

## **In the Real World**

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I am a person with autism who has written two international bestsellers, *Nobody Nowhere* and *Somebody Somewhere*. Both of my books brought me into contact with a wide range of people with autism of varying "levels of functioning" from all around the world and I have come to see that this group share more in common, in terms of the mechanisms of adaptations to their autism, than in terms of the forms those adaptations take. So much of what is misassumed about autism is based on those forms; on what appears rather than what is. One thing I found we all shared in common was that none of us neatly fitted the stereotypes. There were all manner of emotions, reasoning, actions, awareness, and abilities (whether stored copies of other people's expressions or from their own selves) that would have been assumed impossible according to the (non-autistic authored) textbooks about autism and people with autism. One thing was clear—none of us could presume to speak for what appearances were or were not "autism."

Some of the people with autism I had contact with did not speak or write. Many did both, but predominantly had more "social" or "personal" written language skills than they did functional verbal ones. Two of these people had little verbal functional language but exceptional and highly distinctive writing skills through facilitated communication (FC) via which they have, over a period of time, become "independent" typers. Both had been diagnosed as "autistic" and were previously also wrongly considered "severely mentally retarded."

### **What is Autism Then?**

Autism is a pervasive developmental disorder affecting all systems of functioning: recognition and comprehension on every sensory level including proprioception, relationship between body parts, sense of self, sense of other, cognitive visualization, sequencing, categorization, synthesis, analysis and retrieval skills relating to information on all levels (sensory, emotional, mental, proprioceptive, social-interactive) and the integration of those systems.

### **Functional Systems, Integration, and "Forfeiting"**

In any one individual with autism, these "systems" may be more or less integrated, some may have been forfeited entirely in favor of others, or all systems may be in a constant state of forfeiting to maintain some level of "functioning." It is because of this that level of ability in a person with autism has neither a necessary nor an observable connection to level of functioning.

All individuals with autism find (consciously or subconsciously) their own adaptations to their pervasive developmental disorder. That is, they will find their own way of managing the relationship or non-relationship between their various systems and how they operate in interaction with "the world." This means that, for example, someone whose systems are not sufficiently integrated may ignore all emotional signals but can accumulate and process factual information in an unemotive, purely logical way. It may mean that auditory processing is "switched off" while visual or tactile processing is "switched on." It may mean that auditory comprehension is "switched on" but the processing of all "body messages" (such as need to use the toilet, hunger, cold, etc.) are put "on hold." It may mean that someone with difficulty holding awareness of two things at the same time, such as internal and external may switch awareness to one or the other but be unable to make sense of or interact at a functional level when required by the environment to use both internal and external awareness at the same time. These combinations of "systems forfeiting" are almost infinitely variable but help minimize "overload" (and its behavioral consequences).

These combinations of systems forfeiting are also almost unimaginable to people without autism, in whom systems of functioning have a reasonable degree of working integration. This inability, on the part of experts (who don't have autism) to imagine (and thereby plan out how to work with successfully) this manageable (autistic) state of disarray can lead to (among other things) two unfortunate circumstances for FC: (a) use of inappropriate testing techniques that are based on misinformed premises and faulty assumptions and (b) misinformed assumptions (and proclamations) of how things work or don't work that undermine credibility.

My stance, therefore, is that both the critics and proponents of FC are wrong for the same reasons.

### **The Problem with Testing**

People with autism who have a pervasive developmental disorder are generally pushed and pulled in directions by people who do not have autism, whose systems of functioning are reasonably integrated, and who, therefore, make sense of interaction, environment, sensory stimuli, emotions, body messages and make mental connections in the "usual," non-autistic way. When people without autism assume that people with autism are merely "slow" or "broken" versions of themselves, they may not only insult, but additionally confuse and frustrate the person with autism with behavior that naturally stems from these arrogant and ignorant assumptions.

The person with autism, in my view, learns quickly that the ways of people who do not have autism do not work for them. What is more, I feel they learn quickly that when they attempt to manage or sort out (and, inevitably react to and be frustrated by) their own systems" chaos, people without autism will generally treat their attempts as a "problem" and will

interfere like dentists working with garden tools who refuse to admit their way may not be the only comprehensible and right way of managing things and learning. One result for this may be that people with autism generally learn to "smell out" the dentists who come along with garden tools and arrogant assumptions. An inability to read body language or intonation or even to comprehend auditory stimuli is not necessary to "sensing" when a "brick wall" is approaching you. Many animals have this sensing and it requires neither telepathy nor complex processing.

Perhaps one of the reasons that FC users work better with FC proponents than with critics is that the FC user senses the "brick wall" nature of those with closed-minded assumptions who come, not to be with them, but to test them out. This has nothing to do with facilitators controlling the messages produced.

Although prompting may look like control, there is a definite distinction in practice when it comes to getting a valid or sensible response.

Although I can speak exceptionally well on many logical, intellectual concrete topics (that may require categorization, systematization but not visualization), when it comes to social language or personal-emotional expression, I can have great difficulty at times. The production of nonsense when there was previously sense is something I myself experience under frustration. Here is an example that happened this week.

After making a whole string of provoking statements, I was asked what it was that I wanted. I had been wanting something for many weeks but was unable to organize how to have this want fulfilled (which, unless having observed someone else get the same thing, requires a complex process expressing it "in the real world" out loud, getting someone to help me plan the steps to follow it through, and having them prompt the action to follow the steps). At the prompt of "what is it that you want," my first answer was "I don't know" (although I did know but could not connect and access). My mind ran amok with stored evasive responses. I had wanted to say, "a pottery wheel." The stored picture that jumped into my head came from a category of "things we couldn't have." Instead of saying "pottery wheel" I blurted "cat." When that response was checked, I again wished to say, "pottery wheel," but the stored picture that jumped into my head (which I compulsively named) came from a category of "things we already had in our house" and I said "ironing board." There was no way that I wanted either an ironing board or a cat (which we couldn't yet take care of). I had been preparing a pottery shed for the past weeks and thinking of a pottery wheel; however, I was totally unable to organize fully or even express the want without being prompted or triggered to do so. My husband is a person with autism. His prompting was not a matter of control, neither did he give me a selection of "his" tracks to follow (although sometimes that is required when I cannot come up with a selection of potential responses by which to get closer to expressing the one I mean).

Another problem with testing is the issue of self and other. As mentioned, one of the problems that can arise from a lack of systems integration, is an ability to hold awareness of two tracks at the same time-I call this being "mono."

On a simple level, this sort of "mono" can mean that one can process a sentence about "what John did" as long as John remains the central or only subject. When one of the things that John did was to meet the dog who did X, Y, and Z, cognitively either the part about the dog doesn't get processed and the part about John gets aborted as useless information. "Mono" happens on every information level.

Another expression of "mono," on a more complex level, is the inability to monitor consecutively a sense of self and other (internal-external) at the same time-the "self-other system." Although there are many adaptations to this difficulty, what this essentially means is that there is awareness of either (a) only self without a sense of other; (b) a conscious sense of other with no sense of self; (c) a fluctuation between the two; or (d) in some cases, a shutdown or forfeiting of the entire system with no awareness of either.

Any of this being the case, the manipulation of FC interaction by a tester can be a reckless and ignorant undertaking that takes no account of the adaptations the person with autism may have worked out regarding sense of self and other (internal-external). Here are some examples:

1. A person with autism's adaptation to self-other difficulty may be consciously aware and voluntarily responsive of external other (the facilitator, one's own hand, the keys) but be unconsciously aware and only automatically responsive regarding what one is expressing. In this adaptation, what one wants to express is difficult, if not impossible, to retrieve voluntarily upon request (as required by a tester), though it can (as in dreams) be prompted or triggered (which testers won't allow on the ground that it interferes with the "scientific" procedure). The output in this adaptation would be more in line with the facilitator's prompting and, therefore, assumed invalid.
2. Now, consider the opposite case in which one is consciously aware and voluntarily responsive regarding (internal) self but unaware of (external) other (including one's own hand). The prompting touch of a facilitator may be essential to getting the person to use his or her hand as a tool to communicate this awareness (as in the same case with one's mouth, lungs, voice box- but this involves more complex interactive mechanics than a hand for someone mono). In this case, the output would be different also. The output likely would be more idiosyncratic and less accommodating (or not accommodating at all) of the facilitator's attempts to guide monologue into dialogue.

3. Consider another situation of the self-other (internal- external) system at work. Not all people with autism have developed the adaptation as simultaneously maintaining conscious/voluntary and subconscious/automatic to get around self-other difficulties. Such a person, in practice, may have only subconscious awareness and automatic responsiveness of self. In a relaxed flexible FC situation, such a person may be able to express fluently, receiving feedback and conscious awareness through the reading process as the words come back through the eyes. Introduce a tester with a rigid format into this situation and the FC user may be pushed to become consciously aware of his or her actions in a way they have never been able to function and this case is doomed to "fail" the test.

4. In the opposite case in which the person has conscious awareness only of self and no awareness, subconscious or otherwise, of other, this person may be as intelligent or more intelligent as anyone in spite of a mountain of labels, but may be unable, regardless of the amount of physical guidance, to connect with his or her own hand (or voice box, lungs, or mouth) enough to demonstrate this trapped awareness. In such a case, the facilitator can only be ultra-attentive to the barest impulse within the hand and must guess the rest, stopping at the point of selection to detect any counter hand impulse. Such a case would have no hope of passing rigorous testing, yet be valid.

5. Consider another, more tragic case, in which one is subconsciously aware and automatically responsive to (external) other but has no connection with self-a case that is vulnerable to the manipulation of an overzealous facilitator-a puppet with puppet-like output.

6. Consider the case in which an FC user is consciously aware and voluntarily responsive of other but has no connection to self and you have a robot with robot-like output.

Now, finally, imagine the situation in which the FC user's adaptation to self-other difficulties is to fluctuate between several of the combinations above. Introduce a constant change of facilitators and testers and there is bound to be a dramatic shift in the nature and quantity of output, none of which proves that the FC was invalid (as suggested by critics). Just as likely, it may be the case that critics assume this to be proof of invalidity, because they do not understand mechanisms and adaptations they have never experienced and, therefore, have extreme difficulty imaging or catering for these in their non-autistic, integrated, non-mono, perceptual-cognitive-emotional-linguistic-and social-reality). Add to this (though secondary) that the facilitator supports the FC user in adhering to the adaptation that works for that FC user, and the FC user is also more likely to feel a rapport with the facilitator than with the tester.

### **Where the FC Critics and Proponents Have it Wrong**

Biklen had it right in stating that retardation is a social construct. Having "dysfunctional" or "abnormal" brain organization does not dictate the level of one's intelligence or even one's functioning-functioning is subject to adaptations and shifts among a selection of adaptations.

That people without autism with integrated systems need to learn consciously how to read and write or play music, do mathematics, design, paint, and so forth, does not mean that people with autism with poorly integrated systems cannot learn subconsciously and have this subconscious learning triggered under the right conditions-conditions requiring fewer connections and less direct interaction (such as writing over speaking).

That the person with autism may be able to absorb subliminally, process subconsciously, and use senses peripherally does not mean that he or she will, therefore, use what he or she knows, for one can have much knowing without knowing they have it (such as dreams or imagination in people without autism). It also does not necessarily mean that crude testing based on assumptions of a hidden non-autistic reality would yield results.

On the other side, a self-other problem relating to poor systems integration cannot be reduced to a mere "movement" problem (though it may feel like one). FC proponents have been cornered and called to answer questions for which they have no more answers than do the critics.

It is true that FC may forge new pathways where there had been a shutdown or permanent forfeit. It is true that FC may build awareness through visual feedback of what is expressed automatically or quicken the shifts in self-other awareness necessary for the semblance of social or communicative interaction. It is true that FC may help improve word-finding difficulties and other functional weaknesses in various other systems.

It is true that FC may prompt expression of fact and of fantasy and that some of those facts or fantasies may tread on the toes of other people's morality, ego, power, and theories. It is also a fact that although, despite the stereotypes, some people with autism can fantasize, mislead, evade, or even lie, most people with autism deal in facts that are more concrete, visual, tangible, and reliable to work with cognitively. In the telling of those facts, people with autism may be more graphic than many people without autism.

In my opinion, most claims of abuse will have substantial grounding in fact (provided the abused person has developed the self-other and other system adaptations required to communicate these facts). It is certainly true that a majority of people with autism I have heard from have experienced abuse that was either explicitly sexual or was perceived to be physically invasive. I know this was true of my own life. What is more, despite appearances, the families of people with autism are subject to greater stresses, social isolation, and a sense of impotence than many families and this, combined with the autistic difficulties that make the person with autism a likely target, must be taken into consideration regarding family support services rather than being something people shove to the side of their plates with disgust.

If FC produces claims of abuse, it is the moral obligation of people to deal with these claims objectively not be testing the validity of the FC but by testing primarily the validity of the allegations in terms of whether or not the alleged events feasibly could have occurred. It is the validity of the allegations that is in question, not the validity of the method of communicating those allegations.