressure in the facilitator's touch could influence the AAC user to type words and phrases anticipated by the facilitator, 'picking up (the facilitator's) ... unconscious signals, and ... checking on her (the AAC user's) guesses and extending them through the use of word prediction and message-prediction strategies' (1997, p. 221). Crossley argues that for such cuing to actually work in the condition where the AAC user is supported by minimal touch (e.g. hand on the back or on the leg), 'requires a highly

sophisticated knowledge of vocabulary and language structures on the part of the student' (p. 221) and is therefore different than the more frequent problem of unconscious cuing that can occur when an AAC user's hand or arm is being supported during pointing.

- [7] Two years ago, Rubin graduated from Whittier High School and entered Whittier College as a Whittier Scholar. In making the transition to college, she moved from her parents' home to a home of her own on in a neighborhood nearby Whittier College. At her house she has staff who she hires to support her in daily living, for going out into the community, and to support her in communicating. Rubin laments the fact that sometimes her behavior gets the best of her: 'I am quite horrible around my support staff ... What I need is a lot of structure in my life and support staff who are firm, fair, and confident.'

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