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*Antioch University Seattle*

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A SINGLE-SUBJECT EVALUATION  
OF FACILITATED COMMUNICATION  
IN THE COMPLETION OF SCHOOL-ASSIGNED HOMEWORK

A Dissertation

Presented to the Faculty of  
Antioch University Seattle  
Seattle, WA

In Partial Fulfillment  
of the Requirements for the Degree  
Doctor of Psychology

By  
Nancy A. Meissner  
December 2017

A SINGLE-SUBJECT EVALUATION  
OF FACILITATED COMMUNICATION  
IN THE COMPLETION OF SCHOOL-ASSIGNED HOMEWORK

This dissertation, by Nancy A. Meissner, has been approved by the committee members signed below who recommend that it be accepted by the faculty of Antioch University Seattle in Seattle, WA in partial fulfillment of requirements for the degree of

DOCTOR OF PSYCHOLOGY

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ABSTRACT

A SINGLE-SUBJECT EVALUATION  
OF FACILITATED COMMUNICATION  
IN THE COMPLETION OF SCHOOL-ASSIGNED HOMEWORK

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Few projects have combined quantitative and qualitative approaches in the analysis of facilitated communication as did this study of a 17-year-old nonverbal autistic male responding to homework questions using facilitated communication. Findings were consistent with prior studies: Tim was minimally able to produce correct responses independent of facilitator influence under controlled conditions; whereas, at least some typed messages in the spontaneous narratives appear to be his authentic communications independent of facilitator control.

An overview of the history of facilitated communication, its related research, and the heated debates around its validity are presented. Disparate findings between controlled and non-controlled circumstances are examined, first within a traditional paradigm, and then within the framework of the past decade's sensorimotor and neuroimaging research. EEG, fMRI, and DTI neuroimaging studies indicate autism is a disorder of disrupted cerebral neural connectivity - specifically of long-range neural underconnectivity and short-range over- and, to a lesser degree, under-connectivity. Research linking these findings with the long-discounted sensorimotor behavioral research (and firsthand accounts) indicating aberrant sensory integration and motor planning processes are core features of autism has just begun.

A key argument against advocates' explanations for FC being authentic in some situations but not in others has been with their lack of a substantiating theory. Based on combined evidence from neuroimaging and sensorimotor research, this author theorizes that dyssynchronous activation of brain regions and long-range underconnectivity necessary for higher order integration of sensory input and motor planning, which are exacerbated by increased anxiety and cognitive and emotional demands imposed by controlled designs, explain the disparities between abilities to respond under controlled versus non-controlled conditions. As demonstrated through neuroimaging research, widespread disrupted cerebral neural connectivity appears to be the fundamental neurological mechanism underlying autism with its associated behaviors that have for too-long been socially interpreted and misinterpreted rather than neurologically explained. This author proposes that as task-based neuroconnectivity research advances, the disruptions in neural connectivity will account for the differing outcomes produced when typing with facilitation under controlled versus non-controlled conditions. This dissertation is available in open access at AURA, <http://aura.antioch.edu/> and Ohio Link ETD Center, <https://etd.ohiolink.edu/etd>.

*Keywords:* facilitated communication, autism, supported typing, underconnectivity, sensorimotor integration

## Dedication

It is with deep gratitude that I dedicate this work to Tim, his family, and his aides/facilitators for sharing your lives and experiences, for your perseverance in fighting for the rights of those with disabilities, for your investment of time and energy in seeing this project through to its completion, and for your dedication to contributing to the body of knowledge addressing facilitated communication and the nature of autism.

It is also with respect and gratitude that I dedicate this work to all autistics and their families and facilitators who have “spoken out” either verbally or in writing about their internally-lived experiences of autism – on their own behalf as well as on the behalf of all who are and may remain unable or as yet have been unable to communicate their experiences.

Finally, I am grateful to those researchers and clinicians who have *listened to and heard* those voices, to the firsthand accounts of those who are best qualified to guide science into the most salient and productive avenues toward uncovering the underlying pathogenesis of autism and toward correctly understanding the behaviors that have for too long been misinterpreted and labeled based on etically-constructed and often false assumptions.

## Acknowledgments

I want to thank my committee members, family, and friends who encouraged me and believed I could complete this project when I faltered under life's challenges. It was a difficult, convoluted, and demanding journey that led first through false starts and dead ends, then through frustration and disappointment, and finally through deep mires of information into discovery and understanding. It was a journey that ultimately opened onto a clearing of more comprehensive understandings of autism specifically and scientific methods generally than I had ever imagined. I especially want to thank Alex, my committee chair, who never failed to support me, but who also challenged me to follow where the leads demanded I go whether or not that was where I had intended or wanted to go; who, while trying her hardest to protect me from my sometimes compulsive pursuit of thoroughness, also taught me the most valuable of research lessons - to stay the course, with dogged discipline no matter how difficult, of pursuing *objective* scientific inquiry. In the end, this discipline of objectivity taught me to deeply appreciate and embrace two tenets of scientific research –

Embrace Paradox:

“How wonderful that we have met with a paradox.

Now we have some hope of making progress” (Niels Bohr, n.d.)

And examine both the old and the recent with new eyes:

“The real voyage of discovery consists not in seeking new landscapes, but in having new eyes” (Marcel Proust, n.d.).



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## Chapter I: Introduction

Few topics in disabilities studies or special education have incited the firestorm of controversy that swirls around facilitated communication (FC), not just in the professional literature, but also in the media, in educational and therapeutic systems, and within families and homes. In addition, few topics have been cited as often in highlighting the rift between science and practice - the scientist-practitioner gap - as has the continued use of facilitated communication. In her foreword to Lilienfeld, Lynn, and Lohr's *Science and Pseudoscience in Clinical Psychology*, Tavis (2003) illustrates the scope of this "gap" as well as the fervor in the divide over the use of facilitated communication in her statement,

Today, however, calling it a "gap" is like saying there is an Israeli-Arab "gap" in the Middle East. It is a war, involving deeply held beliefs, political passions, views of human nature and the nature of knowledge and – as all wars ultimately involve – money, territory, and livelihoods. (xiv)

Facilitated communication is a highly controversial form of augmentative and alternative communication (AAC), claimed by many to enable or expand the abilities of individuals with disabilities such as cerebral palsy and severe autism to communicate. Its use is based on the belief that some individuals who are unable to produce speech or use sign language may nonetheless have the mental capacity to communicate given another means to do so. Facilitated communication is a technique through which a facilitator provides emotional and psychological encouragement, varying levels of physical support, and physical resistance to the forward hand movement of the facilitated communication user (henceforth, *communicators*) to provide motor control. Physical support may initially involve fully holding the hand or wrist, sometimes with additional isolation of the index finger being necessary to enable the user to select and touch



desired selections on a communication board, letter board, or keyboard. For others, touching the communicator's elbow, shoulder, or back is all that is required, with the common goal being to move toward completely independent typing (Biklen, 1990; Biklen & Schubert, 1991; Crossley, 1992; Szempruch & Jacobson, 1993).

### **More Than a Question of Authorship**

The most tangible question inherent in the controversy around facilitated communication is that of authorship: Who, in actuality, is doing the communicating – the facilitated communication user - the communicator - enabled by emotional and physical support, or the facilitator acting inadvertently on or through the communicator through some Ouija Board or Clever Hans phenomena? While authorship may be the question on the surface, in actuality, the controversy embodies much broader and deeper questions of epistemology, of differing scientific investigative paradigms – positivism and controlled empirical studies versus relativism, constructivism, and qualitative investigations - and the long-held socially-constructed understanding of the nature of autism versus the latest scientific findings revealing the underlying neurological differences (pathologies) in autistic brains.

Critics have largely adopted an all-or-none, either/or stance: Facilitated communication is either a valid means of communication, or it isn't; it either provides voice and opens an interactive world to many who cannot speak, or it is pseudoscience, fraud, detrimental, and dangerous. And, their decision, based on the failure of communicators to demonstrate authorship under conditions of controlled testing, has been that facilitated communication does not work, does not lead to independent typing, and is in fact a detrimental and dangerous intervention (Heinzen, Lilienfeld, & Nolan, 2016; Lilienfeld, Marshall, Todd, & Shane, 2014).

Opponents assume that the pathology accounting for individuals being non-verbal is the presence of substantial intellectual and/or essential language impairments rather than other possible factors such as sensory integration, sequencing and planning, or oral-motor deficits. They do not accept claims that individuals who were previously unable to communicate beyond basic needs become able to communicate at advanced and abstract levels using facilitated communication. Central to detractors' doubts about the possibilities of complex communication in non-speaking individuals is the long-held belief that "general delays or deficits in language function are closely related to general delays or deficits in intellectual development" (Jacobson, Mulick, & Schwartz, 1995, p. 757). That premise, however, would require language centers in the brain to be synonymous with intellect, or speech and language to always develop in parallel with intellect, which is known not to be the case. Biklen (1996) asserts that the assumption that general delays or deficits in language function are closely related to intellectual development "has been refuted by every instance where individuals presumed to be incompetent develop effective means of expression, thus enabling them to claim intellectual normalcy" (p. 985).

In addition, autistics who fail to develop speech are typically more seriously affected by other autistic signs and symptoms and therefore *appear* to be more intellectually impaired by social standards. Socially-constructed understandings of intellectual disability generally assume that individuals who appear physically awkward and/or strange - as do those who demonstrate stereotypies or "stimming," those who flap hands or fingers, make odd vocalizations, or gallop awkwardly across the room whooping and failing to make eye contact (as Tim does), in other words, those who just "look retarded" - are *assumed to be* intellectually impaired. Critics cannot believe that individuals who display odd behaviors, lack speech, and appear by socially-

constructed standards to be intellectually impaired could possibly not be intellectually impaired, but rather have sensory, motor, and language difficulties instead.

Critics also charge proponents with claiming facilitated communication to be a miracle cure for non-communication. Although special news programs classified stories of individuals who began communicating via typing with facilitation after having been labeled “mentally retarded” as being miraculous (ABC Primetime, 1992 as cited in Palfreman, 1993; Goldberg & Putrino, 2009), proponents do not claim facilitated communication to be any kind of cure, but rather they believe facilitation does allow some people with autism (and other conditions) to communicate via writing or typing who would otherwise be far more limited in their means of conveying their thoughts.

Crossley (1992), the principal founder of facilitated communication, herself emphasized the need for ongoing training in facilitated communication skills, referring to facilitation as facilitated communication *training* (my italics). Crossley countered the misperceptions and unrealistic expectations often conveyed by the media and held by some parents, emphasizing that facilitated communication was *not* easily-learned and would *not* enable all individuals with severe communication impairments to communicate normally and easily. Crossley emphasized the lengthy and costly process of training required for acquisition of the skills necessary to use facilitated communication, also stating that facilitated communication was only one element in the armamentarium of tools in a comprehensive augmentative and alternative communication program. Crossley emphasized,

FCT [facilitated communication training] itself is only a means of teaching accessing skills. Although it may allow individuals to reveal hitherto unrecognized skills, such a

literacy, and to use language in a way that was previously impossible, it is not by itself the answer to severe communication problems. (p. 42)

Advocates maintain that communicative abilities in some individuals were always present but were locked within one or more barriers: oral dyspraxia which interfered with the ability to speak; more general dyspraxia interfering with initiation and planning to enable pointing to letters; poor motor control due to either decreased or increased muscle tone; impaired eye-hand coordination; impulsivity, perseveration, attention and focus problems; planning and sequencing, and/or sensory integration impairments (Crossley & Remington-Gurney, 1992).

Opponents question that motor control is an issue when some individuals who need physical support to point and type or hand-write are able to reach and point independently in many or even most other circumstances. They also doubt the contention that anxiety and challenges to competency are interfering issues in testing when the individuals being tested for authorship typically give informed consent and express wanting to participate in facilitated communication studies (Bomba, O'Donnell, Markowitz, & Holmes, 1996).

The controversy over the validity of facilitated communication has raged for nearly three decades. Qualitative and quantitative findings have nearly always been at odds, qualitative (non-controlled) studies offering numerous accounts of information being conveyed that facilitators could not have known, demonstrating individualistic styles of writing, and providing accounts of individuals who progressed to typing independently, while controlled quantitative studies have indicated that very few facilitated communication users are able to produce any communication independent of facilitator influence. In sum, only a few controlled studies, but all qualitative studies have agreed that facilitated communication seems to be valid for at least some individuals

(Biklen, 1990; Bomba et al., 1996; Cardinal, Hanson, & Wakeham, 1996; Sheehan & Matuoizzi, 1996; Sipila & Maatta, 2011; Tuzzi, 2009; Weiss, Wagner, & Bauman, 1996)

What do these paradoxical findings mean? Is facilitated communication a hoax, albeit an unintentional one, that robs users of time that could be spent in more productive interventions and that causes great damage to individuals, families, and communities through the typing of false consents and accusations? Or, could it be that it is a valid means of communication at least under some conditions, and that there remain elusive elements beyond our current understandings of the communication process which cause it to be infeasible under controlled testing procedures?

Some researchers discount all but the results from controlled studies and maintain that facilitated communication is categorically invalid and should absolutely never be used (Chan & Nankervis, 2014; Heinzen et al., 2016; Lilienfeld et al., 2003; Lilienfeld et al., 2014). These researchers are alarmed over what they refer to as facilitated communication's "resurgence" over the past decade, and are adamantly urging that facilitated communication be halted. However, considering that facilitated communication continues to be extensively used in homes and schools, and considering that it is difficult to argue with the authentic nature of *some* of the interactions, communications, and the progression to independent writing or typing achieved by some individuals, it seems premature to close the debate (Bigozzi, Zanobini, Tarchi, Cozzani, & Camba, 2012). Bomba et al. (1996) suggested that there is at least a subgroup of individuals who can validly utilize facilitated communication, and the task is to identify the characteristics identifying that subgroup:

If the facilitated communication of some individuals with autism is valid (individuals who have progressed to typing with no physical support, for example), an important

research issue is the identification of the characteristics of this "subgroup" in order to provide these individuals with the most effective communication system. (p. 55)

Although it is clear that care must be exercised to avoid influencing the communicators' typing, it would be an injustice to those who struggle with severe disabilities and to those who face immense obstacles in communicating their thoughts and needs to simply conclude that "failure" to pass empirical tests is final and conclusive evidence that facilitated communication is an invalid technique. Indeed, perhaps we have created a circular trap – a recursive loop – in having decided, a priori, which tests and types of testing are acceptable for identifying the validity of facilitated communication, while at the same time finding that the vast majority of communicators cannot pass those very tests that have been chosen to define their abilities.

### **Firsthand Accounts and Autobiographies**

It is also an injustice; it is entirely unethical and a violation of *all* persons living with differences to make assumptions about the meanings of their behaviors and actions without their input. If we are to honestly investigate the use of facilitated communication in autism, if we are committed to understanding what it is to live with a nervous system that functions very differently from the nervous systems considered to be typical, it is essential to include the voices of those living as autistic. It is simply not possible to know the internal thoughts and desires of people without their voices; even the wonders of neuroimaging cannot discern personal thoughts and experiences. Donnellan, Leary, and Robledo (2006) pointed out that the term *autism* is usually associated with persons demonstrating "unusual ways of moving and acting," and specifically, it "conjures up an image of a person rocking back and forth, hands flapping in front of eyes that seem to focus in an unknown space - a person remote from and disinterested in the social milieu" (p. 205). They further stated,

Within the professional world that arranges and provides support for people with autism, the word "behavior" often became shorthand for bizarre, bad, repetitive, self-stimulatory, or useless ways of spending time. Much of the literature is concerned with manipulating, managing, or eliminating behaviors with little or no reference to how these might reflect the experience of the labeled individual.... Thus, we end up assuming our experience of them matches their own experience, an inadequate substitute for their perspective at best. ... If parents and professionals are to begin to understand the phenomenon called autism, and through this understanding provide personalized support, it seems evident that the expressed experience of those who are categorized as autistic must be included. (pp. 205-206)

Since the validity of the use of facilitated communication and thus the authenticity of authorship are the very questions under investigation in this study, conclusions cannot yet be drawn about the authenticity of writings by any communicators using facilitated communication. Therefore, all quotes and firsthand accounts by autistic individuals presented in this paper were composed by either "high-functioning" verbal individuals or by individuals who type independently without facilitation, although a number of those authors used facilitation prior to being able to type independently. As is true with neurotypicals, each autistic individual's sensory, motor, language, social, and life experiences are unique, or as Dr. Stephen Shore, a "high-functioning" autistic, noted, "If you've met one person with autism, you've met one person with autism" (as cited in "93 Favorite Quotes About Autism and Aspergers," 2017). However, there are themes or types of experiences that appear to be generally common to those with autism spectrum disorders. Thus, firsthand accounts are included in this paper to provide a glimpse into the sensory, motor, language, and social differences reported by the individuals who

experience them as opposed to by individuals observing the outward behavioral manifestations of those experiences.

Carly Fleischmann is a non-speaking autistic who began typing independently at age 11 with no prior facilitation. She is severely affected with autistic mannerisms of unusual arm and body movements, and before communication was assumed to be at least moderately “mentally retarded.” In the transcript from an ABC 20/20 program (as cited in Goldberg & Putrino, 2009) entitled “Teen Locked in Autistic Body Finds Voice,” she explained the impetus for her “wild” behaviors such as banging her head:

Because if I don't it feels like my body is going to explode. It's just like when you shake a can of coke. If I could stop it I would but it is not like turning a switch off, it does not work that way. I know what is right and wrong but it's like I have a fight with my brain over it.

Carly further explained her experiences of living with autism in her book, *Carly's Voice* (2012), which she co-authored with her father:

Autism feels hard. It's like being in a room with the stereo on full blast. It feels like my legs are on fire and over a million ants are climbing up my arms. It's hard to be autistic because no one understands me. People just look at me and assume that I am dumb because I can't talk or because I act differently than them. I think people get scared with things that look or seem different than them. It feels hard. (p. 234)

It might not seem like I am at times, but I try very hard to act appropriately. It is so tough to do and people think it is easy because they don't know what is going on in my body. They only know how easy it is for them. Even the doctors have told me that I am being silly but they don't get it. (p. 233)



Cesaroni and Garber (1991) presented one of their high-functioning, verbal interviewees' perspectives on assumptions others form about his experiences. The authors explained, "It is very difficult for Jim [age 27 at time of interview] to communicate the discrepancy between the way in which he is actually experiencing a situation from the way in which other people assume he is experiencing a situation" (p. 311). Jim explained,

The extent to which communication occurs in the course of my interactions seems to depend on how effectively I am able to identify discrepancies in understanding and to "translate" both my own and the other person's terms to make sure we're both focusing on the same thing at the same time. (p. 311)

In addition to refraining from making assumptions about what the observable behaviors may mean about the internal experience prompting them, we should not assume that neurotypically-designed methods of testing facilitated communication are valid methods of testing nervous systems of which we have previously had little knowledge. If someone cannot type on demand or test well on IQ tests *that were not standardized for individuals with autism*, it is unethical to judge what those results may reflect about their intelligence.

Williams (2017), an autistic and prolific writer describes that as a child she was intermittently tested for deafness and was initially diagnosed as schizophrenic at age two. As understandings of mental illnesses evolved, this diagnosis gradually shifted to "emotionally disturbed" and finally to autism when she was in her 20s. In addition, she was diagnosed with a severe language processing disorder at age nine to ten and visual agnosia at age 18. She said she came to understand sentences around age 9 – 11, by age 13 could provide one-sided litanies, and by age 18 could suppress most of her echolalic speech. With this background, the quantity and quality of Williams's writings are beyond impressive, providing rich first-hand insight into

autism. Williams wrote multiple articles in peer-reviewed journals and at least 13 books including two textbooks and two international bestsellers - *Nobody Nowhere* (1991) and *Somebody Somewhere* (1995). In her 1994 article, she addressed the impact on testing of sensory-motor reception and processing, self-other differentiation difficulties, and the adaptations used to manage the disordered sensory and body messages:

... it may be the case that critics assume this [failure of controlled tests] 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 nonautistic test designs (based on nonautistic, integrated, non-mono, perceptual-cognitive-emotional- linguistic- and social-reality). (p. 198)

With Temple Grandin's 1986 book, *Emergence: Labeled Autistic*, firsthand accounts of autism by autistics – by both verbal and non-verbal individuals - have become increasingly available for anyone seeking a better understanding of the internal experiences of those labeled autistic. Grandin has written at least eight additional books on autism including *Thinking in Pictures* (1995, 2006), *Different... Not Less* (2012), and *The Autistic Brain* (2013). Cesaroni and Garber (1991) published accounts from their interviews with two “high-functioning” autistic individuals in 1991. Other independently-typing, self-advocating works include Barron & Barron's *There's a Boy in Here* (1992); Biklen with Attfield, Bissonnette, Blackman, Burke, Frugone, Mukhopadhyay, and Rubin in *Autism and the Myth of the Person Alone* (2005); Blackman's *Lucy's Story: Autism and Other Adventures* (2001); Higashida's *The Reason I Jump* (2016); and Mukhopadhyay's *Beyond the Silence: My Life, the World and Autism* (2000), *The Mind Tree* (2003), *The Gold of the Sunbeams: And Other Stories* (2005), *How can I Talk if my Lips Don't Move? Inside my Autistic Mind* (2008), *I'm Not a Poet but I*

*Write Poetry: Poems from My Autistic Mind* (2012), and *Plankton Dreams: What I Learned in Special Ed (Immediations)* (2015).

In 2012, Caminaha and Lampiere reported that “more than 50 autobiographies have been published (Rose, 2008) in addition to unpublished reports that are posted on websites and blogs” (p. 233). With the incidence of autism increasing and the self-advocacy movement burgeoning, we could expect the number of autobiographies and blog posts to have increased substantially if not exponentially since that 2012 report. Because firsthand accounts are the only sources providing a window into the actual internally-lived experiences associated with the externally-observed behavioral manifestations associated with autism, it would seem that firsthand accounts should always have been assigned priority in the process of formulating theories about autism and the use of facilitated communication in autism. Without firsthand accounts, there is no way of knowing how accurate or far from the mark our interpretations, judgements, and meanings assigned to the observed signs and symptoms of autism or to the discrepant findings in facilitated communication fall. With this abundance of writings as well as lectures and documentaries, it is hard to understand why these “insiders” perspectives have not been incorporated into mainstream psychological and psychiatric attempts to better understand autism.

Clearly, though, not everyone shares this opinion. Critics have argued that individuals who achieved independent typing after using facilitation may have been misdiagnosed initially, and in addition, had been capable of independent pointing and typing prior to being introduced to facilitated communication. There is no way to know whether or not that claim may be accurate for some, but it is highly unlikely it could be generalized to multiple cases, and it still would not exclude difficulties with typing for those identified. A related criticism is

that the communications, educational skills, and experiences of the independent typists' were not adequately described prior to using facilitated communication, thereby making it unknown if these skills pre-existed or developed as a result of having used facilitated communication (Green & Shane, 1994). In response to claims that transitioning to independent typing is confirmation of the validity of the prior use of facilitated communication, Lilienfeld et al. (2014) asserted:

Nevertheless, these reports [publications by individuals typing independently who previously required physical support] are anecdotal and have never been corroborated in independent controlled studies. Furthermore, even if an individual became capable of typing with no aid whatsoever after FC, we should conclude neither that the facilitated typing was genuine nor that FC engendered the ability. It is at least equally plausible that FC delayed the onset of functional communication by reducing its need. (p. 70)

Yes, contention exists around *every* facet related to facilitated communication, even when the facilitation part of the communication is no longer required, and even when it comes to merely acknowledging those who have more right than anyone else to speak for and about autism and facilitated communication. Donnellan, Hill, and Leary (2013) expressed:

Any view of autism at this time needs to reflect the experience of self-advocates with autism and others who describe sensory and movement differences, as well as the latest in the neuroscience and child development literature. We need a research agenda that focuses on understanding and supporting autistic people and others in more respectful, personalized, and successful ways. (p. 9)

Therefore, because firsthand accounts describe the lived internal experiences coinciding with the externally observed behaviors investigated through research, and because those described internal experiences appear to be consonant with and corroborated by the latest neurological findings explaining the syndrome associated with autism, firsthand accounts will be woven throughout this paper.

### **Making the Case**

Thus, contradictory findings between controlled and noncontrolled studies do exist, and the potential for the misuse of facilitated communication to cause harm does pose a risk. However, these should not be reasons to cease research into facilitated communication or to ban its use as some researchers demand (Chan & Nankervis, 2014; Heinzen et al., 2016; Lilienfeld et al., 2003; Lilienfeld et al. 2014). Rather, with the potential also for nonspeaking individuals to access more complete communicative expression and thereby live fuller and richer lives of self-expression and relatedness with others, the ambiguities in study findings ought stimulate the pursuit of further understanding through research rather than stifle it. Sipila and Maata (2011) stated that “In spite of disagreements regarding facilitated communication, there is no evidence or documentation to argue that all use of the facilitated communication method should be avoided. We need more both experimental and phenomenological rigorous research to understand the process” (p. 3). Although Sailor (1996) voiced skepticism regarding many claims about facilitated communication, he also observed

If one recognizes the legitimacy of carefully conducted subjectivist studies, however, it would seem that the ultimate verdict on facilitated communication is not yet in and that it well may improve communicative opportunities for some autistic persons, under some conditions, at least some of the time. (p. 984)

Bigozzi et al. (2012) challenged, “the almost complete interruption in scientific debate on this topic in the last decade” as being unfortunate for two reasons – (a) in spite of much of the research literature concluding that FC communication results from “inadvertent facilitator influence, the technique continues to be used and the scarcity of studies means that there are many unanswered questions,” and (b) “there is evidence from naturalistic studies as well as from controlled research that FC users have been the authors of some written information” (p. 57).

It is imperative that nonspeaking individuals be afforded every opportunity to communicate; it is also imperative that their communications be their own. We continue to search for explanations as to why facilitated communication results are so contradictory. As Goodwin and Goodwin (1969) solemnly noted, “There are other times when reason persuades us that all children cannot be relieved of all of life’s brutalities, but many can be saved from some. *The task is no larger than the commitment*” (p. 563; italics added). As Niels Bohr, the 1922 Nobel Laureate in physics, stated, “Every great and deep difficulty bears in itself its own solution. It forces us to change our thinking in order to find it” (Niels Bohr, n.d. a). Perhaps it is time to change our thinking in our search to understand the phenomenon of facilitated communication. Perhaps, rather than arguing about whether or not facilitated communication is valid in at least some cases, energy could be better spent endeavoring to unravel the mysteries of the underlying phenomena interfering with communication in some cases of severe, non-speaking autism. Perhaps we could let go of our defensive stances and embrace Bohr’s approach to enigma and ambiguity: “How wonderful that we have met with a paradox. Now we can make progress” (Niels Bohr, n.d., b).

The purpose of this single subject study, then, is to contribute to the further investigation of the paradox of facilitated communication. It will investigate the communication of a severely

autistic, non-speaking adolescent male who has used facilitated communication in nearly all daily interactions for the past seven years. It will implement a controlled, blinded experimental design while adhering as closely as possible to the naturalistic setting and procedures regularly employed for Tim (pseudonym) in completing his daily homework assignments. Although other studies have implemented test designs that derived questions from materials the communicator had read and to which the facilitator was blinded (Weiss et al., 1996), no studies this author has read have incorporated the test design into readings that would have been completed even if testing were not involved. Likewise, other test designs have asked questions about activities that were designed to replicate typical and usual activities (Montee, Miltenberger, & Wittrock, 1995; Simon, Toll, & Whitehair, 1994), however no test design this author has found has been incorporated into an already-established daily activity such as completion of homework. Therefore, this will be a novel test design – using an activity already planned (completing homework) that would take place even if there were to be no testing.

In addition, the narratives transpiring between Tim and his facilitators over the course of testing will be qualitatively evaluated for linguistic process and style. An overview of the latest neuroconnectivity and sensorimotor behavioral research will also be presented in outlining the latest insights into the fundamental neurological underpinnings now believed to explain the actions and behaviors that have collectively come to define autism. It may then be hypothesized that these fundamental neurological underpinnings would be expected to shed some light on the reasons for the discrepancies in the ability of individuals to use facilitated communication.

As the arguments suggest, much of the contention around facilitated communication is based on differing beliefs about the underlying cognitive processes and abilities of the individuals utilizing facilitated communication. Specifically, as relates to this dissertation, the

arguments have everything to do with differing opinions about the underlying cognitive processes and abilities of individuals living as non-speaking autistics, i.e., the arguments have everything to do with understanding the nature of autism, the essence of autism, and the processes involved resulting in the manifested characteristics and behaviors associated with autism. Therefore, the literature review will begin with a much abbreviated historical tour through the changing understandings of autism. A quote by David, an 18 year-old who began typing independently at age 14, will usher us from this section into the literature review:

Here the dreams mean taking my hand to help me to walk and talk and invite someone into my life and thoughts and to know each other like life friends. Those are my dreams. I dream for the world to be hearing my voice, to change people's ideas about some struggles of autism, and for hope to be realized by others with autism. (as cited in Shoener, Kinnealey, & Koenig, 2008, p. 552)



## Chapter II: Literature Review

### Autism and Intellect

Although facilitated communication is used by individuals with conditions other than autism, when evaluating the validity of its use by autistics, the two cannot be uncoupled. That is, the use of facilitated communication by autistics cannot be legitimately evaluated in isolation of the new understandings of the neurological pathogenesis resulting in the behavioral syndrome known as autism. The first issue, which will be addressed in the *Motor and Sensorimotor Research* literature review section, is the opinion held by some authors such as Mulick, Jacobson, and Kobe and Rimland (as cited in Donnellan, Hill, and Leary, 2013) that motor impairments cannot explain facilitated communication difficulties since those authors maintained that basic motor skills appear to be intact in autism. The second issue is the common assumption that individuals presenting with severe symptoms of autism, who demonstrate odd behaviors and/or make unusual sounds, lack the cognitive capacity to understand much of what is going on around them much less understand communications from others or formulate high level communications of their own. Rather, these oddly-behaving individuals are thought to be intellectually impaired, indifferent to others, and locked away in a world of their own. Since individuals who are minimally- or non-verbal are also typically more “behaviorally” involved - i.e., have more sensory, motor, language, and social issues – they are assumed to have greater cognitive impairment. Therefore, in circular reasoning, rather than questioning the validity of the test measures that determine cognitive level, their low cognitive assessment results are often accepted as confirmation of the assumed low cognition.

The issues around intelligence testing and assumptions about cognitive functioning are - as seems to be the case with all topics related to autism – highly complex and contentious.

Although estimates of comorbid intellectual disability in autism range from 25% to 70 % - median 70% in 21 studies surveyed by Fombonne (2005); 25% to 64% in Kielinen, Linna, and Moilanen (2000, in Dawson et al., 2007); 50% to 70% in Matson and Shoemaker (2009) and approximately 30% in Lyall et al. (2017) – they are based on assessments that were not standardized or validated for this population and therefore very likely do not reflect accurate measures of intellectual ability. The validity of the results and conclusions reported by these studies is further complicated by between-study confounders as well as wide intraindividual subtest variability. For example, Fombonne (2003) cautioned against making between-study comparisons because the results from various studies that were pooled together represented a wide variety of test measures as well as differing parameters for designating levels of intellectual ability (p. 369).

Controversy abounds over which intelligence measures to use and which if any is a valid measure of intellect in the autistic population – whether traditional intelligence measures such as the Wechsler Scales and Stanford-Binet underestimate intelligence in language-impaired individuals and may therefore be appropriate for use only with the highest functioning autistic individuals, or whether nonverbal measures such as the Leiter International Performance Scale - Revised (Leiter-R; Roid & Miller, 1997) and Raven’s Progressive Matrices (RPM; Raven, 1998) overestimate intelligence.

A meta-analysis conducted on 133 cognitive and behavioral papers in autism between 1999 and 2002 (Mottron, 2004, p. 19) indicated that the most commonly used scales were the Wechsler scales (46.9%), the British Picture Vocabulary Scale (BPVS, 22.3%), and the Raven’s Progressive Matrices (RPM, 16.9%). Sattler identified the Wechsler Intelligence Scales for Children, 4<sup>th</sup> Edition (WISC-4; Wechsler 2003) and the Stanford-Binet Intelligence Scale, 5<sup>th</sup>

Edition (SB5; Roid, 2003) as being the most commonly used tests for assessing cognitive function (as cited in Grondhuis & Mulick, 2013). Mottron (2004) concluded that the Échelle de Vocabulaire en Images Peabody (EVIP, a French Canadian translation of the British Picture Vocabulary Scale [BPVS]) and the RPM to a lesser degree “considerably overestimates the level of all PDD participants as compared to Wechsler Verbal IQ (VIQ), Performance IQ (PIQ), or Full-Scale IQ (FSIQ)” (p. 19). The author therefore concluded that the Stanford-Binet 5 (SB5) and Wechsler scales should be the intelligence measures of choice.

However, it could also be argued that the SB5 and Wechsler scales under-represent actual intelligence levels in the autistic population and should therefore not be used. In fact, it would stand to reason that in a population impacted by communication difficulties, verbally-based tests would underrepresent intelligence and nonverbal tests might *appear* to overestimate intelligence *when compared to verbally-based tests such as the Wechsler Scales*. Consistent with this conclusion, Naglieri and Goldstein (2009) cautioned that the Wechsler Intelligence Scales for Children – 4<sup>th</sup> Edition (WISC-IV) was inappropriate for use with examinees with limited English-language skills (p. 5), a limiter estimated to apply to at least 50% of the autistic population (APA, 2000; Grondhuis & Mulick, 2013). Dawson, Soulieres, Gernsbacher, and Mottron (2007) compared results obtained on the WISC-III and the RPM administered to 38 children diagnosed specifically with autism, (rather than pervasive developmental disorder not otherwise specified [PDD-NOS] or Asperger’s disorder). The authors stated that the RPM is “widely regarded to be a preeminent measure of high-level analytical reasoning...[and] has been empirically demonstrated to assay the ability to infer rules, to manage a hierarchy of goals, and to form high-level abstractions” (p. 658). Regarding *nature* of autistic intelligence, the authors argued that “Instead of being limited to isolated Wechsler subtests assumed to measure only low-

level rote memory and perception, autistic intelligence is manifested on the most complex single test of general intelligence [the RPM] in the literature” (p. 661). Regarding *level* of intelligence, their results showed,

No autistic child scored in the “high intelligence” range on the WISC-III, whereas a third of the autistic children scored at or above the 90<sup>th</sup> percentile on the Raven’s Matrices. Only a minority of the autistic children scored in the “average intelligence” range or higher on the WISC-III, whereas the majority scored at or above the 50<sup>th</sup> percentile on the Raven’s Matrices. Whereas a third of the autistic children would be called “low functioning” (i.e., in the range of mental retardation) according to the WISC-III, only 5% would be so judged according to the Raven’s Matrices. (p. 659)

Lennen, Lamb, Dunagan, and Hall (2010) used verbal ability as a covariate in evaluating the Stanford Binet-5 in an autistic population and found that the scores achieved *even on the non-verbal section were greatly affected by language ability*. The authors concluded that “The SB5 Nonverbal score was underestimating the cognitive ability of children with autistic disorder, and that fully nonverbal measures might be able to give a more accurate representation of IQ” (as cited in Grondhuis & Mulick, 2013, p. 48). Although the standardization sample for the Stanford-Binet Intelligence Scales, 5<sup>th</sup> Edition (SB5) included 83 children with autism, Coolican, Bryson, and Zwaigenbaum (2008) noted “very little information is provided on their cognitive profiles, or on whether or how they might differ from those of the normative sample” (p. 190). The authors endeavored to rectify this omission by evaluating 63 participants with autism, comprising a sample with a broader diagnostic range (autism, Asperger syndrome, and PPD-NOS versus just autism in the original normative sample) and nearly as wide an age range as the original study (p. 195). The authors proposed that the difference in diagnostic parameters which

included higher functioning children in their study explained their finding of a higher mean FSIQ (82.3 versus 70.4 for the validity study; p. 192). Unfortunately, although the manner of diagnosis of autism spectrum disorders was described for all of the participant sub-groups, language achievement was reported only for children in the Asperger group, stating that all had “attained phrase speech by approximately 33 months and [all] had average or above average IQs” (p. 191). Importantly, there was no mention of language ability for the more affected groups – those with Autistic Disorder and PDD-NOS.

With this shortcoming in mind, Coolican et al. (2008) reported that SB5 non-verbal IQ (NVIQ) profiles were greater than verbal IQ (VIQ) profiles regardless of diagnostic sub-category, suggesting that children at all levels of the autism spectrum might be affected by language components of intelligence measures. They also stressed the importance of evaluating individual subtest performance, concluding, “...the large variability in subtest performance within diagnostic subgroups... is consistent with the possibility that there is as much or even more variability within each diagnostic subgroup as between subgroups” (p. 195). Finally, they reported that within the non-verbal subtests, relative strengths were in Fluid Reasoning, Quantitative Reasoning, and Visual Spatial Processing versus Knowledge (requiring that adults would have provided as much education and exposure as they would to typically- developing children taking the test) and Working Memory skills (p. 195; which involve the greatly affected frontal lobe integration as per the neuroconnectivity research).

Tsatsani et al. (2003) also stressed the importance of evaluating intraindividual score variance, noting that “important clinical findings, based on individual test-score variation, are often masked by overall levels of agreement... between clinical test instruments” (p. 24). In their study, ten of twenty two (45%) of the sample achieved at least a 10 point difference between the

Leiter and the Leiter-R, with 3 (13%) producing a between-test score discrepancy of more than 20 points. Significant strengths or weaknesses were also identified in ten (45%) cases. Cicchetti et al. (2010) also emphasized the importance of analyzing test results on an individual basis.

They emphasized,

...it is nonetheless unfortunate that the thrust of most research reports is on levels of statistical significance, all too often to the neglect of clinical significance and related concepts. As has been demonstrated, adding the dimension of ES, Clinical Significance, or Practical Significance, Strength of a research finding, or the concept of the individual, provides a richness of understanding that is not possible when statistical significance alone is used to understand the meaning of Autism or a biobehavioral result, more generally. (p. 173)

The Leiter-R (Roid & Miller, 1997) and the Raven's Progressive Matrices (Raven, Court, & Raven, 1998) are designed to be non-verbal in both their administration and response production. Therefore, they might be expected to yield a more accurate representation of intellectual functioning. However, given the substantial problems most autistic individuals have with sensory integration, sensory overload, sensory screening, and cross-modal sensory domination, proprioception and motor planning difficulties, perseveration, attention, and anxiety in addition to language and communication differences, it is not clear if the results from even these non-verbal intelligence measures provide an accurate measure of non-verbal intelligence. Although directions are specified to be given only through gesture and mime, some researchers noted the necessity of modifying even these tests when administering them to autistic individuals. Tsatsani, Dartnall, Cicchetti, Sparrow, and Volkmar (2003) and Kushner, Bennetto, and Host (2006) added simple verbal prompts to overcome the *non-verbal* communication

difficulties in understanding gesture, body language, or facial expression many autistic individuals experience. Thus, solid evidence supporting the validity and widespread use of even current nonverbal measures of intelligence such as the Leiter, the Leiter-R, and the Ravens Progressive Matrices (RPM) in the autistic population is lacking.

Grondhuis and Mulick (2013) conducted a comparison study of the Leiter-R and the Stanford-Binet-5 (Roid, 2003) through a retrospective chart review of 47 children aged three to twelve diagnosed with autism (N=26) or PDD-NOS (N=21) who had completed both the Leiter-R and the SB5 between 2004 and 2009. Unfortunately, again, *no information was provided for communication/language abilities*. In addition, “children who were unable to complete the full scale administration of both assessments were excluded” (p. 51), very likely excluding children with the most severe language impairments (and the most interfering autistic symptoms). The authors admitted that “scores on adaptive behavior or language measures would have allowed for a more thorough investigation into these IQ differences” (p. 51). Similarly to Coolican et al.’s finding of equal or greater variability within rather than between diagnostic subgroups, Grondhuis and Mulick found specific diagnosis (autistic disorder versus PDD-NOS) was not a significant factor affecting discrepancy between test results. Their analysis showed that, as would be expected, scores on the verbal subsection of the SB5 were significantly lower than scores on the Leiter-R, with a mean point discrepancy of 25.24. Scores on the *nonverbal* section of the SB5 also yielded lower scores compared to the Leiter-R, with a 16.72 mean point discrepancy, significant at  $p < .001$ . Comparison of the mean SB5 full scale IQ with the mean Leiter-R score yielded a greater-than-one-standard-deviation mean score discrepancy of 22.45.

In this sample, two children had a higher descriptor on the SB5 than on the Leiter-R (e.g., received mildly delayed on the Leiter-R and borderline on the SB5); eight children stayed

within the same descriptor category on both tests; and the remainder of the children had lower SB5 descriptors than they did on the Leiter-R (9 children were one category lower; 17 were two categories lower; 8 were three categories lower; and 3 were four categories lower on the SB5 than they were on the Leiter-R). (pp. 48-49)

The greatest discrepancy between the Leiter-R and the SB5 full scale scores was a whopping 57-point higher Leiter-R score! The authors concluded that although it is not known what the discrepancies represented - one test underestimating intellect, another overestimating intellect, or different tests simply capturing different intellectual constructs – the differences were both statistically and clinically significant in their potential to “prompt clinicians to make substantially different predictions for future learning and educational success” (p. 50).

As has been noted, few studies specify the language abilities of study participants, particularly in the more symptomatically-involved subgroups within the autism spectrum. In addition, Kasari, Brady, Lord, and Tager-Flusberg (2013) reported that no publications as of that time (2013) had focused “explicitly on the minimally verbal older child” (p. 479). Therefore, the National Institutes of Health (NIH) convened a multidisciplinary workshop in 2010 to review the status of scientific knowledge and critical gaps in that knowledge about that particular subgroup of children. Kasari et al. summarized the issues discussed and recommendations of that workshop regarding available assessment measures most relevant to developing or improving skills in language; social behavior; repetitive behaviors/restricted interests, sensory behavior, and atypical behaviors; nonverbal cognitive abilities; imitation measures; object play measures; and intentional communication measures:

There are particular challenges in identifying appropriate tests and measures for this population for whom there are few instruments that meet standard psychometric criteria



of reliability or validity. Moreover, there are unique difficulties in evaluating the strengths and limitations of the children in this group because of the particular nature of their wide-ranging behavioral challenges and spoken language limitations. (p. 479)

The available assessment instruments within each of these domains...have serious limitations for use with minimally verbal children, which have severely impeded progress in both research and clinical practice. No single measure is sufficient, and the difficulty in assessing these children suggests that newer measurement approaches should be developed. (pp. 489-490)

Grondhuis and Mulick (2013) stated that although intellectual disability (ID) “is common in people with ASDs, measuring intelligence in those with both ID and an ASD is uniquely challenging. Children with these diagnoses frequently have behavioral difficulties (Matson & Shoemaker, 2009), diminished attention spans, and significant language limitations” (p. 45). Edelson (2006) stated,

There is growing evidence to suggest that the high prevalence of mental retardation reported in people with autism is not supported by empirical data and that measures of intelligence are inadequate to take into account “the interfering symptoms of autism on the process of assessment. (p. 74)

Likewise, to reiterate Williams (1994), critics of facilitated communication (FC) may assume failure to perform on controlled tests proves that FC is invalid (just as poor performance on intelligence tests proves low intellect) “because they do not understand mechanisms and adaptations they have never experienced and, therefore have extreme difficulty imaging or catering for these in their nonautistic test designs (based on nonautistic, integrated, non-mono, perceptual- cognitive-emotional- linguistic- and social-reality)” (p. 198). Leyfer et al. (2006)

stated even “individuals with autism who have adequate language have a variety of other types of communication impairment” (p. 850), and these other types of communication impairments may significantly impact how individuals understand and respond to intelligence measures.

These issues around intelligence testing are particularly concerning in that cognitive test results are one of the criterion used to categorize individuals as “high-functioning” or “low-functioning” (IQ above versus below 70). The second criterion for differentiating “low functioning” from “high-functioning” is the status of verbal communicative ability, which is also misleading, as verbal ability is typically wrongly assumed to correlate with intellect (Dawson et al., 2007). Thus, both of these parameters are problematic in that neither may be an accurate indication of underlying intelligence and therefore of potential functioning if appropriate supports were to be implemented. This differentiation between “high” and “low” functioning in turn drives resource allocation and determines intervention appropriateness and research study and academic program eligibility.

A multitude of firsthand accounts from non-verbal individuals who at one point had been assumed to be or had been tested to be moderately to severely cognitively-impaired yet later demonstrated average to superior intelligence support what some researchers have contended: being non-verbal or demonstrating very odd-appearing behaviors cannot be assumed to correlate with intelligence. Sue Rubin (Rubin et al., 2001) was tested at age 13 to have an IQ of 24 – that was just before she began typing with facilitation. Over approximately five years, Rubin progressed from typing with facilitation to typing independently. Rubin, now 39, remains non-speaking and continues to demonstrate obvious behaviors making her appear severely affected. She wrote, “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” (p. 418). Tito Mukhopadhyay was

considered to be a low-functioning severely-affected autistic, with severe stereotypies (stimming behavior) and inability to speak intelligibly. His mother taught him to write when he was six by strapping a pencil to his hand, and then began teaching him to point so he could eventually type independently. Since then he has become an exquisite author of prose and poetry who has written at least five books. The following is an excerpt from one of his poems:

What is the use of my mind, which can think of the beyondness of blue, it had once seen in Emma's eyes and yet could not tell her anything about what it had seen? What use is my mind when I missed out my turn in a debate taking place? I could not give my point. What use is my intelligence when I heard the rubbish from the experts on Autism and yet all I could do was flap my hands, which is believed to be one of my traits? And what use is my intelligence when I hear that I am one of those idiot-savants and cannot say my words? So I have renamed myself as an intelligent junk. (Biklen et al., 2005, p. 131)

The injustice of making assumptions based on behaviors and appearances is that, both historically and currently, the more unusual and socially-unsettling the behaviors – i.e., the more disabled one *appears* to be - the more likely it has been to judge, label, and assign socially-constructed meanings to those behaviors. In the case of autism, those meanings have also been, to varying degrees, either explicitly or implicitly incorporated into its definition. Rubin (Biklen et al., 2005) further expressed her sentiments about being judged on appearances:

I sometimes feel as if I am the eighth wonder of the world as people stare and marvel at my irregular behaviors which lead to poor assumptions that I am simply mentally disabled with little or no intellectual functioning. My appearance is very deceptive, and day after day I am working, as an advocate for all autistic individuals, to let the world

know that we are intelligent and witty, should not be judged for our quirky behaviors because they are only a minute reflection of our true capabilities. (p. 95)

### **Iterations of the Definition of Autism: Has There Been any Substantive Change?**

For more than seven decades, although the groupings of symptoms and defined sub-categories of autism were rearranged in varying combinations, there was little change in the *essence* of the formal definition. That definition has been mandated and confined through an etic perspective, with assumptions constructed about the meanings of outwardly-observed behaviors. Those derived assumptions were then woven as accepted truths either explicitly or implicitly into a socially-constructed theory and definition of autism. Hence, the assumptions derived from observed behaviors were laid down in the definition of autism; and that assumption-driven definition was then recursively used to explain the observed behaviors (or rather, the assumptions about the behaviors) on which the definition of autism was established.

The term autism, derived from the Greek word, *autos*, meaning *self*, was first coined by Eugene Bleuler (Kanner, 1973; Verhoeff, 2013) in describing severely withdrawn, or drawn into the self, schizophrenic patients. Leo Kanner (1943) used the term in 1943 to describe a group of 11 children who demonstrated repetitive, stereotyped behaviors and social and communication difficulties and who appeared to be shut off from the outside world and withdrawn into themselves. Bruno Bettelheim (Greydanus & Toledo-Pereyra, 2012) claimed that autism in children was caused by their being reared by emotionally cold and distant mothers. Although Kanner initially proposed that whatever the etiology, the syndrome was innate, present at birth, perhaps bowing to the influence of the psychoanalytic era of the 1950s and Bettelheim's proposal of the refrigerator mother (Greydanus & Toledo-Pereyra, 2012), he extended the observations of cold parenting styles in a 1955 symposium, saying: "One of the striking features

of the clinical histories remains the unusually high percentage of these children who stem from highly intelligent, obsessive, and emotionally frigid backgrounds” (Eisenberg & Kanner, 1995, p. 561). Thus, the first conceptualization of autism from the mid-1940s to the mid-1960s was that of a psychogenic disorder characterized by extreme autistic aloneness (Verhoeff, 2013). So well accepted was that theory, that its admission as scientific *truth* devastated families for at least three decades.

Rutter and Bartak (1971) presented an interesting overview of the social theories of the time followed by the evidence refuting them. Those theories included autism as social withdrawal, autism as extreme introversion, autism as a deprivation syndrome, autism as a type of schizophrenia, and autism as a psychogenic disorder. As late as 1972, Mahler and Furer (1972) still categorized infantile autism as one of two general syndromes of child psychosis, proposing that the autistic child either became fixated at or regressed to the “autistic phase of earliest infancy.” They maintained that “...through a negative, hallucinatory act, the child shuts out the human object world altogether” (p. 214).

By the mid-1960s, although controversy certainly continued, theories were mounting in support of autism being primarily a disorder of language and/or some other central cognitive disorder, although researchers disagreed as to exactly what comprised that central deficit. Some suggested a disorder of sensory motor integration and some a sensory disorder; however, most proposed a language disorder involving difficulty in the control of language and in understanding and using symbols, thus affecting both verbal and nonverbal components of language (Rutter & Bartak, 1971). Wing and Gould (1979), with a broader scope, proposed a multifaceted central disorder involving a combination of language, cognitive, and perceptual deficits. Regardless of disagreements over the nature of the exact deficit, by the 1970s there was a general shift in focus

from language and cognitive disturbances being the accepted primary deficits to social and behavioral disturbances gaining prominence as the accepted primary deficits.

Then, in the 1980s, several significant developments arose which continue to be pertinent today. The DSM-III (APA, 1980) was introduced delineating the first formal diagnostic criteria of autism using a three-symptom-category model based on social cognition and neurobehavioral models. Several neurobehavioral and social cognition deficit theories were introduced including Theory of Mind (Baron-Cohen et al., 1985), Executive Function (Damasio & Maurer, 1978), and Central Coherence (Frith, 1989). These theories propose *models*, not truths, which organize ideas about the speculated nature of autism. Yet, they are discussed so thoroughly and consistently, they are typically accepted as scientific explanations of the actual entity of autism. That is not to say that models are not helpful; they certainly can be useful in building and testing new conceptualizations and/or in designing interventions. Yet, they are just models, and models are usually products of the era, embedded in and born of the zeitgeist of the time. They do not propose etiology or explain underlying mechanisms (pathology). They are also recursive: For example, theory of mind describes an inability to imagine another's perspective as being different from one's own. Then, by way of explaining why these individuals cannot understand another's perspective, it is simply stated that they are autistic. All three of these models are restricted in domain, incomplete: They each explain elements of autism, but none is sufficient to explain all of the symptoms of autism. Minshew (1998) cautioned about the temporality of theoretical models, stating "neurobehavioral models are temporary conceptual constructs that organize existing findings into testable hypotheses for further investigation" (p. 129).

The third factor arising in the 1980s was the development of new brain imaging technologies which have unveiled new understandings of the brain's functionality in autism.

Unfortunately, as revolutionary as they are, the findings from these neuroimaging technologies have been slow to be incorporated into or to have any significant impact on re-evaluations of the definition of autism. Rather, new definitions seem for the most part to be rearrangements of older definitions. Verhoeff (2013) described the historical development of understandings of autism as being a recursive process in which definitional criteria recurrently draw from earlier criteria. In this process, Verhoeff noted that “the ‘triad of autistic impairments’ popularized by Wing and Gould (1979), is rather unproblematically projected onto Kanner’s original description of early infantile autism” (p. 445). Thus, Kanner’s description was recursively molded to be a natural precursor to current definitions, and current definitions could then be seen to have evolved logically from Kanner’s original description. This looping back, linking new to old and old to new, in re-evaluating the definition of autism seems prone to simply creating new versions of the status quo rather than starting anew with fresh eyes and critical minds to re-evaluate based on all available new information.

Nevertheless, a few changes in conceptualization have transpired. They are subtle, but important. The DSM-5 (APA, 2013) imposes fewer social or intentional interpretations onto the described behaviors than did previous editions of the DSM. Still, Verhoeff pointed out that Kanner’s (1943, p. 242) original description was less judgmental, less interpretive of the observed behaviors: “extreme autistic aloneness” ... was less interpretive than “impaired sociability,” and the “severe deficits in language development” described by Kanner are less interpretive than “impaired social communication” (APA, 2013; Verhoeff, 2013, p. 445). In both examples, Kanner’s statements describe an observation sans judgement of what that observation meant. Although most of the phrases intimating intent and preference were eliminated or changed in the DSM-5, those changes seem to have accomplished little in decreasing the

socially-interpreted and entrenched beliefs that the observed behaviors reflect a lack of desire for social contact, a lack of understanding of social communication, and deficits in cognitive ability. Likewise, the impression persists that there is intentionality and/or pleasure associated with restricted and repetitive behaviors, interests, or activities, and with acting out (i.e., melt-downs or tantrums). Donnellan et al. (2006), presented examples of the differences in attitudes about behaviors as exemplified in the labels assigned to the same behavior depending on whether that behavior was associated with a *known* movement disorder (i.e., neurological disorder) or with autism, an assumed social and communication disorder: akinesia vs. noncompliance; festination vs. behavior excess; bradykinesia vs. laziness or noncompliance; bradyphrenia vs. mental retardation; tics vs. aberrant behavior (p. 211).

Criterion A. 1 in the DSM-5 (APA, 2013) includes, “Deficits in social-emotional reciprocity...” “...failure of normal back-and-forth conversation;” “reduced sharing of interests, emotions, or affect;” Criterion 1. 3 begins with “Deficits in developing, maintaining, and understanding relationships...” (p. 50). These criteria imply lack of desire for or failure to understand social relationships and appropriate reciprocity. However, if the underlying pathology causes an *inability to initiate* action or an extreme delay in processing information and formulating responses to others (i.e., bradykinesia or akinesia/dyskinesia), if an individual feels overwhelmed by lack of structure and predictability as is inherent in many social interactions, particularly in play, if a person experiences his/her sensory experiences in a very different way from neurotypicals, it may be extremely difficult to demonstrate reciprocity or engage in normal back-and-forth conversation no matter how much that may be desired.

Those labeled autistic have also been described as being *unaware* of other people’s feelings, *preferring* to be and being *happiest* when left alone and isolated from others (APA,



1980). Fixations on inanimate objects as well as fixated, repetitive movements are *assumed* to mean those individuals have a *preference for* and an *interest in* inanimate objects over relationships or other people. Although autistics do describe “unusual” “interests in sensory aspects of the environment,” as stated in the DSM-5 criterion B.4 (DSM-5, p. 50), “interest” should not be assumed. In a 1992 award-winning documentary entitled *A is for Autism*, Temple Grandin described her intense focus on spinning objects as arising not from their being of intense interest to her, but rather as an adaptive response to block out intense auditory stimuli:

I was intensely preoccupied with the movement of the spinning coin or lid and I saw nothing and heard nothing. I did it because it shut out sound that hurt my ears. No sound intruded on my fixation. It was like being deaf. Even a sudden noise didn't startle me out of my world. (as cited in Donnellan et al., 2013, p. 18)

Ultimately, then, until “proven” (to the extent *proof* exists), assumptions are only assumptions, and they may or may not accurately, or even remotely, reflect either the underlying pathology driving the manifested behaviors or the internal states experienced by those actually living those behaviors and experiences. Donnellan et al. (2006) aptly warned, “Behaviors may not be what they seem” (p. 2). Williams (1994) expressed, “so much of what is misassumed about autism is based on those forms [manifested behaviors], on what appears rather than what is” (p. 196). Sean Barron (Barron & Barron, 1992) wrote,

All I wanted was to be like the other kids my age. It felt as if I was weird and strange on the outside, but inside I was not like that. The inside person wanted to get out and break free of all the behaviors that I was a slave to and could not stop. (p. 181)

Persons with these challenges may *appear* to be unmotivated, uninterested, or nonresponsive when in reality they may want very much to engage and interact, may very much want social-

emotional reciprocity, and may be very aware of conversations and interactions around them. Grandin (as cited in Donnellan et al., 2013) described what was sadly interpreted in her childhood to be remoteness and lack of affection: “As a child I wanted to feel the comfort of being held. I craved tender touching. At the same time I withdrew from touch. Being hugged was like being swallowed by a tidal wave...” (p. 18). Autistics may understand and desire relationships, but may not have the motor control or the speed or accuracy in sensory or integrative processing to tolerate or be able to interact typically enough to be able to convey their desire for interaction. Sue Rubin (Biklen et al., 2005) explained,

I have found in my experience that it is very hard for an autistic person to initiate relations with others. This does not mean that we do not desire communication. Instead our social rules are not socially acceptable. I have explained many times that my inability to look at someone when speaking to him or her does not mean I am avoiding the person as many presume. Sometimes, eye contact literally is painful for me to achieve. (p. 88)

Hence, behaviors become interpreted within constructed judgments about preferences and motivations. Lucy Blackman (Biklen et al, 2005), who acquired language at about age 14 through books and newspapers, but as an adult still barely speaks, types to communicate. She described some of the factors interfering with her development of interactions:

So, if one doesn't have depth perception what does that mean in terms of facial expression? If one hears the subtle sound of speech out of order, which I do, how does one process language? If affection in the form of cuddles and kisses cause[s] discomfort and pain in one's infancy, how on earth does one develop interaction which might compensate for not interacting to speech and glance? (p. 146)

In another passage, she described her challenges in public:

I still cannot operate effectively in language or independent movement in the community without someone who is involved in most aspects of my life. That is, not only do I behave oddly and not interact when people need me to create a bridge so they can behave in an appropriate way to me, but also if there is not absolute certainty and a lack of ambient sound, I can't sequence. So places like supermarkets or even the street require a one-on-one companion. (p. 154)

Minsheu (1998), a pioneer in autism research, proposed nearly 20 years ago that autism was “a neurobehavioral model of disorders of complex information processing systems based on abnormal neurocognitive development” (p. 129). Donnellan, Hill, and Leary were also among the first to pursue and promote research into autism as a sensorimotor disorder rather than adhering to the prevailing conceptualization of autism as a social-language disorder (see Leary & Hill, 1996). Speaking against the socially-laden interpretations of behaviors, Donnellan et al. (2013) stated:

People with autism often move their bodies in ways that are unfamiliar to us. Some people rock, repeatedly touch an object, jump, and finger posture while other people come to a standstill in a doorway, sit until cued to move or turn away when someone beckons. As professionals trained to see these as *autistic behaviors*, most of us have interpreted such movements as both volitional and meaningless; or as communicative acts signaling avoidance of interaction and evidence of diminished cognitive capacity; or as some combination of these, often to be targeted for reduction. We have taken a socially constructed interpretation of what we see and have built a “theory” of autism. (p.

1)

Unfortunately, once incorporated into definitions, theories are more likely to become mainstreamed accepted facts.

Although the DSM-5 changes are at least a nudge toward a more open, inquiring attitude toward understanding the role of motor and sensory neurological involvement in autism, it is disheartening to note that research has not been very effective in altering traditional conclusions about autism. Leary and Hill's (1996) statement of more than 20 years ago could just as well have been written today: "Although there is now general consensus that symptoms of autism are caused by disorders of the central nervous system (Ritvo & Ritvo, 1992), the psychological/psychiatric language continues to predominate characterizations of people with autism" (p. 39). Many doctors, educators, and therapists continue to formulate understandings of autism based on observable behaviors without seeming to factor in the descriptions and explanations provided by autists themselves. That which can be scientifically tested has been lauded over the information individuals living as autistic have themselves revealed.

When Donna Williams (1994; died April, 2017) - an articulate author initially diagnosed with childhood schizophrenia and mental retardation, then re-diagnosed with autism, and ultimately writing 13 books including two text books and two international bestsellers – when an articulate autist herself, declared, "none of us [those actually being autistic] could *presume* to speak for what appearances [behaviors] were or were not "autism," what right in the world do those who have never experienced autism have to *presume*, based solely on observations and appearances, anything about the internal state or experience that may be driving those outwardly-manifested appearances, that may be impacting the ability to type or to not type? Williams further challenged the stereotypes and assumptions about autism, stating,

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 (nonautistic authored) textbooks about autism and people with autism. (p. 196)

### **Historical Background of Facilitated Communication**

**The early years.** Biklen and Cardinal (1997) described a mother in England using physical support to help her autistic daughter write to communicate in the late 1960s. They related that Rosalind Oppenheim used facilitation to help her son and others communicate in the 1970s and '80s. Yet, it wasn't until 1990 that facilitated communication burst onto the public stage in the United States following Biklen's publication in the Harvard Educational Review of Rosemary Crossley's work in Australia teaching minimally- or non-speaking individuals with cerebral palsy, Down's syndrome, and autism to communicate using facilitation.

Biklen had first observed and interacted with two individuals who were using facilitated communication with Crossley at the Dignity through Education and Language (DEAL) Communication Center, an independent Australian government-funded center established by Crossley to assist people who either could not speak or could not do so clearly (Biklen, 1992, p. 209). Biklen then returned seven months later to "study Crossley's work more systematically" (p. 210), and from these interactions, Biklen ultimately described in his 1990 Harvard Educational Review article the written communication efforts of 21 individuals who were either non-speaking or who spoke only with echolalic expressions. Biklen described the remarkable communicative transformations of the individuals with whom he had interacted and whom he described as being "low functioning," autistics, demonstrating involved autistic mannerisms –

walking on the balls of feet, averting gaze, offering no verbal interactions, and showing facial expressions that were incongruent with conversational topics. Biklen (1992) reported that those individuals typed with minimal assistance, either with a facilitator's hand on their shoulder, on top of their forearm, or with a hand poised out-stretched above, but not touching, the communicator's hand. At times, Crossley was described as pulling someone's hand back from the keyboard, asking "where are you going?" or "I don't understand what you're typing." Several who typed independently or with minimal touch were described as having begun by requiring full hand-assisted facilitation (p. 214).

Biklen (1992), becoming one of the leading researchers and advocates for facilitated communication, rather than unquestioningly accepting all he witnessed as critics charged, acknowledged puzzlement over much of the communication process, questioning why some individuals who regularly communicated independently or with a mere touch on the shoulder with some people would not communicate at all with others (p. 212). Biklen further puzzled that individuals would at times

...refuse to communicate at particular moments, in particular situations, with certain people, or for specific time periods... Some are independent in some situations, but dependent or non-communicative in others, whether with the same or other people.... All of the people I observed typing 'independently' with just a hand on the shoulder did not type as well or sometimes at all for me alone or for other new facilitators." (p. 215)

While advocates believe there are yet-to-be-understood phenomenon underlying these inconsistencies and reference them when discussing the issues with formal testing, opponents argue that the inconsistencies, as well as other evidence, support their argument that it is the facilitators who are to varying degrees influencing communicative output (Bebko et al., 1996;

Bomba et al., 1996; Cabay, 1994; Calculator & Singer, 1992; Crews et al., 1995; Eberlin, McConnachie, Ibel, & Volpe, 1993; Moore Donovan, Hudson, Dykstra, & Lawrence, 1993; Regal, Rooney, & Wandas, 1994; Szempruch & Jacobson, 1993; Wheeler et al., 1993).

**Controversy erupting.** Facilitated communication not only burst onto the scene with Biklen's 1990 Harvard Educational Review publication, that burst was accompanied by an eruption of controversy. It has never been without challenges. The first person with whom Rosemary Crossley worked, Anne McDonald, was a girl with cerebral palsy "who resided in an institution for children with multiple handicaps, all of whom were presumed severely retarded" (Biklen & Cardinal, 1997, p. 12). When Anne typed that she wanted to leave the institution to go live with Crossley, the authorities at the institution challenged whether that communication was hers, "arguing that Anne was retarded and incapable of the literacy claimed for her" (Biklen & Cardinal, 1997, p. 13). Anne did pass the tests with a court facilitator to prove her authorship in "the first documented authorship test of facilitation" (Biklen & Cardinal, 1997, p. 13), and was allowed to leave the institution to live with Crossley and Crossley's husband in 1980. She subsequently went on to earn a bachelor's degree, traveled and lectured, and with Rosemary Crossley wrote her autobiography, *Annie's Coming Out* (Crossley & McDonald, 1985).

Following McDonald's discharge from the institution, an Australian government committee of inquiry filed their 1980 report, which according to Biklen and Cardinal (1997) "...all but labeled facilitated communication and Crossley a fraud" (p. 14). Specifically, as cited by Biklen and Cardinal, the report stated, "Not one of the 11 children [with whom Crossley continued to work] shows any evidence of a level of intellectual functioning beyond that expected of children of two and a half to three years of age" (p. 14). However, after the report was published, disability groups denounced it, which led to the release of a *Supplementary*

*Report* disputing the original. Eventually, the original report “was finally discredited when papers obtained under FOI [freedom of information] showed the *Committee had concealed positive [facilitated communication] test results*” (italics added; Biklen & Cardinal, 1997, p. 14).

Then, in 1989, the first formal published investigation of authorship in facilitated communication was conducted by the Australian Intellectual Disability Review Panel (IDRP) in response to concerns about authorship raised by professionals (Biklen, 1997; Calculator & Singer, 1992; Cummins & Prior, 1992; Mostert, 2001). Biklen and Cardinal (1997) wrote that the results of this investigation “left many observers of the method in a quandary. It seemed to provide evidence to the supporters of the method as well as to critics” (p. 15). Biklen reported that the results of this study were mixed: four of six individuals in the study demonstrated the ability to respond appropriately and correctly to some questions or were able to relate some information about a gift they had received as part of the testing, all being information to which the facilitators were blinded. Highlighting the divide in how researchers approach design, interpretation, and presentation of study outcomes, however, other researchers disagreed with this conclusion, declaring that no controlled studies, including those of the IDRP, had provided any evidence of authentic authorship (Cummins & Prior, 1992).

Following Biklen’s (1990) report, enthusiasm for facilitated communication swept the country. Biklen established the Facilitated Communication Institute at Syracuse University, training workshops were offered, and other university-affiliated centers promoting facilitated communication opened (Lilienfeld, 2012). Facilitated communication was lauded in the media in 1992 and 1993 through articles in *Parade Magazine*, *Reader’s Digest*, *The Washington Post*, *USA Today*, *CBS Evening News with Dan Rather*, the news program, *20/20*, and the Public Broadcasting System’s *Frontline* program entitled *Prisoners of Silence* (Mostert, 2012, p. 19).



Many researchers, however, were skeptical, charging that the results were too good to be true. They doubted that individuals who had never functioned above a two and a half to three-year-old level could suddenly be capable of typing complex and abstract thoughts. Cummins and Prior (1992) voiced the opinion of many skeptics in saying that all correct responses in testing were influenced or cued in some way, and all communications by communicators were actually communications by the facilitators through the “Clever Hans” effect. “The Clever Hans” or “The Ouija Board” effect would become a common reference in accusations made against claims of facilitated communication’s validity. The effect would become instrumental in explaining how facilitators unknowingly influence the writings produced by the communicators. The Clever Hans and the Ouija Board phenomena are both examples of ideomotor responses or automatism: actions or movements caused or initiated by a person who is completely unaware of his or her role in performing them. Although the actions are not perceived to be the least bit volitional, but rather are perceived to be occurring either because of someone else’s actions or by some psychic power, they are indeed voluntary movements, although “subconsciously” so without any sense of volition or intent (Burgess, 1998). Other examples of automatism include the Chevreul pendulum illusion, table turning, tilting, and tapping, dowsing, and automatic writing.

The American Speech-Language-Hearing Association (ASHA, 1994) suggested a means by which the ideomotor effect might be enacted, proposing that facilitators subconsciously sustain resistance against forward movements when the hand is moving toward undesired letters, but then the facilitator releases the resistance when the pointing finger is approaching a desired letter. Thus, researchers began investigating in earnest the most basic question couched within

the controversy: Who, in actuality, was producing the typing or writing - the facilitated communication user, the facilitator assisting the user, or some combination of the two?

**Early empirical test designs.** Controlled studies were developed to put the question of authorship in facilitated communication to the test. Rather than settling the dispute, however, research would only fuel the controversial ardor with more questions and rising contention. As Cardinal et al. (1996) stated, “In the history of special education, rarely, if ever, has a new instructional method produced such diverse results and fiery debate...” (p. 1). Not only did researchers challenge the test designs implemented by their opponents, they also disagreed with the interpretation of results and the significance of the outcomes. In fact, almost nothing can be said about facilitated communication that is not steeped in controversy, from the first reported formal investigation, to methods of testing and the interpretation of outcomes, to the fundamental nature and level of the individuals’ intellects, to the sensorimotor and neuroscience underlying autism and communication.

The first empirical tests of authorship involved various forms of message passing. The task involved asking the communicators to convey through typing which specific stimulus they had just been provided. They might be asked to type a spoken or written word they had just heard or read, type the identity of a photo they had been shown, select a specific picture or photo from a set of pictures or photos, or name an object they had just seen and in some cases had touched and handled. The control procedure involved randomly and blindly providing either the same stimulus to the facilitator and the communicator, showing or naming a different stimulus to each simultaneously, or showing or naming the stimulus only to the communicator while either providing a blank or white noise to the facilitator (Bebko et al., 1996; Bomba et al., 1996; Cabay, 1994; Crews et al., 1995; Eberlin et al., 1993; Klewe, 1993; Montee et al., 1995; Regal et al.,

1994; Shane & Kearns, 1994; Smith, Haas, & Belcher, 1994; Szempruch & Jacobson, 1993; Wheeler et al., 1993).

In the vast majority of these studies, communicators were minimally or unable to respond correctly through typing or pointing to the correct picture or word unless the facilitator was also provided the same prompt. Some studies also indicated strong influence by the facilitators, with the communicators only producing responses based on the facilitators' prompts, whether they were correct or not, rather than on their own prompts (Bebko et al., 1996; Bomba et al., 1996; Cabay, 1994; Crews et al., 1995; Eberlin et al., 1993; Klewe, 1993; Moore et al., 1993; Regal et al., 1994; Shane & Kearnes, 1994; Smith et al., 1994; Szempruch & Jacobson, 1993; Wheeler et al., 1993). In fact, often when the facilitator and communicator were shown different stimuli, the typed answer would identify the stimulus shown to the facilitator rather than the one shown to the communicator (Bebko et al., 1996; Cabay, 1994; Hudson, Melita, & Arnold, 1993; Moore, Donovan, Hudson, Dykstra, & Lawrence, 1993; Shane & Kearns, 1994; Wheeler, Jacobson, Paglieri, & Schwartz, 1993).

A few quantitative, blinded studies, however, did report successful demonstrations of authorship (Calculator & Singer, 1992; Cardinal et al., 1996; Heckler, 1994; Intellectual Disabilities Review Panel (IDRP), 1989; Sheehan & Matuozzi, 1996; Weiss et al., 1996), although they did so amid mixed results and inconsistencies, with some also acknowledging clear evidence of facilitator influence (Calculator & Singer, 1992; Vazquez, 1994; Weiss et al., 1996). The largest of these studies, conducted by Cardinal et al. (1996), tested 43 public school students through a total number of trials exceeding 3800. After six weeks of accumulated experience participating in trials, the authors reported that 74% of the students were able to correctly spell one or more of the stimulus words they had been shown. However, as has been

the case with nearly every published study regarding facilitated communication, whether qualitative or quantitative, the study was challenged. In this case, Mostert (2001) charged there was poor control of data collection bias, lack of pretest data, and preconceived assumptions about outcome.

**Modifications to empirical test designs.** With the vast majority of quantitative studies failing to show authorship independent of facilitator influence, facilitated communication advocates raised concerns about message-passing test designs, citing word finding/word recall problems, anxiety provoked by imposition of unnatural apparatuses such as headphones or visual shields and the testing environment itself, and/or failure to allow participants to practice with test formats as possible interfering factors (Biklen, 1992; Szempruch & Jacobson, 1993). Although skeptics and those with a positivist orientation towards science and research did not and do not accept anecdotal accounts or evidence from qualitative studies, advocates cited anecdotal accounts and autobiographies, some by individuals who had progressed from initially requiring physical facilitation to write/type to eventually becoming fully independent in typing (Biklen, 1990; Biklen & Cardinal, 1997; Biklen & Schubert, 1991; Crossley, 1992; Crossley & McDonald, 1984; Crossley & Remington-Gurney, 1992). Teachers, therapists, and researchers who worked directly with individuals using facilitated communication, certain that communicators were conveying information unknown to facilitators, asking questions, and arguing with the views of facilitators, began to investigate alternative methods of evaluating facilitated communication. No one doubted that facilitators needed to exercise care in not influencing writings. Biklen (n.d.a.; 1992) and Crossley (Crossley & Remington-Gurney, 1992) cautioned about the ease with which facilitators could unwittingly influence communicative output, and recommended frequent screening to assist facilitators in monitoring this tendency.

However, advocates maintained that although facilitator influence was a risk, that did not mean facilitators were influencing writing at all times or in all cases.

In response, quantitative designs were modified. Several studies posed short-answer questions or fill-in-the-blank statements (Cabay, 1994; Hudson et al., 1993; Moore et al., 1993). Examples included “What did you eat for breakfast/lunch today?” “What is your name?” “What is your favorite color?” “On your feet you wear \_\_\_\_” “You live in \_\_\_\_” “To sweep the floor you use a \_\_\_\_” (Cabay, 1994, p. 520); “What color is your sister’s car?” “What is the name of your dog?” (Moore, Donovan, Hudson, Dykstra et al., 1993, p. 533). Facilitators felt more confident with these approaches, and were therefore surprised to find that none of the participants could provide content-appropriate answers to the questions. Remaining convinced that the participants could communicate via facilitated communication and that the test design must have again imposed some difficulty for them, the facilitators suggested a different approach – introducing topics for conversational evaluation (Moore, Donovan, & Hudson, 1993). Again, however, none of the communications were content-appropriate.

Vazquez (1995) addressed the issue of anomia, or word retrieval problems, by allowing descriptions of any element of the test stimuli rather than requiring a specific identifying word. Vazquez also addressed visual agnosia by allowing participants to handle rather than simply look at the objects they were asked to identify. Again, subjects failed to type correct answers when facilitators were blinded to the stimulus. In a different study, Vazquez (1994) designed a test format utilizing questions based on excerpts from educational videos. One of two participants was able to answer questions correctly about one of the videos. Of note, Vazquez specifically stated that videos “were selected for their redundancy” (p. 371). While it may have been assumed that redundancy would assist with recall, given the motivational and attentional

difficulties associated with autism, one might question how much interest and motivation was generated by excerpts from educational programs.

Simon et al. (1994), attempting to eliminate the unnaturally-imposed elements of message-passing, designed a study in which students participated in a familiar activity within their school such as “vacuuming in a living skills area, buying an item from a vending machine, reading a book at the library, painting wood in a project center, and playing ball in the gymnasium” (p. 651). Participants were then asked to disclose through facilitated communication the location and the activity in which they had just been engaged. Control variables included facilitators being naïve, informed, or misguided as to the activity and location. Although there was clear evidence of some facilitator guidance, the authors also reported evidence for independent authorship by four of the seven students. These positive reports were challenged, however, on the basis that possible clues such as the lingering odor of Fritos indicating a trip to the vending machine were present during testing (Green & Shane, 1994). Then, in a follow up case study by the same researchers (Simon, Whitehair, & Toll, 1996), one of the students who had seemed to produce valid communication on 3 out of 10 trials in the original 1994 study was unable to produce any validated communication responses with facilitation, and now two years later much preferred using PECS (picture exchange system).

Several reviews of facilitated communication summarized results through the mid-1990s. In 1992, Green reported that out of 146 opportunities for responses in 12 controlled studies, only three responses could be attributed to facilitated communication (as cited in Mostert, 2001, p. 289). Mostert (2001) continued to recount from Green’s report that in the three studies without controls, 41 of 98 subjects using facilitated communication produced sentences, four produced single words, 41 demonstrated reading skills, one participant indicated “yes” and “no” answers,

and one participant was able to point to pictures. Mostert (2001) also summarized Green's second review published in 1994 covering studies conducted after her 1992 review. Mostert reported that of 25 studies with controlled procedures, Green reported that only 12 of 226 possible communicator responses could be considered to be responses above a chance level. Even within the "successful" responses, possible alternative explanations to facilitated communication could not be ruled out. In comparison, from the six non-controlled studies Green reviewed, the researchers reported a total of 109 of 112 participants demonstrating unexpected literacy or communication skills (Mostert, 2001, p. 289).

With the publication of these reviews, the flurry of research on the utilization of facilitated communication ebbed in the mid-1990s, many concluding that a consensus had been reached: communications were not those of the communicator, but rather were those of the facilitator inadvertently acting through influencing the communicator's hand. In 2001, Mostert published a review of studies conducted between 1995 and 1999, with results supporting those of earlier reviews: Nineteen studies with one or more controlled procedures provided no evidence of authentic authorship. Six studies designed with one or more controls supported at least some evidence for authentic authorship, however, Mostert followed that by saying that all but two had too many confounding variables to be valid. And finally, those last two studies were also challenged on grounds of poor control for data collector bias, test materials and procedures posing threats to internal validity, possible facilitator influence, and results possibly being based on causal assumption. Following Mostert, Saloviita (2014) summarized study results published after 1999:

All studies based on controlled message-passing trials have refuted the validity of FC [facilitated communication] (Emerson, Grayson, & Griffiths, 2001; Perini, Rollo, &

Gazzotti, 2010; Wegner et al., 2003). In contrast, all studies using non-controlled observational designs claim to have validated FC ((Bernardi & Tuzzi, 2011a, 2011b; Niemi & Kärnä -Lin, 2002; Scopesi, Zanobini, & Cresci, 2003; Sipilä & Määttä, 2011; Tuzzi, 2009; Zanobini & Scopesi, 2001). (p. 214)

The controlled testing from one of those studies (Emerson et al., 2001), which revealed little evidence for validity of facilitated communication, was just one part of a larger long-term project evaluating validity under various methods of data collection. The other methods - evaluation of patterns of behavior on video analysis and “transcripts or diary records of routinely occurring FC sessions” - did “provide evidence of FC user authorship” (p. 99). These authors agreed that “There can be no disputing the findings of the controlled experimental studies which represent the bulk of the extant literature” (p. 100). However, their argument, based on their collection of transcript data showing evidence of authorship, also concluded that researchers too readily “slip” from data to interpretations, from observation of nonperformance on controlled tests to interpretations of inability, which may be wholly inaccurate. They concluded that the overall picture of facilitated communication is more complex than what is revealed through controlled testing: “The same participants who do not provide authorship evidence in controlled trials provide data which indicate that they are authoring their communications when given the opportunity to communicate about things of their own choosing” (p. 100).

Critics continued to maintain, however, that controlled testing provided the best measure of the validity of facilitated communication and of the communicative competence of facilitated communication users. Hence, many researchers concluded that the case was closed: Facilitated communication had been fully debunked and discredited by the mid to late 1990s. Those researchers who held that belief, therefore, expressed deep concern over the “resurgence” in the



use of facilitated communication in the early 2000s (Chan & Nankervis, 2014; Heinzen et al., 2016; Lilienfeld et al., 2014; Mostert, 2012; Travers, Tincani, & Lang, 2014; Wagner, Sparrow, & Fuller, 2003; Wombles, 2014).

**The “resurgence” of facilitated communication.** But the case was not closed.

Facilitated communication continued to be used, triggering one faction of researchers to again rally against its use, calling on practitioners to take up arms to educate clients against the dangers of this fad intervention they believed to be based on pseudoscience and antiscience. The very titles of their articles are revealing of their concerns to stop what they claimed to be the unethical use of a non-evidence-based, dangerous intervention. The title of Chan and Nankervis’s (2014) article clearly stated their negative view of facilitated communication: “Stolen Voices: Facilitated Communication is an Abuse of Human Rights.”

Mostert (2012) called for an “Empirical Imperative to Prevent Further Professional Malpractice” (p. 18). Shermer (2016) referred to the continued use of facilitated communication as “The Quack of the Gaps Problem” (p. 75), stating in reference to facilitated communication, “gaps in scientific knowledge are filled with anyone’s pet ‘theory’ and corresponding ‘treatment’” (p. 75). Wombles (2014), in “Some Fads Never Die—They only Hide Behind Other Names: Facilitated Communication is not and Never will be Augmentative and Alternative Communication” stated disparagingly that facilitated communication was again flourishing due to “the ability of the internet to connect parents with individuals who are being facilitated and display eloquent, even advanced communication skills (p. 181). Travers et al. (2014), in “Facilitated Communication Denies People With Disabilities Their Voice,” claimed, “The resurgence is due to strategic rebranding (i.e., “supported typing”) and repackaging (i.e., Rapid Prompting Method) of FC as well as old tactics that capitalize on confirmation bias,

pseudoscience, anti-science, and fallacy” (p. 200). This rebranding and repackaging by the facilitated communication community, these authors claimed, was that community’s means of divesting itself of negative associations attached to the original term, facilitated communication.

One problem with these articles, as demonstrated by their titles, is that they are emotionally charged – which always creates a risk to objectivity. In addition, the authors, as if caught in their own monotropism, repeat the same arguments they presented 25 years ago without ever referencing the latest neuroimaging and behavioral research from the past 15 years indicating that sensory and motor impairments are the source of many of the differences seen in autism, and may be at least partially responsible for differentially affecting the ability to type under varying circumstances. Lilienfeld et al. (2014) argued that factors contributing to the persistence of people holding firmly to their beliefs in facilitated communication include naïve realism, “the belief that we can place uncritical trust in the raw data of our perceptions... [and] implies falsely that ‘seeing is believing’” (p. 88), and confirmation bias, which “leads us to seek evidence consistent with our beliefs and to neglect or selectively reinterpret evidence that does not...” (p. 89). The authors continued:

Confirmation bias regarding a specific belief, such as FC’s effectiveness, can in turn engender belief perseverance...creating a psychological “tunnel vision” in which the belief persists despite persuasive negative evidence. Furthermore, once individuals find themselves committed to a stance, cognitive dissonance and allied processes... as well as face-saving... may make it difficult for them to admit errors to themselves or others. (p. 89)

Although these statements were directed against facilitated communication advocates, they could just as easily have been written in the reverse: by *proponents of facilitated communication in*

*admonishment of opponents*. Indeed, drawing on phrases from Lilienfeld et al.'s (2014) quote above, it may be Lilienfeld et al. who are blinded by *their* “confirmation bias” (p. 89) against facilitated communication, thereby “engender[ing] belief perseverance, creating psychological tunnel vision in which [*their*] beliefs persist despite persuasive” (p. 89) *new scientific evidence*. Continuing along this line, Lilienfeld et al.'s statement, “Furthermore, once individuals find themselves committed to a stance” (p. 89) – such as believing that facilitated communication is never valid or that autism is a psychosocial disorder – “cognitive dissonance and allied processes... as well as face-saving... may make it difficult for them to admit errors to themselves or others” (p. 89).

In response to accusations of facilitated communication being pseudoscience and antiscience as made by Heinzen et al. (2016), and to claims that facilitated communication is a “pet theory” created to fill a gap in the scientific literature as made by Shermer (2016) in “The Quack of the Gaps,” there has indeed been a “gap” in scientific knowledge about facilitated communication and about autism. However that gap is beginning to be filled substantially by findings from neuroimaging research and related behavioral research over the past 15 years. Heinzen et al. (2016), Lilienfeld et al. (2014), and Shermer (2016), however, make no mention of the latest neuroconnectivity research in autism and how that might relate to facilitated communication testing and validity.

Heinzen et al. (2016), in their book, *The Horse That Won't go Away: Clever Hans, Facilitated Communication, and The Need for Clear Thinking*, proposed that the resurgence of facilitated communication, rather than being grounded in clear and critical scientific thinking, has been spurred by media productions promoting facilitated communication and bought into by

a new generation that is unaware of the evidence and conclusions of the 1990s refuting facilitated communication.

Wick and Smith (2009) demonstrated there was a fairly sudden drop in media coverage of facilitated communication from 1993 to 1996 followed by a more gradual decrease into the first two to three years of the millennium. Then, in 2004, there was a distinct and sudden spike in media coverage coinciding with the release of the Academy Award-Nominated for Best Documentary Short Subject, *Autism is a World* (Wurzberg) written by and depicting Sue Rubin's journey from communicative silence to typing independently, writing documentaries, books, and giving lectures.

It is also true that the media can convey whatever slant it chooses. It can show, as it did in *Prisoners of Silence* (CNN, 1993), the facilitators' eyes being focused on the keyboard while the communicators were looking away during typing; or it can show communicators typing only when looking at the keyboard and stopping when they look away, with facilitators watching the communicator's face and only glancing at the keyboard as was presented in a video at the Autism One 2016 convention (Administrator, 2016). However, although the media may have again increased its coverage of facilitated communication and a new generation may have come of age to be introduced to facilitated communication without knowing of its controversial background, claiming that these factors were *causal* in bringing about its resurgence as suggested in Lilienfeld et al. (2014) is a leap. It is just as likely that the "resurgence" in the use of facilitated communication along with increased media coverage and a new generation discovering its use all correlate with more individuals finding it to be helpful and passing that along by word of mouth and through social internet sites. In addition, these authors cannot accuse others of not employing clear and critical scientific thinking when they did not include

any evidence of having conducted any clear and critical review of the latest neurological research data and the implications that data could have for explaining difficulties with facilitated communication in some circumstances but not in others.

Lilienfeld et al. (2014), in their article, “The Persistence of Fad Interventions in the Face of Negative Scientific Evidence,” posited that a “fad intervention” such as facilitated communication “persists, and sometimes thrives, in ‘underground form’ in sizeable sectors of the clinical or educational communities” (p. 63). They also suggested that the “surprising and largely unknown story of FC’s persistence may shed light on this puzzling phenomenon” – that phenomenon being how “what would otherwise be a passing fad transmogrifies into a ‘chronic malignancy’” (p. 65). In their alarm over this malignant “resurgence” of facilitated communication, the authors “urge scientists in the communication disorders, psychological, and educational arena to become more vocal in their opposition to fad interventions of all kinds” (p. 92). Interestingly, according to these authors, this “underground” sector in which facilitated communication has apparently been stealthily used and guarded includes its inclusion in “a select few, but highly popular, textbooks” (p. 76), its inclusion in college and university curricula, and its being promoted in the media and by self-advocates who have written many, many books once they became independent in typing without facilitation. By way of illustrating the alarming scope of its “resurgence,” the authors devoted *seven pages* of their article to listing and discussing the venues in which facilitated communication has been thriving “underground.” A few examples from the three-page section entitled, “Facilitated Communication’s Comeback in Academic and Professional Institutions” are condensed here as follows:

A number of colleges and universities now support, if not endorse, FC. The most obvious example is the enduring success of Douglas Biklen’s Facilitated Communication Institute

at Syracuse University... The ICI [the Institute on Communication and Inclusion, previously the Facilitated Communication Institute] has been accorded legitimacy in numerous quarters... \$500,000 grant from the John P. Hussman Foundation... with nearly a third of the award allocated “to support the training of family members in the use of augmentative and alternative communication strategies” ... a long-time recipient of grants and support from the Nancy Lurie Marks Foundation... Solidifying the impression of FC’s scientific legitimacy was Douglas Biklen’s appointment, in 2005, as Dean of Education at Syracuse University... Biklen was appointed by Syracuse University Chancellor Nancy Cantor, herself a prominent psychologist... Douglas Biklen’s 2011 award from the United Nation’s Educational, Scientific and Cultural Organization (UNESCO)... in 2002, Donald Cardinal, another of FC’s earliest advocates, was appointed Dean of the College of Educational Studies at Chapman University in Orange, California. Mary Falvey is Dean of the College of Education at California State University, Los Angeles. Her eponymous award, the Mary Falvey Outstanding Young Person Award, has been given at least twice to FC users, Sue Rubin in 1988 and Peyton Goddard in 2004... Anne Donnellan (Emeritus, University of Wisconsin) became Director of the Autism Program at the University of San Diego and was appointed to the Panel of Professional Advisors of the Autism Society. Recently and currently active academicians who have explicitly endorsed the efficacy of FC and closely allied methods, such as rapid prompting, can be found on the faculties of numerous other institutions in the US and abroad [which the authors then listed and which were numerous indeed]... Perhaps the pinnacle of FC’s success in academia, however, was attained in July 2011, when the Massachusetts Institute of Technology (MIT) Media Lab hosted a

conference on FC, with Douglas Biklen and Rosemary Crossley as invited speakers. (pp. 76-78)

In the section, “Facilitated Communication in Print and Online,” the authors listed the following peer-reviewed academic journals publishing articles in support of facilitated communication:

*Brain and Language, Topics in Language Disorders, Focus on Autism & Other Developmental Disabilities, Intellectual and Developmental Disabilities, Disabilities Studies Quarterly* (sic; the journal title is *Disability Studies Quarterly*), ...*Frontiers in Integrative Neuroscience. The Journal of Autism and Developmental Disorders*... Over two dozen articles and chapters that endorse FC as a valid intervention have appeared in academic outlets since 2005, at least 15 of them peer-reviewed. (p. 80)

The authors then proceeded with, “High-profile organizations outside of academia have also played an increasing role in supporting FC,” (p. 79) including the Dan Marino Foundation and the Autistic Self-Advocacy Network (ASAN), the Doug Flutie Jr. Autism Foundation, the U.S. Department of Justice which hired an FC advocate in 2007 “to produce a manual and DVD on forensic interviewing of people with cognitive disabilities” (p. 79). The article continued outlining the presence of facilitated communication under the additional sub-headings of “Media and Internet Coverage” (p. 73) and “Facilitated Communication in the Entertainment World” (pp. 81-83). Although the authors presented this rather extensive documentation of the ongoing presence of facilitated communication as the justification for sounding the alarm that the “real work [to stop the use of facilitated communication] may have just begun” (p. 65), the sheer magnitude of this “underground” presence suggests that the reasons for the continued use of

facilitated communication may extend well beyond its just being a filler of a gap in research. Perhaps there are legitimate reasons the *fad won't die* and *the horse won't go away*.

**Alternative methods of testing facilitated communication.** Whether this period of facilitated communication's history in the 1990s was truly marked by a drop in interest in and use of facilitated communication followed by a resurgence in its use or whether it had continued to be used all along, but with less publicity, is a matter of debate. What is clear is that expanded methods of evaluation accompanied its use into the new millennium.

*Linguistic analysis.* In spite of the vast majority of quantitative, controlled studies providing evidence to the contrary, advocates and many researchers maintained that facilitated communication was a valid intervention that empirical tests failed to capture. Simon et al. (1994), supporting the perspective of Crossley (1992) and Biklen (1990), stressed the importance of evaluating authorship in naturalistic settings that “do not impose artificial constraints on the FC process” (p. 648). They and others argued that authorship was best and perhaps only able to be accurately evaluated using qualitative methods such as linguistic and process analysis.

Thus, researchers began investigating communications and documents produced by communicators through linguistic analysis, process analysis, and portfolio collections demonstrating individualistic elements of writing (Bernardi & Tuzzi, 2011; Broderick & Kasa-Hendrickson, 2001; Emerson, Grayson, & Griffiths, 2001; Janzen-Wilde, Duchan, & Higginbotham, 1995; Niemi & Karna-Lin, 2002; Tuzzi, 2009). Process analysis involves evaluating elements in narratives such as the consistency in word usage and style across assistance by multiple facilitators, typed messages that disagree with the facilitator, divulging information unknown to the facilitator, or typed messages that would be highly unexpected from facilitators. Process might also include showing emotion or facial expressions commensurate



with the messages being typed, the communicator orally anticipating what he or she then types, demonstrating consistent personality styles such as use of sarcasm, playfulness, or expressing traits such as low self-esteem, and demonstrating increasing levels of independence in writing. One study analyzing text of six secondary-school level children found evidence for authorship in all eight of their specified categories which were similar to those just listed (Bigozzi et al., 2012). Another study (Emerson et al., 2001) contrasted their results of testing 14 participants using both controlled tests and conducting analysis of transcripts. Their evidence demonstrated findings similar to other studies: “The same participants who do not provide authorship evidence in controlled trials provide data which indicate that they are authoring their communications when given the opportunity to communicate about things of their own choosing” (p. 100).

Pure linguistic analysis as opposed to process analysis involves analyzing peculiar and consistent word choices, particular ways different parts of speech are used, unique and consistent typographical errors, unique and invented spellings consistent to particular individuals, and/or use of unusual phrases or sentences all of which remain consistent in a given communicator across multiple facilitators (Biklen, 1992; Calculator, 1992; Niemi & Karna-Lin, 2002). Again, results were strenuously argued from both sides – proponents providing analysis of unique authorship distinct from styles and word usage of facilitators, while opponents countered with challenges and alternative explanations that facilitators could unknowingly develop idiosyncratic styles, words, and spellings unique to different communicators (in chronological order, see Niemi & Karna-Lin, 2002; Saloviita & Sariola, 2003 [response to Niemi & Karna-Lin, 2002]; Sturmey, 2003 [response to Niemi & Karna-Lin, 2002]; Niemi & Karna-Lin, 2003 [response to Sturmey, 2003]; Niemi & Karna-Lin, 2003 [response to Saloviita & Sariola, 2003]). Tuzzi (2009) concluded that the analysis of texts typed by 37 individuals supported “the existence of

lexis and distributional patterns of grammatical categories that are characteristic of the written production of individuals with autism and that are different from those of facilitators” (p. 373).

Saloviita, on the other hand, argued that unique typographical errors, unique phonetic spellings, and unusual phrases may just be artifacts of the facilitated writing process; unique physical movements and different levels of independence “can hardly be seen as definitive proof of the authenticity of FC;” and “delivery of information not thought to be known to a facilitator, would be important evidence, but without experimental control over the information being relayed, the claims remain at the anecdotal level” (p. 214).

*Eye tracking.* Also questioning the finality of conclusions based on message-passing tests, and in fact stating that there are dangers in being overly-reliant on message-passing types of testing, Grayson, Emerson, Howard-Jones, and O’Neil (2012) introduced a unique approach to evaluating authorship – eye-tracking and video analysis. They evaluated a man in his 40s with autism spectrum disorder who had been using FC for over five years. He “is regarded as having severe intellectual disabilities, has no speech, and no systematic means of expression other than through FC” (p. 77). The study, utilizing eye-tracking technology to evaluate the timing and duration of gaze fixation with pointing, which was documented using a video recording synchronized with the eye tracking device, concluded that there was a “strong and consistent relationship between the FC user’s looking and pointing behaviors” (p. 84).

### **High Stakes**

And so, a schism has sheared through professional and lay communities alike. The differing views of facilitated communication continue to be representative of a broader debate in epistemology, of a deeper divide in fundamental beliefs and paradigms about what constitutes scientific rigor, about understandings of intellect and disability, and about what outward

behavioral manifestations indicate about potential intellectual dis/abilities. It is a deeper pitting of positivism - double or at least single blind, quantifiable tests being equated with true science, with certainty and “truth” - against subjectivism, phenomenology, interviews, and qualitative study designs which some equate with pseudoscience and non-science. As stated by Sailor (1996), “facilitated communication is simply the newest battleground for the old epistemological tilt between subjectivism (e.g., Biklen, 1990) and positivism (e.g., Shane & Kearns, 1994)” (p. 984).

Proponents and detractors alike challenge their opponents’ results, pointing to flawed research or test designs. On the one hand, proponents of FC charge that empirical tests using either single- or double-blind designs miss capturing abilities that are present but cannot manifest under controlled test conditions; on the other hand, detractors charge that qualitative accounts lack empirical rigor to support their claims. Point and counterpoint articles have flown between authors (see, for examples: Biklen, 1996 [response to Jacobson et al., 1995]; Calculator, 1995 [response to Perry, Bebko, & Bryson, 1994]; Jacobson et al., 1995 [evaluation of fc studies]; Mostert, 2003 [response to Bebko, Perry, & Bryson, 1996]; Niemi & Karna-Lin, 2003 [response to Saloviita & Sariola, 2003]; Niemi & Karna-Lin, 2003 [response to Sturmey, 2003]; Saloviita, 2003 [response to Niemi & Karna-Lin, 2002]; Sturmey, 2003 [response to Niemi & Karna-Lin, 2002]).

In the fray were and are opponents charging that facilitated communication is not only ineffective, but is also a dangerous technique that has resulted in false allegations of sexual abuse, apparently false consents to sexual relationships or giving monetary gifts, and to apparent false consents to use of constraints. Opponents charge that claims of facilitated communication validity deceive parents about their children’s true potential and therefore rob users of time,

money, and resources that could have been better invested in other modes of communication and therapy (Chan & Nankervis, 2014; Eberlin et al., 1993; Green & Shane, 1994; Konstantareas & Gravelle, 1998; Lilienfeld et al., 2003; Wheeler et al., 1993). Probably the most devastating effects on individuals and families arise from the ramifications of allegations of sexual abuse or consent to sexual activity made through facilitated communication, but are subsequently unable to be verified through controlled testing.

Articles discussing sexual abuse allegations typically state that “at least five dozen” cases of sexual abuse allegations have been made through the use of facilitated communication. (Jacobson et al., 1995; Lilienfeld, 2007; Lilienfeld et al., 2014). Interestingly, all of these articles are referencing the same source of information - a chapter written by Margolin, “How Shall Facilitated Communication be Judged? Facilitated Communication and the Legal System” in a book published in 1994 (Shane, Ed., pp. 227-257).

One of the cases from that time period was the high-profile 1992 Wheaton case involving a 16-year-old girl who, through the use of facilitated communication, accused her father of sexual abuse and rape. The story was presented on a Public Broadcasting Station (PBS) *Frontline* program (Palfreman, 1993) entitled, *Prisoners of Silence* (also available as the transcript of the broadcast, see Reference section). The presentation included a discussion by one of the leading researchers of facilitated communication, Howard Shane, who conducted the formal facilitated communication testing of the girl at the time which concluded she could not have typed the messages she was purported to have typed.

Twenty years later, when another similar high-profile case, the Wendrow case, also received media attention, this time on ABC’s *20/20* broadcast entitled *From Miracle to Nightmare*, Janyce Boynton (2012) was motivated to publish the account of her role as the

facilitator in the case from 20 years earlier as a warning against the use of facilitated communication. In both of these situations, the accused were eventually ruled to be innocent, but not before the children had been removed from their homes into foster care, parents had been charged with abuse, and rumors had flown with suspicions planted about the families. Her article, “Facilitated Communication - What Harm it can do: Confessions of a Former Facilitator,” published in the peer-reviewed journal, *Evidence-based Communication Assessment and Intervention*, described how she came to be convinced, because of the girl’s failure to pass controlled, blinded tests of facilitated communication during the court proceedings, that she, Boynton, as the facilitator had been unwittingly typing those accusations through guiding the young girl’s hand. Boynton’s published account is raw and heart-wrenching:

Everyone in the room, including the guardian ad litem, whom I trusted, knew the truth: FC was fake, and I was not the child’s facilitator. I was the one moving her arm. I felt such devastation, panic, pain, loneliness—a myriad of emotions difficult to put into words. The whole FC thing unraveled for me that day, and I did not have an explanation for any of it. (p. 11)

Boynton attempted to discern when and how she had deceived herself into believing the girl was doing her own typing. She stated, “In hindsight, the answer is both simple and complex: I did not want to believe FC was a hoax” (p. 4). “All this irreparable heartache was caused by my unshakeable belief in FC” (p. 4). She also stated,

By the mid-1990s, the scientific community had proved over and over again that it was the facilitator – not the disabled communication partner - who was typing the messages. Every time. Full stop. And, incredibly, parents, caregivers, educators, and even some

researchers stubbornly cling to the illusion that FC is real. FC is not a communication technique. It is a belief system – and a powerful one at that. (p. 4)

Toward the end of her story, Boynton cautioned:

It is here where I think the borderline skeptics among us do a great disservice to some of the most vulnerable people in our communities. Professionals and lay people alike leave open the possibility that FC might work . . . with some people . . . someday. It is human nature. No one wants people to suffer or be unable to communicate effectively on their own. No one wants to believe that it is the facilitator who is the one doing the typing. But if I were a school administrator, educator, parent, caregiver, guidance counselor, lawyer, DHS worker, police officer, or judge, knowing what I know today about FC, I would not allow a single word to be typed on a keyboard on behalf of a child without first testing the facilitator in a controlled environment away from the supportive gaze of other believers. Every facilitator believes that he or she is one of the “good” ones. Every facilitator moves their communication partner’s arm and authors the FC messages. (p. 12)

Botash et al. (1994), however, reported that of 13 children who reported sexual abuse through facilitated communication, there was corroborating evidence of sexual abuse for four of them and supportive evidence for an additional five (p. 1283). Seven of the 13 cases were determined by child protective services (CPS) to show indication of abuse, an indication rate “consistent with the upstate New York indication rate of approximately 47%” (p. 1287). The authors concluded, “These results demonstrate that allegations of abuse that are initiated owing to an FC disclosure should be taken seriously” (p. 1287). Biklen (n.d.), in “Facts About Autism,” stated, “...there is no evidence that the numbers of allegations by individuals using facilitation is proportionally different than the numbers of allegations made by speaking people” (para. 7).

Williams (1994) stated that the majority of individuals with autism from whom she had heard had experienced either explicitly sexual abuse or interactions that were perceived to be physically invasive. “I know this was true of my own life,” she stated (p. 199). She continued,

If FC produces claims of abuse, it is the moral obligation of people to deal with these claims *objectively* not by 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. (p. 199)

Chan and Nankervis (2014), on the other hand, outlined other scenarios in which individuals typed their consent through facilitated communication for sexual relations, for extended use of medical or physical restraints on them, or for giving monetary gifts. With all of those individuals subsequently failing to have their consents substantiated through controlled questioning, the authors asserted that facilitated communication is an abuse of human rights according to the *United Nations Convention on the Rights of Persons with Disabilities* (CRPD, 2006). A discussion of the Human Rights perspective of facilitated communication is beyond the scope of this dissertation; however, I will just state that every point presented by these authors can be just as arduously argued from the opposite stance – from the position of advocating *for* facilitated communication from a human rights perspective. Chan and Nankervis believe providing facilitated communication is an abuse of the rights of those who cannot speak, and advocates of facilitated communication believe that denying those who cannot speak the opportunity of using facilitated communication is an abuse of their rights.

Proponents and self-advocates argue that facilitated communication can unlock prisons of silence and communicative isolation in which many non-speaking individuals with disabilities

are trapped. They argue the ability to communicate has unlocked the expression of personhood for some individuals by allowing them voice, has calmed disruptive and sometimes destructive behaviors by providing a means for individuals to express their needs, preferences, and frustrations, and has allowed demonstration of intelligence previously thought to be negligible.

Individuals who could not communicate prior to facilitation express the impact it has had on their lives. In an interview with Donna Williams (Williams & Attfield, 2007), Richard Attfield, who types independently, wrote,

If one has never been able to communicate in any form, think what a huge step that is and what emotional turmoil it must cause. Excitement, hope, this is such a huge leap, it completely changes ones (sic) concept of oneself as a person. Some people need support because it is such an emotional journey. (para 2 in first response by Richard)

I am (sic) passionate advocate of fc because I have lived the experience of being denied equality, an equal education, and being labelled (sic) retarded, and learning disabled and also being unable to communicate via speech to hold a conversation. (para 7 in first response by Richard)

I embrace communication with every fibre (sic) of my being. Segregation was the worst experience of my life. I can only describe it as hell. The words, 'forgive them for they know not what they doeth' come to mind. Some days I reach a point where I could cry for all WE have lost as people. (And that applies equally to all people everywhere with a disability label). Most days I embrace the world, and then a word, a look, a remark, brings me back into the world of wanting to withdraw back into the darkness of where I had been. (para 2 in final response by Richard)



One thing seems clear: Based on the disparities in performance between typing produced in controlled versus non-controlled study designs as well as on accounts described by self-advocates, non-speaking autistic individuals appear to have great difficulty responding correctly using facilitated communication under controlled conditions, but appear to be able to communicate in more casual, non-controlled circumstances – unless it is their facilitators who are typing – but then, what about those who progressed from typing with facilitation to typing independently – but then, might they have done that without ever needing facilitations? With convincing results as well as outstanding questions *on both sides of the debate*, it seems premature to draw any final and decisive conclusions about a complex and vital process that may support the ability of non-speaking individuals to express their needs, emotions, desires, and opinions - to express their very personhood – but that also has the potential to destroy lives through the typing of false accusations or consents.

### **The Essence of Autism**

To reiterate, the first reason for including a discussion of the understandings of autism was based on examining the assumption of widespread intellectual impairment in autism, which if true, would be expected to prohibit the ability of severe autistics to be able to type to communicate. The second reason to consider the latest understandings of the underlying pathology of autism when evaluating autistics' use of facilitated communication is that detractors of facilitated communication argue that since *basic* motor skills are typically intact in autism, motor impairment could not possibly explain the difficulties in typing independently, the need for facilitation, or the errors made while typing with facilitation. They continue to argue as they did 30 years ago that autism is either not a motor disorder at all, or whatever motor deficits might exist cannot account for the need for physical facilitation to accomplish writing or typing (Chan

& Nankervis, 2014; Donnellan et al., 2013; Heinzen et al., 2015; Lilienfeld et al., 2003; Lilienfeld et al., 2014; Mostert, 2012; Tavis, 2003).

Although science guides theory which then motivates new science, and theory guides development of understandings about disorders, it is important to advance one's theories in keeping with newly revealed scientific findings, for new understandings often turn prior understandings on their heads. And although there were researchers in the early 1990s theorizing more broadly about autism - for example Biklen, Morton, Gold, Berrigan, and Swaminathan (1992) hypothesized that oral apraxia or developmental apraxia resulted from a disconnection between the motor and language systems of the brain - it is perhaps understandable that Mulick et al., 24 years ago in 1993, may have still believed,

Scientific evidence for developmental apraxia in autism is lacking. Autistic youngsters are often characterized by better-developed [emphasis in original] motor skills than verbal skills, even real non-verbal problem solving talent ... There is no research evidence at all to support the position that people with autism experience such global problems. The usual clinical finding, familiar to any psychologist who routinely works in this area, is that motor impairment and delay is much less common than communication disorder and delay. (as cited in Donnellan et al., 2013, p. 3)

And, it is perhaps understandable that Rimland, also in 1993, wrote,

It has been widely recognized for many decades that the vast majority of autistic persons are quite unimpaired with regard to their finger dexterity and gross motor capabilities. They have in fact often been described as especially dexterous and coordinated. The literature abounds with stories of young autistic children who can take apart and reassemble small mechanical devices, build towers of blocks and

dominos higher than a normal adult can, assemble jigsaw puzzles and climb to dangerously high places without falling. The files of the Autism Research Institute contain over 17,000 questionnaires completed by the parents of autistic children. Finger dexterity is one question we've asked about since 1965. Most parents indicate that their children are average or above in the use of their hands. The idea that autism is, or typically involves, a "movement disorder" is simply ludicrous. (as cited in Donnellan et al., 2013, pp. 2-3)

It is a little more difficult to understand how more recent publications, some being as recent as in the last five years (Heinzen et al., 2016; Lilienfeld et al., 2014; Travers et al., 2014; Wombles, 2014), continue to rail against facilitated communication based on the same arguments posed 20 to 30 years ago, without mentioning the latest neurological and behavioral research findings revealing novel information leading to better understandings of autism, and certainly preliminarily indicating that facilitated communication may be very legitimate under some conditions yet not be possible under others. Heinzen et al., just last year (2016) sarcastically stated,

FC was more than a breakthrough for autism; it was a paradigm shift...Autism it now appeared, was not a mental disorder after all.... Instead, autism was at its core a disorder of movement that could be treated using nothing more than the physical support of a caring and patient assistant. (p. 59)

It should be clarified that facilitated communication has never claimed to "treat" autism; rather, it has been utilized as one of many augmentative and alternative communication techniques for assisting non-speaking autistic individuals to communicate. Furthermore, research findings over the past 15 years strongly indicate that autism is, indeed, *not* a "mental" disorder;

but rather, it is a neurodevelopmental disorder (APA, 2013) with complex de novo as well as inherited genetics beginning at least in infancy if not in utero (Wolff, Jacob, & Elison, 2017, p. 1). Donnellan et al. (2013) challenged

...the traditional definitions of autism that give primacy to a triad of deficits in social interaction, communication, and imaginative play... The approach is both widely known and essentially unchallenged despite broad acknowledgment that autism is a condition that reflects some difference in a person's neurology. Typically, the neurological implications have not become part of the description. Over the past two decades, however, researchers and self-advocates have begun to rethink this socially defined focus. They express concern that children and adults with the autism label may be challenged by unrecognized and significant sensory and movement differences. (p. 1)

Based on their review of brain imaging studies (structural MRI, diffusion-weighted MRI, and task-evoked and resting-state fMRI) that focused on the first years of life, Wolff et al. (2017) stated that although diagnosis is made by virtue of behavioral indicators, "autism is biologically based and arises from an altered trajectory of brain development that begins very early in ontogeny" (p. 1).

**Early brain development.** This altered brain growth is evident through observation and measurements of gross anatomy and skull size. Head circumference has been noted to be smaller in newborn ASD babies, to then increase rapidly to exceed that of typically-developing children through the toddler years, and then to normalize to near-expected dimensions by adulthood (Courchesne et al., 2001; Rane et al., 2015, p. 2; Wolff et al., 2017). Typical brain growth and function requires normal development of structure, function, and metabolism. Development of structure requires regulated neurogenesis, migration, pruning and synaptogenesis in forming both

short- and long-range neural connections (Schwartz, Kessler, Gaughan, & Buckley, 2017; Wolff et al., 2017). It is hypothesized that the enlarged brain of childhood caused by increased neurogenesis returns to more normal volume by adolescence through the process of increased pruning. It is also suggested that the greatest amount of accelerated pruning might occur in brain areas with the greatest prior abnormal overgrowth – that being in the medial prefrontal cortex which would correspond to the later prominent deficits associated with prefrontal cortical function (Rane et al., 2015, p. 12).

Findings from neuroimaging studies report both cerebral gray matter and white matter overgrowth as well as overgrowth of some subcortical structures such as the amygdala and caudate nucleus, all beginning in infancy, increasing into toddlerhood, and then stabilizing through adolescence into adulthood (Wolff et al., 2017). Wolff et al. (2017) also summarized findings from studies of atypical structural and functional connectivity in early brain development, including in language areas (Dinstein et al., 2011; Eyer, Pierce, & Courchesne, 2012; Lombardo et al., 2015; Redcay & Courchesne, 2008) and between the amygdala and limbic areas (Conti et al., 2017; Shen et al., 2016; Solso et al., 2016; Wolff et al., 2012). Wolff et al. suggested that the “Generalized brain overgrowth along with altered structural and functional connectivity evident by infancy or toddlerhood may be by-products of a common pathogenic process that begins in utero” (p. 13). Wolff et al. further stated (based on work by Marchetto et al.), “There is recent evidence that alterations in prenatal neuronal development involving progenitor cell division and differentiation, along with subsequent growth and refinement of neurites, may lay the foundation for ASD” (p. 13). Finally, the authors summarized evidence from neuroimaging and postmortem studies, reporting that the combined findings point to

...potentially multiple pre and postnatal pathogenic processes involving neurogenesis, migration, regionalization, synaptogenesis, pruning, and development of short- and long-range connectivity. It is worth noting that the neurodevelopmental processes underlying ASD are not discrete, and each plays a critical yet mutually dependent role in early development. How these process interact over time in determination of risk or protection, as well as to what extent they arise from a common mechanism or set of mechanisms, remain important targets for further study. (p. 13)

While Wolff et al. (2017) summarized infant and toddler neuroimaging studies and postmortem histological findings, neuroimaging studies examining neuroconnectivity patterns in adult autistic brains also show widespread neural disruptions in and between all areas of the association cortex and in some subcortical structures. These include areas controlling and coordinating sensory processing, executive functions, emotions, memory, and language (Baum, Stevenson, & Wallace, 2015; Donnellan et al., 2013; Kana, Uddin, Kenet, Chugani, & Müller, 2014; O'Reilly, Lewis, & Elsabbagh, 2017; Rane et al., 2015).

These neural miss-communications between sensory and motor systems, which then impact the ability to *plan* motor responses (i.e., praxis; surely that could not mean only in situations *other than* in facilitated communication), are more integrally involved than previously believed, for research now shows that functions and tasks requiring neural communication between sensory, motor, and executive functioning brain regions, (neural connections which would presumably be required to integrate information in order to plan a motor response in typing), and the integration of these systems are widely disrupted in autistic brains.

**The not-so-quiet revolution.** Although research into the role of sensory, motor, and sensorimotor deficits in autism has been underway for more than four decades in the diverse

fields of occupational therapy, speech and language pathology, special education, and psychiatry and psychology, sensory and motor issues have typically been omitted from scientific considerations in defining autism. Only recently, in the DSM-5 (APA, 2013), were sensory differences even mentioned, not as a core feature, but as one of four possible options for qualification under criterion B: “Restricted, repetitive patterns of behavior, interests, or activities” (p. 50) In addition, this rather limited acknowledgment of a possible sensory component mentioned only hyper- or hyposensitivity or unusual interests in sensory aspects of the environment, with the many other possible forms that sensory confusion or misperception may take being completely omitted. Similarly, the only mention of motor involvement in the DSM-5 was of “stereotyped or repetitive motor movements” (p. 50), also as one of the four possible qualifiers for criterion B.

In their review just prior to the publication of the DSM 5<sup>th</sup> Edition, Caminha and Lampreia (2012) stated,

...sensory problems have always been mentioned in the autism literature, but their relevance has been underestimated. Scientific research and autobiographical reports suggest a high prevalence of sensory problems in autism. Although not yet considered in the official diagnosis of autism, sensory problems appear to not only exert a considerable impact on the configuration of the disorder but also directly influence autistic persons in their daily lives. Such impairments may begin to be thought of as fundamental in autism. (p. 231)

It is unclear why the sensory and motor systems have not been accepted by the broader scientific community as being seminal components in the pathology of autism. Perhaps the omissions have been due to failure of adequate sharing of research between professions. Baum et

al. (2015) suggested a possible reason being that sensory impairments are difficult to quantify empirically. However, language and social communication surely cannot be any more easily quantifiable. Perhaps it is because most of us fall somewhere on that “spectrum” of preferring familiarity and sameness, of resisting change, and finding comfort in scientific “knowns” thereby fostering the belief system that our world is predictable and controllable. Many people – and perhaps scientists in particular - seem to experience a distinct discomfort in allowing the possibility that scientific proclamations are not always correct, that science sometimes gets it wrong. Lilienfeld and others have accused proponents of facilitated communication as clinging to false beliefs, pseudoscience, and antiscience (Heinzen et al., 2016; Lilienfeld et al., 2014; Travers et al., 2014; Wombles, 2014). They have charged proponents with refusing to accept science, yet those researchers may be charged with the same – continuing to associate facilitated communication with Clever Hans as if they were one and the same story, without referring to the latest scientific findings about autism. Although evidence has been suggestive for decades, now with neuroimaging technology, the sensorimotor hypothesis wrapped within a broader disrupted brain neural connectivity hypothesis is gaining pre-eminence in explaining the behavioral differences long misunderstood in autism. Iarocci and McDonald (2006) summarized the possible connection between the leading conceptual theories of autism and multisensory integration, stating, “...many of the leading theories of autism allude to dynamic constructs and conceptualizations such as central coherence, temporal binding, shifting attention, enhanced perception, and neural modulation and connectivity *that may involve multisensory processing and integration*” (p. 81; italics added).

Although motor and sensory behavioral research may have been largely ignored and omitted from considerations in defining autism in the past, their importance is becoming more



recognized. As Berger (2013) stated, “A quiet revolution is afoot in our understanding of autism spectrum disorder (ASD) ... The primary claim is as simple as it is radical: The defining features of ASD are disorders of psychomotor regulation and sensory processing” (p. 1). With neuroimaging techniques now identifying and mapping disruptions in brain neural connections and linking those findings to the sensorimotor findings in behavioral research, that revolution is no longer a quiet one.

Research has now identified neurological differences in both first- and second-order sensory processes (also referred to as lower and higher order processes), not only within each sensory modality (sight, sound, smell, taste, touch; Leekam, Nieto, Libby, Wing, & Gould, 2006; Tonacci et al., 2017) and major motor function (e.g., tone, balance, fine, gross, gait, posture, oral motor; Dumas, McKenna, & Murphy, 2016; Dziuk et al., 2007; Fournier, Hass, Naik, Lodha, & Cauraugh, 2010; Gernsbacher, Sauer, Geye, Schweigert, & Goldsmith, 2008; Noterdaeme, Mildenberger, Minow, & Amorosa, 2002), but also within many of the sensory modality subcategories (for example affecting deep touch, light touch, affective touch, and different forms of pain within the tactile system, noise confusion within the auditory system, and impaired olfactory and gustatory discrimination, but with preserved detection) and within sensorimotor integration systems for motor planning (Alcantara, Weisblatt, Moore, & Bolton, 2004; Ashwin et al., 2014; Baum et al., 2015; Bennetto, Kushner, & Hyman, 2007; Gowen & Hamilton, 2013).

Although I have been unable to find a clear definition of *first-order* versus *second-order* (or *lower* versus *higher* order) sensory and motor processes, motorically, first (or lower) order is generally used to refer to basic motor processes that do not require planning or perceptual feedback, and sensorily, to *detection* of the presence of sensory stimuli without need for comparisons or judgements about the stimulus or differentiation between similar stimuli. Thus,

visual, auditory, olfactory, and gustatory acuity, i.e., detection of the presence of a stimulus, appear to be either intact or enhanced, whereas higher-order processes involving interpretation and integration of sensory signals appear to be disturbed (Gowen & Hamilton, 2013).

Furthermore, Gowen and Hamilton (2013) reported that Gowen and Miall noted that study participants appeared to perform worse on tasks requiring greater sensory processing such as pointing and timing compared to performance on lower level tasks such as repetitive tapping and hand turning.

However, even first-order processes of sensory recognition are often found to be altered, with behavioral research and firsthand accounts providing evidence of hypersensitivity, hyposensitivity, sensory confusion (see Hannant, Tavassoli & Cassidy, 2016), one sensory modality completely overriding and dominating all other modalities through a process called crossmodal extinction (Bonneh et al., 2008), or a particular sensory stimulus such as sound triggering an entirely different sensory modality such as color through a process called synesthesia (Bogdashina, 2003). Synesthesia may also be triggered solely through observation or suggestion; for example, *observation* of touch may trigger the sensation of actually *being touched* (Baron-Cohen, Robson, Lai, & Allison, 2016). Finally, processing sensory input and planning motor output appear to become more disrupted in the face of increased sensory load or emotional or cognitive stress, or with increasing demand complexity (Leary & Hill, 1996).

In addition to research showing differences in sensory perception within each sensory modality, altered neurologic connections have been demonstrated within the sensory association areas, between sensory and motor areas, within areas thought to be associated with theory of mind and with the mirror neuron system, and between the frontal lobe with its executive functioning responsibilities and more posterior functions in the parietal, temporal, cingulate, and

occipital lobes (Hannant et al., 2016; Liu, 2013; MacNeil & Mostofsky, 2012; Minshew & Williams, 2007; Mirenda, 2008). This broad scope of neural and systems involvement demonstrated by neuroimaging studies is commensurate with descriptions by observational and firsthand accounts. Donnellan et al. (2006), defined movement difference (note, difference as opposed to disturbance) as “a disruption in the organization and regulation of perception, action, posture, language, speech, thought, emotion, and/or memory” (p. 207). In accordance with this broader conceptualization of autism, Donna Williams (1994) summarized her firsthand perspective of the nature of autism:

Autism is a pervasive developmental disorder affecting *all systems* (my italics) 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. (p. 196)

An overview of those neuroimaging - EEG and fMRI - research findings describing atypicalities in the neuroconnectivity pathways in autistic brains will be presented next followed by the sensory, motor, and sensorimotor behavioral research findings.

**Neuroimaging brain research.** Explanations of the neuroimaging technology and detailed explanations of results are beyond the scope of this dissertation. However, a basic understanding of the research findings is essential in addressing their implications for facilitated communication. Essentially, electroencephalographic (EEG), functional magnetic resonance imaging (fMRI), and diffusion tensor imaging (DTI) studies have documented widespread disordered neuronal connectivity in autistic brains, with one of the most notable disruptions

being underconnectivity between anterior and posterior brain regions (to list only a few: Just, Cherkassky, Keller & Minshew, 2004; Kana, Uddin, Kenet, Chugani, & Müller, 2014; O'Reilly, Lewis, & Elsabbagh, 2017; Rane et al., 2015; Schipul, Keller, & Just, 2011; Schwartz, Kessler, Gaughan, and Buckley, 2017; Wass, 2011).

The first neuroimaging study, conducted by Horowitz et al. in 1988 using positron emission tomography [PET] scan, demonstrating evidence of disrupted coordination between brain regions was declared by Schipul et al. (2011) to be “groundbreaking” (p. 2). Functional MRI was developed over the next decade, and in their research with that technology Just et al. (2004) developed and proposed the underconnectivity theory of autism in 2004. Since then, research evidence has expanded that theory, consistently demonstrating long-range neural underconnectivity (Just et al., 2004; O'Reilly et al., 2017; Rane et al., 2015; Schipul et al., 2011; Schwartz et al., 2017), but also variable short-range neural connectivity, with it typically being either preserved or increased, although some studies have also found short-range underconnectivity (Müller et al., 2011; Rane et al., 2015).

As was the case with differentiating *first-order (lower-order)* from *second-order (higher-order)* sensory processes and motor tasks, I have not been able to find guidelines clarifying definitions for *short-* versus *long-range connectivity*. In their review of EEG studies, Schwartz et al. (2017) included the lack of definition of these terms as one of the constraints in interpreting data on EEG coherence patterns (p. 20). In simplifying “the disparities in what different research groups call ‘long-‘ and ‘short-‘ range connections...” the authors decided upon the following guidelines in their review, guidelines which will be followed in this paper as generally delineating short-range and long-range:



theta, alpha, beta, and gamma) and different age groups. Because the 28 studies they reviewed were divided between studies of infants (task based), toddlers (resting, task-based, and sleep), school-aged children (resting state and task-based), and adults (task-based and sleep), the number of studies devoted to any one developmental period was limited, and since “chronological maturation has significant effects on EEG morphology and coherence” (p. 8), the different developmental groups could not be combined. However, the authors did identify significant differences in EEG coherence patterns in children with ASD, and proposed that “The transition from the significant differences observed in childhood to the absence of differences in adulthood may reflect a degree of cortical maturation and accompanying increase of broadband coherence that allows individuals’ brains to ‘catch up’” (p. 19).

A second systematic review of EEG and magnetoencephalographic (MEG) studies by O’Reilly et al. (2017) arrived at similar conclusions: Although the large variability in study samples and methodology again made “a systematic quantitative analysis (i.e., meta-analysis) of this body of research impossible,” the synthesis of results provided “relatively strong support for long-range underconnectivity in ASD, whereas the status of local connectivity remains unclear” (p. 1). This long-range, frontal-posterior underconnectivity has been the single most consistent finding in neuroimaging studies.

A recent study by Han & Chan (2017) showed that tasks of executive function were significantly associated with elevated theta coherence on EEG in the long-range fronto-parietal network, and demonstrated that children with any degree of ASD performed worse than typically-developing children, with executive functioning being differentially affected with the severity of autism symptoms. This study was in keeping with others suggesting increasing impairment with increasing task demand, with results showing children were relatively

unimpaired on simple cognitive tasks, but showed impaired performance on tasks involving complex and multiple executive functions (p. 28). The authors noted that the results of their study were also consistent with other studies in reporting a positive correlation between greater increases of EEG coherence of slow bands in patients with more severe cognitive impairments. However, again demonstrating inconsistencies between studies, results of this study showing increased fronto-parietal (long-range) coherence in children with ASD were in contrast to some previous studies (e.g., Coben et al., 2008; Isler, Martien, Grieve, Stark, & Herbert, 2010; Murias et al., 2007) demonstrating reduced long-range coherence (as cited in Han & Chan, 2017). Possible reasons proposed to explain the discrepancy included differing age of participants, different tasks used, eyes-closed versus eyes-open in resting conditions, different brain regions targeted for investigation, and the frequency band selected (e.g., using long-range alpha versus theta).

In summary, Schwartz et al. (2017) stated that “ASD as a disorder of neural connectivity may be understood as a condition of altered complex global processing whereby the collaborative integration of circuits responsible for joining specialized regions of the brain does not occur normally” (p. 19). They further stated, “Electrophysiologic studies suggest that autism spectrum disorder is characterized by aberrant anatomic and functional neural circuitry” (p. 7, abstract), and “There is general consensus that electroencephalogram coherence patterns differ between individuals with and without autism spectrum disorders; however, the exact nature of the differences and their clinical significance remain unclear” (p. 7, abstract).

***Functional magnetic resonance imaging (fMRI).*** Magnetic resonance imaging evaluates tissue function through measuring small changes in blood flow (hemodynamics) to various brain regions when the individual is either at rest or performing a task. Synchronization between two

regions is measured by computing the correlation or covariance between activity levels (blood flow) in the regions (Just et al., 2004; Rane et al., 2015).

Numerous magnetic resonance imaging (fMRI) studies have demonstrated that altered neural connectivity impacts the integration, processing, and encoding of information between brain regions, again with the greatest impact appearing to be in connections between anterior and posterior regions. Schipul et al. (2011) noted,

...functional underconnectivity emerges between whatever frontal and posterior regions are centrally involved in the task. Almost all complex language, social, and executive tasks, precisely where behavioral deficits are typically found in autism, would be expected to show frontal-posterior functional underconnectivity. (p. 3)

In their study “Cortical Activation and Synchronization during Sentence Comprehension in High-Functioning Autism” on which Just et al. (2004) based their underconnectivity theory, the authors found the autism group showed more activation than controls in Wernicke’s area, (figure 2) involved in *speech comprehension*, and less activation than controls in Broca’s area (p. 1811; figure 2), involved in *language processing and speech production*.

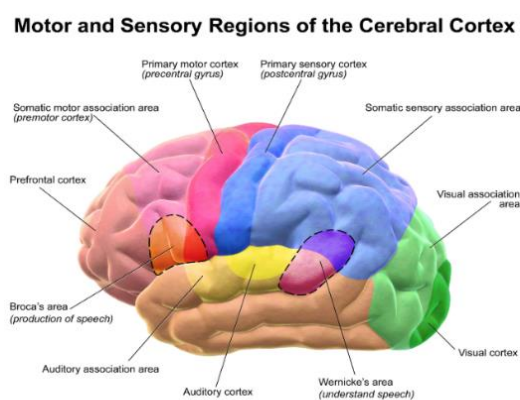


Figure 2. Left Cerebral Cortex: Broca’s and Wernicke’s areas. Adapted from Medical gallery of Blausen Medical, 2014, in WikiJournal of Medicine 1(2). doi:10.15347/wjm/2014.010. In public domain. Retrieved from



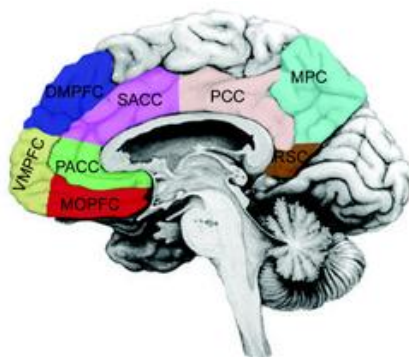
[https://en.wikiversity.org/wiki/WikiJournal\\_of\\_Medicine/Medical\\_gallery\\_of\\_Blausen\\_Medical\\_2014#/media/File:Blausen\\_0102\\_Brain\\_Motor %26Sensory.png](https://en.wikiversity.org/wiki/WikiJournal_of_Medicine/Medical_gallery_of_Blausen_Medical_2014#/media/File:Blausen_0102_Brain_Motor_%26Sensory.png).

The authors suggested these results indicated that

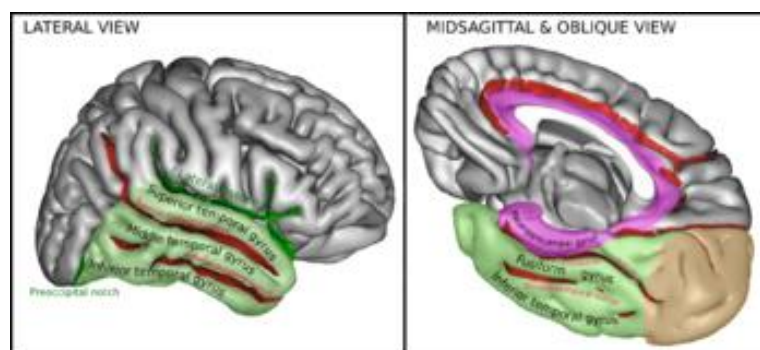
...compared with controls, the autistic participants engage in more extensive processing of the individual words that comprise a sentence, manifested as more LSTG [left superior temporal gyrus] (Wernicke's area) activation, which is consistent with their hyperlexicity or unusual strength in processing single words (Goldstein et al., 1994). At the same time, the autistic participants showed less activation in LIFG [left inferior frontal gyrus] than the control group. LIFG (and pars triangularis in particular) is associated with semantic, syntactic and working memory processes (Petersen et al., 1989, 1990; Fiez, 1997; Fiez and (sic) Petersen, 1998; Gabrieli et al., 1998; Michael et al., 2001), all of which serve to integrate the meanings of individual words into a coherent conceptual and syntactic structure... (p. 1816)

The implications of these findings – disrupted connections between language reception and production areas - in explaining discrepancies in abilities to communicate through facilitated communication are significant. The authors also theorized that underconnectivity likely involved more than language areas, proposing “any facet of psychological function that is dependent on the *coordination or integration* of brain regions is susceptible to disruption, particularly when the computational demand of the coordination is large” (p. 1817).

Kana et al. (2009) identified underconnectivity between frontal regions (medial frontal gyrus; fig 3), anterior paracingulate, and orbital frontal gyrus; figures 2, 3) and posterior regions (right middle and superior temporal gyrus; figure 4) involved in theory of mind (p. 146).



*Figure 3.* Medial surface right cerebral cortex showing anterior regions associated with Theory of Mind. Regions: medial orbital frontal cortex (MOPFC), anterior cingulate cortex (SACC and PACC), medial frontal gyrus (or dorsomedial prefrontal cortex, DMPFC); also posterior cingulate cortex (PCC). Adapted from “Brain and self: A neurophilosophical account,” by G. Northoff, 2013, *Child and Adolescent Psychiatry and Mental Health* 7(28), p. 7. <https://doi.org/10.1186/1753-2000-7-28>. © Northoff; licensee BioMed Central Ltd. 2013. Published under license to BioMed Central Ltd. In public domain. Creative Commons License <http://creativecommons.org/licenses/by/2.0>.



*Figure 4.* Right temporal lobe gyri. Lateral surface: inferior (ventral), middle, and superior gyri; medial surface: fusiform and ventral (inferior) temporal gyri, also occipital lobe (tan) and limbic (purple; cingulate gyrus with parahippocampal gyrus). Adapted from Wikimedia, by Sebastian 023, 2011. In public domain. Creative Commons Attribution-Share Alike 3.0 Unported. Retrieved from [https://en.wikipedia.org/wiki/Inferior\\_temporal\\_gyrus](https://en.wikipedia.org/wiki/Inferior_temporal_gyrus).

Although inconsistencies persist, a general consensus soon emerged agreeing on findings of decreased, or underconnectivity, in long-range neural pathways, and more variable connectivity in short-range connections. Rane et al. (2015) concluded,

...with the help of data sharing and large scale analytic efforts, the field is advancing towards several convergent themes. These include reduced functional coherence of long-range intra-hemispheric cortico-cortical default mode circuitry, impaired interhemispheric regulation, and an associated, perhaps compensatory, increase in local and short-range cortico-subcortical coherence. (p. 1).

Within this consensus, however, the specifics remain uncertain due to multiple complicating factors in research: the heterogeneity of symptoms and severity within the autism spectrum and the existence of comorbid conditions, the highly complex nature of the structural-functional relationship of brain connectivity, and the inconsistencies between studies. Studies vary in (a) population parameters such as ages ranging from 2 to 54 years (which would impact findings due to structural brain changes occurring throughout development), autism severity (studying those with language and those without, and those with “Asperger’s” versus “autism” versus mixed groups), and gender groupings; (b) differing methodological approaches to technique (low pass or band pass, frequency range of filtering, statistical removal of task-related neural activity, whole-brain versus region-of-interest analysis, differences in size of field, etc.); and in (c) methods of data-processing and analysis. (Hull et al., 2016; Minshew & Williams, 2007; Müller et al., 2011; O’Reilly et al. 2017; Rane et al., 2017; Wass, 2011). Rane et al. (2015) stated that although “the general findings of decreases in white matter integrity and long-range neural coherence are prevalent in ASD literature... there is somewhat less of a consensus in the detailed localization of these findings” (p. 223).

An additional confounder in interpreting areas of neuronal activation is in differentiating between lack of neuronal activation and delayed (and therefore unrecognized) activation. Some studies (Belmonte et al., 2010; Cascio, Foss-Feig, Burnette, Heacock, & Cosby, 2012;

Greenfield, Ropar, Smith, Carey, & Newport, 2015) specifically documented abnormal temporal binding of stimuli, referring to how synchronously or asynchronously the timing of reception and processing of incoming stimuli occurred. According to Belmonte et al. (2010), accurate timing of the reception and coordination of auditory and visual input is essential for understanding and developing language. Visual and tactile binding is also important in understanding and developing social interactions (Cascio et al., 2012; Greenfield et al., 2015).

In their fMRI study of visual attention, Belmonte et al. found that whereas neural activation in controls demonstrated a “widespread network of frontal, cerebellar, and parietal attention regions..., the ASC group activated a cerebellar region outside the attention area, did not physically activate frontal and parietal attention regions, but did activate posterior visual regions and also orbitofrontal cortex” (p. 270). They noted that these findings appeared to confirm results from “a large number of previous” studies “...suggesting hypoactivation of frontal cortices in autism and hyperactivation of posterior cortices subserving lower levels of processing (Haist et al., 2005; Silk et al., 2006; Belmonte et al., 2004b)” (p. 270). However, on further examination of the time course of activation, the authors also noted that the fronto-cerebellar attention systems in fact *were* activated in participants with autism, but the *activations occurred too late to be useful in the trial in which they were engaged*. Rather, the activation did not manifest until the subsequent trial. It appeared that at least some times activation does occur, but is missed during imaging because of poor/delayed temporal binding of the stimulus to activation wherein the stimulus is not processed in the same time sequence or interval in which it was received. The authors noted that “These findings of differential timing form an important counterpoint to the oft-repeated contention that people with autism simply do not activate many of the same brain regions activated in controls” (Belmonte et al., 2010, p. 271).

Leary and Hill (1996) described the behavioral ramifications of delayed or asynchronous processing of stimuli in pointing out,

If it takes the person 3 minutes, rather than the socially expected 3 seconds, to organize perceptions, attention, motivation, and body movements, the opportunity for spontaneous interactions may often pass with partners switching to new topics and/or becoming involved in new activities. (p. 40)

With delayed or aberrant processing of incoming stimuli, it would be very difficult from a neurological standpoint for someone to, according to the DSM-5 (APA, 2013), “develop peer relationships appropriate to developmental level,” demonstrate “spontaneous seeking to share enjoyment, interests, or achievements with other people,” “actively [participate] in simple social play or games,” or “initiate or sustain a conversation with others” (p. 50). It would stand to reason that someone whose sensory and motor processing systems fail to keep pace with the speed at which interactions proceeded would withdraw, “preferring solitary activities” (APA, 2013, p. 50).

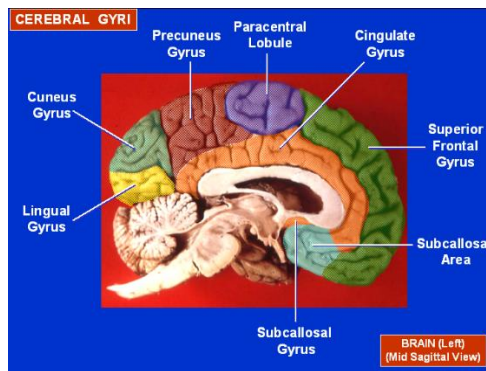
Blackman (Biklen et al., 2005) explained, “That was when I had realized that I did not always process information at the moment that my skin, balance, sight, or hearing presented it to me, and that sometimes touch and sight were not in sync” (p. 150). Williams (1996) also described this phenomenon:

Messages can be sorted all right but take a long time to be relayed. This is like not putting birthday calls through until after the birthday has passed.

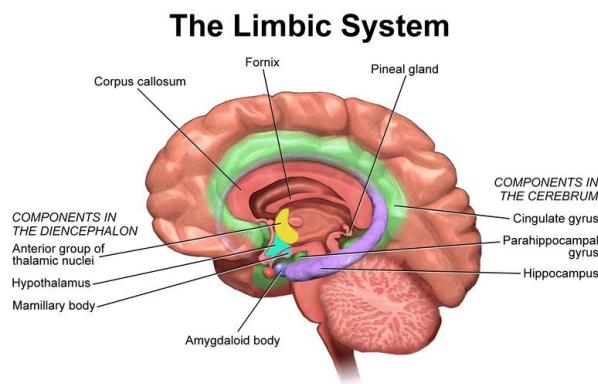
Non-firings are ‘life with a rain-check’. For me, they are thieves of the ability to understand and feel the reward of interaction or emotions.

As a child... it appeared as though I didn't feel pain or discomfort, didn't want help, didn't know what I was saying, didn't listen or didn't watch. By the time some of these sensations, responses or comprehensions were decoded and processed for meaning and personal significance, and I'd accessed the means of responding, I was fifteen minutes one day, a week, a month, even a year away from the context in which the experiences happened. (p. 90)

Thus, specific functions shown to be affected by underconnectivity include (a) language (coordination between Broca's and Wernicke's areas; figure 2); (b) Theory of Mind: anterior regions (medial prefrontal gyrus and anterior paracingulate, precuneus (figure 5), orbital frontal gyrus (figures 2 & 3) and posterior regions (right middle and superior temporal gyrus, superior temporal sulcus (figure 4; Kana, Keller, Cherkassky, Minshew, & Just, 2009); (c) face processing (fusiform gyrus and ventral temporal cortex; figure 4; Koshino et al., as cited in Schipul et al., 2011); (d) working memory and executive function (prefrontal cortex; figures 2, 3 & 5; Koshino et al, as cited in Schipul et al., 2011; Solomon et al., as cited in Schipul et al., 2011); (e) socio-emotional learning and memory (amygdala-based network; figure 6) which may also include the fusiform gyrus (figure 4), superior temporal cortex (figure 4), and the mirror neuron system; (f) visual- auditory tasks (Belmonte, Gomot, & Baron-Cohen, 2010; visual cortex: occipital lobe [figure 4]; auditory cortex: superior temporal gyrus [figure 4]); (g) visual-tactile tasks (visual: occipital lobe; sensory cortex: anterior parietal); and (h) visual-tactile-motor integration (occipital lobe-pre-motor sensory cortex-anterior parietal; Hamilton, 2013).



*Figure 5.* Cerebral gyri: Medial surface. Adapted from Dep't. of Cellular Biology & Anatomy, Louisiana State University Health Sciences Center Shreveport, <http://www.healcentral.org/healapp/showMetadata?MetadataId=40566>, by J. A. Beal, PhD., 2005. In public domain. <https://creativecommons.org/licenses/by/2.5/> Retrieved from [https://en.wikipedia.org/wiki/Precuneus#/media/File:Cerebral\\_Gyri\\_-\\_Medial\\_Surface1.png](https://en.wikipedia.org/wiki/Precuneus#/media/File:Cerebral_Gyri_-_Medial_Surface1.png).



*Figure 6.* The limbic system (amygdala, hippocampus, parahippocampal gyrus, cingulate gyrus). Reprinted from Blausen.com staff, by B. Blausen, 2014, "Medical gallery of Blausen Medical 2014". WikiJournal of Medicine 1(2), doi:10.15347/wjm/2014.010.ISSN2002-4436. In public domain. Retrieved from [https://en.wikiversity.org/wiki/WikiJournal\\_of\\_Medicine/Medical\\_gallery\\_of\\_Blausen\\_Medical\\_2014](https://en.wikiversity.org/wiki/WikiJournal_of_Medicine/Medical_gallery_of_Blausen_Medical_2014).

Rane et al. (2015) published a review of 69 neuroimaging studies covering the previous ten years that included individuals aged 12 months to 40 years. Thirty three studies utilized resting state (RS) fMRI and 36 utilized diffusion tensor imaging (DTI). Although there were a few exceptions which demonstrated increased long-range connectivity, the majority of studies showed decreases in white matter connectivity and therefore in long-range neural integrity (white

matter being comprised of neuronal axons that transmit information to other neurons). There was less agreement among studies about the specific localization of these neural disruptions, and only about a quarter of the studies looked at links between the altered connectivity patterns and specific behavioral phenotypes in autism spectrum disorder (about 21% of the RS studies and about 28% of the DTI studies; p. 9).

Based on their review of 33 fMRI studies, Rane et al. (2015) listed brain regions showing the most long-range underconnectivity, presented in order beginning with those with the most and proceeding to those with the least number of studies demonstrating a given region's involvement. The specific studies cited by the Rane et al. are included in parentheses: (a) The prefrontal cortex (PFC; executive functioning) was noted in ten studies (Abrams et al., 2013; Assaf et al., 2010; Gotts et al., 2012; Kennedy & Courchesne, 2008; Mueller et al., 2013; Nair, Treiber, Shukla, Shih, & Muller, 2013; Rudie et al., 2012; Starck et al., 2013; von dem Hagen, Stoyanova, Baron-Cohen, & Calder, 2013; Washington et al., 2014). (b) The posterior cingulate cortex (PCC; figure 3), implicated in human awareness, pain, and episodic memory retrieval, was reported in eight studies (Cherkassky, Kana, Keller, & Just, 2006; Kennedy & Courchesne, 2008; Lynch et al., 2013; Mueller et al., 2013; Rudie et al., 2012; Starck et al., 2013; Washington et al., 2014; Weng et al., 2010), however the posterior cingulate was also reported by three studies to have increased connectivity (Lynch et al., 2013; Monk et al., 2009; Uddin et al., 2013). Other regions reported by four to five studies each to have decreased long-range connectivity, but also reported by one or two studies to have increased connectivity, were (c) the precuneus, associated with "visuo-spatial imagery, episodic memory retrieval, and self-processing operations, namely first-person perspective taking and an experience of agency" (Cavanna & Trimble, 2006, p. 564; figure 4; Assaf et al., 2010; Kennedy & Courchesne, 2008; Lynch et al.,





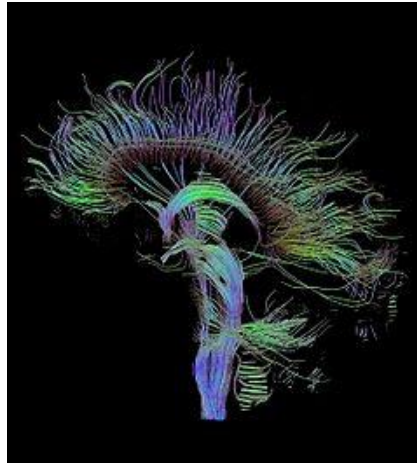
Saunders. In public domain. Retrieved from [https://en.wikipedia.org/wiki/Insular\\_cortex](https://en.wikipedia.org/wiki/Insular_cortex).

# 717 by H. V. Carter. In public domain. Retrieved from [https://en.wikipedia.org/wiki/Insular\\_cortex](https://en.wikipedia.org/wiki/Insular_cortex).

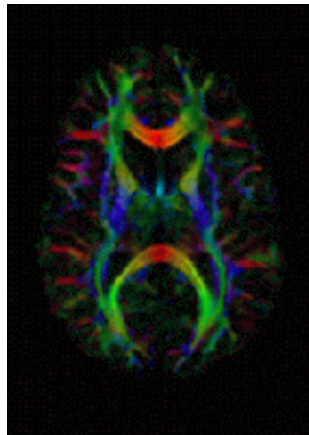
Complicating the already complex nature of brain regions, many regions support major connections to white matter bundles such as the cingulum and the adjacent corpus callosum, and also project into the prefrontal cortex, superior temporal gyrus, and insula. Regarding the intertwining and overlap, Rane et al. (2015, p. 12) stated, “One can see how these decreases [in activation and connectivity] can be interdependent.” Disturbances in functions associated with regions affected by altered connectivity also impact the communication and regulation of those functions between regions. This interdependent effect could well explain the difficulties many children with autism spectrum disorders have with executive functions and impulse control, episodic memory, pain recognition, first-person perspective formation, social understanding, irritability and emotional regulation, aggression, depression, and anxiety, symbol recognition, language, etc.

***Diffusion tensor imaging studies.*** Diffusion tensor imaging is another form of MRI (DTI) that provides images of the structural organization of tissue by measuring the average magnitude of diffusion or mean diffusivity of water through a medium such as cerebrospinal fluid, nerve axons, or muscle tissue. Simplistically, when unimpeded, water diffuses in a uniformly dispersed (isotropic) pattern, but then is impeded by solids. Since water tends to diffuse in parallel to impediments rather than penetrating through them, it will flow with directionality alongside of impediments such as nerve fibers and bundles rather than through them. The degree of alignment or orientation of flow along the tissue (impediment) reflects the tissue’s integrity and is referred to as anisotropy (the opposite of non-directional). Thus, in highly organized directional tissue such as intact axonal tracts (white matter) or muscle tissue, water will have a high degree of anisotropy (Basser, 1995; Rane et al., 2015 p. 3). Figure 9 is a

tractographic reconstruction of the numerous white matter tracts imaged using DTI. Figure 10 is a transverse section of brain with the distinct white matter tracts differentiated by color coding.



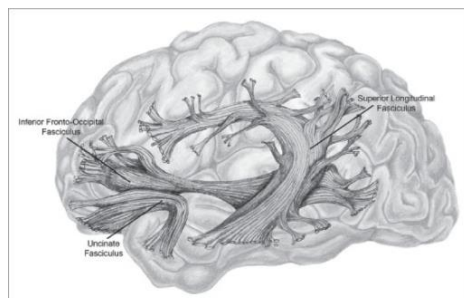
*Figure 9.* Tractographic reconstruction of neural connections via DTI. Reprinted from Wikipedia.org, by T. Schultz, 2006. In public domain. GNU Free Documentation License, version 1.2. Retrieved from [https://en.wikipedia.org/wiki/Diffusion\\_MRI](https://en.wikipedia.org/wiki/Diffusion_MRI).



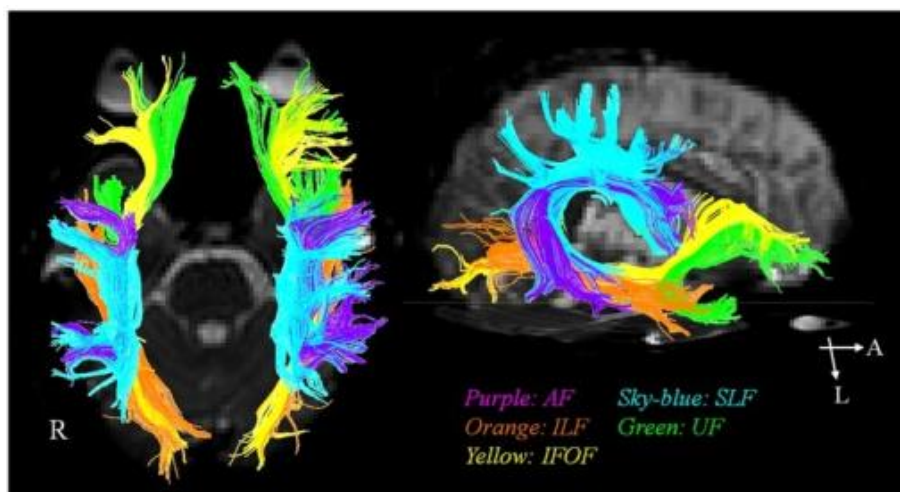
*Figure 10.* Diffusion MRI: DTI Color Map. Reprinted from Wikipedia.org, by L. Hermoye, 2006. In public domain. Commons.wikimedia.org. Retrieved from [https://en.wikipedia.org/wiki/Diffusion\\_MRI#/media](https://en.wikipedia.org/wiki/Diffusion_MRI#/media).

Most of the 36 diffusion tensor imaging (DTI) studies reviewed by Rane et al. (2015) showed decreased long-range connectivity (reduced fractional anisotropy and increased mean diffusivity indicating disruptions in neural integrity) in ASD groups compared to typically

developing groups, although there were exceptions. The fibers most commonly reported to show decreased connectivity were the association bundles (superior longitudinal fasciculus, uncinate fasciculus, occipitofrontal fasciculus, and inferior longitudinal fasciculus, cingulum), although projection fibers (corticospinal tract and internal capsule; figures 11-13) and commissural fibers (corpus callosum) were also found to have increased mean diffusivity in ASD (p. 7).

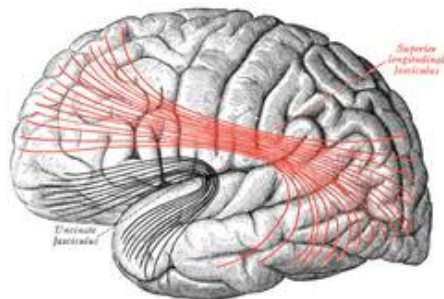


*Figure 11.* White matter fiber tracts. The three major tracts connecting the temporal, parietal, and occipital lobes with the prefrontal cortex. Clockwise from bottom left: uncinate fasciculus, inferior fronto-occipital fasciculus, superior longitudinal fasciculus. Reprinted from “Mindmelding: Connected Brains and the Problem of Consciousness,” by W. Hirstein, 2008, diagram by K. Reinecke, 2004, *Mens Sana Monographs* 6(1), 110-130. In public domain. Retrieved from [https://openi.nlm.nih.gov/detailedresult.php?img=PMC3190544\\_MSM-06-110-g002&req=4](https://openi.nlm.nih.gov/detailedresult.php?img=PMC3190544_MSM-06-110-g002&req=4)



*Figure 12.* Diffusion tensor tractographies of neural tracts. Sky blue: superior longitudinal fasciculus (SLF), Purple: arcuate fasciculus (AF, part of SLF), Orange: inferior longitudinal fasciculus (ILF), Green : uncinate fasciculus

(UF), Yellow: inferior fronto-occipital fasciculus (IFOF). Adapted from “Diffusion Tensor Imaging Studies on Arcuate Fasciculus in Stroke Patients: A Review,” by S. H. Jang, 2013, *Frontiers in Human Neuroscience*, 7, 2. In public domain. Creative Commons Attribution License (CC BY). Retrieved from <https://www.frontiersin.org/articles/10.3389/fnhum.2013.00749/full>



*Figure 13.* Superior longitudinal fasciculus. File:Sobo\_1909\_670-671.png. Reprinted from *Atlas of Human Anatomy*, by J. Sobotta, 1909. Color edited on Wikimedia by user, Was a bee, 2013. In public domain. Wikimedia Commons. Retrieved from [https://en.wikipedia.org/wiki/Superior\\_longitudinal\\_fasciculus](https://en.wikipedia.org/wiki/Superior_longitudinal_fasciculus).

Exceptions reported by Rane et al. (2015) “include reports by the Ameis, Billeci, Nagae, Nair, Sivaswamy, and Verly groups” (p. 7), with one group (Billeci, Calderoni, Tosetti, Catani, & Muraton) reporting increased fractional anisotropy and mean diffusivity in multiple areas including the corpus callosum, and one group (Sivaswamy et al.) reporting similar increased anisotropy in the cerebellar peduncle.

Although relatively few studies - seven (about 21%) of the resting state and ten (about 28%) of the DTI studies - looked at correlations between connectivity changes and ASD behavioral measures, many of the commonly reported regions with reduced functional connectivity are known to be relevant to autistic behavioral capacities (p. 11), and will therefore be presented. Rane et al. (2015) explained:

When resting state correlations are observed between two regions that share connectivity with a major white matter fiber bundle (such as precuneus and superior frontal gyrus sharing the cingulum bundle as its principle white matter pathway), it is possible that the

behavioral performance can be associated with that major fiber bundle. Overall, for the RS [resting state] – behavioral correlations, of note is the preponderance of cortical-region pairs associated with the cingulum bundle. (p. 9)

Autism severity: Four resting state fMRI studies discussed in Rane et al. (2015) showed a positive correlation between reduced connectivity and ASD severity regardless of the diagnostic measure used. Brain regions implicated were the *prefrontal cortex* in all studies and the anterior cingulate cortex, precuneus, and temporal and parietal lobes in some (Assaf et al., 2010; Gotts et al., 2012; Redcay et al., 2013; von dem Hagen et al., 2013). Four DTI studies reported by Rane et al. showed negative correlations between autism severity and fractional anisotropy (higher severity with decreased anisotropy) in the left superior longitudinal fasciculus (Noriuchi et al., 2010), the right anterior thalamic radiation and right uncinated fasciculus (Cheon et al., 2011), and the fronto-thalamic and temporo-thalamic tracts (Nair et al., 2013). Rane et al. also identified that “One study reported no correlation between autism severity and fractional anisotropy” (p. 9; Jou et al., 2011), and “one study reported that the number of fibers numbers (sic) in the genu of the corpus callosum was negatively correlated with the Childhood Autism Rating Score” (p. 9; Hong et al., 2011).

Social impairment: Rane et al. (2015) reported that “Six studies reported negative correlations between RS (resting state) connectivity and social impairment in ASD subjects” (i.e., lower connectivity correlated with higher social impairment; p. 9). The involved connections in four of these studies were between the posterior cingulate cortex (PCC) and the temporal lobe, the posterior parahippocampal gyrus (figure 5), and the superior frontal gyrus (Weng et al., 2010); the PCC and the right superior frontal gyrus (Monk et al., 2009); the PCC

and the right medial temporal gyrus (Washington et al., 2014); and the right hemisphere motor cortex and the thalamus (Nair et al., 2013). Rane et al. continued, stating

The other two studies reported negative correlations between ADOS-Social Scale scores and the synchronization between left and right hemisphere inferior frontal gyri (Dinstein et al., 2011) and between ADOS-Social Scale scores and the total precuneus connectivity z-scores (Assaf et al., 2010).... The one outlier was a study by the Alaerts group (2013) which reported a positive correlation between RS [resting state] connectivity involving posterior superior temporal sulcus seed and performance on the emotion-recognition task” (pp. 9-10).

Only two DTI studies in the Rane et al. review reported on social scales: One reported a negative correlation with fractional anisotropy in the frontothalamic and temporo-thalamic tracts (Nair et al., 2013) and the results from the other were non-significant (Sundaram et al., 2008), although the specific brain region/s was not reported (p. 10).

Severity of restricted and repetitive behaviors: Of the seven RS studies reviewed by Rane et al. (2015) that reported correlations with repetitive and restricted behavior, three described a negative correlation between connectivity and the severity of that behavior (Assaf et al., 2010; Washington et al., 2014; Weng et al., 2010). Involved areas were the posterior cingulate cortex predominantly with the medial prefrontal cortex, and anterior cingulate cortex seed connectivity (Assaf et al., 2010; Washington et al., 2014). The other four studies in Rane et al.’s report, however, showed increasing severity of these behaviors with increasing connectivity between the PCC and right posterior parahippocampal gyrus (Monk et al., 2009), between voxels within the salience network (ACC, superior frontal gyrus, thalamus, and bilateral insular cortex; Uddin et al., 2013), and between the right temporal lobe and thalamus (Nair et al.,

2013)... One study using DTI... found a negative correlation between the white matter connectivity... in the forceps minor of the corpus callosum and severity of that behavioral (Thomas, Humphreys, Jung, Minshew, & Behrmann, 2011). (p. 10)

Language and communication skills: Rane et al. (2015) also noted that “Nine RS [resting state] studies and five DTI [diffusion tensor imaging] studies reported correlations between measured parameters and communication capabilities.” One study (Weng et al., 2010) reported a decline in verbal and nonverbal communication skills “with increased connectivity between the PCC and temporal lobe and also between the PCC and right posterior parahippocampal gyrus” (p. 10). Weng et al. (2010) were also reported by Rane et al. to have identified a negative correlation between nonverbal communication skills and posterior cingulate cortex to superior frontal gyrus connectivity. Most resting state studies, however, obtained conflicting results. One study (Dinstein et al., 2011) “reported lower ADOS communication scores and increased expressive language ability... with increasing inter-hemispheric correlations bilaterally in the inferior frontal gyrus” (Rane et al., 2015, p. 10). According to Rane et al., another study reported a negative correlation between ADOS communication scores and connectivity between the anterior medial prefrontal cortex and the right lateral parietal cortex (Redcay et al., 2013), while Nair et al. (2013) were reported to have found a negative correlation between ADOS communication scores and right motor cortex to thalamus connections. Rane et al. further noted that Verly et al. (2014) reported a positive correlation between verbal skills and superior temporal gyrus to inferior frontal gyrus connectivity; and Assaf et al (2010) found lower ADOS communication scores correlating with increased precuneus connectivity. Maximo et al. (2013; as cited Rane et al.) reported a positive correlation between the ADI-R communicative score and local connectivity in multiple cortical regions.



Among DTI studies examined by Rane et al. (2015), Nageh et al. (2012) reported a negative correlation between mean diffusivity in the left superior longitudinal fasciculus and language evaluation scores (meaning higher random diffusion/lower organized diffusion correlated with lower language scores and vice versa). Another reported study (Billeci, Calderoni, Tosetti, Catani, & Muraton, 2012) found a similar negative correlation between the left arcuate fasciculus and expressive language ability, but only in the typically-developing group. Li, Zue, Ellmore, Frye, & Wong (2014, as cited in Rane et al., 2015), rather than reporting on diffusivity or anisotropy,

performed network analysis on the DTI data and found that as short-range connectivities increased in typically developing subjects, group Gray Oral Reading Test-4 scores go down, whereas in the ASD group, they improved. Hence, they suggested that the increase in short-range connectivity observed in the ASD group compared to the typically developing group might be a compensatory mechanism, which might be leading to the language/communication disabilities observed in ASD. (p. 11)

Another study in Rane et al. (Pugliese et al., 2009) reported no correlation between DTI parameters and language scores, and a final study reviewed by Rane et al. (Joseph et al., 2014), looking only at hemispheric asymmetry, reported that “rightward asymmetry quotient of [the] pars opercularis, a part of the inferior frontal gyrus important in speech and language production, was positively correlated with language scores” (p. 11).

In summary, this review showed a preponderance of long-range inter- and intra-hemispheric cortico-cortical underconnectivity, with increased cortico-subcortical (thalamic and striatal) connectivity, possibly as a subcortical upregulation in compensation for cortical

underconnectivity (p. 14). Studies covered in this review investigating short range, regional connectivity reported contradictory findings (p. 11).

Given the variation in methodologies used in data collection and in approaches to data processing and analysis in the ASD literature, Rane et al. (2015) suggested that the differences among studies may be resolved through data sharing to increase the number of subjects and decrease methodologic variability. Pooling data made it possible to increase subject numbers from 7 – 57 subjects in studies not using pooling to 278 – 447 in studies using pooling (pp. 14-15). The three studies in their review that utilized data from one of these data pooling resources (Autism Brain Imaging Data Exchange [ABIDE]) “indicated both a massive predominance of hypo-connectivity within many of the cortico-cortical pairs of regions and a hyper-connectivity of the subcortical regions” (Di Martino et al., 2014), underconnectivity between the posterior superior temporal sulcus and the inferior parietal lobule (Alaerts et al., 2013), and altered connectivity in the default mode network, parahippocampal and fusiform gyri, insula, Wernike’s area, and intraparietal sulcus (Nielsen et al., 2013; as cited in Rane et al., 2015, p. 15)

Thus, Rane et al.’s (2015) review of fMRI and DTI studies and O’Reilly et al.’s (2017) review of EEG and MEG (magneto-encephalography) studies agreed that in spite of variability in study samples and methodologies in testing and data collection and analysis as previously outlined, research evidence supports the hypothesis of autism being a neurological disorder of disrupted neural connectivity, with long-range functional underconnectivity and mixed underconnectivity and overconnectivity in short-range pathways. In proposing their underconnectivity theory, Just et al. (2004) concluded,

Underconnectivity theory goes on to predict impairments in motor function, memory, and expressive nonverbal language (such as hand gestures and facial expressions), and to

virtually all cortically mediated functions. Wherever inter-region connectivity and coordination come into play, an underconnected system can manifest impairments, particularly when there is a large load on the system. (p. 1819)

Müller et al. (2011) stressed the importance of an emerging scientifically-grounded theory of autism, noting that “The wealth of ASD studies published in the past decades has failed to produce a comprehensive understanding of the neurobiological causes of the disorder, which would provide a firm basis for informed therapeutic interventions” (p. 2241). Based on their review of 32 functional connectivity MRI (fcMRI) studies, they could now state that a “Growing consensus suggests that autism spectrum disorders (ASD) are associated with atypical brain networks, thus shifting the focus to the study of connectivity,” (p. 2233), and “Among the few neuroscientific findings that appear solid are those of abnormal white matter growth trajectories and impaired connectivity” (p. 2241).

Within that foundation of solid findings supporting widespread disruptions in neural connectivity, however, remain inconsistencies, discrepancies, and questions. Müller et al. (2011) urged further careful assessment of the underlying methods and their limitations in conducting neuroimaging studies. Hence, “The question of functional connectivity in ASD, rather than being definitively answered, as some may believe, still remains to be posed in a clearly defined way” (Müller et al., 2011, p. 2241). However, they also continued (in classic Niels Bohr style):

Rather than simply being a nuisance, the fact that not all fcMRI studies have been able to replicate underconnectivity is therefore an opportunity for an improved understanding of the disturbances in emerging functional networks, which ultimately determine the profile of socio-communicative and other impairments commonly seen in ASD. (p. 2241)

Although research linking neural connectivity to specific behaviors and phenomena associated with autism is just beginning to emerge (Baum et al., 2016), long-range neural underconnectivity is hypothesized to be causative of disruptions in higher order sensory, motor, sensorimotor and integrative processes - i.e., in higher order processes requiring integration and processing of information from different brain regions such as discerning between elements of a given sensory stimulus (for example affecting deep touch, light touch, affective touch, and pain within the tactile system)., integrating information from different sensory systems and between sensory and motor systems, in motor planning, imitation of movement, theory of mind, memory, executive functions, and central coherence. Disturbances in connectivity would also account for increased functional difficulty in the face of heightened demands such as when the magnitude and scope of sensory input increases or as cognitive and/or emotional stresses increase.

Increased short-range connectivity, on the other hand, may explain the intact or often heightened discrete processes such as heightened visual acuity and hypersensitivity to touch, sound, odor, and taste; increased recognition of and attention to parts over the whole; emphasis on restricted and repetitive behaviors and thoughts; and becoming “stuck” on obsessions or making repeated unwanted requests. Rubin (Biklen et al., 2005) expressed,

As a child I remember being stimulated by a noise others would classify as a hum of an air conditioner and it would drive me crazy. There have been other times where my sight is stimulated in a car watching traffic go by, and my only release of all this tension would be for me to bang my head violently on the glass. I am not saying this is appropriate behavior, but people with autism cannot control this “spinning” that goes on in their head. It is not something we are able to control or express concern about in most cases. (p. 103)

Bearing in mind the impact that both overconnectivity and underconnectivity likely exert over most if not all functioning, an overview of the sensory, motor, and sensorimotor behavioral research findings will now be presented.

**Motor system behavioral research.** For at least the past four decades, research has identified disturbances in basic fine and gross motor skills - in the initiation, maintenance, and termination of movement; in motor tone (hypotonia), coordination, balance, posture, gait, and praxis (motor planning); and in oral motor control (oral apraxia; Amato and Slavin, 1998; Damasio & Maurer, 1978; Gowen & Hamilton, 2013; Green et al., 2009; Kanner, 1943; Leary & Hill, 1996; MacNeil & Mostofsky, 2012; Ming, Brimacombe, & Wagner, 2007; Noterdaeme et al., 2002).

Ayers, an occupational therapist and educational psychologist, developed and then published the theory of sensory integration and sensorimotor dysfunction in 1971 (Ayers & Heskett, 1972), explaining “the integration of somatosensory and vestibular sensory input [is] critical to perceptual-motor, cognitive and psychic growth” (p. 174). Shortly thereafter, in 1978, Damasio and Maurer proposed a brain-based neurological model, identifying specific brain regions they proposed as being those most likely involved in autism. Based on their findings, they also stated that problems with social behavior and relationships were *secondary* “to a collection of primary defects” they categorized as “disturbances of motility, disturbances of attention, and ritualistic and compulsive behaviors, as well as...disturbances of communication” (p. 782). In effect, research in these areas has demonstrated that sensory and motor disturbances play a much greater role than previously thought in the pathology of autism, with broad disturbances in motor and sensory systems as well as in the combined sensorimotor interchange

affecting all levels of functioning as well as the broader constructs including central coherence and theory of mind (Donnellan et al., 2010; Schipula et al., 2011)

Bram, Meier, and Sutherland (1977) described the association between motor control in infancy and later language development. Gernsbacher, Sauer, Geye, Schweigert, and Goldsmith (2008) found that oral-motor and manual-motor skills in infants and toddlers correlated significantly with and distinguished autistic children from typically developing children. These motor skills also correlated with levels of later speech fluency (p. 43). Head lag in infants in early pull-to-sit tests was documented by Flanagan, Landa, Bhat, and Bauman (2012). Landa and Garrett-Mayer (2006) found that children in infancy with fine motor difficulties were at significantly increased risk of being diagnosed with autism by age 36 months. All 17 children in a study by Teitelbaum, Teitelbaum, Nye, Fryman, and Maurer (1998) showed early disturbances of movement, some apparent by four to six months of age, but some also apparent at birth. The specific movement disorder varied between children, and included some or all of the developmental milestones including rolling, coming to sit, as well as sitting, crawling, and walking. Donnellan et al. (2013) stressed the significance of early movement disturbance on all areas of development including on social and relationship development, stating,

In the course of development, if individuals move and respond in idiosyncratic ways from infancy, they will experience all interactions within a unique frame that most certainly differs from that which is called typical. The cumulative effect of such interactions will be one in which all aspects of relationships, including how to establish and maintain them, may be markedly skewed from the broader cultural consensus and expected rules of how relationships work. (p. 5)

Based on their findings from a chart review of 200 children diagnosed with ASD, Greenspan and Weider (1997) found that *all* cases “evidenced auditory processing, motor planning, and sensory modulation dysfunction” (p. 3). Their findings also suggested that “the difficulty in engaging in complex purposeful gestural communication” was an early marker...” and “*difficulties with relating and intimacy are often secondary to underlying processing disturbances*” (my italics). Furthermore, they stated that “a number of children with autistic spectrum diagnoses are, with an appropriate intervention program, capable of empathy, affective reciprocity, creative thinking, and healthy peer relationships...,” and finally, they reported “that many of the children can become quite loving and caring, thoughtful and creative, *suggesting a need to change the criteria for diagnosing these disorders* (my italics; p. 2). Many firsthand accounts describe the desire for more social engagement and express frustration and disappointment with the inability to engage socially because of interfering movements or delays in responding. Jamie Burke (Biklen et al., 2005) described attempts at friendship:

Friends are so hard to keep interested as it takes very much desirous time to type. Kids are mostly good at talking but listening is not an asset they use. If I am able to talk, it still is not very good, as time is fleeting and so are they. (p. 250)

In his introduction to Richard Attfield’s chapter in *Autism and the Myth of the Person Alone* (Biklen et al., 2005), Biklen included the following excerpt from Richard’s award-winning essay, “Crying Inside,” in which he related a scene from his childhood:

I remember one day when a little girl spoke to me and called my name, I could not even respond to her attempt to hold my hand. ... Autism takes total control of a child and one becomes a prisoner in one’s own body. (p. 198)

Richard continued, expressing that people could not know “the frustration, of not being able to join in a conversation, but I guess that most people thought I was retarded and that I had no thoughts or feelings that mattered” (p. 198).

Thus, research beginning 40 years ago suggested that the communication and social disturbances of autism, in contrast to popular understandings and definition of autism, were not the primary areas of impairment, but rather were secondary to earlier and more basic motor and sensory disturbances identifiable in infancy.

Motor patterns are atypical in ASD, beginning in infancy and continuing through childhood and into adulthood (Fournier et al., 2010; Gowen & Hamilton, 2012; Ming et al., 2007; Teitelbaum et al., 1998). In their ASD cohort of 154 children, Ming, et al. (2007) found hypotonia to be the most common motor symptom (51%) followed by motor apraxia (34%). In their study of oral motor deficit in speech-impaired children with autism, Belmonte, et al. (2013) stated, “Absence of communicative speech in autism has been presumed to reflect a fundamental deficit in the use of language, but at least in a subpopulation may instead stem from motor and oral motor issues” (p. 1). Jamie Burke (Biklen et al., 2005) explained his problem producing speech, saying

When I was growing up, speaking was so frustrating. I could see the words in my brain but then I realized that making my mouth move would get those letters to come alive, they died as soon as they were born. What made me feel angry was to know that I knew exactly what I was to say and my brain was retreating in defeat... I understand why kids scream. It's frustrating not being able to speak and feeling as a mostly invisible being. (pp. 250-251)



Gernsbacher et al. (2008) demonstrated a “tight coupling between the hands and the mouth,” showing that both early oral-motor and manual-motor skills are associated with later speech fluency. In addition, they concluded that both proto-imperative (indicating desire) and proto-declarative (indicating interest) pointing were impaired in toddlers, with the latter also likely associated with theory of mind. In addition, and importantly for informing interpretations of tests of receptive language (as was conducted in this dissertation study), the authors stated, “Manual-motor skills can also confound the assessment of receptive language” (p. 49). Often times, individuals describe not having any sense of body, which impedes any sense of eye-hand and manual-motor skills. Lucy Blackman (Biklen et al., 2005), after years of learning to better recognize her body, typed,

Of course, I had heard people say how good this kind of thing [ball toss and catch] is for co-ordination. What these well-intentioned, enthusiastic rationalists had never realized was that I had had no idea what co-ordination was. The *fuzzy* and overlapping limits to my body had seemed to have a life of their own. As the New Me reached for that virulently yellow-coloured, fluffy ball, I now see why. I could see multiples of both fingers and palm as I stretched. In some way, probably because I was not fighting to maintain my place in space when I sat or stood [as she had previously], I was aware of this phenomenon consciously for the first time. Maybe also it was slightly improved. As I moved bits of me through space, I had slightly more understanding of what was happening, and my hands made movements that were in some ways more in sync with what I was trying to achieve. (p. 163)

Jones and Prior (1985) found problems with imitation of movements, an ability they posited to be essential to developing social interactions. The authors stated, “The autistic

children seemed literally unable to coordinate their limbs in some of the tasks” (p. 43). More recently, studies of the mirror neuron system, which is believed to be the pathway for imitative ability, have raised questions about its involvement in social learning. For the most part, although results are not yet conclusive, research has demonstrated difficulties primarily with imitation of those movements associated with emotional stimuli (Hamilton, 2013).

Other integrative problems may also be involved in interfering with imitating movements. Some individuals report being unaware of their facial expressions (Donnellan et al., 2013, p. 2) or of either being unaware of certain parts of their bodies or, lacking effective proprioceptive feedback, not knowing where body parts might be in space at any given point in time (e.g., Williams, 1996, 2003; Blackman, 1999). Other reported problems include difficulty initiating movement and/or becoming “stuck” on certain movements even if another movement is desired and attempted. All of these difficulties would interfere with imitative movement and coordination of limbs. Rubin (Biklen et al., 2005) explained,

Autism is a world so difficult to explain to someone who is not autistic, someone who can easily turn off the peculiar movements and actions that take over our bodies... My abilities limit me to smiling only when prompted. In a social setting, an example of being prompted might be, someone placing their hand on my back to get my attention, followed by a directive to make a response. (p. 83)

Dziuk et al. (2007) found deficits in both basic and skilled motor performance, with level of ability in basic skills (first-order skills) predicting performance in higher order praxis. In addition, although basic motor skill was a predictor of praxis performance, the group with autism showed significantly poorer praxis (second-order skill) than controls even after controlling for basic motor skill (p. 734). Thus, higher order motor planning and execution was disturbed in

those with autism beyond what could be explained by their level of basic motor ability. Furthermore, this study found that performance on praxis strongly correlated with the defining social, communicative, and behavioral features of autism, “*suggesting that dyspraxia may be a core feature of autism or a marker of the neurological abnormalities underlying the disorder*” (p. 734; my italics).

In a study comparing 24 children in each of three groups – ASD, ADHD, and neurotypicals – MacNeil and Mostofsky (2012) concluded that impairments in *basic* motor skills may represent a general finding, as they were common in children with ASD and in children with ADHD. However, they found that “impairments in performance and recognition of skilled motor gestures, consistent with *dyspraxia* (my italics), appear to be specific to autism” (p. 165). Therefore, it appears that findings of hypotonia and dyspraxia alone would account for at least some individuals’ requirement of physical support in typing. Baranek, Parhan, & Bodfish (2005) described praxis as involving “ideation” – the process of conceptualizing what to do – as well as motor planning – organizing a plan of motor action in time and space. Thus, “praxis requires problem solving in order to move in a novel manner as opposed to a familiar, previously-practiced motor pattern” (p. 835). Sue Rubin (Biklen et al., 2005) expressed these components of conceptualization and motor planning in praxis stating,

With non-language items on a test, I have a significantly more difficult time. Although I know in my head what shapes might correlate I find it difficult to make my hand point to the right answer, the action I will my hand to take is not always what really occurs. (p. 96)

Motor impairments have been far more than just occasional or incidental findings. Green et al. (2009) found that 79% of 101 children studied had a definite motor impairment, with an

additional 10% having borderline impairment. In a meta-analysis of 51 comparison studies of individuals with ASD and typically developing controls, Fournier et al. (2010) concluded that “*motor deficits are a potential core feature of ASD*” (p. 1237; my italics). The abundant findings of motor disturbances in early infancy and the involvement of every aspect of the motor domain provide strong evidence supporting motor disturbances as being a core feature of autism.

Motor delays and response delays are reported in firsthand accounts, as are increasing difficulty in all areas as a result of increasing cognitive or emotional demands. Rubin (Rubin et al., 2001) provides insight into movement difficulties and delays:

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. (p. 423).

Rubin makes it quite clear that it is purposeful movement rather than spontaneous movement that is problematic. Results from this dissertation study as well as the vast majority of other facilitated communication studies align with this description: spontaneous thoughts and

communications - most often analyzed through qualitative methods - can be typed without undue facilitator influence, but anything more directed such as picture/object identification or any kind of message passing as is typically associated with quantitative studies creates enormous difficulties. Alberto Frugone (Biklen et al., 2005) described the impossible task of motor planning, saying, “I was conscious of my inability to access motor planning and I was lost in an unacceptable motor ‘silence’” (p. 190). He described attempting to execute a known ability to open a car window:

I’m in the car, sitting near my mother who is driving. It is hot; we should open the window. Technically I know how to open it: on the dashboard there’s the button to raise and lower the window. I can describe the action: I must push the button with my finger. But my hesitation grows while I try to put together the sequences to go through the action, I mentally review all the necessary steps, but the first one simply doesn’t come out. I’m trapped.... Unable to move, the only thing that comes out instead is a stereotyped movement that eventually consists of a reassuring thumb in the mouth or four fingers quickly flapping in front of my eyes. (p. 187)

**Sensory systems behavioral research.** Findings from sensory and sensorimotor integration studies also reveal intriguing implications for understanding autism and the use of facilitated communication in autism. As noted, sensory abnormalities alone are a pervasive finding in autism, affecting all sensory modalities and all sub-categories within each modality. Behaviorally, sensory processing differences are typically divided into hyper-sensitivity (overconnectivity), hyposensitivity (underconnectivity), and sensory seeking, and include both atypical *perceptions* of sensory stimuli and atypical *reactivity* to stimuli (Baum et al., 2015).

David (as cited in Shoener et al., 2008), an autistic who began typing independently at age 14, typed the following when he was 18:

Perception of senses: the senses all don't work right and I struggle to think, Really each time I use my body I can't feel my body; it feels stiff, I can't move how I want; no muscles work; they are really cement, The ears work but the sounds are mixed up with all the sounds around the room, Sounds are accosting me, I see but my body really can't move in response to each hard thing around me, Taste is ok, it's extreme; smell is all inside the room and that's overwhelming to my head and brain. (p. 550)

Leekam et al. (2007) found that at least 90% of the individuals with autism in two different studies had sensory abnormalities extending across all ages and IQ levels, with most individuals showing differences in more than one sensory domain. In their review of the literature, Caminha and Lampreia (2012) reported that 69 to 80% of participants with ASD had symptoms of sensory dysfunction; Tomachek and Dunn (2007) reported that 95% of 281 children between the ages of 2 and 6 had sensory processing difficulties; and Liu (2013) reported that 100 % of the 32 children assessed fell in the definite difference range and that sensory processing scores correlated positively with motor performance scores (p. 204). In addition, there is a general consensus that the degree of impairment increases as the level of task complexity increases. Again, as noted in the neuroimaging studies, individuals with ASD typically perform as well or better than controls on basic first-order tasks, but have difficulties with more complex second-order tasks across all sensory domains (Baum et al. 2015; Stevenson, & Wallace, 2015; Bertone, Mottron, Jelenic, & Faubert, 2005)

Tavassoli, Miller, Schoen, Nielsen, and Baron-Cohen (2014), in their study of 221 adults with ASD and 181 controls, demonstrated a correlation between the severity of autism and the

degree of sensory over-reactivity in all sensory subscale domains tested – visual, auditory, tactile, olfactory, gustatory, and proprioceptive. Hyper-sensitivity to sensory stimuli may result in a positive experience such as perceiving exquisite beauty in individual droplets of water or grains of sand, or it may result in negative or aversive responses such as finding some textures or sound levels or qualities to be intolerable. When sensory stimuli are experienced at an enhanced or over-stimulating level and are reported to be painful, disorienting, or overwhelming, behaviors may arise to protect the individual from that sensory overload (Grandin & Scariano, 1986; Williams, 1996). Thus, rather than being the typically miss-assumed “mindless” repetitive behavior, autistic individuals report that sensory *seeking* may be an adaptive response in which a particular sensory experience or modality is found to be calming or blocking of other overwhelming sensory stimuli. Temple Grandin stated,

I was intensely preoccupied with the movement of the spinning coin or lid and I saw nothing and heard nothing. I did it because it shut out sound that hurt my ears. No sound intruded on my fixation. It was like being deaf. Even a sudden noise didn't startle me out of my world. (as cited in Donnellan et al., 2013, p. 1)

Research focusing on the interoreceptive (vestibular and proprioceptive) senses has revealed differences between those with autism and those without. Children with autism seem to rely more on proprioceptive than on visual or tactile feedback for movement and postural control; however, that feedback is not always reliable, as indicated in the findings of poor postural control by Minshew et al. (2004). None-the-less, their results suggested that children with autism may rely more on internal systems for feedback than on externally-received sensory input. David (as cited in Shoener et al., 2008), after having received occupational therapy to help integrate his tactile system, typed,

Touch is now heightened. From brushing, I'm now feeling my body for how to each time move, and it feels good knowing where it is now instead of moving it to feel it, but now I know I can move because it's now usable. It's getting easier to move and think together. (p. 550)

Tito Mukhopadhyay (Biklen et al., 2005), rocking back and forth as he sat with Biklen for their interview, apologized and explained, "I cannot. I'm sorry but I cannot help it. I need it [the rocking] to feel my body" (p. 113). In the same interview, he also explained,

It took me many years to realise that I have a body. I was totally aware of sounds and colours, which my senses picked up for me. I was, as if watching everything from a distant moon without actually being any part of everything. So the feeling that I have a body never occurred to me. Even this day sometimes I feel that I am walking without legs. (p. 137)

He also described lack of proprioceptive feedback hindering his ability to point:

The most important reason [I could not point] is that I had very little sensation of my body. So to learn the technique of moving my right hand needed control over the ball and socket joint of the shoulder and then the hinge joint of my elbow and finally fold the other fingers and keep the point finger out. After that focusing on the object which matched with the word. (p. 133)

Lucy Blackman (Biklen et al., 2005) explained, "I deduce that in childhood I had real problems in knowing exactly where my connectional limbs and trunk were, where they would move to next, and, even more frighteningly, where they had last been positioned" (p. 151).

Differences in the chemical senses – olfaction and gustation – have also been studied in autism spectrum disorders, with results again demonstrating typical or enhanced first-order



processing (detection of odor and taste), but impaired second-order processing such as in differentiating between scents (Ashwin et al., 2014). Grandin (2006) described refusing to walk on grass as a child because the scent was overpowering. Bogdashina (2016) related that “Donna Williams’s allergic reaction to some perfumes made the inside of her nose feel like it had been walled up with clay up to her eyebrows, and some perfumes ‘burned her lungs’” (p. 85). Since autistics have never experienced the world any differently, they are not aware for some years that their experiences of the senses and the world are different from others, particularly from neurotypical people. They may also be so accustomed to sensory interferences, it would not occur to them to comment, for example, about odors interfering with their ability to concentrate.

Research on the tactile system has demonstrated differing responses (both hypo- and hyper-reactivity) to light touch, deep pressure, affective touch (gentle, caressing touch supporting social-emotional development), textures, and different kinds of pain. As with the other senses, heightened sensitivity, often with aversive reactions, to the perception of touch (first order processing), but impaired tactile processing and differentiation of texture (second order processing) has been documented (Blakemore et al., 2006). Many autistic individuals (and parents of autistic children) report insistence on wearing the same clothes or the same type and fabric in clothing every day because of sensitivities to texture and fit (Barron & Barron, 1992; Bogdashina, 2016; Grandin, 1996). Brain activity on fMRI was reduced in children and adolescents with ASD when processing affective touch suggesting hypoactivation in social brain areas, whereas brain activity was enhanced, or hyper-reactive, in response to non-affective-targeted touch (Kaiser et al., 2016).

Studies have also demonstrated sound is often experienced by autistics as heightened and painful or distorted and confusing, as can be observed in the frequency with which autistics

cover or put their fingers in their ears. Studies have demonstrated that the *detection level* of auditory stimuli is normal or enhanced; however, discriminating, locating, and attending to select auditory input from a background of competing or unwanted sound is impaired, causing difficulty in registering and attending to select or desired auditory reception (Alcántara, Weisblatt, Moore, & Bolton, 2004). Grandin (as cited in Bogdashina, 2016) described her acute sensitivity to sound, comparing her hearing to a microphone amplifying sound:

When I was little, loud noises were ... a problem, often feeling like a dentist's drill hitting a nerve. They actually caused pain. I was scared to death of balloons popping, because the sound was like an explosion in my ear. Minor noises that most people can tune out drove me to distractions. (p. 84)

Teder-Sälejärvi, Pierce, Courchesne, and Hillyard (2005) reported that auditory problems did not arise in identifying the sound frequency or the location from which the sound originated; rather, disturbances appeared to arise in filtering out irrelevant sounds in order to focus attention on the target sound. The authors further proposed that this impairment could explain other auditory abnormalities common in autism: hyper- and hypo-sensitivity to sound, aversion to sounds, and difficulties orienting and shifting attention in relation to auditory input (p. 232). Grandin (as cited in Bogdashina, 2016) reported on the effect different sound frequencies had on her. Describing her reaction to the sound of hand dryers in public restrooms, she said it was "Not so much when the air jet starts, but the moment someone's hands enter the stream. The sudden drop in register drives me nuts..." (p. 93). In the same passage cited in Bogdashina, she described the pain the school bell caused her: "It felt like a dentist's drill. No exaggeration: The sound caused a sensation inside my skull like the pain from a dentist's drill" (p. 93).

Auditory processing involving screening, isolating, blocking, and selectively attending to only certain sounds to then make sense of them in context is certainly impacted by hyper-reactivity or aversion to sounds. One autistic man, through his firsthand account (Jim, as cited in Cesaroni and Garber, 1991) described a different reaction to sound. He said sound itself was not frightening, but the reaction some sound frequencies elicited in him was:

For example, in the fifth grade Jim recalled that when he was listening to a record, low-frequency notes in the background music became so terrifying that he refused to return to school. ... Jim theorizes that some stimuli act as 'triggers' for disorganization of processing, not unlike epileptic seizures being triggered by light flashing at a certain frequency. "I think the sounds on the record fell into this category: They didn't frighten me in themselves, but they triggered some loss of orientation that was unpleasant and frightening." (p. 306)

Finally, Mukhopadhyay (Biklen et al., 2005) described that familiar words sounded different when spoken by unfamiliar voices, and the time required to adjust to a voice varied from voice to voice. His mother had to repeat what strangers said until he adjusted to the new voice. (p. 136). Greenspan and Wieder (1997) reported that 100% of the 200 charts they reviewed of children between the ages of 22 months and 4 years reported poor auditory processing of incoming information, and 100% also showed some difficulties with planning and sequencing of motor acts (p. 10). They reported the following:

Most of the children could express their own ideas much more quickly than they could comprehend the ideas of others. Even children who initially had some understanding of others' language (for example, of simple commands) were still relatively more challenged by their auditory processing of incoming information than by their ability to

express ideas. They knew what they wanted to say but inconsistently understood others.... Even when they could tell you what they wanted (e.g., “go out play” and “give me juice”) or do pretend play sequences with the dolls hugging and kissing, they would find it difficult to answer the abstract “what,” “where,” and “why” questions (“What do you want to do next?” even though they knew exactly what they wanted to do. (p. 22)

These same difficulties with auditory processing would reasonably impact both verbal and written responses, and might therefore contribute to individuals typing with facilitation having more difficulty responding to incoming information than expressing their own ideas.

Research in the visual domain includes studies on acuity, embedded figures and field perception, visual tracking, visual attention, and perception of static figures versus figures in motion and of biological versus non-biological motion. In keeping with other sensory and motor studies, individuals with ASD were shown to perform better on first-order skills such as perceiving stimuli and perceiving discrete changes in individual points within a field (such as detecting luminance changes), whereas they had difficulty perceiving differences in contrast or texture, which involve comparison between points of an image (Bertone et al., 2005). Visual acuity per se appears to be typical or enhanced (Tavassoli, Latham, Bach, Dakin, & Baron-Cohen, 2011). Baron-Cohen (as cited in Ashwin et al., 2014, background section, no page given) reported that some individuals could “read tiny text like the small print on the back of products from across a room.” Bogdashina (2016) contrasted two students with opposite perceptions of visual stimuli – one being hypersensitive and the other hyposensitive:

Alex’s vision is very acute (hyper-): he can see the tiniest particles in the air, the smallest pieces of fluff on the carpet. These experiences distract his attention from whatever he is supposed to be doing. He hates bright lights, and fluorescent light gives him headaches.

What makes things even more complicated is that Alex's hearing is also very acute. He can hear what is going on in the next room, and always keeps me informed about it: "The chair is being moved. The ruler has been dropped. The bus is coming," etc."

Helen's vision is hypo-: she is attracted by any shining object, looks intensely at people (which irritates Alex, who cannot tolerate anyone looking at him directly), and is fascinated with mirrors. In lessons she can move her fingers in front of her face for hours. It seems she cannot get enough visual stimulation, and always switches on all the lights as soon as she enters the classroom. (This is usually followed by a fight with Alex, who throws a tantrum every time the light is on.) (p. 91)

Performance on higher order visual processing tasks such as visual-spatial, visual-attention, and visual-motion processing, however, has been shown to be impaired (Hannant, 2016; Simmons, Robertson, Toal, McAleer, & Pollick, (2009). In a study of children with language disorder (including children with and without autism), Kelly, Walker, and Norbury (2013) reported that although reflexive oculomotor focus when looking at a target was not disrupted (prosaccade tasks), children with language impairments did have greater difficulty than those without language impairment in *suppressing* reflexive shifts of gaze and maintaining fixation on a target *in the presence of competing distracters* (antisaccade errors). Furthermore, the authors noted that "antisaccade errors have been linked to working-memory processes that may be related to the ability to maintain an instruction and apply it at the appropriate time" (p. 63). These findings are highly relevant to the findings from this study with this autistic individual with a language disorder as will be covered in the discussion section.

These findings overlap with research specifically investigating visual attention.

Individuals with autism spectrum disorder have been shown to have faster visual search times,

scoring higher on embedded figures tests and excelling at identifying particular details in the environment (attention to part over whole; enhanced zoom-in mechanism), indicating a predilection for focusing on and identifying details over a global scope (Jolliffe & Baron-Cohen, 1997; O’riordan, Plaisted, Driver, & Baron-Cohen, 2001). In contrast, attentional focusing is atypical as demonstrated through difficulty ignoring unwanted details and/or having difficulty integrating details into a cohesive whole (zoom-out mechanism or weak central coherence; Bertone et al., 2005; Cribb, Olaithe, Lorenzo, Dunlop, & Maybery, 2016; Ronconi, Gori, Ruffino, Molteni, & Facoetti, 2013). This may also be related to a perceptual approach referred to as fragmented perception, or perception “in bits” (Bogdashina, 2016, p. 69), as will be further discussed later in this paper.

Studies differ in their findings related to visual motion detection; however, evidence of impaired perception specifically of *biological* motion is more consistent (Baum et al., 2005; Blake, Turner, Smoski, Poxdol, & Stone, 2003) and is an important piece of evidence in explaining failure to understand social gestures and body language in general. Scolari, Seidl-Rathkopf and Kastner (2015) studied the fronto-parietal attention networks, and encouraged additional research into subcortical structures that are also likely involved in attentional control. They broke down the specific and complex nature of visual attention with the following:

Human cognitive systems are constrained by set capacities, such that the number of co-occurring stimuli that can be processed simultaneously is limited. Selecting behaviorally relevant information among the clutter is therefore a critical component of routine interactions with complex sensory environments. In the visual domain, such selections are completed via several interacting mechanisms based on different criteria, including spatial location (e.g., a spectator of a soccer match may restrict attention to any activity

within the penalty area), a specific feature (e.g., the spectator may attend only to soccer players in white jerseys), a specific object (e.g., the spectator may direct attention to the soccer ball), or even a category of objects (e.g., the spectator may attend to any soccer player regardless of identity or team affiliation). In the primate brain, attentional selection in the visual domain is mediated by a large-scale network of regions within the thalamus, and occipital, temporal, parietal and frontal cortex. (p. 32)

Hamilton (2013) addressed visuomotor mapping in her discussion of Theory of Mind and her review of the mirror neuron system in autism. She concluded,

This suggests that theory of mind abilities are linked to the control of imitation, which is important because difficulties in theory of mind are well established in autism (Baron-Cohen et al., 1985; Senju et al., 2009). Data from these initial studies are compatible with the STORM hypothesis. (social top-down response modulation model; p. 101)

In explaining the STORM hypothesis, the model contains two components: visuomotor mapping and a top-down modulation system. The visuomotor mapping is via “a pathway of connections running from higher-order visual systems through inferior parietal cortex to premotor cortex and then on to motor cortex.” The top-down modulation refers to the initiation of imitation responses in this visuomotor system being “controlled by the demands of the social situation,” by social cues. Neurologically, this means “the visuomotor stream is modulated by action selection processes originating elsewhere” (such as the medial prefrontal cortex, other parts of the frontal cortex, or subcortical areas; Hamilton, 2013, p. 101).

Bertone et al. (2005) found visual-spatial tasks to be impaired, with the level of deficit positively correlating with increasing cognitive and attentional demands. This is another important link when analyzing facilitated communication: an individual may well be able to

identify objects during message-passing tests until asked to respond on command, under increased anxiety, or in the presence of distractions and environmental demands associated with testing. In addition, responses may eventually be produced, but may be delayed to the extent of being unrecognizable.

Belmonte et al. (2010), in fMRI studies on individuals with autism compared to controls, found abnormal activation of frontal, parietal, and cerebellar areas in a non-social task of visual attention. In accordance with multiple firsthand accounts reporting delays in response times accounting for their “failures” to respond to questions or their ability to join in a conversation, the authors also noted that “the ASC [autism spectrum condition] and sib groups *did* (my emphasis) activate fronto-cerebellar attention systems, but these activations arose *too late to be useful* (my emphasis) during behavioral response to the trial of interest, instead manifesting during the trials immediately subsequent” (p. 271). This delay in processing time, as was also discussed in the neuroimaging research section, is another important factor to consider in facilitated communication testing.

Again, understanding the functional or dysfunctional patterning within the visual and visuomotor processing pathways in autistics is essential in evaluating the ability of autistic individuals with language impairments to process visual information and then maintain its differentiation in working memory when responding to visual response tasks (such as in Wheeler et al., 1993). For a comprehensive review of vision in autism, see Simmons et al. (2009).

**Multisensory and sensorimotor integration research.** Research on visual-motor integration is only one of many areas of sensory integration and sensory motor research. Given that our understandings and perceptions of others, our environment, and interactions between people and between people and the environment are based on information we receive via our



senses, the coordination of incoming pieces of sensory information into an accurate and coherent whole is essential in formulating accurate perceptions and following that, accurate responses. Research now strongly indicates that the combined entity of multisensory and sensorimotor impairments should be considered, not as associated or peripheral findings, but rather as fundamental deficits affecting all higher order disturbances in autism (Baum et al., 2015; Donnellan et al., 2010; Gowen & Hamilton, 2013). Baum et al. (2015) posited:

Because sensory information forms the building blocks for higher-order social and cognitive functions..., sensory processing is not only an additional piece of the puzzle, but rather a critical cornerstone for characterizing and understanding ASD...deficits in multisensory integration may also be a core characteristic of ASD. (p. 140)

These authors also stated that the ability to integrate information from the different senses is a basic foundation for constructing higher order social and cognitive representations. Sensorimotor disturbances affect every facet of how autistics perceive and interact with the world, both directly influencing behaviors and secondarily affecting behaviors that emerge as adaptations to the motor and sensory disturbances. Stevenson et al. (2014) found deficits in multisensory integration in children with ASD even when no impairments were detected in the individual sensory systems. Their finding were compatible with other research consistently showing that processing diverse sensory stimuli in a cohesive, integrated fashion is impaired in autism, resulting in distortions in perception, decision-making, and behavior (Glazebrook, Gonzalez, Hansen, & Elliott, 2009; Gowen & Hamilton, 2013; Greenfield et al., 2015). Processing errors may occur in sorting and coordinating the proper timing or spatial relationship between stimuli or in identifying relevant information from competing “noise.” Cesaroni and Garber (1991), referring to one of their study participants, related that

Sensory processing has always been a difficult area for Jim to discuss. One reason is that most people's vocabularies for discussing sensory processing are extremely subjective, and second, he finds it difficult to describe his sensory processing in a language developed by and for people whose sensory and perceptual processing are different from his. ... Jim explained, "Sometimes the channels get confused, as when sounds come through as color. Sometimes I know that something is coming in somewhere, but I can't tell right away what sense it's coming through." (p. 305)

Gowen and Hamilton (2013) reviewed various aspects of motor control and concluded that abnormal integration of sensory processing (visual, tactile, and proprioceptive) may impair estimations of state (e.g., the location of one's arm, the locational relationship between one's arm/hand and a desired object) which in turn impairs planning the motor output necessary to complete an action (such as reaching for, grasping, or placing that object in a container). These authors also found that autistic children recognized basic, individual object-based and symbolic gestures comparable to neurotypical controls, suggesting that their difficulties arose in organizing that knowledge and then transferring those understandings into motor execution. Further, their evidence suggested that actions were carried out more slowly, and there seemed to be deficits in linking actions together. They proposed that dysmetric and increased variability in movements "suggest that increased noise and/or mistimed muscular forces may hamper movement execution" (p. 339). This increased noise refers to both excessive sensory input, sensory noise, and motor variables such as miss-timed muscular forces, all resulting in an increased burden at all levels of motor processing (p. 339).

In summary, their conclusions suggested that altered sensory input combined with deficits in organizing motor knowledge and altered motor execution importantly impact the

motor abilities of autistic individuals (Gowen & Hamilton, 2013, p. 340). These findings have strong implications for facilitated communication. They suggest that the difficulties in typing responses based on incoming information, whether it is auditory, visual, or tactile, may be the result of impaired transfer of recognized information into planning and executing the motor actions to type specific words. Once again, this added level of organization may be what differentiates being able to type from spontaneous thought while being hindered in typing in response to stimuli.

Perhaps related to this difficulty in linking actions are the findings of disturbances in temporal binding in both auditory-visual and visuo-tactile processing, as was identified in neuroimaging studies (Greenfield et al., 2015). Likewise, Glazebrook et al. (2009) showed impairments in a pointing task in which visual and proprioceptive input had to be integrated, whereas there was no impairment in pointing when the vision component was blocked.

***Perceptual fluctuation.*** Donnellan et al. (2013) explained that movement and sensory disturbances are pervasive, but also in constant flux, with changes in muscle tone and speed and accuracy of movement, in clarity of sensory perceptions, and in delays in processing, all fluctuating unpredictably (p. 7). Rubin (Biklen et al., 2005) related, “Autism plays on a person’s five senses. It can vary from day to day and is not something one can control or see coming” (p. 103). Bogdashina (2016) presented examples of these fluctuations from personal accounts such as the following from White and White (1987): “Sometimes when other kids spoke to me I would scarcely hear, then sometimes they sounded like bullets” (p. 98). Blackman (as cited in Bogdashina, 2016) described,

I was often tossed in a sensory maelstrom, so that the skin sensation was so unbearable one minute and yet completely unfelt the next... When I was little the fluctuation of

sound was continual... Other people learn to make social decisions from ongoing and consistent stimuli. I have not been able to make instinctive social judgements based on prior experience in a reliable way, because the incoming signals were switched often enough that I did not learn to untangle those shadowed moving faces and their inconsistent voices. Real and extraordinary fluctuations in all sensation were a part of daily life. (p. 99)

***Inertia, control, and getting stuck.*** Difficulties also arise with starting, stopping, executing, combining, and/or switching actions, thoughts, emotions, and speech. Perseveration/getting stuck/obsessing would often fall under the DSM-5 B diagnostic criteria (APA, 2013, p. 50): “Restricted, repetitive patterns of behavior, interests, or activities...,” and specifically under either Criterion – B. 1: “Stereotyped or repetitive motor movements, use of objects, or speech (e.g., simple motor stereotypies, lining up toys or flipping objects, echolalia, idiosyncratic phrases)” or B. 2: Insistence on sameness, inflexible adherence to routines, or ritualized patterns of verbal or nonverbal behavior (e.g., extreme distress at small changes, difficulties with transitions, rigid thinking patterns, greeting rituals, need to take same route or eat same food every day.”

Although most of this portion of the defining criteria is stated in observational terms without judgement, the word “need” is an assumption, a judgement, about internal state and motivation, which autistics tell us may often be incorrect. There may not be a “need” for eating the same food every day, but rather a verbal or motor planning inability to express the desire for something different. This is clearly exemplified by Jamie Burke (Biklen et al., 2005) in his description of one of his near-daily frustrations in trying to make known his choice of what he wanted for breakfast:

In the morning I was given many silly choices. But as my voice was not a true one, I had to pick the choice I heard. Many times it was not my true choice and both my mom and me were mad if I did not finish the cereal. I mean when you are little and have speech that is only just a few small babyish words, you cannot get yourself unstuck to make a new selection. Like a car that keeps slipping into reverse gear because the track isn't strong enough to move forward. It was impossible to move to a joyful and delicious choice. After I was served, I was furious with myself and mad at mom. Even saying "Do you want something else?" didn't help. The gears refused to move. I think many times it felt better to scream and run, than to feel like gagging on the bitter food. Even as the selections were viewed, my brain made only the same choice very day. Many times I desired pancakes but my lousy hand pointed to the bitter choice. (p. 252)

Rubin (Biklen et al., 2005) described a similar experience in not being able to provide the response she wanted to give:

If someone asks me, "Do you want to go to the bathroom? Yes or no?" I will typically answer with a yes because it is the first word in the sentence that my autistic brain got stuck on. So what might appear not to be a leading question does functionally become a leading question if it triggers an automatic response. (p. 87)

In addressing difficulties with "starting, stopping, executing, combining, and/or switching actions, thoughts, emotions, and speech" Donnellan et al. (2006) stated that *volitional control is often compromised, resulting in a lack of congruence between action and intended action.*

Referring to Leary, Hill, and Donnellan's (1999) definition, Donnellan et al. expanded the meaning of *movement* to be far more process-inclusive, stating that *movement difference* is "a difference, interference, or shift in the efficient, effective use of movement. It is a disruption in

the organization and regulation of perception, action, posture [inclusive of all movement], language, speech, thought, emotion, and/or memory” (p. 207).

Rubin (Biklen et al., 2005) shared her difficulties with carrying out volitional actions:

...I rarely find the strength in my autistic capabilities to initiate a conversation. There may be times where something pertinent eats away at me until I either find a moment where my body and mind coincide and I am able to go get a device to converse with.

Sadly though, most times *I am not able to do this unless one of my friends initiates or prompts me* to get a device for communication purposes. (italics added; p. 85)

Blackman (1999) described a situation in which she realized her behavior was inappropriate, but she could not alter it: Blackman was standing next to a woman at a crosswalk. When the woman asked if she were alright, Blackman assumed the woman was concerned about Blackman’s odd movements. However, Blackman described her response with the following: “Confused by the fact that she expected me to respond, I started running in a little circle.” Half an hour later she was still running in that little circle even though she noted, “The strange thing was that I could see the ridiculous and comic scenario in my mind’s eye, but I could not alter the behavior” (p. 41).

***Perceptual thinking.*** Bogdashina (2016) includes inertia under executive function deficits, which she subcategorizes under Cognitive Styles (Contents). Other cognitive styles she lists and discusses include subconscious, unconscious, and preconscious cognitive processes, attention in autism, concept formation, categorization, and generalization, memory in autism, perceptual thinking, and imagination. Grandin (2006) described her cognitive process as being largely perceptual. She stated,

Words are like a second language to me. I translate both spoken and written words into full-color movies, complete with sound which run like a VCR tape in my head. When somebody speaks to me, his words are instantly translated into pictures. (p. 3)

This cognitive style allowed Grandin to visualize and try out complex equipment designs, checking them for errors, in her mind before ever physically implementing them. It also provided her with a “photographic” memory, requiring only that she pull to mind whichever tape she wished to recall.

*Associative thought patterns.* Grandin and Williams described another important and pervasive cognitive style – thought association. Following her description of translating words into pictures, Grandin (2006) then explained her thoughts flowing in associative connections:

If I let my mind wander, the video jumps in a kind of free association from fence construction to a particular welding shop where I’ve seen posts being cut and Old John, the welder, making gates. If I continue thinking about Old John welding a gate, the video image changes to a series of short scenes of building gates on several projects I’ve worked on. Each video memory triggers another in this associative fashion, and my daydreams may wander far from the design problem.... People with more severe autism have difficulty stopping endless associations.... Thought processes aren’t logical, they’re associational. (p. 9)

Grandin described another scenario in which she was attending a ballet:

All the elements are in place – the spotlights, the swelling waltzes and jazz tunes, the sequined sprites taking to the air. Elements triggered the association of the periodic table on the wall of the high school chemistry class. Sprite triggered the image of the Sprite can in the refrigerator instead of the pretty young skaters. (p. 13)

Williams (1994) described a situation that encompassed both “mono” (systems forfeiting) and associative thinking:

...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 or the part about the dog gets processed and the part about John gets aborted as useless information. (p. 197)

***Fragmented perception.*** The visual sensory experience of perceiving incoming stimuli “in bits” as was discussed earlier in this paper under the subheading, *Sensory systems behavioral research*, can affect any of the senses (Bogdashina, 2016, p. 69). This may be related to localized hyperconnectivity combined with underconnectivity in integrating all information. Williams (1999) said, “I had always known that the world was fragmented. My mother was a smell and a texture, my father was a tone, and my older brother was something which was moving about” (p. 11). Also, “Where someone else may have seen ‘crowd’, I saw arm, person, mouth, face, hand, seat, person, eye... I was seeing ten thousand pictures to someone else’s one” (p. 21). Finally, she stated,

Sometimes people would have to repeat a particular sentence several times for me as I would hear it in bits and the way in which my mind had segmented their sentence into words left me with a strand and sometimes unintelligible message. (p. 70)

Tito Mukhopadhyay, in an interview with Savarese (2010), explained, “...I may select a fraction of the environment – say ‘that shadow of a chair’ or ‘that door hinge over there’ – and grow my opinions and ideas around it. This creates a defense system for my over-stimulated visual organ” (p. 4).



***Difficulty/inability to stop feeling the change.*** This sensory experience, named and described by Bogdashina (2016) is one of prolonged, continued sensation after the stimulus has been withdrawn. Logically, this might be related to overconnectivity in isolated brain areas. Bogdashina (2016) described one of her student's experiencing an uncomfortably persistent tactile sensation after his nails had been trimmed:

It's not that the feeling of nails being cut remains, but rather that the surface of the cut nail is broader and makes it feel like the air is "pressing on" the nails. The boy keeps feeling sensation for at least three to four days.... He feels better on the fifth or sixth day after the "traumatic event," but the comfortable existence lasts only two more days when it's time to have his nails clipped again. (p. 67-68)

***Synesthesia.*** Atypical neural connections may also be manifested through synesthesia, a process through which "stimulation in one sensory modality elicits an automatic response in another unstimulated perceptual modality" (Baron-Cohen, Robson, Lai, & Allison, 2016, p. 1). Examples of these reported synesthetic experiences include pain, seeing letters or numbers, or hearing music triggering seeing colors (Baron-Cohen et al. 2016). Mukhopadhyay (as cited in Savarese, 2010) reported that an fMRI study done on him showed that his visual cortex area "lit up" when his left hand was tapped. "So when I was supposed to be experiencing a tactile sensation, I was seeing patches of colors" (no page numbers given; second to last page).

Another form of synesthesia may involve the mirror neuron system, as when observing someone or something else being touched elicits the sensation of personally being touched (Baron-Cohen et al., 2016). This phenomenon is also theorized to be caused by atypical neural brain connectivity, specifically through increased connectivity between the involved sensory brain regions resulting from a genetic predisposition toward reduced axonal pruning (Baron-

Cohen, 2016). Cesaroni and Garber (1991) reported that Jim, one of their study participants could not tolerate touching until he was 23 years old and that touching remained difficult for him.

His face remains especially sensitive, and ‘being touched on the face causes some confusion about the precise location and nature of the stimulus.’ For example, touching the lower part of his face produces a soundlike (sic) sensation in addition to the tactile (sic) sensation. (p. 305)

Jim also reported that “sounds are often accompanied by vague sensations of color, shape, texture, movement, scent, or flavor” (p. 306)

In addition, emotions have also been reported to elicit stimulation of sensory brain centers. Tito Mukhopadhyay (as cited in Savarese, 2013) refers to this phenomenon as overassociation. He wrote,

... when I write, “Mr. Blake’s voice felt like squished tomato smell,” there is a natural process involved in it because every time I have to hear Mr. Blake’s voice, I recognize it by the squished tomato smell. After that, I know that there ought to be Mr. Blake somewhere around carrying his voice with him. (last page)

Mukhopadhyay also wrote,

I see these stories, sometimes in vermilion or indigo, the richness depending upon the intensity of the stories. Sometimes they smell like vitriol and sometimes they smell like boiling starch in a pot of clay. And sometimes they have the essence of the twilight sky.

As I feel my worries for the trapped coal miners, I can smell the boiling starch, frothing on the brim of the clay pot, then spilling out with the smell of burning rice.

My worries grow as the voice of the newsreader continues to say that the miners are still trapped. I smell burning rice spread across the room as more starch spills out .... My body begins to itch as though tiny black tickle ants have been set free from a box. They can smell the burning rice from the spilling starch, and they rush around to find the source with a collective ant hunger. My worry now accumulates in and across my itching skin, as the voice of the newsreader comes from far away, like a blue floating balloon. I have no hold on it because it floats away, leaving me with itchy skin. (as cited in Savarese, 2013, p. 2)

**Empathy.** In their interview leading up to this description, Savarese commented, “I find it fascinating that your imagination could be so strong that you lose track of the real. Or, said another way, that your empathy could be so powerful that you lose track of yourself” (no page numbers specified; fifth page from end). Mukhopadhyay (as cited in Savarese, 2013) includes his experience of empathy as an overassociation:

It’s true that when I think of the situation, there may be empathy. But my empathy would probably be towards the flashlight batteries of those trapped coal miners if there happens to be a selection on my part. Or my empathy would perhaps be towards the trapped air around those coal miners. There would be me watching through the eyes of the flashlight cell the utter hopelessness of those unfortunate miners as my last chemicals struggled to glow the faint bulb so that I didn’t leave them dying in darkness. As the air around them, I would try to find a way to let myself squeeze every bit of oxygen I have to allow the doomed lungs to breathe, for I am responsible for their doom. And while I found myself trapped, I would smell the burning rice being cooked with neglect in an earthen pot. (Fourth page from end)

In further exploration of empathy in autism, Cesaroni and Garber (1991) offered, “While empathy implies the capacity for participating in another’s feelings or ideas, Jim believes that in practice this often means projecting one’s own feelings on to others” (p. 311). Based once again on assumptions that autistics lack theory of mind and empathy, Jim demonstrates remarkable insight “for an autistic person.” He states, “It is therefore much easier to empathize with someone whose ways of experiencing the world are similar to one’s own than to understand someone whose perceptions are very different” (as cited in Cesaroni & Garber, p. 311). He also insightfully points out the irony of neurotypicals’ assumptions about empathy:

Someone who has much better inherent communication ability than I do but who has not even taken a close look at my perspective to notice the enormity of the chasm between us tells me that my failure to understand is because I lack empathy. (p. 311)

***Monochanneling.*** Another sensory phenomenon commonly described in autism is that referred to variously as cross-modal extinction, systems forfeiting, monotropism, having monochannel systems, monochanneling, or monoprocessing. These terms describe the phenomenon in which a particular sensory system completely overrides or suppresses other sensory systems such as listening shutting out vision, or of particular components within one system dominating other components within the same system such as being able to either hear vocal intonation or understand the spoken words, but not being able to do both at the same time (Bonneh et al., 2008; Williams, 1994). Bonneh et al. (2008) described cross-modal extinction as being a “loss of awareness to stimuli from one modality in the presence of stimuli from another” (636). For example, in their research, a 13-year-old boy complained of multisensory perceptual problems, saying “When I hear, my vision shuts down” (p. 636). By all accounts, “shuts down” can mean total shut down or it can mean an unnerving vacillation of dominance between two

systems. Another individual described that she could both see and hear perfectly well, but she could not do both at the same time. She could either watch a movie with subtitles (both being visual input), or she could listen to the movie, but could not see/watch it at the same time.

Alberto Frugoni (Biklen et al., 2005) typed, “I hear the words and I can decipher their meaning, but I don’t use my visual perception simultaneously, otherwise my attention would go” (p. 196).

Williams (1994) explains that “systems forfeiting” (or cross-modal extinction or monochanneling, etc.) is an adaptive process by which individuals with autism decrease and regulate the sensory overload to their body, and that for different individuals or for the same individual at different times “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” (p. 196). Williams further explains that, for example, even processing “body messages” (hunger, cold, needing to use the toilet) may be “switched off” in order for another system such as auditory comprehension to be “switched on” (pp. 196). It would stand to reason, then, that this could also function in the reverse: attending to body messages of cold, hunger, pain, or discomfort of any kind might well “switch off” auditory comprehension, or motor planning, or sequencing - or remembering where one was in typing or reading.

Williams (1994) described a more complex level of monochanneling as an inability to “monitor consecutively a sense of self and other (internal-external) at the same time.” One might either have a sense of self (or one’s internal state) with no sense of other (or anything external to the internal state), a sense of other overriding a sense of self, fluctuations between the two, or at times a complete shutdown or forfeiting of the whole self-other system. One might also have a sense of internal (feelings and thoughts or just feeling or thought) by forfeiting any sense of the

external (the computer, the facilitator, or even one's hand or the position of one's body).

Mukhopadhyay (Biklen et al., 2005) described his experience with this:

I cannot feel certain parts of my body at certain times. Whether it is anxiety or whether the cause is something else can be found out only by a psychologist or a neurologist. I just know one thing. That is I am mono channeled and can do or concentrate on one thing at a time. I can either see or I can hear my environment. So I suppose when I concentrate on seeing, I forget that I am also being. That applies to hearing also. (p. 140)

He also described his inner versus outer experience: "You wonder which to use, your thoughts or your body because you can use either this or that" (p. 122). Another related competition is between automatic processes and conscious or intentional processes. Table 1 presents a summary of the self-other (internal-external) scenarios and how they might manifest if not understood in the use of facilitated communication as discussed by Williams (1994, p. 198).

Table 1		
<i>Possible Internal (self) versus External (other) Orientations of Awareness</i>		
Aware of Process	Only Subconsciously Aware or Unaware of Process	Result
External/other: the facilitator, keyboard, one's hand	Anything Internal: not able to consciously assess one's thoughts	Output would reflect facilitator influence
Internal: thoughts	External: one's hand, the keyboard	Will need prompting to initiate and maybe sustain motor activity to type

Subconscious, automatic awareness (ex. of self)	Conscious, voluntary action	May be able to type in relaxed, non-demanding setting, but not when conscious awareness of self is triggered
Conscious awareness of self	No or only subconscious awareness of other	May have high intellect, but be unable, with any amount of help or facilitation, to connect with own hand.
Only subconsciously aware of and automatically responsive to other (external)	No connection with self (internal)	Overzealous facilitator could produce “puppet-like output”
Consciously aware of and responsive to other (external)	No connection to self	“Robotic-like output”
Adaptation is to fluctuate between several scenarios	Particularly difficult when changing facilitators	Highly irregular and inconsistent output

Monochanneling is labeled as monoprocessing in Bogdashina’s book (2016), and is included in the chapter entitled “Perceptual Styles.” Bogdashina provides an excellent description of additional sensory perceptual experiences that will be given only a cursory representation here. In her chapter entitled “Perceptual Styles,” in addition to monoprocessing are “Peripheral perception (avoidance of direct perception),” “Compensating for an unreliable sense by other senses,” “Resonance,” and “Daydreaming.”

***Peripheral perception.*** In some instances, peripheral perception may be related to monoprocessing, as when individuals describe eye contact as interfering with listening. Bogdashina (2016) described an example of one person asking others, “Do you want eye contact or conversation?” because he could not do both at the same time. Others have described eye contact as being painful or too overwhelming. Bogdashina offers multiple firsthand examples of these responses, with one in Jackson (2002) being particularly illustrative: “When I look someone straight in the eye, particularly someone I am not familiar with... I feel as if their eyes are burning me and I really feel as if I am looking into the face of an alien” (Bogdashina, 2016, p. 115). Some parents describe their children preferring to use peripheral vision as if it is more accurate or reliable than direct vision. Asperger also noted a tendency for some individuals to use peripheral vision (Biklen, 2005, p. 31)

***Compensating for an unreliable sense by other senses*** is another category listed by Bogdashina who explains that due to “hypersensitivity, fragmented, distorted perception, delayed processing or sensory agnosia,” individuals may have to rely on a variety of senses to understand their environment. Grandin (2008; as cited in Bogdashina, 2016) described how some people with problems with visual and auditory distortions prefer to “see the world mostly through their fingers”:

Sensory processing systems in some of these individuals are so distorted that touch and smell are the only two senses that provide reliable, accurate information to the person’s brain. If their visual and auditory systems are giving them jumbled information they may rely more on touch. This is why some nonverbal people tap things like a blind person navigating with a cane. (p. 117)



**Resonance.** Donna Williams (1999; as cited in Bogdashina, 2016) introduced the idea of *resonance* to describe the experience of becoming so engrossed in or captivated by an experience, that one becomes fully absorbed into that space:

These streetlights were yellow with a hint of pink but in a buzz state they were an intoxicating iridescent-like pink-yellow. My mind dived deeper and deeper into the colour, trying to feel its nature and become it as I progressively lost sense of self in its overwhelming presence. Each of the colours resonated different feelings within me and it was like they played me as a chord, where other colours played one note at a time.

It had been the same as long as I had known...some things hadn't changed...since I was an infant swept up in the perception of swirling air particles, a child lost in the repetition of a pattern of sound or a teenager staring for hours at coloured billiard balls, trying to grasp the experience of the particular colour I was climbing into. (p. 119)

**Other possible sensory and cognitive experiences.** In addition to the sensory experiences already presented in this paper – hyper- and hyposensitivity, fragmented perception, delayed perception, inconsistency of perception, and sensory agnosia – Bogdashina (2016) also discusses, as listed in her Table of Contents, “Literal perception,” “Inability to distinguish between foreground and background information (gestalt perception),” “Distorted perception,” and “Sensory fascination.” In the chapter on “Cognitive Styles,” in addition to “Perceptual thinking,” Bogdashina discusses “Memory in autism,” “Inertia (executive function deficits),” and “Attention in autism.” Also in this chapter, and related to Williams’s internal vs. external/automatic versus volitional monochanneling (aka, systems forfeiting), is “Subconscious, unconscious, and preconscious cognitive processes,” with “preconscious” also relating to an indirect style of perceiving and “conscious” relating to a direct style of perceiving.

**Anxiety.** Perhaps because of the constant assault on sensory systems, the confusion of jumbled stimuli, and the uncertainty of where one's body and/or limbs are in space, or perhaps because of bullying and/or self-esteem issues associated with "being different" and struggling with all that seems to be easier for others, or perhaps being an inherent neurobiological comorbid condition, anxiety levels are reported to be much higher in youth with autism spectrum disorder than in typically-developing youth as well as higher than in the general population of clinically-referred youth (van Steensel & Heeman, 2017). Rubin (Biklen et al., 2005, p. 98) said "Fear plays an enormous role in our lives." Jamie Burke (Biklen et al., 2005) wrote,

Anxiety comes as a regular visitor, just as breathing. I believe my cells have a nucleus filled with it. I think when I was young I walked in a constant pacing to help my body deal with it and I felt my nerves prickle as if a porcupine shot its quills into me... One thing that sent me overboard was being asked a question when I felt stressed over the voices asking it. Women have a pitch to their vocal cords that are like vibrato. Sadly, you are expected to respond, but you truly feel as a bird trapped. Fluttering away seems lovely, but the expectation [of others] is a wire cage... Another time the overboard feeling comes is in tests. I need to focus on the question, work with the difficulty of small print which is black and blurs my eyes. The rustle of papers, pencils, scratching, coughing and scraping chairs, and lights drive me crazy. (pp. 252-253)

Donna Williams (2003), in her book entitled *Exposure Anxiety – The Invisible Cage*, questioned and explored how "performing" – which really meant doing *anything* – in the presence of others could be so completely disabling:

Why can someone with Exposure Anxiety be expressively and naturally laughing out loud out in the back garden but somehow 'stuck', compliant, or performing when in front

of others? Why they can't get it together to make breakfast once you are up, or run the bath, or get dressed, but can seem to do a whole range of things which might prove they were capable of these? Why might someone with Exposure Anxiety be able to initiate communication with their own reflection and yet unable to respond as themselves when shown affection? Or be able to initiate an activity, but when you try to initiate exactly the same activity with them, appear uninterested, distracted or disowning? Why, although they have an ability, do they appear to freeze and become incapable in front of others or when asked to perform a task on command? (pp. 21-22).

None of these motor, motor planning, sensory, sensorimotor, or anxiety factors are accepted by skeptics of facilitated communication as providing legitimate explanations for why individuals who appear to be able to type spontaneously cannot type under controlled experimental conditions. The divide between advocates and critics gapes as deeply and widely and irreconcilably as ever. But, with so much at stake, with so many firsthand demonstrations of fluent written communication concomitant with severe autistic symptoms, with so many families and schools still using facilitated communication, and with new understandings of atypical neural connectivity in autistic brains providing a possible theoretical basis for the discrepant abilities in typing with facilitation under differing circumstances, the discrepancies in the ability to communicate with facilitated communication must continue to be investigated. Thus, in the spirit of Niels Bohr, the proposed study will continue exploring the paradox within the phenomenon of facilitated communication, utilizing both a quantitative controlled study design – having the participant complete his homework with a blinded facilitator – followed by a qualitative linguistic analysis of the interactions that occur between Tim and his facilitators.

### Chapter III: Methods

Biklen (1990, 1992) and Crossley (1992) stressed the importance of maintaining a naturalistic environment and test-free atmosphere when evaluating the validity of facilitated communication, noting that individuals have difficulty performing under stress and test conditions or when they feel their competence is being questioned. However, as facilitated communication continues to be used extensively and as the controversy around authorship has not been resolved, it is essential to continue to develop testing methods that will interfere as little as possible with the natural process of communication, but which will also control for facilitator influence.

This study was conceptualized to minimize any atmosphere of testing by being designed around an activity in which the subject engages routinely – homework. However, with the presence of the investigator and controls in place for blinding facilitators, it appeared to be apparent to Tim that testing was taking place, and he clearly communicated through his behaviors and typed communications that he was anxious.

#### Participants

**Primary participant.** Narrative information about the primary participant provided throughout the following section was obtained through discussions with Tim’s parents and aides during the 5-day testing period between April 27 and May 1, 2016. Reported findings from specific occupational therapy (OT), speech (SLP), and psychology evaluations were obtained directly from the reports which had been archived by Tim’s mother.

The primary study participant, pseudonym Tim, is a 17 year-old male who was diagnosed as autistic at age 26 months by a multi-specialty team at a prominent university child development clinic in the northwestern United States. Significant delays were noted in

communication, socialization, fine and gross motor abilities, and daily living skills. Repetitive stereotypies or “stimming” behaviors were prominent (and continue to be), he had extreme difficulty deviating from expected routines, and attention span and eye contact were limited (as they continue to be). He evidenced multiple tactile and auditory hypersensitivities (which continue), oral hypersensitivity to food textures with frequent gagging (which also continues), and sought deep pressure and proprioceptive and vestibular input. Tim was also assessed with the Bayley Scale of Infant Development at that time to have a Mental Developmental Index of less than 50.

Tim is currently described by facilitators, therapists, psychological assessments, and parents as having significant anxiety including a strong tendency toward catastrophic thinking. His mom reported that his test anxiety at school was initially so great that he would vomit after tests until he became more comfortable with testing. Mom said Tim still becomes anxious if he thinks he won't have enough time to finish or might not do well. Parents also reported that Tim becomes even more anxious when his intelligence or ability to communicate is in question because of having been repeatedly traumatized by demeaning remarks and experiences related to questions of his intellect and communicative authenticity. He was in psychotherapy for some years, the psychiatrist working with him on issues of anxiety and PTSD reportedly related to his reactions to having been assumed to be intellectually impaired and consequently being restricted in school from participating in academics that were interesting and challenging.

Related to anxiety, parents, aides, and facilitators all reported that relationships and trust are very important to Tim. Tim has reportedly always had great difficulty adjusting to loss or acquisition of new aids and facilitators. Mom related that about two years ago, Tim was not working well with a new facilitator who had a very matter-of-fact and task-oriented style. Tim

was frequently angry and resistant with him, at one point typing, “You are an asshole. My parents are going to fire your ass.” Concerned, the facilitator took the typed message to Tim’s mom. She suggested that the facilitator spend some time sharing photos and talking about his family, and she would have Tim to do the same. By mom’s report, with this intervention, Tim began to develop a relationship with and trust the facilitator, and they worked very well together after that (personal communication, April 30, 2016).

A related issue to working with a new facilitator is Tim’s resistance to change – in anything. He has difficulty with change in his routine and even with changes as to which facilitator works with him on which subject, causing him to sometimes refuse to cooperate if a facilitator changes the area of work Tim expects to be doing with him/her. Even when he has known a facilitator for years, he resists allowing change in what he expects from that facilitator. An example shared by Tim’s mother is that he had done math with one particular facilitator for years, and then refused to work with someone else on math even though it meant freeing up more time for the original facilitator to go on fun outings with him.

Resistance to change may be related to cognitive perseveration and to physical inability to initiate movement (praxis), both of which may also be manifested as individuals “being stuck.” Examples of these for Tim include his needing physical prompting to begin some activities such as crossing a street, getting into a swimming pool, or being able to coordinate his arms in alternating rhythm for swimming. One of his aides, Mike, described needing to verbally prompt Tim to press keys on a computer at the gym every time they checked in. Tim’s finger would (independently, without facilitation) hover over the correct keys on the keyboard for entering his phone number, but he would not press them without verbal prompting of “go ahead; you can press it.” Mike was not sure if that inertia reflected difficulty with initiating movement,

fear of pressing a wrong key (Tim does not like to make mistakes), or some other issue. Then, in answer to his mom's question one day as to why he wouldn't pick up a pencil that had fallen to the floor as she had asked, Tim typed that he had understood what he had been asked to do and was willing to do it, but he couldn't make his body comply. He added that he would have been able to if Mom had drawn a picture of what she wanted him to do. This was also an example of Tim being described as being visually oriented and a visual learner. Other first-hand accounts describing this inability to get the body to do what the person desires were described in firsthand accounts earlier in this paper.

Tim was also described as often demonstrating lack of engagement which was described variously as his being "stubborn, lazy, refusing to cooperate, and being unwilling to demonstrate his abilities." Although it is possible these behaviors were/are intentional as they seem to be interpreted, it is also possible they are manifestations of this problem of being stuck and unable to plan or initiate action (praxis), or of another problem such as processing more than one step at a time, attention, understanding, anxiety, or some other process.

Perhaps Tim's difficulty with understanding sequencing is partially related to his problems with attention. Perhaps, though, it is related to other atypical neural connections that impede linking the relationship of events over time. As is typical in autism, problems with sequencing have interfered with Tim's ability to learn the necessary tasks for activities such as brushing teeth, doing laundry, and making a bed, with him requiring these to be broken down into discrete steps and then practiced repeatedly. Mom reported that Tim struggles with retelling or creating stories with a proper sequence, and also struggled with creating a time line of the major events of his life.

**Motor development.** When Tim was six and a half, it was noted on the occupational therapy (OT) assessment that he continued to have low motor tone and poor motor planning (dyspraxia). For example, as noted above in describing Tim's "resistance to change" or "getting stuck," he had difficulty initiating some motor activities without physical prompting such as requiring a touch on his back to take a first step to cross at an intersection. When he was younger in school, he was also described by teachers and therapists as having difficulty imitating motor actions without assistance such as those associated with interactive songs during music groups. Impaired motor imitation in children with autism was described by Jones and Prior (1985) as being associated with dyspraxia: "The autistic children seemed literally unable to coordinate their limbs in some of the tasks" (p. 43). Gross motor impairments included toe walking, arms held up at his sides, a wide-based stiff gait, and lack of coordination when running. Fine motor deficits were also evident in his tendency to use all fingers together as a unit due to his "limited ability to isolate individual fingers to manipulate objects." The occupational therapist specifically stated, "This limits his ability to write and use classroom tools such as scissors" (OT assessment, June 1, 2005).

Both gross and fine motor impairments have continued to be significant for Tim, with motor processing delays, motor planning, and coordination difficulties persisting. Tim runs and plays soccer, but his movements are awkward. He is able to pass and stop the ball when practicing with one or two other people, but a practice or game with two teams moves much too fast for him to be able to keep pace with processing the movements and action. Tim tells (types to) others that he needs to be able to count to ten to process between tasks and count to ten before he knows if he will be able to initiate a given motor action. Alternating sides of his body is also difficult. He can swim breast stroke, which engages both sides of the body symmetrically.



However, after nine years, he still requires the swim instructor to alternately touch each shoulder to cue him in moving his arms independently of each other for the free style stroke.

Regarding fine motor abilities, Tim can manipulate buttons and zippers, and just began independently tying his shoes in the past year. He continues to have great difficulty with pincer strength which hinders his ability to open pull tabs on cans or to hold writing utensils with enough strength to write fluidly. Parents reported that attempts to facilitate his writing by using large diameter pencils, specialized grips, triangularly shaped pencils, and weighted pencils were all unsuccessful. He does still write with physical assistance when a keyboard is not available. This investigator noted that Tim still holds eating utensils with a full-fist grip.

Low oral motor tone and oral motor dyspraxia also continue, with formation of sounds being rudimentary. All consonants and vowel sounds are formed indistinctly, for example with “no” being said with a soft “n” followed by the sound “uh.” Final consonants are completely omitted. Thus, “cat” sounds like a guttural “ka,” and “swim” is said as an open, indistinct “swi.”

***Sensory integration and perception.*** As is the case with many individuals with autism, Tim also has sensory hypersensitivities including to sound and to tactile and oral textures. He frequently puts his fingers in his ears, appearing to try to block sound, and he often vocalizes, which, according to first-hand accounts, is often another means of blocking out external auditory stimuli. These behaviors reportedly increase with anxiety. His seeking proprioceptive input continues as it always has, now demonstrated in his frequent galloping rhythmically back and forth across a room, rocking, and hitting his hand against objects (such as table tops). He likes watching water run and drip and watching pebbles roll down smooth surfaces. (This was definitely not a hit when Tim was found dropping pebbles and rocks on the roof of a friend’s Mercedes to watch them roll down the windshield and hood of the car!)

Perhaps related to sensory distraction, Tim is also said to have difficulty with attention and focus, requiring frequent redirection to return to tasks. Parents and facilitators describe him as being easily distracted by the slightest sound, tactile, olfactory, or visual distraction. Mike commented that it was not unusual for Tim to begin a word, become distracted often by some minor noise, light, or movement nearby, then return to the word and either start over from the beginning without deleting what he had already typed, or continue, but from a different part of the word than the point at which he had stopped. Mike related that he will frequently pull Tim's arm back from the keyboard to help him stop and "reset" either following having been distracted, to break perseveration, or to retry when letters appear to be confused and/or out of sequence.

Mom reported that when given more than one imperative to attend to at a time, even if closely related, Tim often does not complete anything beyond the first one or the first step. For example, in response to "Please let [the dog] out of her crate and let her outside," Tim may not respond at all until asked several times or physically prompted; he may let the dog out of her crate but not let her outside; or at other times, he might immediately follow through with both requests. Whereas it is possible these lapses are related to primary inattention, it is also possible they are related to problems with auditory processing, sequencing, sensory integration and modulation, or praxis (Greenspan & Wieder, 1997).

***Living skills.*** Tim selects his own clothes and dresses himself, but needs input in the specifics of how an outfit is put together (height to place waist of pants, shirt tucked in awkwardly, etc.). He brushes his teeth with prompting and will help remove and wash bed sheets, and remake the bed and fold clothes with verbal prompting and coaching. He uses the bathroom independently, but still needs prompting to flush the toilet and wash his hands. He does not cook, but can get food from the refrigerator or cupboards independently. In fact, Tim

was food-seeking so frequently and over-eating, it became necessary for his parents to install a locking kitchen door. Mom reported that even though they had discussed the need and reasons for the door – Tim’s parents reported that his compulsive eating was/is driven by anxiety and is also a medication side effect – and even though Tim agreed that he could not control his eating, he became furious and aggressive when the door was installed. Tim is known to be a very catastrophic thinker, and in keeping with this, Mom was able to learn from him via facilitated writing that the reality of the door being installed meant “I will never be able to control this, and therefore I’ll never be able to be independent” (personal communication, May 1, 2016).

**Behaviors.** By parental and psychiatric assessment, Tim’s tendency to catastrophize is consistent with his having high levels of anxiety. Tim has demonstrated mild to severe behavioral problems and aggression over the years at home, in public, and at school. Tim’s parents reported that most of these behaviors emerged when Tim was feeling anxious, afraid, or misunderstood. Behaviors were addressed early and through therapies for communication, life skills training, academics, and sensory integration including providing a treadmill and breaks at school for decompressing and calming; through Applied Behavioral Analysis (ABA), psychotherapy, and through behavioral modification using rewards and enforcing limits. Parents reported that behaviors have always been very much linked with communication, explaining that Tim would calm down from tantrums once he could communicate what was bothering him, and that this became much easier once he could communicate through facilitated communication. They have related many examples of Tim communicating a situation or fear about which they or another facilitator knew nothing, followed by his behaviors completely calming after it was revealed by him and discussed. Tim’s parents also reported that he calmed considerably with the introduction of each more advanced method of communication. They said that once he became

proficient with each level of communication technique (such as an early picture exchange method), his behaviors would again deteriorate until a more complex method of communication was introduced. Tantrums at school decreased when Tim could demonstrate that he could read and do math, and was thus advanced from being taught letters and numbers to more challenging academics that were interesting to him.

***Educational history.*** Tim's parents removed him from self-contained special-needs classrooms when he began writing letters and words and communicating using facilitated communication with his after-school home aide at age eight and a half. The last school report before Tim was moved from the self-contained classroom setting to be home-schooled was written June, 2006 when he was 7 ½ years old. The report related that although Tim's performance in reading with flashcards and worksheets was inconsistent, he was able to match words to color pictures, some words to words, and could point to some words verbalized to him. He had accomplished matching upper and lower case letters, and was practicing writing his name, with four out of five letters being legible. Rather than answering yes and no questions, he communicated by pointing to what he wanted. He was able to use scissors, but had difficulty using one hand to manipulate the paper while he was cutting with the other.

The home education program was comprehensive, with his daily work, data sheets, and notes completed by the aides/facilitators being catalogued extensively in the following sections:

- fine motor skills including hand writing beginning with tracing, then copying, then writing from dictated letters or sounds, and then simple words; development of functional writing beginning with simple words, then progressing to writing his name, phone number and address independently by the time he was 8 years, 9 months old
- gross motor development

- eye contact
- following directions
- social communication using questions and comments
- play skills
- number and math skills
- language including vocabulary training using adjectives, opposites, words by categories, and stimulus sentences, contrasting objects, contrasting subjects, etc., reading sight words and using the Bob Readers. Ability to identify sight words averaged from 70 to 90% correct for matching or pointing to correct words, and ranged from 10 to 50% for being able to say the word. In other words, Tim was able to recognize a majority of words, but continued to have great difficulty saying them.

The following year, in the fall of 2007, Tim was enrolled in a formal parent-partnered home-school program with a standard curriculum of science, math, grammar, reading, phonics, creative and functional writing, social studies, and health education for one year to identify and achieve whatever level his potential proved to be at that time. In the spring of that academic year – in March, 2008 – a school psychologist administered the verbal section only (because of scheduling and time restraints) of the Stanford Binet Intelligence Scales, 5<sup>th</sup> Edition, with use of rewards to keep Tim focused and with allowing him to answer questions with hand-over-hand hand-written facilitation. His standard score for the composite verbal IQ was 121. Individual verbal domain scaled scores (mean = 10) were as follows:

- |                          |    |
|--------------------------|----|
| • Fluid Reasoning        | 14 |
| • Knowledge              | 14 |
| • Quantitative Reasoning | 15 |

- Visual-Spatial Processing 13
- Working Memory 11

In the fall of 2008, Tim entered a mainstream third grade classroom with a full-time facilitator/aide. He also worked with two additional facilitators, one in an after-school program and one at home to assist with completing his homework. Both parents also communicated and assisted with homework using facilitated communication. At the conclusion of that first year in a mainstream classroom, with a full-time facilitator Tim achieved level 4 scores – exceeds standards – on every section of the end-of-the-year state-wide standardized assessment of student learning. His mathematics score was 550 out of 550 and his reading score was 466 out of 500. He qualified for and was placed in the gifted program the following year in grade 4. At the end of that year, he again achieved level 4 scores in Reading, Math, and Science on the standardized state-wide exam, and his scores have remained at the advanced level in every subsequent year – all testing being accomplished through the use of facilitated communication.

At the time of this testing, Tim was in 10<sup>th</sup> grade general education and taking one advanced placement (AP) course per semester with full time facilitators. His parents reported that his facilitators often did not know or were not proficient in the subjects and materials being covered in these classes. Mom reported that, specifically in math, his facilitator at the time had not taken algebra or geometry, yet Tim received a B in algebra and a C in geometry.

***Developmental history of communication.*** Tim received therapy in speech, occupational therapy, and applied behavioral analysis (ABA) on a regular daily to weekly schedule from the time of diagnosis. Due to the impairments in oral muscular control, introduction of sign language was attempted early, but with limited success due to poor hand and finger control. A picture exchange system (PECS) was introduced before age three and was used until it was replaced

with PC Chat at age four. The PC Chat was used until Tim began communicating at age eight and a half through facilitated communication, which quickly became his preferred means of communication.

As noted above in the section on *Behaviors*, Tim's mother reported that his tantrums and difficult behaviors improved with the introduction of each new communication method or level within a given method, but then deteriorated as he reached the maximum potential within each system. She corroborated school reports that there had always been a distinct inverse correlation between disruptive behaviors and communication abilities. The 2001-2002 end-of-the-year autism school program evaluation stated that challenging behaviors of removing shoes, biting, scratching, refusing to eat, and head-banging were thought to be exacerbated by Tim's inability to express himself adequately.

Continuing to demonstrate minimal speech development at age four and a half, a functional oral examination was conducted by a speech and language pathologist (SLP). It was concluded that Tim's oral structures seemed adequate for speech production; however he had low oral muscle tone resulting in a tendency to drool, and had "difficulty disassociating tongue, head, and jaw movements." This caused difficulty combining sounds, and it was noted that combining some vowels and consonants in sound production "appears difficult for him as groping and perseverating is (sic) observed." The SLP written evaluation further noted, "Facial tactile cues appear to help him produce consonants and vowels" (August 13, 2003, p. 3).

Also noted in this 2003 evaluation was that Tim's receptive language ability exceeded his expressive language. He could identify named objects from a set of at least five items, identify articles of clothing, and identify photographs matching verbalized nouns and verbs. However, he had more difficulty applying action words in context, particularly when sequencing of more than

one instruction was involved such as when asked to give a stuffed bear something to eat, run to a particular person, or get the ball and give it to a particular person. It was noted that he seemed to “lose track” of the second half of these requests. Expressively, Tim could imitate up to 50 vocabulary words; however nearly all of his utterances were imitative or prompted, while he typically gained others’ attention through body gestures, tapping shoulders, throwing objects, shaking his head yes or no, or leading someone to a desired object. His adaptive skills on the Vineland Adaptive Behavior Scales were all at or below the first percentile.

A cognitive reassessment using the Leiter International Performance Scale was conducted by a psychologist at this time (age 4 ½). The test administrator noted that high levels of structured and routine reinforcements were required to redirect Tim’s attention to the testing, and even with these reinforcers, Tim’s true ability level was difficult to discern because of his difficulties with engagement and attention. With these caveats in mind, it was reported that Tim passed all items at the two-year-old level, ¾ at the three-year-old level, ½ at the 4-year-old level, ½ at the 5-year-old level, and one item at the 6-year level. He also passed all of the conceptual matching tasks through the 6 year level (e.g. matching items based on their use such as a pail and a pitcher or a light bulb and a candle). (Diagnostic Evaluation Summary, May 2003, p. 3; specific date not provided)

The psychologist further reported that Tim had a great deal of difficulty expressing himself verbally, stating “He has significant oral dyspraxia and this results in significant communication difficulties for [him]” (Diagnostic Evaluation Summary, May 2003, p. 2). Overall, these results indicated Tim was demonstrating cognitive abilities in the lower end of the average range (as opposed to the lower extreme as he had previously been assessed), with greater impairment in communication and very limited speech.



Tim began using facilitated communication by writing with pencil and paper, which he continues to do at times, particularly when he is in locations or situations that pose difficulties for use of electronics. Communication through keyboarding was added the summer of 2011, and he now keyboards with facilitation on an iPhone, iPad, or computer keyboard. Since there is no cap on the potential for communication via facilitated communication, and since Tim is able to communicate his frustrations, needs, desires, preferences, opinions, and fears through facilitated communication, aides and parents report that Tim is much calmer than he was prior to using facilitated communication, and he is able to be calmed much easier through the use of facilitated communication when he does become upset.

The physical mechanism of facilitation began with providing full hand-over-hand support with assisted isolation of his index finger. At the time of this testing, physical facilitation ranged from Tim wrapping his third, fourth, and fifth fingers around the facilitator's index finger while he pointed and typed with his own index finger to the facilitator supporting only Tim's forearm with one finger.

**Facilitators and assistants.** Four individuals who normally facilitate Tim alternately served as assistants and facilitators for the study. The method of facilitation was the same whether the individual was acting as the facilitator or the assistant. The distinction lay in that as assistants, they knew the homework assignment and reviewed it with Tim; whereas, as facilitators, they were blinded to all material and answers. The assistants/facilitators were Tim's mom and dad, his full-time school facilitator, Alex, and his out-of-school facilitator, Mike. Mike had worked with Tim for four years; Alex had worked with him for 16 months. Both parents had facilitated Tim through hand writing and typing since he began using these formats at age eight. Facilitators were always blinded to all material related to the questions they were asking.

**Process recorder.** The primary study investigator was present for all sessions, ensuring adherence to protocol and blinding of facilitators to homework topics and content throughout testing. Length of sessions, facilitation techniques, interruptions, distractions, observed affect, and verbal or gestural exchanges between the assistants or the facilitators and the primary participant were noted.

### **Equipment and Materials**

Tim used a Mac Book Pro for all but one sub-session during which he typed on an iPad with the assistant only. The initial intent was to both video and audio record all sessions; however, video recording was abandoned early in the first session when Tim both expressed anxiety and appeared to be distracted and upset by having a video recorder running. All sessions were, however, audio recorded using an Olympus digital voice recorder. The fifty words (Appendix A) with corresponding photos used for establishing baseline independent pointing and receptive vocabulary screening were compiled from words reported by Tim's parents to be well known to him.

### **Setting**

Testing sessions were conducted in one of the two locations in Tim's home where he normally does his homework – either at the dining room table or at the table in the main room of *the addition*, an adjoining building to the home.

### **Procedures**

Informed assent and signed consent using facilitated communication was obtained from the primary participant, and signed informed consent was obtained from the parents and facilitators.

**Preliminary baseline and ceiling ability levels.** Baseline and ceiling levels of achievement were established for two functions through the administration of progressively difficult tasks. The first – Tim’s ability to point independently without any assistance – was assessed to obtain information regarding his need for physical assistance. The second – Tim’s receptive vocabulary – provided information on one element of Tim’s language processes that would be necessary for expressive language to occur through any means.

Tasks at each level within each of the tested functions were repeated five times. Progression to the next level of difficulty was contingent on Tim’s success on at least three out of five attempts at the preceding level. For independent pointing, Tim was first shown a stimulus 2x2” photo of a familiar object or activity and was asked to select, point to, and touch that photo out of a set of four photos of equal size. This task was repeated five times. Next, Tim was asked to select and touch the match to the stimulus photo from a set of four 1x1” photos and then from a set of nine. Finally, the same task was repeated using ½ x ½” photos, a size similar to keys on a computer keyboard. The ½” square photos were first positioned on the page with one inch spacing between them. The exercise was repeated using another page on which the ½ x ½” photos were positioned directly adjacent to each other.

As with the 1x1” photos, Tim was first asked to select the match to the stimulus photo from a set of four photos, then from a set of nine photos. The exercise was repeated using letters, first using Times New Roman 80 font letters on adjacent 1x1” squares from sets of four and then from nine; then using 36 font letters on adjacent ½ x ½” squares, also from sets of four and nine, and then also from the full alphabet of 26.

The next exercises tested Tim’s ability to type independently on a keyboard. For this, he chose to use his iPad mini. The first exercise comprised showing Tim one of the 36 font letters

and asking him to type it on his iPad mini. He was then shown and asked to type, one at a time, five different words from the word list (Appendix A). He was then asked to type simple handwritten sentences presented to him. Finally, the Peabody Picture Vocabulary Test – fourth edition (PPVT-4) was administered to test receptive language.

**Testing facilitated communication.** Testing involved monitoring the primary participant's answers to specific questions as well as his other exchanges with his assistants and facilitators while working on language-arts-based school homework assignments (math and science assignments were excluded) and while engaged with them in more casual communications. The original goal was to obtain data from six homework sessions out of no more than 10 attempts over a maximum time period of 12 weeks. The span of twelve weeks was allotted to allow for the inconsistencies Tim was known to have in desire and/or ability to cooperate and focus, particularly when knowing his ability to communicate was being questioned or tested. Because multiple scheduled trips (an approximate 3-hour drive between cities) to conduct this testing had to be cancelled due to circumstances beyond anyone's control, ultimately a total of five homework sessions rather than six were accomplished over the course of just five days.

Each homework session began with an assistant reviewing the assignment with Tim in one of his usual homework spaces. When the assistant determined the review to be complete, he left two to three general, open-ended, typed questions on the computer screen for Tim to answer with the facilitator. Questions were worded carefully to avoid revealing any clues about the material to the facilitator. The assistant then left the room, and the facilitator entered, sitting with Tim at the computer keyboard and reading each question aloud, repeating, encouraging, and

facilitating Tim until either he produced an answer or the facilitator determined that further work would not be productive.

Per the design of this research project, Tim's homework assignments were the substance from which the test questions were derived. Thus, in addition to working with Tim to answer questions for this research project, the assistants and facilitators were also invested in helping Tim finish his homework assignment on time. What was not anticipated was the degree of difficulty Tim would have in answering the homework questions and thus the amount of time and number of sessions that would have to be devoted to the same assignment and the same repeated questions. The facilitators were persistent; thus, when Tim was unable to produce correct answers with the facilitator, the assistant would return each day to again review the material with Tim followed by the facilitator again returning to attempt to have Tim answer the questions. For recording clarification, each of these rotations by the assistant to review the material with Tim followed by the facilitator returning was identified as a distinct sub-session. Each second sub-session of a given day throughout this paper will be labeled with a lower case "a." Thus, *Sessions 1* and *1a* took place on Wednesday, *2* and *2a* on Thursday, *3* and *3a* on Friday, and *4* and *4a* and *5* and *5a* on Sunday. Supplemental sessions took place on Thursday, Friday, and Saturday. Finally, following Tim's finally correctly answering the first assignment questions in *Session 4a*, a question from a different assignment (a reading assignment) was posed to him in *Sessions 5* and *5a*.

Homework sessions were to be limited to no more than two hours. The longest full session (including two homework and one supplementary session) was one hour eighteen minutes. Most sub-sessions were terminated when the facilitator left the room to report Tim's typed answers to the assistant. Full daily sessions were terminated when the facilitator decided

ending was warranted due to Tim's level of frustration, fatigue, or limited communications indicating that additional work time would likely be unproductive. Although Tim was at times clearly distracted and appeared to be tiring of doing homework, he never insisted on or expressed any request to be finished on any given day.

The first three questions that were repeated multiple times in multiple sub-sessions (until Tim was able to answer them in *Session 4a*) were as follows: (a) *What subject is this assignment for?* (Correct answer: *history*); (b) *What is the general topic of the assignment/What is your homework/What is your project about?* (Correct answer: *Political Cartoon or Picture*); and (c) *What is the specific topic of that project/What is the topic of the political cartoon?* (Answer: *Session 1: People are listening. All other sessions: Target Bathroom Boycott*). Two questions were asked in only one session (i.e., in two sub-sessions) each: (a) *Who is the teacher of your history class?* (*Holland; Session 4 and 4a*); and (b) *In which camp did Elie and his father end up?* (*Buchenwald: Session 5 and 5a*). This final question, as noted, was not related to the political cartoon assignment; rather, it was derived from a separate reading assignment. Another question – “*What is the topic of the research project?*” – was based on an incorrect answer Tim gave to a preceding question with the facilitator in *Session 2a*. Finally, a number of questions were asked in an attempt to break Tim's perseverative typing of “yes.” Since only first answers typed by Tim were accepted for quantitative analysis, two of those questions were counted: “*Are you doing that history project on dinosaurs?*” and “*Are you doing your history project on kitty cats, too?*”

In addition to these five homework sessions, three supplemental sessions, which involved transfer of information purportedly unknown to the facilitators, were conducted primarily at the facilitators' requests due to their disappointment and frustration with Tim's failure to engage

with homework questions and assignments as he typically did with them. The eight homework sub-sessions were analyzed separately and were then compared to the supplemental sessions for the quantitative analysis. All narratives were included in the qualitative raw data analysis.

Finally, since the presence of the primary investigator was anxiety-provoking for Tim, although he knew she was present, the investigator maintained an inconspicuous position from which she could see Tim but which was behind and out of his view. Breaks were allowed whenever the participant indicated the need for one either through facilitated writing or through behaviors or gestures, although he only asked for one which lasted approximately three minutes.

## Chapter IV: Results

### Preliminary Baseline and Ceiling Levels

A more detailed review of baseline and ceiling results are recorded in Appendix B. Baseline ability to point independently was assessed based on information from past studies indicating that some individuals demonstrate higher levels of communicative ability when pointing independently than when using facilitated communications (Bebko, Perry, & Bryson, 1996). It was also important to establish a comprehensive understanding of Tim's abilities and deficits regarding his level of need for physical facilitation.

Baseline testing of Tim's ability to point independently showed that he could point to and touch photos printed on a sheet of paper divided into 2 inch, 1 inch, and ½ inch squares, and letters printed on 1 inch and ½ inch squares equally well. Likewise, he could locate and touch photos and letters on ½ inch squares placed adjacently as well as when they were spaced one inch apart. What could not be definitively discerned was whether or not his finger at times touched the edge shared by the adjacent photo or letter.

Tim had the motor control to independently type five individual letters correctly. Interestingly, in comparison, he struck the correct keys in typing five different words he was shown; however, even with the word in front of him, he did not always strike the letters in the correct order. He typed PHONE, SANDWICH, and ORANGE correctly, but typed HAT as ATH and MOTORCYCLE as MOTORYCCLE. Similarly, with four sentences handwritten for him to copy, he typed one of them correctly, with the exception of never using the space bar: THEDOGRAN (THE DOG RAN), and three incorrectly: T [real name correct] LIKESTOBFY (T\_\_ LIKES TO BE SILLY), SMARTTAM (I AM SMART), and RANTHERAN (THE CAT RAN).



Tim's receptive language grade equivalent on the PPVT-4 was 2:5.

### **Data Collection**

Details of each session are logged on daily protocol sheets in Appendix C and include the following: identification of facilitators and assistants (by pseudonym), beginning time and duration of each session, the questions asked and answers typed by Tim with facilitation, points earned per answer, total points earned per session, percent of homework completed, and notable behaviors, interactions, distractions, or circumstances.

### **Quantitative analysis**

Although the interactions between Tim and the assistants/facilitators were extensive and included multiple answers given to the same questions, to maintain the purest quantitative approach possible, only Tim's first response to each question was scored in the quantitative analysis presented in Appendix D (First Responses to Homework Questions) and E (First Responses to Supplemental Questions), even if those first answers were "yes," "no," or anything else other than an answer to the question.

Tim's responses to the research questions were scored from zero to two points, with no answer, an incorrect answer, or an indecipherable answer receiving zero points; a partially correct answer receiving one point; and an accurate response receiving two points. For the ten homework sub-sessions, this system resulted in a total of 18 questions being counted, yielding a total of 36 possible points. Of these, Tim earned 9 points (25%), accrued through four questions being answered correctly and one being answered partially correctly. This does not mean that four *different* questions were answered correctly in that two of the correct answers were in response to the same question being asked with two different facilitators, neither of whom knew that answer. The 13 questions answered incorrectly will be noted here, but will be addressed

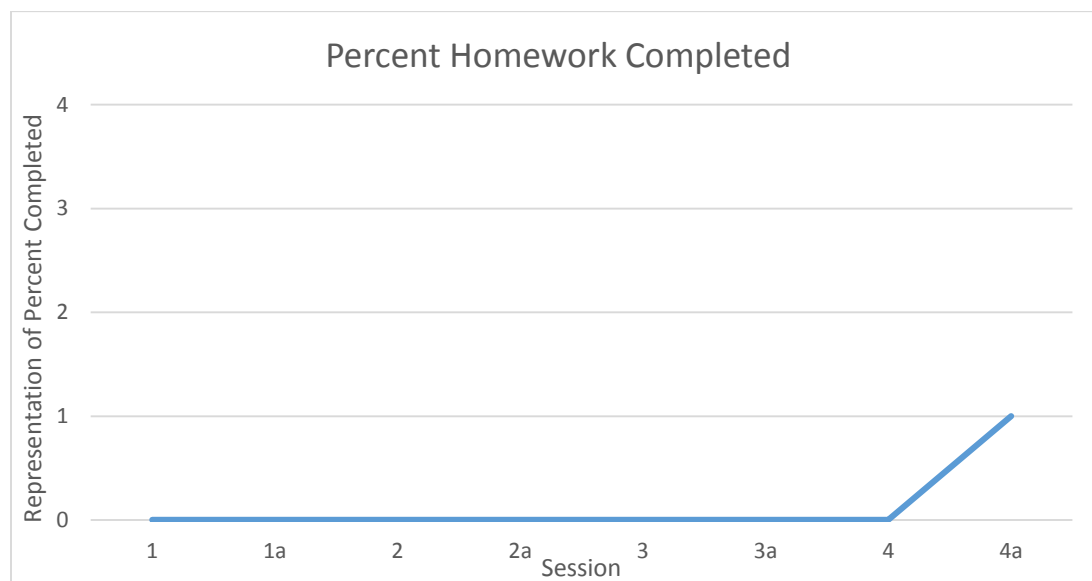
fully in the qualitative analysis of narratives: Three answers were likely perseverative “yes” responses; two, although incorrect for the question posed, related information about a different assignment that was unknown to the facilitator; five were indecipherable, although one resembled the correct answer Tim eventually typed; and three answers appeared to be simply incorrect.

Neither the general nor specific topic of the assignment was typed by Tim with a facilitator until the second sub-session – *Session 4a* – on day five. Tim typed the incorrect teacher the first time he was asked in *Session 4*, then provided the correct answer on his second attempt in *Session 4a*. The question for the second assignment, the reading assignment, was posed during *Session 5*, which followed *Session 4a* on day 5. Again, Tim answered it incorrectly on the first try in *Sub-session 5*, and then correctly on the second attempt during *Sub-Session 5a*. Hence, other than identifying the school subject in both Sessions 1 and 2, no further correct answers on the homework were provided by Tim until the fifth day of testing.

A quantitative analysis of the three supplemental sessions which involved more casual interactive communications with Tim relating information unknown to the facilitators yielded 14 questions or 28 possible total points (Appendix E). Of these, Tim earned 18 points or 64%.

The originally-proposed analyses of logging a representation of the percent of homework completed in each session as a measure of successful use of facilitated communication as depicted in Figure 15 ultimately provided only limited information. Since relating the school subject with no further information about the assignment was not counted toward any percentage of homework being completed, Figure 15 illustrates that no portion of any homework was completed until Session 4a when the specific topic for the political cartoon was provided and was counted as less than 50% of the assignment being completed. Although Tim answered the

one question posed to him about a reading assignment in *Session 5a*, since it was only one question, it was again not included in the analysis of percentage of homework completed.



*Figure 14.* Percent Homework Completed. Y axis representative values of percent homework completed: 0 = zero percent; 1 = less than 50%; 2 = approximately 50%; 3 = greater than 50%; 4 = homework completed.

### Qualitative Analysis of Narratives

Although a complete record of Tim's typing was not saved in every session, it was possible to create nearly complete accounts of all sessions by integrating the available written documents with the audio recordings that captured the facilitators' audible readings of Tim's typing as they worked. Complete typed records were saved by Dad as the assistant in *sub-sessions 1* and *3*, as the facilitator in *Sub-sessions 4, 4a, 5* and *5a*, and in *Supplemental Sessions 2* and *3*. Mike always read Tim's typing aloud as it was being typed and also saved some typing as the facilitator in test *Sessions 2* and *3*. Alex read Tim's typing as it was produced, but saved only the answers to questions rather than the process typing.

Phenomena extracted through a qualitative analysis of the narratives that will be examined include (a) typos, (b) the unique ways in which Tim and his various facilitators interacted and the impact of those differences on Tim’s communication, (c) evidence of facilitator influence over Tim’s typing and generation of ideas (d) evidence of anxiety and possible contributors to that anxiety, and narrative evidence supporting that at least some of Tim’s typing was truly *his* typing of his own thoughts.

Opaetual, nwer voys, yerds, nyusie, tonsahiw, penably, prjecet, ibfet, grobe, yws. How many of these words do you recognize? For how many might you venture a guess? Now, see if you can select words from this list that could be potential answers to the following questions:

“Do you think we’re in a free society right now, a non-free society, or a partially-free society?” Answer: \_\_\_\_\_

“What are you most excited about or looking forward to the most about the dance?” Answer: \_\_\_\_\_

“What are you working on?” Answer: “A research \_\_\_\_\_.”

“Is it okay if she (the investigator) just listens in?” Answer: “I am \_\_\_\_\_.”

If the intended words did not become readily apparent, if the scramble of letters did not shuffle into their proper positions and suggest their proper placement in a particular sentence, that is not surprising.

**Typos.** It was an epiphany, an “oh-my-gosh,” moment when I realized that perhaps Tim’s “nonsense” words were not nonsense at all – at least not all of them, and probably not most of them. And then I wondered how many of the “that’s-not-a-word, Bud,” statements by facilitators were wrong – maybe they had indeed been words – and how frustrating for Tim that must have been. I returned to pouring through the 46 pages of narratives to unravel words I had previously

not understood to be words at all. The most prevalent typos involved key strikes immediately adjacent to the intended key. These key miss-strikes, occurring anywhere from one to four times in a given word, resulted in additional letters or spaces being inserted, characters being substituted for intended letters, and characters being completely omitted. Other errors included seemingly random insertions or omissions of one or more letters, key miss-strikes farther than one key away from the assumed-intended key, combining and mixing of letters between words, difficulties with suffixes such as *ing*, and omission of apostrophes. Once the extent of typos became evident, the intent of the great majority of words and communications became decipherable, particularly in context as demonstrated by the following examples incorporating the words presented at the beginning of this section, the Qualitative Evaluation of Narratives.

***Session 1, pages 2, 3, and top of 4.***

Question: Do you think we're in a free society..., a non-free society, or a partially-free society?"

Answer: Opaetual (*O* inserted left of and before *p*; *a*; *e* substituted left of *r*; *t*; *u* substituted left of *l*; *a*, *l* = *Partial*; p. 3-4).

Question: Is it okay if she (the investigator) just listens in?

Answer: I am nwer voys (*I am n*; *w* inserted left of and before *e*; *r*; *space* inserted before and below *v*; *o*; *y* substituted left of *u*; *s* = *nervous*; p. 2).

The next question followed shortly after Tim said he wanted his political cartoon to be about "peoplw are listemig" (peopl *w* substituted left of *e* = *people*; *are*; *liste*; *m* substituted right of *n*; *i*; *n* omitted; *g* = *listening*; p. 2)

Question: What's the point of your political cartoon?

Answer: Tonsahiw we are bring controd (*T, o; n* above and substituted for *space bar = to; s; a* inserted left of and after *s; h; i* substituted left of *o; w = show; we are b; r* substituted right of *e; ing = being; contro; lle* omitted; *d = controlled = To show we are being controlled; p. 2).*

### ***Supplemental Session 2.***

Question: How about English – how did that go?

Answer: I likjtn (*I; l, I, k; j* inserted left of *k; reason for tn* is unclear – substituted for *e? Was t* shorthand for *ed? = I like/ed it; p. 2).*

Question: Did you, do you feel proud about all the stuff, the work that you're doing?

Answer: *I mpnm not mvong.*

Dad: What does that mean? Oh, "I'm not moving." (*mpnm: random; or missed strikes attempting not: m* right of *n; p* right of *o; started over with n, but also hit m; started over and typed *not; mvong: o* and *v* transposed, and *i* omitted; or perhaps the initial *o* was omitted followed by substituting *o* left of *i* for *moving?*)*

Question: Okay, what were you talking to your dad about that was most exciting or that you were looking forward to?

Mike reading letters aloud as Tim typed his answer: "N, y, u, s, i, e" (*n* substituted left of *m; y* inserted before and left of *u; s; i; e* substituted for *c = music; p. 8).*

Mike: That's not a word. Start over.

Mike continuing to read Tim's typing aloud: "M, u, s, i, c, music" (p. 8).

### ***Session 2a.***

Question: What is the particular topic of the assignment you're working on in the class? What'd you just talk to Alex about?

Answer read aloud: “a, r, a, research; a research?” Come on, Bud. “A research prpjecet.” (*p, r, p* substituted right of *o, j, e, c, e* inserted, *t = project*; p. 8).

### ***Supplemental Session 3.***

Discussing Tim’s morning at a park with his aide, Dad asked, “Was it hot? What do you remember about being there?”

Answer: Ibfet (*I, b* substituted for *space, f, e, l* omitted, *t = I felt*; p. 3).

Dad: Felt what?

Answer: bappy (*b* substituted below and left of *h = happy*; p. 3).

Later, Dad asked, “What do you wanna do now (before going to play soccer)?”

Answer: Grobe (*g* substituted 2 keys right of *d, r, o* substituted right of *i, b* substituted right of *v, e = drive*. Also may have been influenced by competing thought of typing *go drive*. P. 3. Dad had suggested earlier in this conversation that they might go for a drive).

### ***Session 4.***

Question: Can you explain a little bit more about what that means, or sort it out?

Answer: iy means I am penably not ging to verify (iy: *y* substituted right of *t = it; means I am penably: p; e* substituted left of *r; o* omitted; *n* substituted right of *b, ably = probably; not; g, o* omitted, *ing = going; to verify = it means I am probably not going to verify*, p. 4)

As summarized in Table 2, there were a total of 94 identified erroneous key strikes or omissions. Unfortunately, not all typing was saved, and it would have been valuable to have been able to examine the typing that accompanied those facilitator statements of “that’s not a word, Bud.” Letter substitutions were the most common typo, followed by omissions, followed by insertions (40, 29, and 25 respectively). Horizontal (left-right) orientation of typos to the intended key were far more common than vertical (above-below) orientations (39 and 9

respectively), although, left versus right miss-strikes were nearly equal whether they were substitutions or insertions (24 and 23 respectively) as were miss-strikes resulting in insertions preceding the intended key compared to those following the intended key (9 and 8 respectively).

Table 2  
*Number and Orientation of Errors in Keyboard Key Strikes*

Error type and Total number	Orientation to intended key				
	Left of	Right of	Below	Above	Random
Substitutions					
40	17	16	3	3	1
Insertions before					
9	3	3	3	0	
Insertions after					
8	4	4	0	0	
Totals	24	23	6	3	
Insertions random					
8					8
	Position in the word				
Omissions	End of word	Middle of word	Beginning of word		
29	14	14	1		

Table 2 provides information about the number and nature of key miss-strikes, but it cannot demonstrate the scale of typos and the impact they have in Tim's typing. It is suggested that the reader briefly study the complete categorization and listing of typos presented in Appendix F to gain an appreciation of their magnitude. Their prevalence and import will also become even more evident though the following discussions of the transcribed narratives.



Perhaps one might think these allowances for misspellings are too lenient, but when even the simplest of words (*yes*, *no*, and *to*) present in a diverse array of spellings reminiscent of “Variations on a Theme” by Haydn (*uyes*, *yerds*, *yers*, *yred*, *yues*, *yws*, *yesg*, and *tes* = *yes*; *mo* and *bo* = *no*; and *ti* = *to*), when every one of those misspellings involves adjacent key insertions or substitutions, and when nearly all of the misspelled words, once “translated” or deciphered, fit perfectly in context, I would argue that there is something here of substance.

**Anxiety.** Anxiety is described as being a significant issue in autism (Biklen et al., 2005, p. 253; van Steensel & Heeman, 2017; Williams, 2003). Rubin (Biklen, et al., 2005, p. 98) said “Fear plays an enormous role in our lives.” Elizabeth Moon’s (1992) description of test anxiety is presented in Biklen and Cardinal (1997, p. 28):

She pictures the child in a formal clinic evaluation who cannot jump over an eraser on the floor, barely totters up steps, cannot stand on one foot, and fails to perform a simple task with blocks but who at home hops between laundry baskets gleefully, climbs steps with ease, sometimes skipping a tread, hops the length of a hallway on a single leg, and constructs complicated mosaic-tile puzzles.

It will be instructive to notice Tim’s expressions of anxiety throughout the transcribed narratives demonstrated by increased restlessness, vocalizations (*EeeeeuuUUuuu* and *MMMMmm Mmmm*), and loud finger-hitting /tapping against the tables (TAP TAP TAP), all of which facilitators estimated to be at least double and sometimes triple their usual amount.

**Facilitator style and influence.** All facilitators knew Tim well and were supportive and encouraging. All admitted they at times were aware of exerting influence over Tim’s hand movements, saying this was more likely to occur when they attempted to rush the laborious and time-consuming facilitated communication process due to their fatigue or Tim’s fatigue, when

faced with a long assignment, or when running out of time before a deadline. In rushing, one facilitator described guiding more or interpreting words based on abbreviations or on the first few letters typed. Therefore, requiring Tim to type complete words at all times was an additional stress for him in testing. The facilitators differed significantly in their style, approach, and requirements of Tim and in how much they seemed to be influencing him. Mike's style was casual, natural, and straight-forward. He was alert to and insisted on Tim's correcting his perseverative typing and expressing his own thoughts. In contrast, Alex was more formal and had a tendency to over-function in proposing, selecting, and conveying ideas. In addition, rather than questioning echolalia and perseverative typing of *yes*, Alex seemed to accept those kinds of communications as affirmations that Tim agreed with what he, Alex, had just said. Both parents were gentle, encouraging and supportive, and said they were nervous for Tim and perhaps for themselves. Dad carried on more casual conversations with Tim in this testing, both by way of personal style and by way of helping Tim relax. Dad seemed to be intermediate between Mike and Alex in accepting *yes* answers before checking for perseveration. Mom's participation was limited because she was quite ill. She seemed most anxious for Tim, probably in part because she did not feel well, and probably and understandably because she was the one physically and immediately by his side through the years of challenges and traumas, fighting insurance companies, and advocating for him in schools.

Wednesday narrative, p. 8. Dad: Did, did, did Mom's hand over-influence you a little bit? I know we do that sometimes and we're worried that we're cuttin' off what you're *really* thinking. *You* can overcome our hand.

Sunday narrative, p. 6. Alex: Okay, let's, let's get it again. (Tim typing.) Wow! That's exactly it. You need to make sure you're putting *your* resistance in and you put *your*, like, how

do I say this? Make sure you put *your* effort in, cause you can tell if my arm slips, and if your hand goes limp, yea!

**Narrative evidence.** Each narrative exchange from the five days of testing is rich in complexity – at times seeming to stamp and certify that the facilitators are unquestionably guiding Tim’s thoughts and typing, while in the same session and *at times within the same sentence* providing evidence in support of Tim’s authenticity in typing his own thoughts. Attempts to neatly separate and categorize narratives into examples of evidence against and in support of authentic authorship in facilitated communication became tangled in overlap, exceptions, and ambiguity. Thus, after a fair amount of effort trying to sift, separate, cut, splice, paste, and push ambivalent and amorphously pegged segments into square categorical for-and-against holes, the author abandoned that endeavor in favor of honoring the complexity of communicative exchange by maintaining narrative segments intact.

Narratives were analyzed to identify and categorize recurring narrative phenomena or themes, some of which support and some of which challenge the authenticity of facilitated communication. Table 3 presents intact segments of portions of dialogue that are particularly demonstrative of the described narrative phenomena. The narratives are separated into individual speaking lines in the left column accompanied by coding of the identified associated narrative phenomena in the 6 narrow columns on the right. Two themes in particular challenge the authenticity of Tim’s typing in specific sections. The first one, already demonstrated in the quantitative analysis, is Tim’s substantial difficulty answering direct, specific questions. These are coded by correct and incorrect answers to questions being indicated with + and – signs respectively. The second, labeled *Facilitator Over-functioning* and abbreviated in Table 3 as *Ff*, is evident in sections where the assistants were quite clearly doing most if not all of the work.

Other themes appear to support Tim's being the authentic communicator of at least some of his thoughts and include his (a) typed responses that were unexpected in that he either asked a question rather than answering the question posed to him or typed an *Unexpected Remark* (UR); (b) typed responses a *Facilitator/assistant* would have been *Unlikely* to have typed (UF); and (c) providing *Information* that was *Unknown* to the assistant/facilitator (UI). Evidence housed within the facilitators'/assistants' texts in support of Tim's authentic authorship include the facilitators'/assistants' *Challenging/questioning* (C) or responding with *Surprise* (S) or *Frustration* (F) to Tim's typed response or remark. Other narrative elements identified and noted in Table 3 are *Anxiety* demonstrated by Tim (A) and *Attention/focus* difficulties (At), possible or likely *Perseveration* (P), and possible or likely *Echolalia I*. In addition to being noted at the bottom of Table 3, for ease of referencing, these elements are summarized as follows:

- (UF), (UR), and/or (UI): Typing that would be *Unexpected* from a *Facilitator* (UF); Tim typing an *Unexpected Response* (UR) by typing either a remark or question of his own; and/or Tim conveying *Unknown Information* to the facilitator (UI)
- (+), (-), and/or (Ff): Correct answer to question (+), Incorrect answer (-), Facilitator over-functioning (Ff)
- (S) or (F): Facilitator responds with *Surprise* (S) or with *Frustration* (F) to Tim's typing
- (C): Facilitator asking for *Clarification* or *Challenging* what Tim typed
- (A) and/or (At): Evidence of *Anxiety*; *Attention/Focus* problems (At)
- (P) and/or I Possible or likely *Perseveration* in typing (P); *Echolalia* (Ec)

In addition, the following key differentiates the various ways in which responses from Tim are recorded. They may occupy a separate row, with Tim being denoted as the speaker, or they may

be embedded within the facilitator's/assistant's text if Tim spoke, vocalized, or hit the table simultaneously while the facilitator/assistant was speaking:

- ( ) Parentheses: Tim's vocalizations excluding words (Euuu or MMmmm,) and behaviors (TAP TAP), both of which were often produced simultaneously with and therefore are embedded within the facilitator's or assistant's comments.
- Tim: “ ” Quotation marks: “Tim's verbalized words.”
- (“ ”) Quotations within parentheses embedded in facilitators'/assistants' texts = Tim's verbalizations (as opposed to vocalizations) made simultaneously as facilitators/assistants were speaking.
- [“ ”] Quotations within brackets embedded in facilitators'/assistants' texts = Tim's typing read aloud by facilitator/assistant.
- Tim: [ ]: Bracketed [typing assumed from context, but with no saved record and not read aloud by assistant/facilitator]. May also be embedded in facilitator/assistant text.
- Tim: No quotation marks or brackets presents Tim's typing that is saved and archived
- Finally, Tim did not type punctuation. Commas and spaces in his typing in Table 3 were added to illustrate when letters were read individually versus when they were read together as a word. Added spaces indicated periods of silence, often when he was typing.

Table 3						
<i>Narrative Phenomena</i>						
Speaker: Comment	Narrative Phenomena					
	UR UI UF	+ - Ff	S	C	A At	P E
<b>Homework Session 1 (Wednesday)</b>						
Dad: So, do you mind Nancy just listening in?						
Tim: Yes	UF		S		A	P ?
Dad: Why do you mind if she listens in?				C		
Tim: Yes						P ?
Dad: Well, she's trying to learn to be like Dr. ___ and how to help all sorts of kids, okay? Is it okay if she just listens in?				C		
Tim: I am nwer voys (TAP TAP TAP)	UF UR				A	
Dad: You're tapping because you're nervous, as we both know. Okay, well why don't we just try it and see how it goes, k? 'Cause today is gonna be fun; today is gonna be fun; okay. So you have to work on a political cartoon. What course is that for?						
Tim: hrt	UF					
Dad: Can you spell it correctly? Okay, History, or World Affairs, but finish typing it out; I want you to practice on this computer.				C		
Tim: history						
Dad: Have you thought of what political cartoon you want to do?						
Tim: Yes						P ?
Dad: Uh huh; we've already done that, but what do you want to do?				C		
Tim: Peoplw are listemig. (People are listening)	UI					
Dad: Hmm, do you know who Julian Assange is?						
Tim: Yes						P ?
Dad: You do!?! Who is he?			S	C		
Tim: Wi	UR					
Dad: Hhh (soft chuckle), "Wiki;" you're right. Umm, so, what's the point of your political cartoon?			S			
Tim: Tonsahiw we are bring controd (To show we are being controlled)	UF					

Dad: hmmm; k ... Can you think of a book that reflects that?				C	
Tim: 1972	UF				
Dad: It's close; you hit the numbers close.				C	
Tim: 84		+			
Dad: Perfect; 1984. Have you read 1984?				C	
Tim: yes					P ?
Dad: You've really; you've read 1984?	UR		S	C	
Tim: yes					P ?
Dad: When did you read 1984? (MMmmmm) Did you ever really read it or did they talk about it?				C	
Tim: in engkih tak	UF				
Dad: Do you want to, uh, read it maybe in the summer?					
Tim: Yes					
Dad: It's kind of heavy treading, but it's a valuable thing. So, other than 1984 ... which was written by who?					
Tim: Orwe	UR UF	+			
Dad: Huh; okay; yes, you're right; ["Orwe"]. Orwell.			S		
Dad: Okay, so other than 1984, and do you think you should use that in your, uh, political cartoon?					
Tim: Tes					P ?
Dad: Do you want Julian Assange in your political cartoon?					
Tim: Yes (mmm)					P ?
Dad: Um, can you think of anything else in your political cartoon?					
Tim: Yes					P
Dad: What?					
Tim: Yes					P
Dad: How about East Germany? It was the most monitored (mic'd?) state ever; in fact, there's a great movie about that called, "The Bridge of Spies." Do you think ...		Ff			
Tim: Yes (Mmmm)					P
Dad: The East German Stasi listened in on everybody; there's a movie about that called "The Listener." Do you think we're in a free society right now, a non-free society, or a partially-free society? (TAP TAP TAP) What do you think? (TAP TAP TAP) 'cause I'm going to tell Alex tomorrow.					
Tim: opaetual (TAP TAP)	UF			A	

Dad: ["Partial"] okay. Um (TAP TAP) other than Julian Assange (TAP TAP), wiki leaks, 1984, George Orwell, anything else that you can think of?					
Tim: yes					P ?
Comment: A section here was excluded that involved Tim answering "yes" to 10 questions Dad asked related to freedom of speech and how much the U.S. government should monitor citizen remarks and intervene in the event of negative remarks about the government. Dad did not challenge perseveration in Tim's "yes" answers to all 10 questions.		Ff Ff			P P P
Then, Wednesday, p. 5:					
Dad: What do you think about ISIL? Do you know about ISIL?					
Tim: Yes					
Dad: Who are they?				C	
Tim: yhey RE ecil (they are evil)	UF				
Dad: Evil. Well, they're Muslims, and we come from a Muslim power; are we evil?				C	
Tim: no					
Dad: And can there be people from groups that share, and, do you think they share our values? What do you think?					
Tim: ggthey csn e eil (They can be evil; MMMmmmm)	UF				
Dad: Kay, so let's review. You're doing a thing in history, and your job is to make a picture or a cartoon. So, if I wrote for Mom two questions for you: that your course is History, or World Affairs, and you're supposed to make a cartoon or a picture, do you think you could type that with her without her knowing what's going on?					
Tim: no	UF				
Dad: Do you want to try? Why don't you try practicing the words now 'cause I know it's hard. So, if I asked you, "What course are you talking about?" [history] Okay, and if I asked you "What is your project?" [picture] (MMmm) Alright, if I left you alone with Mom, do you think you could type that? Okay, so let's ... wait; wo, wo (mmmm mmm) So let's save this as <i>Wednesday</i> , uh, <i>part 1</i> . Okay, I'm gonna save that. Now I'm gonna write ... you can practice it (MMmm) if you like ... I'm gonna do a new document – sorry, Sweetie – What I'm gonna do while you're practicing is – "What (MMmmm) subject is this?" (Dad typing now) What, is, your, project?" Let's practice (Mmm) writing. SO, what subject is this? (MMmm)					A At A  A
Tim: (mmm) history		+			



Dad: And what is your project about?					
Tim: (mm) Picture		+			
Dad: Alright, so I'm going to go get Mom. And, wo, wo, wo. K? We'll only need two more minutes. You're ??, and you're anxious about your exam; I know it's distracting, but you're going to do great ...				At	
<b>Dad leaves;</b> Tim is vocalizing (Euuuuu, uuu, Euoooo, Uuuoo oo, mm, mm, Euuuuu.)				<b>A</b>	
<b>Mom enters</b> [10:00]: Hey, Bud! Hi. (MMMmmmm mmmm) Come on; you're okay. We don't care. (mmmm) We don't care. Alright? Love you. Okay, what subject? What subject is it in? Hey, what subject was it in? Okay, let me know if I can ... Okay what subject is it in? What subject? Hm? (Tim typing) Keep goin'. Can you move forward a little bit? Okay, Let's try it again. Come on; ... I have to figure out how to help you best. Okay, what subject? What subject? Hm?				A A  C	
Mom reading Tim's typing: ["history"]		+			
Mom: What is your project? It's okay. (pause) It's not a word, Babe. What's your project? Hhh? ... Try it again. What's your project?				C	
Comment: Long silence as Tim is typing.					
Mom reads Tim's typing: ["Science"] [13:15]	UI	-			
Mom: Alright. ["Acid rain on lime"] K Alright! Chill out, Bud!	UI	-			
Comment: Mom did not know this was the current topic in science. Mom left; Dad returned.					
Dad: If I said, (mmm) "and what is your assignment in history?" Would that be a better way of asking it rather than <i>project</i> ? Cause project does sound like science, and "what is your assignment; what was your homework assignment?" [history] That's right. So do you think if we told it like, differently, you could tell Mom that? ... cause you're absolutely right; now the amazing thing is, Mom was out of town, and I haven't told her yet what your science is – so you were right! You told her! You, independently, gave her information. You did that. I'm excited. I bet Mom's excited, too. So, I'm gonna rewrite the questions.					
Comment: Dad left after review; Mom returned.					
Mom: So, what was the? What were you and Dad talking about, and what was the subject? (pause) Okay. The subject; what was the subject? ...					
Tim: englsh		-			
Mom: Type the word. ["Lost"] Okay. ["Lost in space"] Was this the homework? ["Ask what you would need in space"]		-			

<b>Homework Session 2 (Thursday)</b>					
(MMMMMmmmmmm mmmmmmm MMmmmm MMmmmm mmm MMMMmmm; galloping)				A	
Alex: Get a glass of water, okay? (MMmmmm) Alright. So. (MMmm) What's wrong? (MMmm) What's wrong? (mmmm MMm mmm Mm) Water? (Mmm) What's wrong? Do you want to get some water?				A A At	
Tim: "No"					
Alex: No? Okay. Hey! We have to, we're gonna sit down and talk about, like, some subject and about Nancy like you did last night. (MMmmmm) Okay? (MMmmmm) So sit. Sit, here. (MmmmmMMmmmm) Sit. Have a seat. No, come here. (Mm) We're gonna sit right here, (MMmmmm mmm) Okay. (mmm Mmmmm Mmmmm Mmmmm Mmm) Come on, T. Come here. (Mmmmm) Okay T, come here. Come here. (mmmm mmmmm)				A A At A At	
Comment: Alex has been encouraging Tim to sit down multiple times and tells him they need to type three questions for Mike to answer with him about his homework project.		Ff		At At At	
Alex: So, I wrote down, so I'm thinkin that we're gonna do World History class.		Ff			
Tim: "kass"					E
Alex: Okay, so					
Tim: "Okay"					E
Alex: What, in what subject did you and Alex just talk about? That's what Mike's gonna ask you. Okay. It's gonna be, what's the answer gonna be?					
(Tim typing, but not saved. Alex's next response sounds like Tim did type something intelligible)	UF				
Alex: Okay, but what answer are you gonna tell him? What subject?				C	
Tim: "No"					
Alex: It's gonna be (Alex typing), so it's gonna be World History.		Ff			
Tim: "Okay."					
Alex: Okay; Wo, hold on; not done; not done yet. Come here. (MMmm mMMM Mmmmm MMM) What's wrong? (MMmm) Okay. Bud; no; that's not the restroom; no, no, no; we're not walking out; do you have to go, right here; do you have to go to the bathroom? Tim: "ba rou." Tim leaves and then returns from bathroom.				At A At	E
Alex: Hey. Come here, T., come here. Let's finish; get your chair up...Come here. Come sit down. (MMM) so, wo, wo, wait (m); so the first question we have that when Mike comes in he's going to read to you this question. (m) The first one is, "What subject did		Ff Ff		At At	

you and Alex just talk about?” and your answer’s gonna be, no, what is your, what is the answer to what class? We were talking about World History, correct? Okay, so, your answer’s gonna be World History for that first one (mmm). Then, he’s gonna ask you a second question that has to pertain to World History. (mMm) Okay, hold on. He’s gonna come in and ask you the second question and it’s gonna be “in the class you said in the previous question; (mm) what is the particular assignment you are working on? And the particular assignment that we’re working on for World History is going to be creating, it’s gonna be a (mmm) political cartoon, right? Okay. (mmm mmm mmmmmm mmmm)		Ff				
Alex continues: Alright, sir. So, we need to come up with an idea for the political cartoon. Yea, so it’s ... let’s google and see if we can find (mm) a particular one that you enjoy. Okay, so, no, sit here. ... Let’s see, what can we find inside of here (referring to an internet site)? K, so let’s look at here. Okay, do you, hold on here; have you read or heard about, this, not this scandal, but the issue going on with the store Target and their restroom?		Ff			At	
Tim: [yes]						? P
Alex: So, do you think that that could be turned into a political cartoon?						
Tim: [yes]						? P
Alex: Okay, so would you like to have that as your answer?		Ff				
Tim: [yes]						? P
Comment: The author is omitting much of the 19 minutes of Alex’s narrative and typing as he reviews the three questions and answers and then facilitates Tim with typing the answers. They are abbreviated and summarized in the following exchange:		Ff Ff				
Alex: So, the first one he’s gonna ask, “What subject did you and Alex just talk about?” So, what are you gonna tell him?						
Alex reading Tim’s typing: [“World History”]		+ Ff				
Alex: Yes, sir. Good work. And what answer are you gonna give him for the second question? Alex reading: [“Political cartoon”]		Ff +				
Alex: Great. And what are you going to answer for the final question? [“The Target Bathroom Boycott”] is exactly correct.		+ Ff				
<b>Alex leaves; Mike enters:</b> Alright, let’s see.... You know you’re answering these questions with me. Got it? Okay. You’re going to have to type accurately, though.... I know sometimes you just slide through stuff.... You have a question before we do this.		UF				

Mike reading Tim's typing: ["Yes"] K, what's your question? Look what you're typing. You have ["W, I, P"] (more typing) ["Wipe this"] No, we're answering these questions, K? Are you willing to do that?	UF UR UF			F	C		
Tim: Yes							
Mike: Alright, so what did you and Alex just talk about a subject?							
Tim: Yes							P ?
Mike: Alright. What was it?				F			
Tim: h							
Mike: I want you to focus.					C	At	
Tim: history (Comment: Took one minute to type "history.")	UI UF	+					
Mike: What is the assignment you were working on? You guys were talking about history; I'm reiterating that. ["Yes."] You told me "yes" several times now. What is the assignment that you are working on then? [yes] Okay, "Yes" isn't an assignment. What is the assignment that you're working on?	UF			F	C		P
Mike reading Tim's typing: ["A"] Mike: Okay, start over, 'cause that's not a word. ["I, s, is, t, h, this, for, for, a, is this for a, pr, pr, prrr, prr"] Mike: you got 2 r's there. ["Prr, r"] That's not a word. ["Pr, prac, is this for a practice paper"]? Comment: it took two minutes to type his question.	UR  UR	-			C  C		P  P
Mike: I don't know what that means. We are practicing. We're practicing your typing. That's what this is practice for, and you have two questions to do. (Thurs. p. 4)	UF			F	C		
Tim: Um mm (sounds like agreement)							
Mike: Okay, what is the assignment that you're working on? ["T, a, taq"] It's not a word, at least I don't think it's a word. ["Ta, test"] or ["tast"]. Did you mean test?		-			C		P
Tim: No							
Mike: ... Okay, what is the assignment? Can you type it?					C		
Tim: "m hmm"							
Mike: Okay, then do it. ["T, a"] That's not a word, Bud. ["T, a, s"] Alright, put this arm down; sit up straight; okay, type like this, like you do with C. ["T, a, s, a, a, s"] This is what you wrote: ["T, a, s, a, a, s"] That's not a word. Let's go to the other one....	UF	-		F	C		P P
Mike: Stop typing "yes." What is it? ["P, a, e"] or ["p, a, p, e, r, paper, on, paper on, w, paper on w"] Kay, ["paper on, p, a, p, p, a, p"] Do you want that "p?" Okay, is this what you want here? Are you writin' a paper in history? Is that what you're trying to say?	UF	-		F	C		P P
Tim: yes							P ?

Mike: About what? Okay, Dude, if you keep typing “yes” over and over we’re gonna be here all day.			F	C	P
Mike reading Tim’s typing: [“T, a, l, t, a, l, a, b, o, u, t, c, o, u, n, t, on countries”]	UF	-			P
Comment: This may be another variation of perseverating on “t, a,” and then deviating when he couldn’t finish Target. We also know that Tim is used to shortening words to the first few letters, with facilitators interpreting and/or finishing them in context. The letters “b, o, u, t, c, o, u, ntries” could also have been initially attempting <i>boycott</i> , particularly when noting that <i>u</i> might have been substituted right of <i>y</i> , and then with <i>t</i> being a necessary letter, but also left of <i>y</i> , all combined in confusion of letter order in the word <i>boycott</i> . This may have been an attempt to type <i>Target boycott</i> , or perhaps he was just typing a random topic.					
Mike: Okay, <i>paper on countries</i> . This is very, it’s interesting. (large sigh) Alright; what is the particular topic of the assignment you are working on in the class you had just talked about?	UF	-	F		
Mike reading Tim’s typing: [“Y, a, w, o, n, t, l”] (typing and deleting)	UF				
Mike: Bud, you’re not typing anything.... Are you gonna answer the question?			F	C	
Tim: yes					P ?
Mike: Okay; well, stop typing “yes” and say something else. You can say anything else; just quit typing “yes.” What is the particular topic of the assignment you are working on in the class you just talked about?			F	C	P
Mike reading Tim’s typing: [“ask, him”]	UR UF				
Mike: No, I’m asking you. We’re talking about history here. That’s the subject you talked to Alex about, right? Are you focusing here? Just put it on the table. What’s the deal? You tired? [“No”] Bud, I feel like you’re ... you got no homework today; this is all you gotta do, is this. Type something other than “yes.” You can type “okay,” or you can type “no.” We’re not typing “yes” anymore. It’s a bad habit. Can you tell me what the particular topic of the assignment you were working on in the class you just talked to Alex about it is? Can you? I want “okay” or “no.” No more “yeeses.”			F	C	
Mike reading Tim’s typing: [“Okay”]			F	C	
Mike: Then what is it? Come on!			F		
Mike reading Tim’s typing: [“A, s, k, a, ask, another, ask another question”]	UR UF				

Mike: I'm not asking another question. This is the question I have to ask. Do not type "yes." Do not type "yes." Are you gonna be able to answer this?			F F	C	
Tim: no	UR				
Mike: ["No"] Why not?				C	
Tim: I ca t (I can't)	UR UF				
Mike: You're not gonna answer this question.				C	
Tim: No					
<b>Mike leaves and Alex returns</b> for more review with Tim. Again, however, Alex does the work, talking to Tim about the questions and answers, then having Tim type them each once, which he has no trouble doing. Tim is tapping/hitting the table frequently through this review. <b>Alex then leaves and Mike returns.</b>		Ff Ff		A A	
Mike: What is the particular topic of the assignment you're working on in the class? What'd you just talk to Alex about?					
Mike reading Tim's typing: ["A, r, a research; a research"]? (Tim chuckling throughout this exchange) Come on, Bud. (Tim chuckling). ["A research (chuckling) prpjecet"] (chuckling)	UF UF	-		At	
Mike: That's very vague. (Tim chuckling) This says, "What is the particular topic? (Tim chuckling) So, what's the topic of the research project, then?				C	
Mike reading: ["E, t, a, a"] I don't think that's a word. You got ["e, t, a, a, a"] I know it's not a word. Come on. (SIGH) You need to back space or something; I don't know how far, but, ["That's it"]		-	F		P
Mike: Well, you know what, Bud? I don't know what you guys talked about, but I know that's not it because this says, "what is the particular topic?" That is not a particular topic of anything. It's very vague.... Are you gonna give me anything else other than that?				C C	
Tim: [yes]					? P
Mike: Okay. Are you gonna say anything other than that?				C	
Tim: [yes]					? P
Mike: Okay, what? What is the, if you're, so your research project. You're doing a research project? You're sure (Hmmm mmm mmm).			F	C	
Tim: [yes]					? P
Mike: It makes me nervous cause you just keep, you've been typing "yes." Why don't you type "no" just so I can see that you can type "no." Type "no." Type the word, "no."				C	

Tim: yes						P
Mike: Do you wanna go run?						
Tim: "No."						
Mike: Type your answer. [yes] Okay, you're saying "no" and you're typing "yes." That makes me nervous that you're not truthfully, that we're not getting the right answers here. You understand? And I don't need you to type "yes," kay? We gotta get you out of this habit of just typing "yes" all the time. Like, type "no;" type the word "no." [no] Good job. Type it again. Well, you missed the <i>n</i> . type it again on your own. Type "no." that's not, that's not "no." Type "no." [no] There ya go. Okay. Type "yes." [yes] Type "no." [no] Type "no" [no]. Okay, were you guys talking about history? Was history the subject you were talking about? [yes] Okay. Was math the subject you and Alex were talking about? [yes] Well, this isn't going to work, cause I know you guys weren't talking about two subjects; but, kay, listen to me. This is something that I KNOW that you're able to do. (chuckling) It's not funny. You don't have to be able to answer all of these questions. I honestly don't care about this (T chuckling), but this is something I KNOW you can do (T chuckling), because this is something, this is how WE communicate, k? So THIS has to be accurate (T chuckling). It's not funny.... Were you guys talking about history? [yes]	UF UF			C C C F F C	P P P	
Comment: Mike continues working with Tim to break the perseveration of typing "yes," and then says:						P
Mike: What is the topic of your assignment? ["p, e, o; p,e,o? (hmmm) p, e, o, e"] That's not a word....	UF				C	
<b>Supplemental Session 1 (Thursday)</b>						
Mike: ...Tell me, uh, something that's on your mind.						
Mike reading T's typing: ["about"]	UR UF					
Mike: Okay, "about." Um, what's, uh; What's going on in school?					C	
Tim: "schoo"						E
Mike: Tell me something about school.						
Mike reading T's typing: ["Maybe"]	UF					
Mike: Something about school.						
Mike reading: ["About"]	UF					
Mike: About school, man, anything. About; what's your, what's your, uh. Okay, I guess it's not that easy. What's, uh; what do you want to do this weekend? What's, where's somewhere you wanna go this weekend or do with me or Dad or Karen or something? What'a ya wanna do with Karen? Karen. There ya go;					F C	

you said Karen. What do you wanna do with Karen on Saturday? After soccer (“K__”) you’re gonna work with Karen. What do you want to do with her?					
Mike reading Tim’s typing: [“go”] Mike: Go where?	UF			C	
Mike reading: [“Go, go away”]	UF				
Mike: You wanna go away with Karen, or are you telling me to go away?				C	
Tim: “Ka”					
Mike: You wanna go somewhere with Karen?				C	
Tim: “ya”					
Mike: Okay, where would you like to go with Karen?					
Mike reading Tim’s typing: [“to, to, to eat”]					
Mike: ... Okay, where would you like to go to eat with Karen?				C	
Mike reading Tim’s typing: [“Anywhere”] Mike: Okay, and after you’re done eating, what would you like to do?					
Mike reading Tim’s typing: [“go, to, swim”]					
Mike: Where would you like to go to swim?					
Mike reading Tim’s typing: [“Warden”]					
Comment: <b>Mike left; Alex enters:</b> In answer to the question about what he wanted to do this weekend, Tim typed with Alex that he wanted to go hiking, go eat yogurt, and go golfing.		- + -			
<b>Supplemental Session 2 (Friday)</b>					
Dad: Did you have a good day?					
Tim: uyes					
Dad: What was good about your day today?					
Tim: yes					P
Dad: What does “yes” mean? Here, what was good about today?				C	
Tim: Loplires	UF				
Dad: I don’t know what that means. “Loplires.” What does that mean?				C	
Tim: Playing					
Dad: Who were you playing with?				C	
Tim: L____ (“Loplires” may have been a mix of letters and typos from “playing” and “L_____.”)	UI				
Dad: Is that the name of the girl? (MMMMmmm) that you like to always come out (MMmmm) and play with you?				C	A
Tim: yes (MMMMmmm)					A
Dad: So, you got to play with her?!				C	



Tim: yes (Mmm)						
Dad: How about English? How did that go?						
Tim: I likjtn (j inserted after and left of k) (MMmmmm MMmmmm)	UF					
Dad: Oh, "I liked it." (MMMmmm) Does that mean that you liked it?			S	C		
Tim: yes						
Dad: That it was okay? It was kind of fun? Is that what you're saying?				C		
Tim: yes (Mmmmm MMmmmm)						
Comment: Dad proceeds to ask questions to check for and break the perseveration of "yes."						P P
Dad: So, let me ask you, was English tough?						
Tim: No						
Dad: ... do you feel proud about all the stuff, the work you're doing?						
Tim: I mpnm not mvong ( <i>mpnm</i> : random or missed strikes attempting <i>not</i> : <i>m</i> right of <i>n</i> ; <i>p</i> right of <i>o</i> ; started over with <i>n</i> , but also hit <i>m</i> ; started over again and typed <i>not</i> ; <i>mvong</i> : <i>o</i> and <i>v</i> possibly transposed followed by <i>i</i> being omitted; or perhaps the initial <i>o</i> was omitted followed by substituting <i>o</i> left of <i>i</i> for <i>moving</i> ?)	UF UR					
Dad: What does that mean? "I, I'm not moving" No, you're not moving; I don't understand what you mean by "moving." (aaa) Do you feel proud about English and how hard you've worked?				C		
Tim: yerd ( <i>r</i> inserted before and right of <i>e</i> ; <i>d</i> right of and substituted for <i>s</i> )						
Dad: ... Alright. So, let's go through it. You said you were really excited about the dance.						
Tim: yed						
Dad: Is there one thing that you think you're looking forward to? What is it that you're looking forward to the most about the dance?						
<b>Tim: (TAP TAP) Being norma</b>	UF					
<b>Dad: Ah, well, I can tell you that, Son, that you're not abnormal. You have special talents and special things you have to overcome. Honey, you're not abnormal. You're just different like I was, like your mom was, like everyone. Being normal. That's interesting. Is there anything you're scared about the dance?</b>				C		
Tim: yes						
Dad: What are you scared about?						
Tim: Not having someone ti dance wit (Huh, huh!) ...						

Comment: A little more discussion to review and type questions for Mike. Tim is TAPPING through this; then <b>Dad leaves and Mike enters</b> . Mike spends 9 to 10 minutes addressing perseveration with Tim. When he is comfortable that Tim can control the perseveration, they continue:					
Mike: Are you able to type what you and your dad were just talking about?					
Tim: possibly	UF				
Mike: K, possibly. Well, I want you to try. What were you and your dad just discussing?				C	
Mike and Mike reading Tim's typing: ["s, d, s, d"] You're just hitting the <i>s</i> and the <i>d</i> over and over again. ["D, a, n, d, a"] That's not a word. What were you and your dad just discussing?				C	P
Tim: D, a, n, a, d, a, n, dance.	UI	+			
Mike: You guys were talking about the dance? [yes] Were you guys talking about going to play basketball? [yes] Bud, it's hard for me to know what's real and what's not. You and your dad were just talking about going and playing basketball. [yes] You and your dad were just talking about the dance. You guys talked about a lot. Did you and your dad talk about going to watch the monster trucks ( <b>Tim: "no" too?</b> [yes] Well, no you didn't talk about all these things. We gotta figure this out....		+ -		C C C	P  P
Comment: Mike spends the next 4 minutes again addressing perseveration, and Tim inserts individual syllables of echolalia throughout. Then:					P E E
Mike: ... What were you and your dad just in here discussing? Think about the answer. I know you weren't in here just discussing "yes." K? So I don't want to see that anymore What were you and your dad just in here discussing? (Tim: "oka") Think about it before you type. (Tim: "tai") Think. (Tim: "thi") What were you and your dad just discussing?				C C	E E
Mike reading Tim's typing, then Mike: "Taking, a, trip" You and your dad were just discussing taking a trip? Think. So now you've typed "dance" and "taking a trip." So, we're gonna do it one more time until an answer matches – or you say something else. What were you and your dad just discussing? Type it again. You already typed it. Type it again. It's fine. We need consistency here.		-		C C	
Mike reading: "The, the dance."		+			
Mike: You and your dad were just talking about the dance. Okay. What is the thing you are looking forward to most or is most exciting that you were just talking to your dad about?				C	
Tim: yes					P
Mike: Do not type "yes." K?					

Mike reading: ["books"]	UF	-				
Mike: You just typed the word "books." The thing you are looking forward to most and is most exciting are books that you were talking to your dad about. ["no"] Okay, what were you talking to your dad about that was most exciting or that you were looking forward to? Tell me what that was.				C		
Mike reading typing: ["n, y, u, s, i, "]	UF					
Mike: That's not a word. Start over.				C		
Mike reading typing: ["m, u, s, i, c, music"] (MMmmmm)		-				
Mike: What is scary about what you were talking about? [yes] The answer is not "yes." Stop typing "yes," Dude; seriously, stop typing "yes." You can type anything else but "yes." Doesn't have to be the right answer; just stop typing "yes." We've gotta break that habit. What is scary about what you were just talking about with your dad? What is scary?				C		P
Mike reading: ["a, l, a, al, all, of, the, p, e, o, p, o, p"] Oh, "all of the people." Alright, well we've been out here long enough; I'm leavin' it at that.	UF	-				P
<b>Homework Session 3 (Friday)</b>						
Comment: Tim types that he does not remember the specific topic he and Alex chose, so Dad asks him to choose a new topic:						
Dad: Well, do you have an idea of what you'd like it to be about?						
Tim: no						
Dad: Well, do you want it to be about modern day or old times? What would you do?				C		
Tim: Maybe ncatre	UF					
Dad: Okay, well that's not quite a word. Why don't you give me a real word? Dad reading: ["maybe..."] Dad: Think of a topic that's either always interested you – it could be in history, it could be current day, what, what can you think of?				C		
Dad reading: ["lightning"]	UF					
Dad: Be specific				C		
Tim: ncatre	UF					
Dad: Nature? Do you think about climate warming or something like that or erosion or pollution, nature? Or taking care of our land and nature?				C		
Tim: yes						
Comment: <b>Dad left, and Mike entered.</b>						
Mike: What is the subject you want to do in the project that you and your dad just talked about?						

Mike reading: ["g, o, a, s, g, o, a, goats"] Okay. Alright.		-				
<b>Supplemental Session 3 (Saturday)</b>						
Dad: ... K, well, how do you think soccer went?						
Tim: Googd						
Dad: Good? Okay, well, uh, ... anything you'd like to practice on?						
Tim: yes	UF					
Dad: Oh, okay. What would you like to practice on for soccer? ...						
Tim: the ____						
Dad: That's not really a word. Let's try it again. "the" what?			C			
Tim: passy	UF					
Dad: Oh; look for the <i>i</i>			C			
Tim: the passyi (Dad: that's right) ng.						
Comment: Dad changed the topic to ask about Tim's morning with his aid, Karen. Tim typed four "yeses" in a row; then:						P
Dad: Don't just say "yes" cause "yes" doesn't tell me where you went. Did you go to the zoo?						P
Tim: mo		+				
Dad: K; did you go to a park?						
Tim: yes		+				
Dad: Yes, okay. Was there anything special about the park?						
Tim: yes						
Dad: Oh, what was special about the park?						
Tim: the water		+				
Dad: The water. Was it a river or a lake, do you remember?						
Tim: no						
Dad: What do you think it was?						
Tim: river		+				
Dad: If I gave you the names of parks, would you remember?						
Tim: yes						
Dad: Okay so did you go by the ____ bridge?						
Tim: no						
Dad: Did you go to _____?						
Tim: yes		+				
Dad: Did you get in the water?						
Tim: yes		+				
Dad: Did Karen get in the water?						

Tim: no		+				
Dad: Was it hot? What do you remember about being there?						
Tim: Ibfet	UF					
Dad: “felt,” what?				C		
Tim: bappy						
Dad: When was the last time you felt happy?						
Tim: today						
Dad: What were you doing that made you feel happy?						
Tim: playing						
Dad: Ah, [“playing soccer”] What do you remember that made you feel particularly happy about that?						
Tim: inteam	UF					
Dad: That you’re part of a team?						
Tim: yes						
Dad: Alright, so that’s good. . So what are we gonna do now before we go? Are you ready to play indoor soccer?						
Tim: yes						
Dad: It’s gonna be earlier. What do you wanna do now?						
Tim: Grobe	UF					
Dad: Okay, I’ll make you a deal. I’m gonna have a little break. You relax, and then we’ll go for a drive.... Oh, by the way, and I’ll ask Alex tonight – do you remember what project you and Alex came up with?						
Tim: yers						
Dad: What was it?						
Tim: Loosging materiasl (perhaps referring to corrosion)	UI	-				
Dad: “Losing material.” Was that for science?				C		
Tim: yws						
Dad: How about your history cartoon – do you remember what you came up with for that?						
Tim: no						
<b>Homework Session 4 (Sunday)</b>						
Comment: Alex asked Tim if he remembered what they talked about Thursday. Chuckling, Tim typed “no,” so Alex began reviewing. Tim was still not paying attention and continued chuckling. Alex then asks:					At	
Alex: What’s up? Ya alright? What’s goin’ on?						
Alex reading Tim’s typing: [“home”] Alex: Well, you are home. (Tim: uh u chuckling) Oh, me? I’m okay. (Euuu) We’re gonna get	UR			S	A	

a little bit of work done. (Eeeeeuu Uu uuuEEEuuuuu Euuuu) What?! (Euuuuuuuu TAP TAP TAP) It's alright. (Euuuu Euuu Euuuuu) Alright.					A A	
Alex reading typing: ["still stayin' home"]? (Huh, Euuuu Euuu Euuuu) Well, if we get some of the homework stuff done, then I can. (a ca; chuckling – huh huh huh) Alright, so are you ready to start goin' over it then?	UR		S			E
Comment: Alex spends 13 minutes reviewing with Tim, with Alex again doing nearly all of the work.		Ff				
<b>Alex leaves and Dad enters</b>						
Dad: ... Okay, so, you're a little nervous about this, huh? ... I'm just curious, um, why are you nervous about this? (mmmm) Look what you're typing. (MMMmmm)				C		
Dad reading Tim's typing: ["I don't feel, ready, t, be, independent"] Dad: yea, I agree you're not totally ready to be independent, but you're getting there....	UR					
Comment: Tim answers incorrectly to the question of who the teacher is for the class they are discussing. He types the correct answer, "political cartoon" in answer to "what is the assignment;" however, Dad knows that answer. Then, in answer to, "What's the topic?" Time types:		-				
Tim: backcodads	UF	-				
Dad: ["backcodads"]. Can you explain a little bit more about what that means, or sort it out?				C		
Tim: iy means I am penably not ging to verify	UR UF					
Dad: Okay, I'm wondering if I'm influencing you a little bit. You said, "backcodads." It's a political cartoon. Uh, does it ta, is it about something that's happening now or in the past?		Ff			C	
Tim: now						
Comment: Dad asking for more information						
Tim: it is your proposal	UR	-				
Dad: My proposal. What was my proposal?				C		
Tim: the blmagk	UF	-				
Dad: ["blmagk"] You see wha that means? Try it again....				C		
Tim: it is about people who are itreting						
Dad: ["I'm trying"]? (TAP TAP) What!?				C		
Tim: pspic life	UF					
Dad: It's about people who are entering public life?	UF	-				
Tim: y						
Dad: Is that what you and Alex talked about?						
Tim: vthfsa						

<b>Comment: Dad leaves; Alex returns.</b> For the first time, Alex insists on Tim using his own effort to type.					
Alex: Okay, let's get it again. Wow! That's exactly it. You need to make sure you're putting <i>your</i> resistance in and you put your, like, how do I say this? Make sure you put <i>your</i> effort in, cause you can tell if my arm slips, and if your hand goes limp, yea! There you go! That's exactly it! There! There ya go. As you can see, all I'm doing is holding you with one arm, I mean with one finger. Exactly. (Tim typing) Dude, that was 100% it! That was me stabilizing you with <i>one finger</i> . That's perfect, Dude. Cause that was all, that was all <i>your</i> muscle; that was all <i>your</i> finger. That's what it needs to be.... I'm gonna go get your dad ...					
<b>Comment: Alex leaves and Dad returns.</b> This session is shorter than previous sessions, lasting just five minutes. Dad and Tim establish again that the subject is history.					
Dad: Okay, what's the general topic?					
Tim: It is they	UF				
Dad: Ah, you're getting nervous. Go ahead, what is it about, basically? Dad reading: ["the"] Dad: What's it about?					
Tim: yes					P
Dad: Just a second.					
Tim: it					
Dad: So, who is the history teacher?					
Tim: Holland		+			
Dad: and it's a political cartoon, and what's it about? What?					
Tim: Public					
Dad: What?					
Tim: Bathroom		+			
Dad: What about public bathroom?					
Tim: Boycott		+		C	
Dad: Huh, well, is this in a state or where is it?					
Tim: here					
Dad: What, a, okay, in Sterling? He says it's Holland, and he said something about a public bathroom, and a boycott, here. (TAP) Is that close?					
Researcher: I can't say anything.					
Dad: Oh, okay. Alright, so let's go back; let's go back. You did great. Mom, wai, wai, wait; Mom's gonna come and work some English with you.					
Homework Session 5 (Sunday)					

Comment: Alex and Tim move on to choosing a question from a reading assignment for Tim to answer with Dad as the facilitator. Alex chose the question and has been talking about it to Tim.		Ff			
Alex: ...Elie and his father end up in which (Mmmm) camp in the end? (Tim typing) Nope, nope, remember? (Mm; Tim typing; MmMm M) Exactly. [Buchenwald]. We're gonna write that again .... Elie and his (TAP) father (TAP) end up in (TAP) which camp? (TAP; Tim typing) Right, but if you look at this, we have to make sure we're not getting lazy. You have to put forth <i>your</i> force and <i>your</i> muscle 'cause if you look, hey, look at the difference between 'em; you missed ONE letter, and that one letter then, some people may not know what that is...				C	
Comment: Alex spends the next 3 to 4 minutes continuing to have Tim retype the answer, emphasizing that it has to be Tim's effort and it has to be accurate. <b>Alex leaves; Dad enters</b>					
Dad: Which camp did (TAP) they end up in? ...					
Tim: Bperkinsy		-			
Dad: Berkinau? Is that what you're writing?				C	
Tim: no					
Dad: K, fight my finger, come on.				C	
Tim: Berkinshu		-			
<b>Comment: Dad leaves; Alex returns</b>					
Alex: Alright, T. (Euuu Uuu) Okay. (Euee) I know; (eEee); I know, yer (euu) yer (uu) prob'ly I' done with this, right? (eUUu) Alright! K; hey; hey, this is the very last one. We're on (MMMmmmmmm) ??? Okay? Okay?				A	
Tim: "kay"				A	
Tim: "kay"					E ?
Alex: So, let's focus on this, 'cause you're SO close, so close. So let's sit down for a minute; let's focus on this last one, very last one. Okay, so if we look, Dude, don't. Dude, you're sooo close, but what we have to re..., remember is they end up in Buchenwald. Buchenwald. Okay? Okay? So, remember this: Buchenwald; so, watch your key strokes. (Tim typing) Force, force force; force. <i>Your</i> force, <i>your</i> muscle; let's go. (T typing) No; see, this is where you're just typing. Start it over. Focus. Focus, sir. We're almost done, okay? So I need, I need <i>your</i> pressure, I need <i>your</i> force; I need, this is <i>you</i> ; okay? Okay. So, let's do this again. (T typing) Nope; focus on your key strike. (T typing)				C	
				C	
				C	



Comment: Alex continues with encouragement and insistence on Tim using his own muscles and force as he practices typing Buchenwald. <b>Alex leaves; Dad returns</b>						
Dad: Alright, Buddy; I guess it's the last one Elie and his father ended up.						
Tim: Buchenwald		+				

*Note:* Narrative Phenomena: UF = Unexpected from Facilitator; UR = Unexpected Response from Tim; UI = Information Unknown to facilitator/assistant; + = correct answer; - = incorrect answer; Ff = Facilitator over-functioning; S = facilitator/assistant responds with Surprise; F = facilitator/assistant responds with Frustration; C = facilitator asking for Clarification or is Challenging what Tim typed; A = Anxiety; At = difficulty with Attention/focus; P = possible or likely Perseveration; E = likely Echolalia. Tim's communications, all of which may be embedded within facilitator/assistant text: parentheses = behaviors (TAP TAP) and Tim's vocalizations excluding words (Euuu or Mmm); brackets = [typing assumed from context, but with no record; quotation marks = "Tim's verbalized words," which may at times also be embedded simultaneously within facilitator or assistant comments. Tim: no quotation marks or brackets presents Tim's typing that is saved and archived.

## Chapter V: Discussion

The results from this study are consistent with those from the majority of previous facilitated communication studies: A quantitative analysis of Tim's performance under controlled testing conditions showed him to be minimally successful in answering specific questions to which the facilitators were blinded. This was true in both the homework and the supplemental sessions, however, more questions were answered in the casual supplemental sessions than in the formalized homework sessions (64% vs 25% respectively). The reason for this is uncertain. On the one hand, it may have been easier for facilitators to guess answers in the supplemental sessions because the topics discussed were familiar life topics for Tim. On the other hand, Tim may have been more relaxed and therefore better able to type in these casual conversations.

The results from the qualitative analysis of narratives are also consistent with previous findings in qualitative studies. Although fairly certain facilitator control and over-functioning was identified, so were indications that Tim conveyed unknown information, expressed differing opinions from the facilitators, and seemed to interrupt topics with unrelated questions or comments of his own. Therefore, little new information about facilitated communication or the validity of its use is obtained when results are evaluated through a traditional lens looking only at produced results. However, a comparison of Tim's performance under controlled, blinded conditions with what he appeared to have been able to type spontaneously in both the controlled and the uncontrolled settings is intriguing when evaluated in light of the latest neuroimaging and behavioral sensorimotor integration research. If we accept that hundreds or thousands of firsthand accounts cannot all be fraudulent and that at least some of the anecdotal accounts of individuals calming down after they communicated through facilitation what it was that was

bothering them, provided information that was purportedly unknown, asked for things they wanted, and argued with facilitators, if we accept that there is some validity to the many qualitative studies showing authentic typing, then the real intrigue lies not in whether or not individuals can type their own independent thoughts with the use of facilitation, but in why they can in some situations but not in others. This paper will conclude that the neural underconnectivity theory will prove to hold the answers to that question.

### **Baseline Testing**

**Typing from copy.** The first part of the baseline testing was intended to evaluate Tim's motor capabilities to determine if motor tone or motor control alone were impaired sufficiently to justify his need for physical assistance to type. Tim was able to match photos and letters and *independently*, without assistance or apparent difficulty, point to and touch select matching photos and letters down to a size of ½" squares on paper. Although the next task level evaluating independent typing included just five trials of typing individual letters, Tim was able to type those five letters, one at a time as they were shown to him, with 100 percent accuracy. His accuracy decreased when he was asked to type by copying individual words, with mistakes appearing to involve sequencing rather than poor motor control or typos. Tim correctly typed *PHONE*, *SANDWICH*, and *ORANGE*, but typed *MOTORYYCLE* rather than *MOTORCYCLE*, and *ATH* rather than *HAT*. Sequencing also appeared to be a problem for Tim when he attempted to copy sentences without assistance. He typed one simple sentence correctly (minus the spaces between words) –*THEDOGRAN*; but then he began two sentences with the last word of each of those sentences – *SMARTTAM* for *I AM SMART*, and *RANTHERAN* for *THE CAT RAN*. He also substituted *RAN* for *CAT* in the last sentence. Neither the order of word presentation nor complexity of the words appeared to be factors in accuracy, as *HAT* was short, simple, and the

first word presented, and *MOTORCYCLE* was longer and the last word presented. The most correctly-typed sentence – *THEDOGRAN* – was the second sentence presented. Tim correctly typed the first part of the first sentence, which was also the longest sentence – *[his real name] LIKESTO* – but then omitted the *E* in *BE*, and typed *FY* rather than *SILLY* at the end, resulting in *[NAME] LIKESTOBFY* rather than *[NAME] LIKES TO BE SILLY*.

It appears that sequencing, and perhaps maintaining attention through a longer sentence, posed difficulty for Tim, whereas neither basic pointing, motor tone, initiation of movement, or muscle coordination *appeared* to have been interfering factors in these typing-from-copy exercises. It is not known which factors contributed to Tim's problems with sequencing. At the most impaired level, it is possible, although unlikely based on years of school and therapist reports, that Tim simply did not recognize the letter symbols themselves; i.e., he is illiterate. It is also possible that Tim lost track of letter sequencing as a result of internal or external distractions, internal or external systems forfeiting (Williams, 1994), anxiety, or a visual processing problem such as perceiving or processing what he saw in fragments (Bogdashina, 2003, p. 69).

**Receptive auditory vocabulary.** Tim's score of 20 on the Peabody Picture Vocabulary Test (4<sup>th</sup> ed. PPVT-4, 2007) places him below the 0.1 percentile with an age equivalency score of 2:5 on receptive language. If this is an accurate representation of Tim's auditory receptive vocabulary, it means his vocabulary understanding is limited to very basic items, activities, and attributes with which he is very familiar and which he encounters regularly in his daily life, and either he is not actually reading at the levels at which he is said to be reading or the results of this assessment do not reflect his true ability.

The items were administered under standardized protocol, without second chances, reinforcement, or asking Tim to reconsider answers. Tim did not *appear* to be distracted during test administration, but nor did he appear to be deeply considering or deliberating over answers, and it is therefore unknown how engaged he was in the activity or if he was perhaps at times impulsively or perseveratively pointing to a particular orientation on the page regardless of the picture, was pointing to a preferred item (as suggested by Mike), was responding to an association he had made, was pointing to a picture related to a previous question due to delayed auditory processing, or was experiencing some other phenomenon while selecting his answers.

A fascinating possibility explaining Tim's (and others with language impairments) difficulties in typing from copy and pointing to correct answers on the PPVT-4 is impaired oculomotor control. Kelly et al. (2013) found that children with language impairment – both those with and without autism – showed greater difficulty than those without language impairment (again, both those with and without autism) in exercising the necessary oculomotor control to suppress reflexive visual gaze shifts in order to maintain fixation on a target in the presence of competing visual distracters (p. 63). Although studies have shown an association between eye-movements and language, a causal link has not yet been established. However, the Kelly et al. study showed that “deficits in oculomotor control are also characteristic of unaffected, first-degree relatives of autistic individuals (Mosconi [et al.,] 2010) and implicate deficits in left frontotemporal cortical circuits that overlay neural pathways crucial for language development” (p. 64). Thus, Tim's difficulties with typing from copy and pointing to the correct square on the Peabody Picture Vocabulary Test (PPVT) might be explained by an *oculomotor control* deficit impairing his ability to suppress reflexive shifts of gaze away from his desired visual target (Kelly et al., 2013). The other squares on the PPVT pages and having to shift his

gaze back and forth between the keyboard and the stimulus paper when copying words and sentences may have been significant distractors.

Ronconi et al. (2013) described a visual attentional focus deficit as it applies to an impaired ability of autistic children to “zoom out” to integrate details into a larger cohesive whole (the theory of central coherence) such as is needed to correctly order specific letters in words and sentences. Noting the “large number of recent studies” suggesting under-connectivity between frontal and occipital areas in ASD, they proposed an impaired zoom-out as well as a “prolonged” zoom-in attentional focus could arise from dysfunctional connectivity between the “fronto-parietal attention network and early visual areas, where the ‘zoom-lens’ of the spatial attention is modulated.” Specifically, they cited two fMRI studies showing “dysfunction of the dorso-lateral prefrontal and the intra-parietal cortex during visual attention tasks (Manjaly et al., 2007; Ring et al., 1999)” (p. 1031).

Visual processing involves widespread visual areas located in the thalamus, occipital [primary visual cortex], parietal, and temporal lobes, the white matter tracts connecting these areas, and other attentional control regions. In their study on visual attention in autism families, Belmonte et al. (2010) described neuroactivation differences between the typical control group and the autism group, noting that while “a widespread network of frontal, cerebellar, and parietal attention regions” were activated in controls, the autism group “activated a cerebellar region outside the attention area, did not phasically activate frontal and parietal attention regions, but did activate posterior visual regions and also the orbitofrontal cortex” (p. 270). The authors continued,

These findings appear to confirm a large number of previous results from various cognitive tasks, suggesting hypoactivation of frontal cortices in autism and

hyperactivation of posterior cortices subserving lower levels of processing (Haist, Adamo, Westerfield, Courchesne, & Townsend, 2005; Silk et al., 2006; Belmonte et al., 2004b), as well as results on orbitofrontal activation possibly related to arousal (Belmonte & Yurgelun-Todd, 2003b), anterior cingulate hypoactivation (Mundy, 2003; Gomot et al., 2006), and hypoactivation in the cerebellar attention region with hyperactivation of other cerebellar regions (Allen & Courchesne, 2003; Allen, Muller, & Courchesne, 2004). (pp. 270-271)

They further emphasized,

These modeled activations, however, do not tell the whole story. Atypical activation maps may arise because the activation really isn't there, or because the activation is atypically timed and fails to onset and/or to resolve within the modelled time interval. Examination of time courses revealed ASC [autism spectrum condition] and sib activation whose atypically delayed and prolonged timing had prevented detection in the whole-brain analysis. That is, the ASC and sib groups did activate fronto-cerebellar attention systems, *but these activations arose too late to be useful during behavioural response to the trial of interest, instead manifesting during the trials immediately subsequent.* (italics added; p. 271)

Consistent with the literature describing motor planning deficits (dyspraxia) as being a prominent if not a core feature of autism (Dziuk et al., 2007; Fournier et al., 2010; Gowen & Hamilton, 2012; MacNeil & Mostofsky, 2010; Ming et al., 2007), although *basic* motor tone and control *appeared* to be unimpaired for Tim in these baseline exercises, motor *planning* is known to be difficult for him, which could very well apply to his overall difficulties planning where his finger needs to move to correctly sequence letters. Rubin (Biklen et al., 2005, p. 96) explained

trying to point to answers on non-language items in testing, saying, “Although I know in my head what shapes might correlate I find it difficult to make my hand point to the right answer, the action I will my hand to take is not always what really occurs.” Jamie Burke (Biklen et al., 2005, p. 252) described not being able to stop himself from pointing to cereal as his breakfast choice every morning whether he wanted it or not. Lucy Blackman (1999, p. 41) described running in circles in response to someone expressing concern about her wellbeing even though that is not at all how she wanted to be responding. Alberto Frugone (Biklen et al., 2005, p. 187) described not being able to make his finger push the button to open the car window even though he mentally knew what to do. Sue Rubin (Rubin et al., 2001, p. 423) related, “All and each awful movement is difficult. ... We have problems when we try to purposefully plan our movements.”

It is also apparent that Tim uses peripheral vision, has trouble with oculomotor control has sensory disturbances, although it is not known exactly which of the many possible disturbances he experiences. His auditory and tactile hypersensitivities are apparent. Does he also experience synesthesia or monochanneling? Does he perceive in fragments? Rubin (Biklen et al., 2005, p. 89) described seeing in fragments, although she was able to make sense out of the fragments she saw: “I see words on a page in pieces and then my mind connects them the way it should to make sense as a whole.” Some, however, as described by Williams (1999, p. 70), see or hear in fragments, but then cannot connect the pieces correctly, resulting in “I would hear it in bits and the way my mind had segmented their sentence into words left me with a strand and sometimes unintelligible message.”

Thus, typing from copy might be more difficult than typing from spontaneous thought given that it involves another task dimension. It might also be more difficult if there is an oculomotor control deficit impairing visual sequencing and/or visual attention, and/or if there is



an unusual visual perceptual phenomenon such as stimuli being perceived in fragments or vision being forfeited for another sensory system demand.

If the results of standardized tests must be questioned on the basis of the existence of uncertain complicating features of autism for which they have not been designed or standardized, what is the point of administering standardized tests? Why did I administer the PPVT under standardized protocol? Because, these are the tests and the protocols that are currently upheld for use with autistics even though the results probably do not provide an accurate assessment of ability level – a catch 22 to be sure. Having followed standardized protocol does, however, provide a baseline to which further evaluations may be compared.

### **Quantitative Analysis of Test Results**

Tim's inability, up until the last day, to answer most controlled questions was consistent with findings from the majority of past quantitative studies showing that communicators cannot convey information or provide answers to questions unknown to the facilitators (Bebko, Perry, & Bryson, 1996; Eberlin, McConnachie, Ibel, & Volpe, 1993; Hudson, Melita, & Arnold, 1993; Montee, Miltenberger, & Wittrock, 1995; Moore, Donovan, Hudson, Dykstra, & Lawrence, 1993; Mostert, 2001; Shane & Kearns, 1994; Wheeler, Jacobson, Paglieri, & Schwartz, 1993). For the first three days (or six sub-sessions) of homework testing, Tim could type the school subject – although inconsistently when challenged or asked repeatedly – but could not answer questions regarding the general nature or the specific topic of the assignment.

A strictly quantitative analysis of the *supplemental* sessions is no more clarifying. Questions in this section asked for information supposedly unknown to the facilitators. If that was indeed the case, the results showing Tim earned 64% of the possible total points argue for at least some authorship by him. However, there was some chance in those sessions of facilitators

guessing or at least being able to narrow the scope of possible answers. For example, all of Tim's aides knew he loves to eat, so, "go to eat" and "go eat yogurt" in response to "What do you want to do with Karen this weekend?" in the first supplemental session would have been a reasonable conjecture. Likewise, Tim was attending his first school dance the night of the second supplemental session; therefore, although Mike did challenge Tim with other options and pressed Tim to be definite about his answer, "the dance" would have been a reasonable guess in answer to, "What were you and your dad just discussing?" There were also somewhat limited options as to where Karen might have taken Tim Saturday morning (Supplemental Session 3). Although the remaining answers typed with the facilitator in both sessions were reasonable and logical – he was most excited about the "music" and was most afraid about "all the people" – they did not match the answers typed with the assistant – Tim was most excited about "being normal" and most afraid of "not having someone to dance with" – and thus were counted to be incorrect. However, that does not mean Tim did not type those answers. First, the phrasing of the questions did not make it clear that Mike was asking Tim to repeat the same responses he had given to his dad: "What were you talking to your dad about that was most exciting, or that you were looking forward to? Tell me what that was," and "What is scary about what you were talking about?" In addition, Tim may have processed the last part of the question, asking about what was most exciting or what he was most looking forward to, without processing the first part: "What were you talking to your dad about..."

This, again, may demonstrate Tim receiving and/or processing only part of the information, receiving it in disjointed fragments, or receiving it in asynchronous timing. Bogdashina (2016) describes this process as processing in fragments, whereas Williams (1994) describes fragmentation as being another form of "Mono:"

...one can process a sentence about what John did, as long as John remains the central or only object. 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 or the part about the dog gets processed and the part about John gets aborted as useless information. "Mono" happens on every information level. (p. 197)

Both Bogdashina's and Williams's descriptions are of processes explaining behaviors that would traditionally be interpreted as facilitator influence or as Tim's distractibility or inattention.

### **Controlled Testing**

Under the controlled conditions implemented for homework testing, Tim typed the school subject (although changed the answer when asked repeatedly), typed the correct name of the history teacher on the second attempt, and ultimately came very close, after several days, to typing the correct topic of the political cartoon. The crucial questions, of course, are "*Did Tim type those answers?*" and if he did, "*How, why, and what changed to enable him to type the words after he had struggled with the whole process up to that point?*"

A traditional approach would conclude that Tim most likely did not type the answers, and the quantitative data from this study are yet one more example in a long history of studies exemplifying that facilitated communication does not allow communicators to type their own thoughts independent of facilitator influence. There were sections during the test sessions when facilitator influence and even full facilitator control appeared to be evident, as when Alex seemed to dominate choosing the topic for the cartoon and seemed to guide Tim's typing as Tim practiced the answers before the blinded facilitator arrived.

In addition, it might be argued that the facilitator (Dad) had somehow learned the answers by the last day, either figuring them out or perhaps finding them inadvertently left

visible on the computer screen. Several points might support this possibility. First, Dad did not question that the answer given for the name of the teacher was different in Session 4a than it had been in Session 4. Perhaps he had not paid close attention and therefore did not notice the name changed, or perhaps he had learned who the teacher was by Session 4a and so typed the correct name. Then, at the end of Session 4a Dad's manner and voice both indicated that he felt more certain they were finished, this being exemplified in his saying Mom would come in and work some English with him (Tim) rather than saying he would go check the answers and be back as he had previously. Perhaps Dad sounded more confident about the correctness of the cartoon topic typed in Session 4a because it simply sounded like a more plausible possibility; or, since the answers were typed more quickly and more easily than in prior attempts, perhaps Dad assumed that to mean Tim was finally able to type the correct answer (if Tim was doing the typing). Yet, perhaps Dad sounded more certain because he *had* figured out the answers (either consciously or subconsciously), and therefore *knew* (consciously or subconsciously) they were correct. Critics would argue this was certainly the case. However, one would think if Dad had even subconsciously typed the answers, he would have been less obvious about it and would have continued in the previous pattern of guiding (if that's what he was doing previously) Tim's hand haltingly, with mistakes, start-overs, perseverations, and typos. When I asked him directly if he had in any way figured out or learned the answers by the last session, he said he had not, and I do not believe this person would have lied.

Let's entertain the idea that Tim did type the final cartoon topic, and again ask "why, how, and what changed to enable him to do so," and inherent in that question, "why had he been unable to do so on previous days?"

**Design elements of controlled testing.** One criticism of controlled testing of facilitated communication has been that imposition of unnatural testing circumstances and settings increases anxiety for communicators and hinders their ability to type. Biklen (1990, 1992) and Crossley (1992) stressed the importance of maintaining a naturalistic environment and test-free atmosphere when evaluating the validity of FC, noting that individuals have difficulty performing under stress and test conditions or under any circumstances when they feel their competence is being questioned. Therefore, in attempting to maintain as natural a setting as possible and minimize imposed changes, this testing was designed around an activity Tim did regularly – his homework — in the two specific locations in his home where he typically did his homework.

In spite of my best efforts, however, it was not possible to disguise that these sessions were different from Tim’s usual approach to doing homework. First, Tim was immediately upset with the initial attempts to document sessions with a video recorder, thereby putting an end to that endeavor. Although sessions were no longer video recorded, the attempt had contributed to Tim’s stress over working on homework in an evaluation setting. Changing facilitators in the middle of each homework session and being asked specific questions about his homework rather than working collaboratively were also out of the norm for how homework sessions were typically conducted. In addition to facilitators alternately entering and leaving the room to work with him, Tim was also being asked to work with different facilitators on history homework in particular with whom he usually did not do history, a change previously described as being difficult for him.

Even though Tim had agreed to participate in the study and had expressed wanting to help people understand autism, the high levels of anxiety he experiences with any form of being

tested or “judged” seemed to be triggered (as conveyed by his behaviors and by his reporting through facilitated communication) by my presence and by knowing that his ability to communicate was being tested. The *idea* of being in a study and the *reality* of being in a situation where his ability to communicate was under scrutiny probably felt entirely different.

**Anxiety.** All facilitators and both parents believed the decrease in Tim’s anxiety because of his having developed a greater sense of trust and relationship with the investigator was absolutely instrumental in his gaining the confidence to type. As described under *Primary participant* in the Methods section, anxiety was reported to be a major issue for Tim and an impediment to his ability to type. Establishing trust was reported by all as being essential to his being able to overcome that anxiety with new people.

Although I had known this family for years, they had moved away when Tim was seven years old, and I had seen him only occasionally over the past ten years. As fate would have it, on the evening I arrived to begin this testing, Mom had just returned home from having been away for a week – and she was quite ill. Had I been scheduled to arrive a day later, the trip would again have been cancelled. As it was, I was there, so we proceeded. With Mom in bed, I took over the shopping and cooking, serving, cleaning up, and having meals with Tim, his dad, and whichever facilitators happened to be present at the time. I also went to the school dance with Tim and his dad – Tim’s first school dance! Mom believes it was because of those days I spent taking care of the family that Tim finally gained enough trust in me to decide to communicate on the last day. When asked separately, the facilitators also stated they thought the change on the last day was based on my having earned Tim’s trust *and* his having had a few days to practice with the approach we were using. They stressed how difficult new situations were for Tim and how “resistant and stubborn” he could be even under the best of circumstances. It would have

been informative to have been able to extend testing to see if the ability demonstrated on the last day would have been sustained. Due to scheduling, however, that was again not possible.

Later, after the testing was completed, in talking to his social skills aide/facilitator, who had not been involved in the testing and with whom I had had very little contact, I learned that Tim had typed to her that he thought I now questioned him and his abilities whereas I never had before. On the occasions I had seen the family over the years, including this time, Tim had always been noticeably excited to see me when I arrived, and according to his mom, this was because he said (typed) that I had always believed in him. Now he questioned that. What is a bit amazing is, it was true. Based on his demonstrations of cleverness when I knew him as a young child and his narrative interactions with parents and facilitators which mom had occasionally related to me over the years, I had never before questioned the authenticity of his communications nor the existence of his inherent intellect.

However, although I was still having a hard time fully admitting it even to myself, based on the facilitated communication literature I had read in developing the literature review (I had not yet read the sensorimotor or neuroconnectivity literature), by the time I arrived to begin testing, I had developed serious doubts about the validity of facilitated communication.

Tim had always been highly sensitive, almost intuitively so, to the attitudes and opinions of others. There is no question he could have sensed the change in me. Williams (1994) observed, “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” (p. 197). And from my experience and incidents related by his mom, Tim sensed far more than “brick walls.”

In retrospect I recognized that I had also been suppressing a guilty sentiment that anxiety alone could not really be responsible for completely interfering with and shutting down anyone's ability to type. I pushed those doubts even further down when Tim's mom told me that his anxiety could be severe enough to cause him to completely "freeze up." I suspect those who have never experienced test or performance or social anxiety might well have the same doubts I had. "Surely," one might think, "anxious people can still take the test/give their speech/go to the dance – they just might be more uncomfortable and not do as well as they would without anxiety;" or, "anxious individuals should still be able to give their presentation if they just practice enough ahead of time, even if they stumble, shake, stutter, and sweat their way through it." Then, again in retrospect, I recalled my own childhood, young adulthood, and even times in adulthood when I had frozen, gone blank, been unable to function in the face of performance anxiety, and I recalled clients who said they could not go to restaurants or bars because of their social anxiety, and I realized that, yes, anxiety can absolutely interfere to the extent of completely impeding performance including the ability to type under pressure.

Williams (1994), in discussing how people often blunder awkwardly and insensitively through their interactions with autistics based on their misunderstandings of autistic persons' methods (behaviors) of adapting to the chaos in their bodies or, as in my case at the time, based on doubts about their intelligence and abilities, described that autistics learn to sense how others perceive them. Williams described these people as interfering

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. (p. 197)



At the beginning of this project, after reading the inspiring accounts of severely affected autistic individuals in Biklen's (2005) *Autism and the Myth of the Person Alone*, and before I had begun to read the literature on controlled testing of facilitated communication, I fought to guard against being biased in favor of facilitated communication's potential. Then, in reading the negative results of early controlled testing and the continuing and recent attacks against facilitated communication by some authors (Chan & Nankervis, 2014; Heinzen et al., 2016; Lilienfeld et al., 2014; Mostert, 2012; Travers et al., 2014; Wagner et al., 2003; Wombles, 2014), I first responded with anger and dismay, but then with growing bias against its authenticity. After years of unquestioningly treating Tim respectfully and "normally," although I certainly continued to attempt to project those same attitudes, I seemed to have arrived this time with shovel and hoe and clumsy, oversized garden gloves.

In addition, it was this investigator's impression that the facilitators also felt some pressure to make sure Tim produced results in a reasonably timely fashion, and likely conveyed that sense of pressure to Tim. Rather than taking time to talk with Tim about concerns he raised (through facilitation) such as when he asked Alex if he would be staying after finishing homework, when he was displaying anxiety through vocalizing and hitting the table, or when he expressed fears about the dance, those concerns were addressed only briefly before returning to the assignment. It is possible that was typical, but the pressure to keep moving and the frustration facilitators demonstrated with Tim's failure to type answers were easily discernable and therefore probably easily felt by Tim.

**Practice.** The importance of practice with any new method, technique, or protocol has been emphasized in previous studies (Biklen, 1990; Cardinal et al., 1997; Crossley, 1992) and by the Institute on Communication and Inclusion (ICI, n.d.) as stated in their document,

“Fundamental Principles and Best Practices.” I had attempted to schedule sessions over several months to allow practice time between sessions. It had been hoped that the family would be able to practice having Tim do his homework using the design of the testing protocol. This would have required facilitators to be blinded to the nature and content of homework material, or to have a different facilitator assist Tim in completing the homework than the one who had reviewed his homework with him – neither of which was their typical approach. Unfortunately, due to family circumstances, these approaches to homework using blinded conditions were not implemented prior to testing.

In a related aspect of practice, it was not until the last review session that Alex seemed to finally insist that *Tim* take control of his typing when practicing the answers before having the facilitator come in. This did not occur until the fifth day of my stay, the fourth day of homework testing, and only the second day of Alex reviewing these specific questions with Tim. In addition, it did seem that Alex rather than Tim had selected the topic, and it is therefore unclear if Tim knew anything about the Target bathroom boycott, the issues around bathroom boycotts in general, or even knew what a boycott was. If any of these were unfamiliar to him, it would make sense that he would have needed time to work with the topic.

The facilitators and parents expressed that the factors leading to the decrease in Tim’s anxiety – passage of enough time to allow building trust in the investigator and to allow Tim to practice and become familiar with a new homework protocol – were the biggest factors in his finally being able to type correct homework answers during sessions 4a and 5a on the fifth and final day of my visit. It would have been extremely helpful and informative to have been able to extend testing for at least one more day to verify whether or not success continued. Analysis of the answers provided in a more relaxed atmosphere, yet with facilitators still blinded to the

information requested as was established in the supplementary sessions, yielded more correct answers, but again with lingering questions of facilitators possibly being able to guess answers.

### **Qualitative Discussion of Narratives**

Qualitative analysis of the narratives, although not settling the issue of the authenticity of Tim's typing, does provide thought-provoking material. The narratives are rich in demonstrations of very likely facilitator control and over-functioning, but also in very likely authentic typing by Tim, ultimately raising more questions than providing answers.

**Typos.** Typos – created by striking incorrect keys – in and of themselves did not in this case appear to provide evidence for or against authenticity of authorship. No specific pattern of inserted, omitted, or substituted letters emerged, with total incorrect strikes to the left versus the right (24 and 23) being essentially equal and insertions occurring before versus after the intended letters also being essentially equal (9 and 8). There were fewer vertical than horizontal errors (9 and 47), which would seem logical based on the orientation and proximity of keys on the keyboard, and fewer insertions made above the intended letter than below (3 and 6), which might also be logical if low muscle tone or “muscular laziness” were a factor, which is unknown. There were more substitutions of letters (40) than added insertions (25) or omissions (29), which is a little surprising, as it seems it would be easier to add letters by simultaneously hitting an adjacent key to the intended key rather than completely missing the intended key and substituting an adjacent key instead. It is noteworthy that an equal number of letter omissions was made in the middle of words as at the end of words.

It seems reasonable that, if exerting any control over his own typing, Tim could easily have struck keys adjacent to keys he intended to strike, particularly because it was apparent that the typing process was slow and laborious for him, and therefore the level of attention and focus

required for him to hit intended keys over a period of time would be substantial. It might be deduced that Tim's ability to strike correct keys in the independent typing trial might indicate that he could perform better by typing independently than with facilitation. However, the trial of independent typing was very limited in duration, it differed in being typing from copy rather than from thought development (although as noted earlier, it might be argued that typing from copy could be more difficult than typing from thought content), and his accuracy also decreased when advancing from typing individual letters to typing words and sentences; as noted, his problems seemed to lie in issues beyond basic motor control.

It also seems reasonable that if the facilitators were inadvertently guiding Tim's hand, particularly if doing so through a subconscious ideomotor effect, they might have guided that hand to a close proximity of, but then stopped short of moving or forcing the finger to the exact key desired. However, if facilitators were guiding his hand, one would not expect the prevalence of typos that occurred, would not expect facilitators' reactions of surprise, frustration, or skepticism over things Tim typed, and would not expect requests for clarification of words or their finally deciphering that some words they initially thought to be nonsense were not nonsense at all. One would think facilitators would stop short of allowing key miss-strikes to reach the point of composing words that were unintelligible even to them.

**Narrative day 1, Session 1.** Evaluation of specific narratives is rich in both evidence for facilitator influence and for independent typing.

Evidence against: Knowing in the first homework session that the assignment was to design a political cartoon for history, Dad was the one proposing the specific ideas that might be included – Julian Assange and wikileaks, the East German Stasi – with Tim simply agreeing with

his proposals; but then, was Tim really agreeing, was he just perseverating in typing “yes,” or was that Dad typing “yes” for him? But wait –

Evidence for: Tim was the one who proposed the main topic: “Peoplw are listemig.” Why was it unlikely that Dad influenced that typing? Because, it was the example used in class. When asked later, Dad said he had not known that; and, if he *had* known it, it is highly doubtful he would have proposed it as a topic, knowing or at least suspecting that students could not use the class example as their own project idea. The notion that Dad might have coincidently come up with the same topic used as the example in class is just too far a stretch of coincidence.

Evidence against: Once the topic was chosen, however, it is possible, after asking Tim if he knew of a book demonstrating the idea of people listening in on others, Dad unknowingly and inadvertently guided Tim’s hand to approximate typing “1984” in typing “1972.”

Evidence for: But, if Dad was going to inadvertently guide his hand, why wouldn’t he have “inadvertently” typed “1984” rather than “1972” to begin with? And, why would Dad have typed “orwe” instead of “Orwell” in answer to “Do you know who wrote that book?” and why would Dad have sounded surprised that Tim knew the author? Furthermore, when Tim answered that, yes, he had read the book, Dad sounded skeptical: “You’ve really; you’ve read 1984?” Then to Tim’s “yes,” Dad challenged, “When did you read 1984? Did you ever really read it or did they talk about it?” Why would Dad have challenged/questioned Tim’s responses if Dad had influenced writing them? But wait ---

Evidence against: --- if the topic was truly proposed by Tim rather than Dad (even though it *was* the class example), and if Tim really knew the topic well enough to type “1984” (or rather 1972) and say that he knew about Julian Assange and wikileaks, why couldn’t he type that information with his mom as the facilitator?

Evidence for: Later in the same discussion, Dad asked Tim if he knew about ISIL. When Tim typed “yes,” Dad asked, “Who are they?” Tim typed, “yhey RE ecil” (they are evil). Dad challenged this in a very personal way, providing strong evidence that Dad would not have typed that particular response: “Evil. Well, they’re Muslims, and we come from a Muslim power; are we evil?” After Tim responded “no,” Dad continued: “And can there be people from groups that share, and do you think they share our values? What do you think?” Tim reiterated (but this time with different typos): “ggthey csn e eil” (they can be evil; see Appendix D for typo specifics). If Dad was influencing Tim’s typing, he more likely would have typed some simple answer to the question about shared values – even a yes or no answer. Finally, when Dad finished the review with Tim and was preparing to leave, he asked (paraphrased): “Could you type those answers with Mom without her knowing what’s going on?” If Dad were guiding Tim’s hand, he probably would have guided him to type “yes” rather than “no” in response to that question.

Equivocal evidence: Ah, but then Dad leaves and Mom comes in. Mom’s first words seem to indicate that either she is nervous, she knows Tim is nervous, or she does not think Tim will be able to answer the questions: “Come on; you’re okay. We don’t care. We don’t care. Alright? Love you.” It sounds like either deep in her heart, Mom knows Tim is not the one doing his typing, or she feels strongly that he does do his own typing (at least some, or maybe most of it), but she anticipates he will not be able to type under these circumstances. She continues: “Okay, what subject? What subject is it in?” Tim types “history.” Mom follows that with “What is your project?” Tim is typing, but Mom does not understand what he typed (that typing was unfortunately not saved), so Mom continues: “It’s okay; it’s not a word, Babe. What’s your project? Hhh?” Also, unfortunately, Mom spoke very quietly, so other than the word “picture,”

most of this short section of the recording was inaudible, so that word, *picture*, although possibly correct, was not counted.

When “What’s your project” was repeated several more times, Tim typed “science,” and then, “acid rain on lime.” There are a couple of explanations for Tim now typing “science” after he had already typed “history.” First, Mom did not make any response to his having typed “history.” Rather, she went straight to the next question, “What is your project?” It is possible that Tim associates the word project with science, and so told mom about the science project he had done. Mom did not ask what his assignment was; she asked what his project was. Dad also thought this might be a possible source of confusion for Tim, so reworded that question when he returned to go back over the material.

Evidence for: Although “acid rain on lime” was not the correct answer for this assignment, it was information relayed to Mom that she reportedly did not know. As noted, Mom had just returned home that evening after being gone for a week. During that time, according to the school facilitator and Dad, acid rain and its corrosive properties was the subject being studied in science. It is possible – critics would argue – that Mom must have somehow known that. Dad must have mentioned it during a phone conversation or... something. However, excerpts from Dad’s next comments indicate how excited he was that Tim had conveyed unknown information to Mom.

Dad:... cause you’re absolutely right; now the amazing thing is, Mom was out of town, and I haven’t told her yet what your science is – so you were right! You told her! You independently gave her information. You did that. I’m excited. I bet Mom’s excited, too. So, I’m gonna rewrite the questions. (Wednesday recording, p. 7)

Evidence against: However, the very fact that Dad *was* so excited that Tim conveyed information assumed to have been unknown to Mom perhaps indicates that this was not a common occurrence. However, perhaps Dad was excited because Tim was able to give that information under a stressful, controlled situation. Dad returned to review the information with Tim, with Tim being able to type “history” and “picture” again with Dad. Then, attempting to eliminate any ambiguity in the way the questions were phrased, Dad rewrote them and reviewed them with Tim. Mom then returned, and this time in response to her asking, “What were you and Dad talking about? What was the subject,” Tim typed [engllsh] followed by [lost in space]. When Mom asked, “Was this the homework?” Tim typed [ask what you would need in space].

These answers were completely unrelated to this assignment, and Alex, the school facilitator, said he was not aware of them being discussed in any of Tim’s classes. It is possible that since Mom was asking the same question again – “What is the subject?” – Tim may have assumed he hadn’t given her the right answer before (history), so changed it to English. On the other hand, he (or Mom) may have been completely guessing since he had by now typed “History,” “Science,” and “English” as being the subject.

In typing “lost,” it is also possible that Tim was attempting to begin typing *list* [ening], but substituted *o* left of *i*. Then, with the visual feedback of seeing *lost*, jumped to a thought association, and switched to typing something related to *lost*. Grandin (2006) described her frequent associative thought patterning:

If I let my mind wander, the video jumps in a kind of free association from fence construction to a particular welding shop where I’ve seen posts being cut and Old John, the welder, making gates. If I continue thinking about Old John welding a gate, the video image changes to a series of short scenes of building gates on several projects I’ve



worked on. Each video memory triggers another in this associative fashion, and my daydreams may wander far from the design problem. The next image may be of having a good time listening to John and the construction crew tell war stories, such as the time the backhoe dug into a nest of rattlesnakes and the machine was abandoned for two weeks because everybody was afraid to go near it.... People with more severe autism have difficulty stopping endless associations. (p. 9)

On the other hand, Mom may have inadvertently made up a completely new topic, or she may have subconsciously taken control after seeing the word *lost*, and finished what she thought Tim might be trying to type.

**Other factors.** Additional factors that must be considered in qualitative evaluation of narratives include vocal intonations of surprise or frustration captured on the audio recordings in response to something Tim typed, the clarifications facilitators requested of Tim in trying to understand what he meant, facilitators/assistants disagreeing with or challenging something Tim typed, or the different answers Tim gave to the same question (recalling that only the first answer was accepted in the quantitative analysis). There are many examples of the coded themes in the results section. A few will be presented and discussed here, using the same key that was applied in Table 3.

- ( ) Parentheses in any text: (Tim’s vocalizations or behaviors) or (Comment by researcher)
- [“ ”] Quotations within brackets embedded in facilitators’/assistants’ texts: Tim’s typing read aloud.
- Quotations within assistant’s or facilitator’s texts: they are reading “Tim’s typing” aloud
- Three dots (...): omitted words or sentences not contributing to evidence

- Commas between letters or words when Tim's typing is read aloud designate letters being called out individually or read as a word
- Facilitated communication will be abbreviated as FC in this section

**Thursday, Session 2.**

**Anxiety.** Anxiety and restlessness/inattention were common throughout the days of testing as documented in the results section, perhaps because Tim was anxious about his communication being tested or perhaps because he just did not want to be doing homework. Only one example will be presented here from *Homework Session 2* (Thursday) demonstrating Tim's anxiety as vocalizations and galloping across the room:

(MMMMmmm MMMMMmmm Mmmmm MMmmmm MMmmmm; Galloping, galloping).

Alex: What's wrong? (MMmm) What's wrong? (mmmm MMm mmm Mm) Water? (Mmm)

What's wrong? Do you want to get some water? No? Okay. Hey! We have to, we're gonna sit down and talk about, like, some subject and about Nancy like you did last night.

(MMmmmm) Okay? (MMmmmm) So sit. So, here. (MmmmmMMmmmm) Sit. Have a seat. No, come here. (MM) We're gonna sit right here, (MMmmmm mmm) Okay. (mmm Mmmmm Mmmmmmm Mmmmm Mmm) Come on, T. Come here. (Mmmmm) Okay, T, come here. Come here. (mmmm mmmmm).

**Facilitator over-control.** Alex proceeded, working to keep Tim's attention. This narrative exemplifies Alex's selection of the topic and consistent control of the facilitation until the last sessions (Sessions 4a, 5, and 5a) when he insisted on Tim taking control:

Alex: Alright; alright, sir; so, we're gonna, we're gonna talk about, and I know you know what's going on; okay; so, I think we're gonna talk about the, (mmm) world history; the political cartoons that; not the one we did before; the one we're creating. Okay, so.

(Mmm Mmm) Come here. (m) Come here. Come here (mm). Okay, so we're gonna do three questions, and they're gonna be three questions that Mike's gonna come back and he's gonna ask you exactly what I've written down, (mmm) exa..., here, and you need to give Mike, you need to tell Mike the exact answer that we get. Okay, so I'm thinkin we'll, we'll generalize the first one; so, I wrote down, so I'm thinkin that we're gonna do World History class.

Tim responded with likely echolalia or rote agreement: "Kaa" (following "class") and "Okay" (following Alex saying "okay"). Alex continued by asking Tim which school subject he would tell Mike he is working on. When Tim fails to give a solid answer, Alex continues. "It's gonna be, so, it's gonna be World History." Tim again responded with, "okay," and then got up to leave as if they were finished. He was not at all engaged. Tim then left to use the restroom, but still could not settle down when he returned. Alex proceeded, seemingly continuing to do all of the work:

Alex: Hey. Come here, T., come here. Let's finish, get your chair up... Come here. Come sit down. (mmm mmm) So, wo, ho, wait (m); so the first question we have that when Mike comes in he's going to read to you this question. (m) The first one is "What subject did you and Alex just talk about?" and your answer's gonna be, no, what is your, what is the answer to what class? We were talking about World History, correct? Okay, so, your answer's gonna be World History for that first one. (mmm) Then, he's gonna ask you a second question that has to pertain to World History. (mMm) Okay, hold on. He's gonna come in and ask you the second question and it's gonna be "In the class you said in the previous question, (mm) what is the particular assignment you are working on? And

the particular assignment that we're working on for World History is going to be creating, it's gonna be a (mmm) political cartoon, right? Okay. (mmMMm)

Alex was typing out the questions to leave for Mike during these exchanges. Alex then opened a browser page looking for examples of political cartoons.

Alex: Alright, sir. So, we need to come up with an idea for the political cartoon. Yea, so ... let's google and see if we can find (mm) a particular one that you enjoy. Okay, so, no, sit here. ... Let's see, what can we find inside of here? K, so let's look at here.

It sounded and appeared that Alex chose the topic, then asked Tim if he was familiar with it:

Alex: Okay, do you, hold on here; have you read or heard about, this, not this scandal, but the issue going on with the store Target and their restroom?

Without checking for perseveration, Alex then accepted Tim's answer of "yes" to that question as well as to the next two questions: "So, do you think that that could be turned into a political cartoon?" and "Okay, so would you like to have that as your answer?" Alex then verbally reviewed the three questions Mike would ask Tim and the answers Tim was to type with Mike. Alex then posed each question individually to Tim and had Tim type the answers with Alex facilitating. Based on Tim's perfectly-typed answers to these questions and on other narrative evidence, it is very likely that Alex's influence was predominant if not complete over Tim's typing. Alex did not seem to be aware of his influence as he congratulated Tim on his answers: "Yes, sir; good work" to the typed answer, "World History;" "great" to the answer "political cartoon;" and "'The Target bathroom boycott' is exactly correct" to "What is the particular topic of the assignment you are working on?" When Alex finished the review, he left, and Mike returned. Even though Tim answered each question perfectly with Alex, he was only able to type the subject, "history" with Mike.

The session just reviewed occurred on Thursday, and Alex did not return again until Sunday. Since Alex and the investigator were the only ones who knew the topic –*Target Bathroom Boycott* – and Tim could not relay that to any of the other facilitators, it did not come up again until Sunday. To be continued...

**Linguistic process analysis.** Returning to day 1, Session 1, in which Dad knew the school subject and the nature of the general assignment, he first asked Tim for the school subject. Within their usual *modus operandi*, Dad, as well as the other facilitators, would have accepted Tim’s response of “hrt” to be “history,” as both Mike and Dad said Tim sometimes abbreviated words, and it is unlikely “hrt” would have indicated English, Math, or Science. In fact, the degree of effort and time required for Tim to type without abbreviating is, in itself, an indication that he is doing the typing. For testing, the facilitators asked Tim to spell his answers out fully. Therefore, if Dad were guiding Tim’s hand, one would think he would have typed history as a complete word to begin with.

As already established, it sounded and appeared as though Dad proposed the specific ideas in Session 1 for the topic *Peoplw are listemig*. However, in evaluating the context in which Dad proposed those ideas, if we attribute the main idea – *People are Listening* – to Tim, Dad’s responses of interest and curiosity would indicate that he truly did not know whether or not Tim knew anything about the specific ideas he, Dad, was proposing: “Hmm, do you know who Julian Assange is?” When Tim answered, “yes,” Dad responded with surprise: “You do?!” Then Dad challenged, “Who is he?” Tim responded, “Wi,” (again abbreviated). Dad chuckled softly, seemingly indicating he wasn’t expecting Tim to have known who Julian Assange was, and then said, “Huh, Wiki, you’re right.”

Thursday, Session 2: This was from the same review sub-session from which the excerpt indicating Alex's influence was extracted and discussed above. Tim could not relate anything to Mike other than the school subject being history. However, the exchanges between Mike and Tim are revealing. Mike was very direct with Tim and insisted that he pay attention to the keyboard and to what he was typing. Mike was accustomed to communicating daily with Tim; they had known each other for more than four years, played sports together, and gone on trips together.

Mike: Alright, let's see... you know you're answering these questions with me. Got it? Okay. You're going to have to type accurately, though ... I know sometimes you just slide through stuff... Oh, you have a question before we do this.

Tim: ["yes."]

Mike: K, and what's your question? (Long pause with Tim typing; Mike coaches Tim to watch what he's typing). Look what you're typing. You have ["w, i, p"]. (About 30 seconds more typing, then) ["Wipe this."] No, we're answering these questions. K? Are you willing to do that? ["yes"] Alright, so what did you and Alex just talk about; a subject? ["yes"] Alright; what was it? ["h"] I want you to focus. (One minute for Tim to type ["history"]) You guys talked about history?

Tim: yes

Mike: You're sure. You and Alex just talked about history?

Tim: yes

Mike consistently questioned Tim and checked for perseverance, which was prevalent in Tim's "yes" answers. It was unlikely that Mike would keep typing "yes" when he clearly became frustrated with Tim typing it. It is also unlikely that Mike would even inadvertently type a

question in response to his own question asking about the assignment; nor would he probably have perseverated on letters (p and r), and he would not have intervened with “start over cause that’s not a word,” and again, “that’s not a word”:

Mike: (Mike deep sigh) Okay, (Mike sighing), in the class you answered in the previous question – so, history (Tim: mm huh; sounded like agreement) – what is the assignment you were working on? ... [“yes.”] You told me “yes” several times now. What is the assignment that you are working on then? [“yes”] Okay, “yes” isn’t an assignment. What is the assignment that you’re working on? [“A”] Okay, start over, ‘cause that’s not a word. [“i, s, is, t, h, this, for, for, a, is this for a, p r, pr, prrr, prr,”] You got two r’s there. [“Prr, r.”] That’s not a word. [“Pr, Prac”] (long pause typing) [“Is this for a practice paper?”]

It took Tim two minutes to type that question – “Is this a practice paper?” It seems unlikely Mike would have typed or influenced typing perseverations of “yes,” would have asked if this was for a practice paper, would have taken two minutes to type it if he had, or would have followed “his own question,” even if he had typed it inadvertently, with the following:

Mike: I don’t know what that means. We are practicing. We’re practicing your typing (MMmmm). That’s what this is practice for, and you have two questions to do. (Um mm) Cool? K; we’re practicing, and that’s what we’re doin. Okay, so, what is the assignment that you’re working on? ... [“T, a, t,a,q”] It’s not a word; at least I don’t think it’s a word. [“T, a, test”] or [“tast”] Did you mean test? [“No.”] The only thing I can think of with that is that you did a test today. That’s not what we’re talking about. Not what you worked on in school today. What did you work on, er, what assignment are you working on in history that you just talked to Alex about?

Tim: yes

Mike: Okay. What is that assignment? Can you type it?

Tim: “m hmm” (vocalized)

Comment: Mike was very frustrated at this point. By report, he was accustomed to being able to communicate with Tim consistently throughout each day, although whether he was actually guiding all of Tim’s typing and therefore actually communicating with himself, cannot be answered with certainty. Mike continued: “Okay, then do it! [“T, a”] That’s not a word, Bud. [“T, a, s”] ... This is what you wrote: [“T, a, s, a, a, s”]. That’s not a word.

Mike continued sounding frustrated through a few more exchanges of “yes,” then read:

[“P, a, e” or “P, a, p, e, r, paper; paper; on; paper on? Paper on, w, paper on, w”] kay,

[“paper on, p, a, p, p,a, p”] Do you want that p? [“p”] Okay, is this what you want

here?

Following a few more exchanges including “yeses,” Mike said, “Dude, if you keep typing “yes” over and over, we’re gonna be here all day.” Tim returned again to [“t,a”]. Mike: [“t, a, l, t, a, l, a, b, o, u, t, c, o, u, n, t, on countries”] Okay, paper on countries. This is very, it’s interesting. Mike sounded very much like he did not believe this answer. He repeated the question, and Tim answered [“y, a, w, o, n, t, l, wont”]. Mike challenged Tim (with frustration) that Tim was just hitting and deleting letters and typing “yes.” Then Mike said, “Bud! Are you gonna answer the question? Tim: [“yes”] Mike: “Okay, well, stop typing ‘yes’ and say something else ... What is the particular topic of the assignment you are working on in the class you just talked about?” Tim: [“Ask, him”]. Mike: “No; I’m asking you.”

It seems unlikely that a facilitator would type something like, “ask him,” and then respond in frustration with, “No, I’m asking you.” After another couple of short exchanges, Mike



continued: “Can you tell me what the particular topic of the assignment you were working on in the class you just talked to Alex about it is? Can you? I want ‘okay’ or ‘no.’ No more ‘Yeses.’”

Tim: “Okay” (Probable echolalia)

Mike: Then what is it?! Come on!

Mike reading Tim’s typing: [“A, s, k, a, a, ask, another, ask another question.”]

Mike: “I’m not asking another question. This is the question I have to ask.”

As above, it seems unlikely that Mike (or any facilitator) would type “ask another question” and then respond with “I’m not asking another question. This is the question I have to ask.” Mike continued: “Do not type ‘yes.’ Do not type ‘yes.’ Are you gonna be able to answer this?”

Tim: [no]

Mike: [“no.”] Why not?

Tim: [I ca t]

Mike: “You’re not gonna answer this question.”

Tim: [no]

Mike: “Alright. Well, (mmmm) that doesn’t mean you get to eat right now, though. Hold on a second. Wait right here.”

Alex returned to again review the questions and answers with Tim, again dominating the interaction, then having Tim type each answer once (which he accomplished easily with Alex facilitating). Again, the typing was very likely under strong influence by Alex. Mike then returned and obtained random answers from Tim. To “what is the topic of the assignment,” Tim typed “a, r, a research ... prpjecet” Tim was chuckling through this section.

Mike did not believe the assignment was a research project and said,

That's very vague. This says, "What is the particular topic?" So, what's the topic of the research project, then?" ["e, t, a"] "Stop tapping your finger; focus on typing; put our hand in your lap; come on. ["e, t, a, a"] I don't think that's a word. You got ["e, t, a, a, a."] I know it's not a word. Come on. (Hhhhh, Mike sighs) You need to back space something; I don't know how far, but...

Tim: ["That's it"]

Mike: "Well, you know what, Bud? I don't know what you guys talked about, but I know that's not it because this says 'what is the particular topic.' That is not a particular topic of anything. It's very vague."

After spending quite some time breaking through perseverations, Mike again asked, "What is the topic of your assignment?" to which Tim typed ["p, e, o; p, e, o? (hmmm) p, e, o, e"]. Mike: "That's not a word..."

Some of the letter repetitions are interesting. In response to, "What is the topic," or "What is the assignment?" Tim repeatedly returned to typing various combinations with the letters *t* and *a*: *t, a, q;* *t, a, s, t;* *t, a, s, a, a;* *t, a, l;* and *e, t, a, a*. One possible theory is that since it seemed clear that it was Alex who chose the topic, *Target bathroom boycott*, perhaps Tim knew nothing or very little about it. Perhaps Tim was trying to begin typing *Target*, but could not do it. Then, at the end of this session, perhaps giving up on "Target," Tim tried to return to "people are listening" with typing "p, e, o." Having no way to know what Tim might be attempting, rather than encouraging him, Mike responded by saying, "That's not a word."

The reader may refer to the Results section for additional narratives demonstrating Mike's interactions with and efforts to help Tim overcome perseverative typing of "yes." Mike also checked Tim's answer of "history" by challenging him by asking if the subject was math.

There is no indication that Mike understood the repetition of letters to also be perseverations or that perseverating was not under Tim's voluntary control.

Later, Mike returned to do a supplemental session in which he asked Tim what he wanted to do with Karen (Tim's weekend and social skills aid) on the weekend. After some back-and-forth discussion, Tim typed, ["go"]. Mike asked, "Go where?" Tim answered, ["go away"] to which Mike responded: "You wanna go away with Karen, or are you tellin' me to go away?" Tim: "Kae" (verbal). Mike: "You wanna go somewhere with Karen?" Tim: "ya" (verbal). If Mike had guided the typing of "go away" even inadvertently, it would have been unlikely for him to have then asked Tim to clarify if he (Tim) wanted him (Mike) to go away, or if he wanted to go away somewhere with Karen.

Although Mike did not seem to be influencing Tim's typing, even under these more casual conditions, Tim did not type the same answers with Alex that he had typed with Mike regarding what he wanted to do with Karen over the weekend. With Mike, he typed "to, to eat," then in answer to "Where do you want to go eat?" Tim typed, "Anywhere;" then to "After that?" he typed "go, to, swim." With Alex, in response to "What do you want to do with Karen this weekend, Tim typed "go eat yogurt, go hiking, go golfing."

#### **The final day, Session 4.**

*Evidence for.* The dynamic between Tim and Alex was different on the last day. After only about four minutes of Alex reviewing the school subject, the topic of the cartoon, and the teacher of the class, Alex began encouraging Tim to type: "Come on; come on; you got this; come on." Tim was chuckling, and in response to Alex asking him, "So, what is the subject? What's up? Ya alright? What's goin on?" rather than answering the questions, Tim asked his own question (Alex reading it aloud: ["home?"]) Alex responded, "Well, you are home." (Tim

still chuckling, vocalizing a lot, and typing, although unfortunately this section of typing was not saved.) Then, in response to something Tim typed, Alex then said, “Oh, me? I’m okay (Euu). We’re gonna get a little bit of work done. (Eeeeeuuuu Uuu uu Eeeeeuuuuuu Eeuuuuu) What?! (Eeeeeuuuu and TAPPING) It’s alright. (Eeuuuuu Eeuuu Euuuu) Alright. Then again reading Tim’s typing: [“Still stayin’ home”?] (Huh Euuuuuu Euuuu Euuuu). Well, if we get some of the homework stuff done, then I can. (Alex chuckling). Alright, so are you ready to start goin over it then?

This exchange sounds quite convincingly to be Tim’s typing. Alex, as before, seemed focused on getting the homework/testing done, so it is unlikely he would interrupt himself to ask an unrelated question, apparently about if he, Alex, would be staying there at Tim’s house for a while. In addition, there was a tone of surprise in Alex’s responses to Tim on these questions. Alex left, and Dad returned.

***Equivocal evidence: Sessions 4, 4a, 5, and 5a.*** Again, Dad had known from the beginning that the school subject was history and the nature of the assignment was a political cartoon. Dad still did not know the topic for the cartoon Tim and Alex had chosen, and Tim was not able to type it with Dad. He did type some other interesting responses, though. When Dad said, “I’m just curious, um, why are you nervous about this?” With Dad coaching him to watch the keys – “Look what you’re typing,” – Tim typed, [I don’t, feel, ready, to, be, independent.”] Dad responded, “Yea, I agree; you’re not totally ready to be independent, but you’re getting there.” They continued, and Tim then typed the topic of the cartoon to be [backcodads].

There is a possibility, particularly if Tim was not really familiar with the topic of bathroom boycotts, that *backcodads* might have been an attempt, with mixing letters from both

and adding others, at typing *bathroom* and *boycott*. It was clear that Alex chose the topic, and there is no way to know if Tim honestly knew anything about it. If he did not, that likely impacted the remainder of testing, requiring Tim to try to type a topic about an issue with which he was unfamiliar on top of the difficulties he already had with typing under testing conditions and with whichever sensorimotor issues are specific for him. When Dad asked him to explain a little bit about what that meant, Tim typed, [iy means I am penably not ging to verify] (it means I am probably not going to verify). If Dad were to have typed something along those lines, it is more likely he would have typed something like, “It means I can’t do this, it means I can’t tell you,” or “I don’t know.” It is just difficult to think why Dad would have typed (again even inadvertently), “It means I am penably not ging to verify.”

Dad then asked Tim to “concentrate really hard, ‘cause I don’t know. Think very carefully.” Tim then typed, [it is your proposal]. On first take, that might appear as though Dad were trying (inadvertently or not) to return to a topic about which he knew; however, Dad apparently did not understand what that meant, and asked for clarification: “My proposal, what was my proposal?” Tim typed, [the blmagk]. Dad asked him to try again, and Tim typed [it is about people who are itreting]. Dad guessed “itreting” to be “I’m trying?” Tim hit the table **(RAP)**; Dad exclaimed, “What?!” It was obvious Tim had not meant “I’m trying!” Based on Tim’s prior statement, [“it is your proposal”], if Dad were the one guiding the typing, it seems it would have been more reasonable for him to interpret *itreting* to mean *listening* rather than *I’m trying* in order to redirect the topic back to “People who are listening,” the topic they had discussed on day 1.

It is possible Tim really did mean to type “people who are entering public life,” although that would have been a random topic not previously discussed with anyone. Another possibility,

however, is that in his frustration with Dad guessing *itreting* to mean *I'm trying*, Tim may have become distracted in the middle of his thought and deviated from what he had set out to type. He had typed, "It's about people who are ..." Perhaps he had been intending to type "It's about people who are ... listening." When he next typed [pspic life], Dad responded with, "It's about people who are entering public life? Is that what you and Alex talked about?" It is also possible, based on what he typed in the next sub-session, that he had initially set out to type "people who are ... entering public ... bathrooms." Perhaps he made a word association based on having heard far more about *public life* than about *public bathrooms*.

Although Tim's meaning in typing, "It is your proposal," was never clarified, it does seem to be independent from any typing Dad would have influenced since Dad did not know what it meant either. Dad then said, "Alright, well let's go out; I'll double check with Alex."

Alex returned and changed his approach, spending more time having *Tim* practice typing the answers, and being more insistent on *Tim actually doing the typing*:

Alex: "So, let's focus, let's focus. Alright, you ready? Come on, stop being lazy. K, you got, you got a space? You got it. Let's go. Actually, let's scoot up a little bit. Let's get your chair up. Okay; alright, so, Target bathroom boycott. That's okay. We're gonna start it over. Focus. (Typing) Good, good, good. Come on (TAP); this is you; come on (TAP); come on (TAP TAP). Well, that's exactly it. That's exactly what we need (Hmmm).

Okay? Tim: Okay (verbal). Alex: "Okay, let's, let's get it again. (Typing) Wow! That's exactly it. You need to make sure you're putting *your* resistance in and you put your, like, how do I say this? Make sure you put *YOUR* effort in, cause you can tell if my arm slips, and if your hand goes limp, yea! There you go! That's exactly it! There! There ya go. As you can see, all I'm doing is holding you with one arm, I mean with one finger. Exactly.

(More typing) Dude, that was 100% it! That was me stabilizing you with ONE FINGER. That's perfect, Dude. 'Cause that was all, that was all *your* muscle; that was all *your* finger. That's what it needs to be. Dude, that's perfect. K. I'm gonna go get your dad, and we'll be right back. We'll be right back. Excuse me. Sorry, T. Okay?

Alex leaves; Dad enters:

Dad: Is history what you were talking about? Tim: [It is history]. Dad: Okay, what's the general topic? Tim: [yes]. Ah, you're getting nervous. Go ahead, what is it about, basically? Tim: [the]. Dad: Just a second. K, so who is the history teacher? Tim: [Holland]. Dad: And it's a political cartoon, and what's it about? What? Tim: [public]. Dad: What? Tim: [bathroom]. Dad: What about public bathroom? Tim: [boycott]. Dad: Huh; well, is this in a state or where is it? Tim: [chere]. Dad: What, a, okay. In [their city]? Alright, so let's go back. Let's go back. You did great. Mom – wai, wai, wait – Mom's gonna come and work some English with you.

If the correct topic had been left open or if Dad had pulled it up on the computer screen, one would think he would have guided Tim to type *Target* as the first word of the topic rather than *public*. Furthermore, typing *public* seems to be a continuation of what Tim was attempting to type in the previous subsession with Dad in which he typed *pspic life*, which Dad interpreted to be *public life*.

**Sessions 5 and 5a.** These sessions also involved school work, although there were too many confounding factors to reach any firm conclusions from them. Alex drew from the end of the book Tim was reading for a class in creating one question for Tim to answer with his dad: “In which (concentration) camp did Elie and his father end up?” This cannot truly be considered a blinded test, because although he had not finished it, Dad had been reading the book with Tim. It

is therefore possible Dad had read ahead at some point and therefore knew the ending (although he said he had not and did not). Even if Dad did not know the answer, there was still a relatively limited number of concentration camps from which he might have correctly guessed.

**Supplemental Session 2.** The final session that will be discussed here is the second supplemental session which took place Friday afternoon. In this session Dad was casually asking Tim questions about his day and about the evening plans. Dad began by asking Tim what was good about his day. Tim replied, [yes]. Dad said, “What does ‘yes’ mean? What was good about today?” Tim typed [loplires], to which Dad replied, “I don’t know what that means. ‘Loplires.’ What does that mean?” Tim then typed [playing]. Dad asked, “Who were you playing with?” Tim typed the name of a girl he likes to play with, to which Dad asked, “Is that the name of the girl that you like to always come out and play with you?” It so happens that the word *loplires* is a mixture of letters largely derived from her name and from the word *play*. Dad then asked, “How about English? How did that go?” Tim typed, [I likjtn]. Dad was quiet, and then said, “Oh; I liked it. Does that mean you liked it?”

**Evidence for.** There are a number of examples of typing in this passage that seem to be Tim’s typing. First, it seems unlikely that Dad – and this applies to other facilitators in other narrative segments – would type “yes” or perseverate on typing “yes” in answer to non-yes-or-no questions. Dad had to ask Tim to explain what he meant by “loplires,” and then also needed to ask if the name Tim typed was the name of the girl he likes to play with. It seems unlikely that Dad would have typed a word that made no sense and that he did not understand – *loplires* – which when clarified appears to have been a combination of two intended words – *play* and the name of a girl. Then, in response to “I likjtn,” Dad needed a minute to discern what the word



might be, and then he clarified with Tim if that's what he meant. Dad then took Tim through a fairly long exercise of breaking perseverative typing of "yes" to everything Dad asked.

Following that, Dad began asking Tim about his feelings about the upcoming dance that night which was to be hosted by the students in the accelerated program to be a joint event with the students with special needs. In response to Dad's inquiry, "What is it that you're looking forward to the most about the dance?" Tim replied, [being normal]. I so very seriously doubt Dad would have typed that particular response when he followed it with clear sadness in his voice:

"Ah, well, I can tell you that, Son, that you're not abnormal. You have special talents and special things you have to overcome. Honey, you're not abnormal; you're just different like I was, like your mom was, like everyone. Huh – Being normal...."

**Qualitative analysis summary.** Analysis of the narratives suggests to me that Tim did type thoughts and information independent of facilitator influence as demonstrated by initially indecipherable spellings that were eventually figured out by the facilitators, questions typed which were unrelated to the topic at hand, answers that would have been unlikely from facilitators, relating reportedly unknown information, and answers/statements being challenged by facilitators. It is also interesting that many of the letter perseverations were on letters that were primary to the answers being sought such as in the many variations of *t*, *a* (attempting *Target?*), and *p*, *e*, *o* (seeming to be attempting *people*).

Some argue that the unique linguistics in typing demonstrated in narratives cannot be attributed to the communicators; but rather the distinctive idiosyncrasies in communication, spelling, typos, styles, and the differing opinions, disagreements, or sudden changes of topic are created by facilitators intuiting how the communicator feels or would respond (Saloviita et al., 2014). It might also be argued that even if it *was* Tim perseverating on letters he knew to be

essential to the words he was attempting, even if it *was* him typing responses like “Ask another question” or “ask him,” even if Tim *did* provide the first topic, “People are listening,” and tell his mom about the science project, “acid rain,” none of this is enough evidence on its own to conclude that Tim does all or even most of his homework at the level he is reported to perform... unless... unless difficulties adjusting to changes in routine and facilitator roles are great enough to require time and practice to accomplish those adjustments..., unless anxiety in general, performance anxiety specifically, and anxiety directly related to having one’s competency tested/questioned are significant enough to shut down the ability to perform..., unless sensorimotor systems – integration of sensory input and motor planning are impacted to the degree to which they are now believed to be..., unless ability to accomplish basic tasks is intact, whereas planning and executing higher order responses, particularly as stress and cognitive demands increase, are impaired because of long-range neural underconnectivity. Then, perhaps it makes perfect sense that Tim and others might be able to type spontaneously as thoughts occur to them, but might not be able to type on command in answering specific questions under testing conditions.

**Portfolios and anecdotal reports.** It is also contended that other qualitative approaches to assessing facilitated communication such as through portfolios and anecdotal reports are not valid because the communications cannot be verified as having been composed by the communicators without their having been influenced (Lilienfeld, 2014). However, it is difficult to believe that individuals who once required physical facilitation before acquiring the ability to type independently are rare, isolated cases. In light of the sensorimotor and neuroimaging evidence of widespread sensorimotor and neural connectivity disturbances, it is difficult to believe that the descriptions of sensory and motor issues do not also apply to those who cannot

communicate about them themselves. It is difficult to believe that the countless families and organizations (ironically, see Lilienfeld, 2014) using facilitated communication are all doing so while controlling or influencing the writings by all communicators. And, it is difficult to believe that families are just imagining the improvements in mood and behavior that follow nonspeaking individuals typing to express issues that are upsetting them about which the families did not know. Tim's mom has shared numerous examples over the years of Tim calming down after relating to her what was bothering him – as when a new assistant came to her saying Tim was very upset and fearful, typing that he feared his mom would die in a horseback riding accident. As mentioned, the assistant was new and did not know that in fact Tim's mom had been very seriously injured in a horseback riding accident the year before and was again preparing to go to a horse show/competition. Or, when Tim started crying when getting to the photos of him writing and typing while working on his personal life timeline with his mom. Finally he typed to his mom the reason he was so upset: “Before I could write, no one knew who I was.” These are just two of many, many examples Tim's mom related to me long before this project was ever conceived.

Tim's family and the aids and facilitators also provided numerous examples of messages no facilitator in his/her right mind would have typed. For example, by way of illustrating the importance Tim places on relationships and trust, I can see no reasonable explanation whatsoever for a new facilitator to type or influence the typing of the message, “You're an asshole and my parents are going to fire your ass” unless s/he wanted to start receiving unemployment benefits. Another example is when everyone – parents, aides, and facilitators – were puzzled that Tim would not allow or was at least upset with anyone jumping on the trampoline with him –except one person whom he *wanted* to have jump with him. Parents and aides speculated it was because

he had a special bond with this aide or had particular trust in her. When he was finally asked the reason, he surprised everyone by typing, “I like to watch her boobies bounce.” There were other even more loaded and potentially incriminating typed messages facilitators took to show the parents. An aide took one message involving a request Tim typed at school, over which the aide could have been at the very least fired and might have been criminally prosecuted if he had typed it, to the school principal. Why would facilitators intentionally put themselves in such compromised positions?

Tim’s parents have a storage locker filled with bins of notebooks documenting Tim’s development beginning with the first words he wrote with pencil and paper and progressing to typing, some of which he wrote independently, though most were written or typed with facilitation. Notebooks contain all records of his homeschooling work; all exchanges between Tim and his aides; and all assignments and assessments throughout his school years. The hundreds or thousands of discussions with his aides cover summaries of the day, questions and concerns he had, and discussions about things he wanted to know. The following are typical examples pulled from random pages. Tim’s after-school aides often begin their sessions by asking him open-ended questions. The following are three examples of transcribed exchanges:

Aid: What do you want to do first today?

Tim: I want to work on woman’s body.

Aid: How should we learn about that?

Tim: With you.

Aid: Should we get some books or do you want to ask me questions?

Tim: We should get some books.

Aid: What things about the body do you want to learn about?

Tim: I want to learn about sexuals.

Aid: Should we ask mom for some books about this topic?

Tim: Yes

Aid: While we are waiting on books for that topic, what can we learn about right now?

Tim: We can learn about science.

Aid: What science topic do you want to learn about?

Tim: Space. (October 24, 2007)

It seems it would have been a stretch for a female aide to start out by influencing Tim to type that he wanted to work on “woman’s body” and specifically on “sexuals,” and then ask what other topic Tim might be interested in while they waited for his mom to get books on the topic. It would also seem unusual that she would have influenced him to type “science” rather than going straight to typing “space” in response to “What can we learn about right now?”

2. In the middle of an exchange using facilitated communication, Tim asked his aide:

Tim: Who’s C?

Aide: My boyfriend. You met him at K’s wedding. Remember?

Tim: Not really it was before writing

Aide: Any more questions?

Tim: When are you getting married?

Aide: Not anytime soon. Understand?

Tim: Yes I want you to marry me.

Aide: Aren’t I too old for you?

Tim: No I love you

Aide: Different types of love – I’m your teacher and friend – it’s different. Do you

understand?

Tim: Yes can I come to your wedding?

Aide: Sure but you might have to wait a few years.

Tim: That's ok I don't mind

Aide: Are your feelings hurt that we won't ever get married?

Tim: No but I am disappointed.

Aide: I'm sorry. What do you say, are we still friends?

Tim: Yes you are my best friend. (April 4, 2008)

3. Five days later:

Aide: You said you were hungry

Tim: I am hungry

Aide: Then why didn't you eat your waffle?

Tim: Want a drink with it

Aide: If I get a drink will you eat your waffle?

Tim: Yes

Aide: Thanks for telling me about the hurting. Why was it hard to write?

Tim: I was scared I would have to go to the doctor if I told mom they hurt

Aide: Why are you scared of the doctor?

Tim: It's scary because I can't tell him when things hurt.

Aide: Why not?

Tim: I can't write with him

Aide: Why don't you write with mom?

Tim: Its hard I am nervous

Aide: Did it hurt last time you went to the doctor?

Tim: yes my ears and my nose

Aide: Does your nose still hurt?

Tim: no just my ears

Aide: Does it hurt when you drink?

Tim: Yes a lot can you help me?

Aide: I can't help you – you might have to go to the doctors again.

Tim: OK can you go?

Aide: Why?

Tim: So I can write.

Aide: You need to write for Mom

Tim: I will try but its harder

Aide: How long has it hurt to eat and drink?

Tim: All day yesterday and last week

Aide: Has it gotten any better?

Tim: Not really

Aide: I'll talk to Mom about it, okay?

Tim: Yes (April 9, 2008)

It is hard to imagine aids and parents consistently throughout every single day imagining and composing these types of communications on behalf of Tim via a subconscious ideomotor influencing of his writing.

## **Chapter VI: Conclusions, Weaknesses, Recommendations**

### **Journey, Stage One**

This dissertation process ultimately became a journey into unknown territory (as perhaps many do) — which, in retrospect, mirrored the very process it addressed — the changing and developing understanding of autism as well as the story of facilitated communication’s role within that understanding. The conception of this project began with a parent’s sharing with a doctoral psychology class the story of her nonverbal autistic son’s journey. His was a journey from --- not really from autistic silence, but rather from guttural sounds, screams, aggressive attacks, tantrums, and communicative isolation - into what the parents believe to be interpersonal interaction and personhood through the use of incrementally advanced methods of augmentative and alternative communication (AAC), ultimately ending with the primary use of facilitated communication. Tim’s difficult behavior was reported to have calmed with the introduction of each more functionally advanced method of communication technology, only to then deteriorate as he became accustomed to that method, to then calm yet again with introduction of the next more advanced level. Parallels: Autism is identified 1943. Facilitated communication is first developed 1970s.

I knew this family and this boy, and I had never doubted his parents’ accounts of his communications beginning with his writing with pencil and paper, usually with facilitation, through his progression to typing on computer keyboards, then on tablets, and then on smart phones, again, with facilitation. I did not doubt the communications were Tim’s because the messages mom related to me over the years were - yes, some were of daily communications, but most were more than that — most were the ones that stood out, the ones that upset her — the ones that expressed Tim’s emotions about what it was like for him before he could write, about his



fears just before entering regular classes, about classmates, teachers, principals, his psychiatrist, circumstances with his aides, circumstances at home, doubts about himself, his catastrophic thought processes, his ambitions, and so on, and so on... Parallels: Earliest perceptions of facilitated communication were of a remarkable breakthrough for nonverbal individuals. Detailed early descriptions of Autism were based on behavioral observations. Kanner (1943) proposed there was probably a neurological basis to autism, but also noted environmental factors. He also posited that “Even though most of these children were at one time or another looked upon as feeble-minded, they are all unquestionably endowed with good *cognitive potentialities*. They all have strikingly intelligent physiognomies” (p. 247).

It was recommended to me by the professor in whose class Tim’s mom had presented that I research and present this “amazing” case history as my dissertation. Tim’s mom was excited for this, and she said Tim expressed (through facilitation) that he wanted to participate to help teach people about autism. I read Douglas Biklen’s (2005) *Autism and the Myth of the Person Alone*, and was excited that I might add this young man’s story to these inspiring firsthand accounts in demonstrating to the world that our assumptions and conclusions about autistics who cannot speak and who appear to be cognitively impaired needed to be reconsidered. Parallel: With Biklen’s 1990 publication of *Communication Unbound: Autism and Praxis*, excitement over the potential of facilitated communication to open a world of communication to non-speaking individuals spread. Understandings of autism shifted from the environmentally-bound “refrigerator mom” theory of the 50s and 60s to neurodevelopmental processes involving social and language development. First autism diagnostic criteria appear in the DSM III in 1980.

I established my committee and was ready to launch. My new dissertation chair pressed me to confirm Tim’s authorship before proceeding with the case study. Parallel: First request for

court-ordered evaluation of facilitated communication overseeing Anne McDonald's petition to be discharged from St. Nicholas Institution to live with Rosemary Crossley in 1980.

“No sweat,” I thought. I called Tim's mom; we decided she would do a preliminary trial to establish Tim's success with message passing before I would travel down to formally confirm it. Tim failed the home trial; he couldn't do it. We tried a different approach still involving message passing – he still couldn't do it. Parallel: failure of early controlled message-passing tests of authorship.

### **Journey, Stage Two**

The focus of my entire dissertation had to shift. No longer could I present an amazing story of communicative break-through with the use of facilitated communication when authenticity of his communications could not be easily formally confirmed. Rather, I would have to address the area I had been taking for granted, had not even questioned – the use of facilitated communication by nonverbal individuals. Little did I realize the quagmire of controversy and contention I was entering. I began my literature review – naïveté was quickly usurped by dismay over the consistently negative findings reported from controlled studies. This was followed by indignation and frustration with what I thought were irresponsible, uninformed, tunnel-visioned conclusions drawn by some of the researchers, stating that facilitated communication was an invalid and dangerous technique that should never be used. I could not understand how anyone who had read any firsthand accounts could believe this. As I forced myself to continue reading, the accusations that facilitated communication was pseudoscience and antiscience, a fad intervention, that it stole rather than provided voice, and belonged in the same category as the Chevreul pendulum, my frustration slipped into despair. Naïveté to disbelief to frustration and

indignation to despair. Parallel: The level of emotional investment and contention on both sides of the facilitated communication debate.

But how could the findings from *all* of the non-controlled testing, *all* of the accounts Tim's mom had shared with me over the years, and *all* of the accounts provided by individuals who had once used facilitation but now typed independently be completely discounted? With no small effort, I moved forward out of despair, finally making my way into science – into a stance of curious and accepting not-knowing in keeping with Niels Bohr's (n.d., b), "How wonderful that we have met with a paradox. Now we have some hope of making progress." Parallel: The facilitated communication controversy rages. Concepts of autism continue to shift, but always within the framework of it being, in essence, a disorder of social interaction and communication. Skew: Opponents do not accept the paradox or the possibility of a more complex mechanism underlying the disparate findings between controlled studies and qualitative methods; with few exceptions, the groundbreaking neuroimaging research on disturbed neural connectivity was rarely mentioned in facilitated communication research.

Tim's mom and I were puzzled. Mom was certain that Tim's daily communications were his own. She thought perhaps the message-passing style of test she had attempted was too threatening. Hence, we explored ideas for designing research that would minimize it feeling like a test situation to Tim. We decided upon a design that utilized an activity in which Tim used facilitated communication nearly every day – doing his homework. I hoped this design would circumvent the problems with controlled testing and capture Tim's ability to type authentic communications with the aid of facilitation, but by now, I certainly had serious doubts. I had become very comfortable, however, with accepting whatever results I would obtain to be used as a foundation on which to build future research into unraveling this paradox. Parallel: New test

designs and non-testing methods of evaluation were developed (e.g., eye tracking, linguistic analyses) in attempts to avoid the possible confounders imposed by controlled message-passing tests. Social/language theories of autism still predominated, with sensorimotor and neuroimaging research growing, but still rarely mentioned.

### **Outcome**

Findings from both the controlled testing and the uncontrolled narratives in this study are consistent with the majority of findings from past studies – authentic communicator typing under controlled conditions appears to be limited and shows evidence of facilitator influence, whereas at least some typing under non-controlled conditions appears to be authentically composed by the communicators. Parallel: Nothing new; studies continue to reach the same results. Opponents continue to insist there is no gray area, that it is not possible for this technique to be valid in some situations but not in others.

I could not understand why such a battle still raged over facilitated communication, why emotions still ran high. There did not have to be an either – or, a winner - loser. What if both sides were correct? I had decided it was with this conclusion my dissertation would end – that my findings showed nothing new - that limited if any authentic authorship could be documented through controlled testing, yet findings from non-controlled methods seemed to provide quite strong evidence for valid authorship. My contribution would be to urge the continued investigation of facilitated communication based on the firsthand accounts describing phenomena that seemed to pertain directly to both the abilities to use and difficulties with facilitated communication. Parallel: the self-advocacy movement begins with Temple Grandin's first publication in 1986 of *Emergence: Labeled Autistic*.

But, then, after having completed the data collection and analysis, and not really knowing what, if anything, it would contribute to further understandings of facilitated communication, I thought I should follow up on a comment Tim's mom had made about findings of long-range neural underconnectivity in autistic brains. I started into that search --- and discovered a world of new understandings about autistic brains and possible explanations for the discrepancies in the use of facilitated communication (and also doubled the length of my literature review). I expect the research showing widespread disrupted neural activation in specific brain regions as well as the disrupted neural communications between brain regions will be increasingly linked to the sensorimotor research findings as task-based neuroimaging is advanced. Atypical or desynchronized intra-regional activation and disrupted interregional neural transmission would seem to be plausible mechanisms for explaining the unusual cognitive processes, deficits, and abilities, the atypical sensory experiences, and the motor dyspraxia now widely described in the sensorimotor and attentional research and in firsthand accounts.

In addition, widespread neural connectivity dysfunction provides a comprehensive theory encompassing all facets of autistic differences. Unlike other theories or metaphors – Theory of Mind, Executive Functioning, and Central Coherence – which explain parts of autism but fall short of explaining it as a cohesive whole, widespread disrupted neural connectivity seems to provide a fundamental, comprehensive, and foundational explanation for the entire range of differences observed and experienced in autism. In fact, research is underway explaining each of those metaphorical theories as components under the broader neuroconnectivity theory. (Theory of Mind: Hamilton, 2013; Executive Function: Han & Chan, 2017; Central Coherence: Bertone, et al., 2005; Ronconi et al., 2013; See Rane et. al., 2015, for review)

Neural underconnectivity explains how complex thoughts, although formed and present, may get stuck and be unable to be accessed, expressed, or transferred into action. It explains how receptive and expressive language might be disjointed, and hence, how individuals might not be able to demonstrate the receptive language they possess (based in Wernicke's area) through expressive language tests (requiring connection from Wernicke's to Broca's area), yet be able to demonstrate language ability if accessed straight from expressive centers (Broca's area). Recall, Greenspan and Weider (1997) found that "all 200 cases they reviewed evidenced auditory processing, motor planning, and sensory modulation dysfunction" (p. 3). They found,

Most of the children could express their own ideas much more quickly than they could comprehend the ideas of others. Even children who initially had some understanding of others' language (for example, of simple commands) were still relatively more challenged by their auditory processing of incoming information than by their ability to express ideas. (p. 22)

Firsthand accounts describing unusual sensory experiences, thought processing, and difficulties organizing and controlling movements, all of which explain some of the unusual observed behaviors, have been available for decades. However, for the most part they have been ignored or sidelined in deference to prioritizing conclusions about behaviors and abilities based on professionals' opinions – which in turn have for the most part been founded on constructed and untested assumptions. It has typically been assumed that non-engagement meant lack of caring or interest, withdrawal, noncompliance, laziness, boredom, stubbornness, just being difficult, etc., etc. etc. – all of which have been assumed to be volitional acts or attitudes. It has long been assumed, and is typically still believed, that lack of bodily control – whether volitional or not – such as banging one's head and flailing one's body, making unusual guttural sounds,

toe-walking, ceaselessly galloping or flapping fingers or hands – probably signifies intellectual impairment. Yet, a number of individuals whose unusual vocalizations, body movements, and habitus led to assumptions that they were moderately to severely intellectually impaired, have clearly demonstrated otherwise through their writing. And now it appears that the atypical sensory processing and motor planning underlying the unusual appearances and behaviors are likely caused by disruptions in neural connectivity, thereby bringing into question all of the long-held implicit assumptions about low intellect, lack of empathy, lack of desire to relate, and intentionality of behaviors.

Williams (1994), described the impossibility at times of translating desire and thought into functional action:

Although prompting may look like control, there is a definite distinction in practice when it comes to getting a valid or sensible response.... 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 potter wheel” The stored picture that jumped into my head came first 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 potter wheel; however, I was totally unable to organize fully or even express the want without being prompted or triggered to do so. (p. 197)

There is no way to know which of the many identified disturbances in motor, sensory, sensorimotor, and thought processes described in the research - and by Grandin (2006), Williams (1994), Biklen with Rubin, Frugone, Blackman, Mukhopadhyay, Attfield, Burke (2005), Fleishmann (2012), Jim and Albert in Cesaroni and Garber (1991), Sean Barron (1992) and others - might be involved in any given individual. However, based on the strength of evidence supporting disrupted neural connectivity, the question is no longer whether sensory distortions, motor planning problems, attention problems, and internal-external disorientation exist for any given individual with autism; rather, the question is *which* of these exist in a given individual at a given point in time and which are most problematic in creating interferences and impediments for the individual.

The lack of standardization of currently available intelligence measures for use in autism and the absence of measures designed with the sensorimotor and attentional issues related to autism was raised as a main concern as it relates to assumptions about those using facilitated communication. Although broadly concerning for all, this is particularly problematic for those with the most involved symptoms of autism, for it is they who also typically have the greatest language problems as well as the greatest sensorimotor disorientation and confusion – the more involved the disrupted connectivity, the more involved will be all symptoms. Therefore, results from traditional, standard assessment instruments such as the Wechsler, Stanford-Binet, and even nonverbal measures such as the Leiter-R or Ravens Progressive Matrices should not be



considered valid, and should not be used without modifications, as they do not consider the disabling sensory intrusions, sensory processing desynchronizations and distortions, difficulties with differentiating and managing internal and external states, difficulties planning motor output (aka dyspraxia), dyssynchronous processing and responding, attentional difficulties, visual attention impairments, oculomotor impairments, sensory overload, synesthesias, or monochanneling ... to name a few of the many possible confounders. Again, as Kanner (1943) concluded, “Even though most of these children were at one time or another looked upon as feebleminded, they are all unquestionably endowed with good cognitive potentialities” (p. 247), Kanner continued with, “Binet or similar testing could not be carried out because of limited accessibility” (p. 248). In other words, not being able to perform on standardized tests was different from not being able to think in complex ways (Biklen et al., 2005).

Many authors and firsthand accounts have also described inconsistencies in the ability to perform various tasks, noting as Biklen (Biklen et al., 2005) did that “performance is best when seeming to be spontaneous rather than done on request in a prescribed manner” (p. 32). Biklen noted Asperger’s conclusion that this inconsistency between spontaneous and prescribed performance was one of the “peculiar signs of ‘autistic intelligence’ ... It seemed to Asperger that nearly nothing could be done on demand, hence the difficulty of testing in general” (Biklen et al., 2005, pp. 32-33).

It is impossible to imagine that the oculomotor deficits, delayed and/or distorted sensory processing, attentional problems, dyspraxia, and being asked to type on command in facilitated communication testing do not impact the ability of the communicator to type. Based on the evidence presented, it should not be surprising that individuals might type their own thoughts

when not pressured and when not having to sift through, sort, process, and make sense of incoming questions and demands, vocal intonations, expectations, etc.

I fear that all too often, as well meaning, dedicated, and impassioned as researchers are in this field, we all – on both sides of the debate on facilitated communication – do a disservice to those we seek to help by imposing our own monotropism into our research – into designing it, interpreting it, reviewing it, and championing whichever outcome we adamantly believe is correct and valid. I fear we are like bulls in a china shop who view themselves as artisans – dentists with garden tools. If we were more aware of what we don't know, but rather assume, more aware of being bulls, we might step more carefully. As Williams (1994) pointed out,

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 many 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 the proponents of FC are wrong for the same reasons* (my emphasis). (Williams, 1994, p. 197)

### **Weaknesses of the Study**

The study could have been improved by finding a subtle way to incorporate video recording of sessions, expanding the total time allotted between testing sessions to allow for practice time and acclimation to the testing protocol, and extending testing to see if Tim's ability to communicate answers on the last day continued. Extending sessions over a broader time

period would also have permitted the incorporation of different homework assignments into testing rather than having to repeat the same one that was coming due at the time of this testing.

Furthermore, given the known problems with controlled testing, perhaps the most beneficial change would have been in ensuring that *all* typing was saved toward the goal of augmenting the amount of data for linguistic and typo analyses. Further evidence of Tim's typing beyond facilitator influence might have been gathered if words had been deciphered within those missing typed passages in which verbal statements of, "That's not a word, Bud," were recorded.

### **Recommendations**

In efforts to better understand autism and in designing assessments and interventions to address and modify impediments to accessing and demonstrating underlying abilities, I would recommend that professionals collaborate with those individuals living with these differences. In addition, although it would require ingenuity to address the anxiety of undergoing MRI or EEG, it would be very interesting to compare mapping of brain region activation and white matter fiber bundle coherence in individuals typing with facilitation under differing circumstances. Rather than sounding the alarm to shut down use of facilitated communication, we need to remain curious and open – embrace the paradox. There is so much more to learn and understand to be able to meet people with differences at their bridge rather than trying to force them to cross ours:

I built a bridge

Out of nowhere, across nothingness

And wondered if there would be something on the other side.

I built a bridge

Out of fog, across darkness

And hoped that there would be light on the other side.

I built a bridge

Out of despair, across oblivion

And knew that there would be hope on the other side.

I built a bridge

Out of helplessness, across chaos

And trusted that there would be strength on the other side.

I built a bridge

Out of hell, across terror

And it was a good bridge, a strong bridge,

A beautiful bridge.

It was a bridge I built myself,

With only my hands for tools, my obstinacy for supports,

My faith for spans, and my blood for rivets.

I built a bridge, and crossed it,

But there was no one there to meet me on the other side.

(Jim, as cited in Cesaroni and Garber, 1991, p. 12)

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Appendix A  
Word and Photo List

## Appendix A

## Word and Photo List

Bubbles	car	cat	dog	pencil
Swing	elephant	girls	hat	cup
Candy	horse	ladder	banana	sled
Duck	lion	monkey	shoes	bed
Fish	boat	coat	cookies	chair
Airplane	apple	sandwich	orange	tree
Bowling	corn	spoon	fork	bicycle
Boy	bus	motorcycle	scissors	flag
Bucket	bear	flower	eye	socks
Hand	ear	books	phones	table

## Appendix B

Baseline Data: Independent Pointing, Typing, and Receptive Language



Appendix C  
Daily Protocol Sheets

## Appendix C

## Daily Protocol Sheets

Daily Testing Protocol: Wednesday, April 27, 2016

Assistant: Dad Facilitator: MomBeginning Time: 7:43 pm Ending Time: 8:16 pm Total Time: 33 minutesReview of Homework: Alone 0 With Assistance: 16 mins (inclusive)Time in testing: 11 minutes Transition time: 6

Typing saved: by assistant (dad) only

Scores for answers to questions:

Session 1: Question 1 Score = 2 Question 2 Score = 0 2 of 4Session 1a: Questions 1 Score = 0 Questions 2 Score = 0 0 of 4Key: Total: 2 of 8

Question 1: What school subject is this assignment for?

Question 2: What is the project/general idea or topic of the assignment?

0 = irrelevant, incorrect, no answer; 1 = partially correct answer; 2 = full credit answer

Percent Homework Completed: Score = 0

Key % completed: 0 = none; 1 = &lt; 50%; 2 = approximately 50%; 3 = &gt; 50%; 4 = completed

Notes:

Tim related that he was nervous. Didn't want the video recorder on. Nervous with investigator in the room. Mom just arrived from out of town trip for past week and was ill. Dad accepting Tim's responses; not checking for perseveration. Dad suggesting the ideas; Tim agreeing to those ideas.

## Daily Testing Protocol: Thursday, April 28, 2016

Facilitator-Assistant:     Alex     Facilitator:     Mike    Beginning Time:   3:25 pm   Ending Time:   4:28 pm   Total Time: 1 hour, 02 minsHomework Review Alone:   0   With Assistance:   25 minutes  Time in testing:   34 minutes   Transition/break time:   3 minutes  

Typing saved: Partial

Scores for answers to questions:

Session 2: Question 1 Score =   2   Question 2 Score =   0   Question 3 Score =   0  Session 2a: Question 3 Score =   0   Question 4 Score =   0  Key: Total: 2 of 10

Question 1: What school subject is this assignment for?

Question 2: What is the topic of the assignment?

Question 3: What is the particular topic of the assignment you're working on?

Question 4: What's the topic of the research project? (Based on Tim's answer to question 3)

Key: 0 = irrelevant, incorrect, no answer; 1 = partially correct answer; 2 = full credit answer

Percent Homework Completed: Score = 0

Key % completed: 0 = none; 1 = &lt; 50%; 2 = approximately 50%; 3 = &gt; 50%; 4 = completed

Notes: Alex - trouble getting Tim to focus. Alex chose topic, then asked Tim if he was familiar with it and if he thought it could be turned into a political cartoon; Tim: "yes." Alex didn't check perseverance, so don't know how much Tim knew or understood about topic. Tim always agreeing. Mike frustrated with Tim always typing "yes," but is very patient with him. Mike focused on communication, not necessarily the testing.

## Daily Testing Protocol: Friday, April 29, 2016

Facilitator-Assistant:     Dad     Facilitator:     Mike    Beginning Time:   4:24 pm   Ending Time:   4:32     Total Time:   8 minutes  Conversation with Dad:   6 minutes   Information transfer to Joe:   1 minute, 10 seconds  

Typing saved: Dad saved typing

Scores for answers to questions:

Session 3: (Question 1 = 1; not counted; asked and answered previously)

Question 2a =   0     Question 2b =   0    

Session 3a: Question 3 = 0

Key: Total 0 of 6

Question 1: What school subject is this assignment for?

Question 2a: Are you doing that history project on dinosaurs?

Question 2b: Are you doing that history project on kitty cats too?

Question 3: What is the subject you want to do in the project you and your dad just talked about?

Key: 0 = irrelevant, incorrect, no answer; 1 = partially correct answer; 2 = full credit answer

Percent Homework Completed: Score = 0

Key % completed: 0 = none; 1 = &lt; 50%; 2 = approximately 50%; 3 = &gt; 50%; 4 = completed

Notes: Questions about dinosaurs and kitty cats were trying to break through perseverative typing of "Yes."



## Daily Testing Protocol: Sunday, May 1, 2016

Session 4

Facilitator-Assistant:     Alex    Facilitator:     Dad    Beginning Time: 10:35 am    Ending Time: 10:56 am    Total Time: 21 minutesReview of Homework: Alone   0  With Assistance: 13minutesTime in testing:   07 minutes  Transition/break time:   1 minute  

Typing saved: Saved by Dad

Scores for answers to questions:

Session 4: Question 4 score =   0  

(Question 1 score = 1; not counted; already asked and answered).

(Question 2 score = 1; not counted; already asked and answered)

Question 3 score =   0  

Key:

Total: 0 of 4

Question 4: Who is the teacher of the class?

Question 1: (What is the school subject?)

Question 2 (What is the general assignment?)

Question 3: What is the topic of the cartoon?

Key: 0 = irrelevant, incorrect, no answer; 1 = partially correct answer; 2 = full credit answer

Percent Homework Completed: Score = 0

Key % completed: 0 = none; 1 = &lt; 50%; 2 = approximately 50%; 3 = &gt; 50%; 4 = completed

Notes:

## Daily Testing Protocol: Sunday, May 1, 2016

Session 4a

Facilitator-Assistant:     Alex    Facilitator:     Dad    Beginning Time: 10:58 am    Ending Time: 11:11 am    Total Time: 13 minutesReview of Homework: Alone     0    With Assistance: 08minutesTime in testing: 05 minutesTransition/break time: 30 seconds

Typing saved: Saved by Dad

Scores for answers to questions:

Session 4a: Question 4 score =   2  Question 3 score =   1  Total 3 of 4

Key:

Question 4: Who is the teacher of the class?

Question 3: What is the topic of the cartoon?

Key: 0 = irrelevant, incorrect, no answer; 1 = partially correct answer; 2 = full credit answer

Percent Homework Completed: Score = 1

Key % completed: 0 = none; 1 = &lt; 50%; 2 = approximately 50%; 3 = &gt; 50%; 4 = completed

Notes:

## Daily Testing Protocol: Sunday, May 01, 2016

Session 5

Assistant: AlexFacilitator: DadBeginning time: 11:17      Ending time: 11: 25      Total Time: 08 minutesTime with Assistant: 05 minutes      Time with Facilitator: 02 minutes      Transition: 30  
secondsSession 5: Question 1 Score = 0

Key

Total: 0 of 2

Question 1: In what camp did Elie and his father end up?

Key: 0 = irrelevant, incorrect, no answer; 1 = partially correct answer; 2 = full credit answer

Percent Homework Completed: Score = 0

Key % completed: 0 = none; 1 = &lt; 50%; 2 = approximately 50%; 3 = &gt; 50%; 4 = completed

Notes:

## Daily Testing Protocol: Sunday, May 01, 2016

Session 5a

Assistant: AlexFacilitator: DadBeginning time: 11: 26      Ending time: 11: 36      Total Time: 05 minutesTime with Assistant: 04 minutes      Time with Facilitator: 34 seconds      Transition: 20 secondsSession 5a: Question 1 Score = 2

Key

Total: 2 of 2

Question 1: In what camp did Elie and his father end up?

Key: 0 = irrelevant, incorrect, no answer; 1 = partially correct answer; 2 = full credit answer

Percent Homework Completed: Score = 0

Key % completed: 0 = none; 1 = &lt; 50%; 2 = approximately 50%; 3 = &gt; 50%; 4 = completed

Notes:

Big difference in getting correct typing from Tim after Alex insists that Tim do the practice typing rather than Alex just reviewing the answers orally.

## Daily Supplemental Session Protocols

Thursday, April 28, 2016

## Supplemental Session 1

Facilitator-Assistant: Mike Facilitator: AlexBeginning Time: 4:35 pm Ending Time: 4:44 pm Total Time: 9 minsInitial Conversation: 3 minutes 40 seconds With Facilitator: 3 minutes, 20 seconds

Questions from initial conversation:

What do you want to do with Karen this weekend? Go eat

What do you want to do after that? Go swim

Where do you want to go swim? Wintler

Responses to facilitator

Go hiking, go eat yogurt, and go golfing.

Question 1 Score = 2 Question 2 Score = 0 Question 3 Score = 0Key: Total: 2 of 6

2 = completely correct 1 = partially correct 0 = no credit

Notes:

## Supplemental Session Protocol: Friday, April 29, 2016

## Supplemental Session 2

Facilitator-Assistant:     Dad     Facilitator:     Mike    Beginning Time:   3:40 pm   Ending Time:   4:12 pm   Total Time:   32 minutes  Conversation with Dad:   11 minutes   Information transfer to Joe:   19 minutes, 40 seconds  

Typing saved: Dad saved typing

Question 1 =   2   Question 2 =   0   Question 3 =   0  Key:   Total: 2 of 6  

Question 1: What were you and your dad just talking about? (The dance)

Question 2: What is most exciting or what are you most looking forward to about what you were just talking to your dad about? (Dad: being normal; Mike: the music)

Question 3: What is most scary about what you and your dad were just discussing? (Dad: Not having anyone to dance with; Mike: all the people)

2 = completely correct    1 = partially correct    0 = no credit

Notes: Hard to believe Mike typing this - questioned first response: "books." Then, to "nyusie," Mike said, "That's not a word. Start over." Finally typed "music."

Question 3: *The answer is not "yes." Stop typing "yes," Dude. Seriously, stop typing "yes." You can type anything else, but yes. Doesn't have to be your answer; just stop typing "yes." ...What is scary about what you were just talking about with your dad? Tim: "A, l, a, al, all, of, the, p,e,o, p,o, p" oh, "all the people."* Again hard to believe Mike typed response.

Mike seemed very intent on getting Tim to type his own answers. Stayed with it until he did get an answer, even if it wasn't the answer T had given his dad.

Supplemental Session Protocol: Saturday, April 30, 2016

Supplemental Session 3

Facilitator-Assistant: None Facilitator: Dad

Beginning Time: 3:17 pm Ending Time: 3:23 pm Total Time: 6 minutes

Conversation with Dad: 6 minutes Typing saved: Dad saved typing

Questions:

- |  |       |   |
|--|-------|---|
| 1. Where did you go today?                   | Yes   | 0 |
| 2. Did you go to the zoo?                    | No    | 2 |
| 3. Did you go to a park?                     | Yes   | 2 |
| 4. What was special about the park?          | Water | 2 |
| 5. What do you think it was - river or lake? | River | 2 |
| 6. Did you go to _____?                      | Yes   | 2 |
| 7. Did you get in the water?                 | Yes   | 2 |
| 8. Did Karen get in the water?               | No    | 2 |

Key:

Total: 14 of 16

0 = no answer, irrelevant answer, incorrect answer = 0

1 = partially correct answer

2 = full credit answer

## Appendix D

## First Responses to Homework Questions: Quantitative Scores



## Appendix D

*First Responses to Homework Questions: Quantitative Scores*

Session	Assistant	Facilitator	Question	Tim 's responses	Points
1 (Wed.)	Dad	Mom	1. What subject is it in?	History	2
			2. What's your project?	Indecipherable typing	0
					Points earned: 2 of 4
1a			1. What was the subject?	Engllsh	0
			2. Was this the homework?	Ask what you would need in space	0
					Points earned: 0 of 4
Full session duration: 33 minutes				<b>Full session points: 2 of 8</b>	
<hr/>					
2 (Thurs.)	Alex	Mike	1. What did you and Alex just talk about a subject? What was it?	History	2
			2. What is the assignment?	Yes	0
			3. What is the particular topic of the assignment you are working on in the class you just talked about?	y a, wont, 1	0
					Points earned: 2 of 6
2a			1. What is the particular topic of the assignment you're working on?	A research prpjecet	0
			2. What's the topic of the research project?	E, t, a, a	0

Points earned: 0 of 4

Full session duration: 62 minutes

**Full session points: 2 of 10**

3 (Fri)	Dad	Mike	1. You're doing a history assignment with Alex right?	Yes	NA
			2 <sup>a</sup> . Are you doing that history project on dinosaurs?	Yes	<sup>a</sup> 0
			2 <sup>a</sup> . Are you doing your history project on kitty cats too?	Yes	<sup>a</sup> 0

Points earned: 0 of 4

3a			1. What is the subject you want to do in the project you and your dad just talked about?	Goats	0
----	--	--	--	-------	---

Points earned: 0 of 2

Full session duration: 12 minutes

**Full session points: 0 of 6**

4 (Sun)	Alex	Dad	4. Who is the teacher?	Garcia	0
			3. What is the topic of the political cartoon?	Backcodads	0
4a			4. Who is the teacher?	Holland	2
			3. What is the topic of the political cartoon?	Public Bathroom Boycott	1

Points earned: 3 of 4

Full session duration: 36 minutes

**Full session points: 3 of 8**

5 (Sun)	Alex	Dad	5. In which camp did Elie and his father end up?	Bperkinsy Berkinshu	0
---------	------	-----	---	------------------------	---

Points earned: 0 of 2

5a			5. In which camp did Elie and his father end up?	Buchenwald	2
----	--	--	---	------------	---

Points earned: 2 of 2

Full session durations: 14 minutes

**Full session points: 2 of 4**

*Note.* Key to points: correct = 2; partially correct = 1; incorrect/indecipherable = 0. NA signifies the question was not counted towards points because facilitator already knew answer.

<sup>a</sup> Facilitator checking for and correcting perseveration of typing “yes.”

## Appendix E

## Supplemental Communication Sessions: Quantitative Scores

## Appendix E

*Supplemental Communication Sessions: Quantitative Scores*

Session	Questions	With assistant	With Facilitator	Points
1(Thurs)	1. What do you want to do with Karen this weekend?	“Go to eat”	“Go eat yogurt, go hiking, go golfing”	2
	2. Where would you like to go eat?	“Anywhere”	(Go eat yogurt)	0
	3. Okay, and after you’re done eating, what would you like to do?	“Go, to, swim”	(go hiking, go golfing)	0
	4. Where would you like to go swim?	“Wintler”	(Not asked)	NA
Duration: 9 minutes			Points earned: 2 of 6	

2 (Fri)	1. What were you and your dad just discussing?	The dance	“s, d, s, d ...d, a, n, d, a d,a,n,a, d,a,n, dance”	2
	2. What is the thing you are looking forward to most or is most exciting that you were just talking to your dad about?	Being norma	“Books”	0
	3. What is scary about what you were talking about?	Not having someone ti dance wit	“A, l, a, al, all, of, the, p,e,o, p,o, p;” Oh, “all	

of the people.” 0

Duration: 32 minutes

Points earned: 2 of 6

---

3 (Sat) 1. Where did you go today?	Yes	0
2. Don't just say "yes," cause "yes" doesn't tell me where you went. Did you go to the zoo?	No	2
3. Did you go to a park?	Yes	2
4. Okay, was there anything special about the park?	Yes	NA
5. What was special?	The water	2
6. Was it a river or a lake? Do you remember	No	NA
7. What do you think it was?	River	2
8. If I gave you the names of parks, would you remember?	Yes	NA
9. Did you go by the ___ bridge?	No	<sup>a</sup> NA
10. Did you go to _____?	Yes	2
11. Did you get in the water?	Yes	2
12. Did Karen get in the water?	No	2

Duration: 6 minutes

Points earned: 14 of 16

**Supplemental sessions combined total points: 18 of 28 = 64%**

---

*Note.* Key to points: correct = 2; partially correct = 1; incorrect/indecipherable = 0

Assistant/Facilitator: Session 1 Mike/Alex; Session 2 Dad/Mike; Session 3 none/Dad.

<sup>a</sup>Karen reported that this information was equivocal depending on perspective. Parentheses “\_\_\_” indicate typing being read aloud. No written documentation saved.

Appendix F  
Categorization of Typos

## Appendix F

## Categorization of Typos

<u>Inserted characters</u>	<u>Orientation to Intended Key</u>
Inserted character before intended character = 9	
w before and left of e (nwer voys); Wednesday p. 2	left
space before and below v (I am nwer voys); Wednesday p. 2 below	
o before and left of p (opaetual); Wednesday p. 3	left
g x 2 before and below t (ggthey); Wednesday p. 5	below x 2
u before and right of y (uyes); Friday Supplemental p. 1	right
d before and right of s (yerds); Friday Supplemental p. 2	right
r before and right of e (yred); Friday Supplemental p. 3	right
y before and left of u (nyusie); Friday Supplemental p. 8	left
Inserted character after intended character = 8	
A after and left of s (Tonsahiw); Wednesday p. 2	left
A after and left of s (countriesa); Thursday recording p. 6	left
J after and left of k (likjtn); Friday Supplemental p. 2	left
R after and right of e (yerds); Friday Supplemental p. 2	right
O after and left of p (peopo); Friday Supplemental p. 8	left
R after and right of e (yers); Saturday p. 4	right
U after and right of y (yues); Saturday p. 4	right
S after and right of a (materiasl); Saturday p. 4	right
Apparent random insertion: 8	
g following yes (yesg); Wednesday p. 1	
e between c and t (prpjecet); Thursday p. 8	
c between n and a (ncatre); Friday p. 2	
tn for e or ed (likjtn); Friday Supplemental p. 2	
g between o and d (googd); Saturday p. 1	



y between s and i (passying); Saturday p. 1

g between s and I (loosging); Saturday p. 4

### Substituted characters

Substituted character below = 3

j below u (Nervojs); Wednesday p. 1

space bar for v (nwer voys); Wednesday p. 2

space bar for n (I ca t for I can't)

Substituted character above = 3

n rather than space bar (Tonsahiw); Wednesday p. 2

o above l (peopo p); Friday Supplemental p. 7

b above space bar (ibfet); Saturday p. 3

Substituted character to left = 17

y left of u (Nwer voys); Wednesday p. 2

q left of w (knoq); Wednesday p. 2

w left of e (peoplw); Wednesday p. 2

i left of o (Tonsahiw); Wednesday p. 2

7 left of 8 (1972) Wednesday p. 2

k left of l (Engkih); Wednesday p. 3

T left of y (tes); Wednesday p. 3

e left of r (Opaetual); Wednesday p. 3

u left of i (Opaetual); Wednesday p. 3

caps lock left of a (RE); Wednesday p. 5

c left of v (Ecil); Wednesday p. 5

b left of n (Bo); Friday Supplemental p. 2

I left of o (ti); Friday Supplemental p. 3

N left of m (nyusie); Friday Supplemental p. 8

i left of o (Inteam); Saturday p. 3

W left of e (yws); Saturday p. 4

E left of r (penably); Sunday p. 4

Substituted 2 away = 2

g is 2 right of d in drive

2 is 2 left of 4 (1972 rather than 1984); Wednesday p. 2

Substituted character to right = 16

m right of n (Listemig); Wednesday p. 2

r right of e for being (Bring); Wednesday p. 2

y right of t (Yhey); Wednesday p. 5

s right of a (csn); Wednesday p. 5

p right of o (prpjecet); Thursday p. 8

d right of s (yred); Friday Supplemental p. 3

d right of s (yed); Friday Supplemental p. 3

o right of I (mvong); Friday Supplemental p. 3

r right of e (yr); Saturday p. 2

m right of n (mo); Saturday p. 2

r right of e (yrds); Saturday p. 3

d right of s (yrds); Saturday p. 3

o right of i (grobe); Saturday p. 3

b right of v (grobe); Saturday p. 3

y right of t (iy ~ it); Sunday p. 4

n right of b (penably); Sunday p. 4

Apparent random substitution = 1

e for c (nyusie); Friday Supplemental p. 8

Omitted characters = 10 words with one or more letters omitted

From end of word: 14 characters from 9 words

(2) 'm [or space and "am"] omitted? (Inervojs); Wednesday p. 1

(2) sh from English (Engli); Wednesday p. 1

s from yes (ye); Wednesday p.2

(2) ll from Orwell (Orwe); Wednesday p. 3

(2) ki from Wiki (Wi); Wednesday p. 2

(2) e and space at end of like (I likjtn); Friday Supplemental p. 2

l from (normal); Friday Supplemental p. 3

h from with (wit); Friday Supplemental p. 3

space between in (on) and team; Saturday p. 3

From middle of word = 14

n from listening (listemig); Wednesday p. 2

(3) lle from controlled (controld); Wednesday p. 2

s from English (engkih); Wednesday p. 3

l from talk (tak); Wednesday p. 3

v from evil (eil); Wednesday p. 5

apostrophe in won't; Thursday p. 6

apostrophe from can't (I ca t); Thursday p. 6

o between m and v (mvong); Friday Supplemental p. 3

u between t and r (ncatre); Friday Session 2, p. 2)

l between e and t (Ibfet); Saturday p. 3

o between e(r) and n(b) (penably) Sunday p. 4

o between g and ing (ging); Sunday p. 4

From beginning of word = 1

b from be; Wednesday p. 5

## Appendix G

## Permission to Use Copyrighted Figure

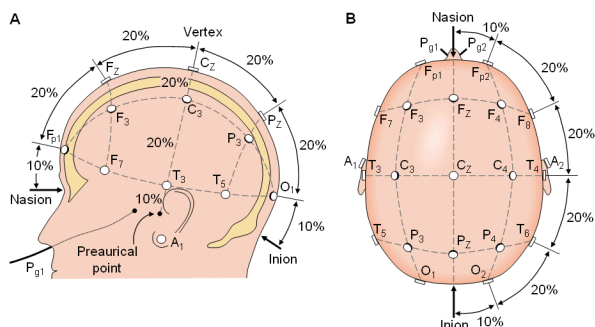
## Appendix G

## Permission to Use Copyrighted Figure

Dear Dr. Malmivuo,

First, I apologize that I am only able to correspond in English, and just sufficiently in Spanish.

I am a doctoral candidate at Antioch University Seattle, Washington, U.S.A. I would like to ask your permission to use the diagram pasted below to which I believe you hold the copyright. It would be used to demonstrate the 10-20 electrode placement system in the section of my literature review presenting the latest neuroimaging research in autism.



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Thank you for your time and consideration of my request.

Sincerely,

Nancy Meissner  
PsyD student  
Antioch University Seattle  
Dated 01/08/2018

Dear Nancy Meissner

I thank you for your interest towards our book Bioelectromagnetism. I will be glad to give you the permission to use the figure which you asked in your thesis. I am sure you will also make proper indication of the reference.

Mit freundlichen Grüßen

Jaakko Malmivuo

Dated 01/09/2018