

“I Like Others to Not Try to Fix Me”: Agency, Independence, and Autism

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Abstract

This article is based on an interpretivist, qualitative research project conducted with individuals labeled with *autism* who type to communicate. Researchers engaged in participant observation and conducted open-ended interviews with 9 participants who were working to develop independent typing skills. Three findings emerged from this research. First, participants shaped a notion of independence that included dependence on various supports. Second, researchers recognized the concept of agency in the interactions between participants and their communication facilitators. Third, participants exercised control of their lives through these expressions of agency.

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This article is about interpreting the actions or performances of individuals labeled with *autism*. More specifically, we discuss viewing competence amid behaviors and actions traditionally linked with incompetence. Individuals labeled with autism, especially those who do not speak, have historically been interpreted as “mentally retarded” and excluded from many of the decisions that affect their lives. Bogdan and Taylor (1976) argued that individuals labeled *mentally retarded* are relegated to the role of the “judged” but never the “judges” (p. 47).

Current norms of competence are based largely on written and verbal language, immediate response or performance on demand, and the illusion of independence (Biklen & Kliever, 2006). Many people labeled with autism do not speak, take time to respond, and rely on various supports to communicate and complete daily tasks. Furthermore, many people labeled with autism experience difficulties with social dynamics and performing tasks on demand because of movement differences, including difficulty starting, stopping, executing, continuing, combining, and switching movements or actions (Donnellan & Leary, 1995). Based on these discrepancies, people labeled with autism are often considered dependent and, therefore, incompetent by others (Olney, 2001). Yet, such assumptions reflect misinterpretations of such behavior:

The presence of these symptoms [movement differences] may or may not indicate limited understanding or lack of interest. It is

not possible to know the inner workings of the mind or the capacity for thought based on the presence of these symptoms. (Donnellan & Leary, 1995, p. 40)

Thus, using various forms of nonspeaking communication and/or a method of augmentative alternative communication (AAC) is important for individuals with movement differences who do not speak to demonstrate their competence. The act of introducing any form of AAC is recognition of the importance of communication to an individual's participation in the world (Facilitated Communication Institute, 2000).

The interpretivist, qualitative research project on which this article is based was conducted with individuals labeled with autism who type to communicate and who desired to develop “independent” communication skills (i.e., typing without physical support, reading what was typed, and speaking). The participants in this study were—and are—faced with the task of demonstrating their competence by validating their supported communication. Facilitated communication training (often called *facilitated communication* or *FC*), is one form of AAC that has been an effective means of expression for some individuals labeled with autism and other developmental disabilities. Facilitated communication is controversial. A number of studies failed to validate authorship and showed that a facilitator's physical support can influence the person's pointing (Bebko, Perry, & Bryson, 1996; Ca-

bay, 1994; Crews et al., 1995; Eberlin, McConnachie, Ibel, & Volpe, 1993; Klewe, 1993; Moore, Donovan, Hudson, Dykstra, & Lawrence, 1993; Shane & Kearns, 1994; Wheeler, Jacobson, Paglieri, & Schwartz, 1993).

Other studies, using a range of testing situations and methods of documentation have successfully demonstrated authorship on the part of the person who uses FC (Broderick & Kasa-Hendrickson, 2001; Calculator & Singer, 1992; Cardinal, Hanson, & Wakeham, 1996; Janzen-Wilde, Duchan, & Higgenbotham, 1995; Niemi & Karna-Lin, 2002; Rubin et al., 2001; Sheehan & Matuozi 1996; Weiss, Wagner, & Bauman, 1996). Some individuals have developed the ability to type without the physical support they once needed (Biklen, 2005; Mukhopadhyay, 2000; Rubin et al., 2001; Wurzburg, 2004), and some individuals have developed the ability to read what was typed and to talk as they type (Broderick & Kasa-Hendrickson, 2001; Kasa-Hendrickson, Broderick, Biklen, & Gambell, 2002). These developments confirm both the validation of these individuals' communication and the length of the process for doing so:

In regard to a small group of people around the world who began communicating through FC (facilitated communication) and now are able to type either independently or with minimal, hand-on-shoulder support . . . there can be no doubt that, for them, (facilitated communication) "worked," in that it opened the door to communication for the first time . . . For them, the controversy has ended. (Beukelman & Mirenda, 1998, p. 327)

The participants in this study were similarly working toward independent communication (i.e., with reduced or no physical support).

The idea of *independence* is always culturally constructed, yet those in human service fields tend to discuss independence only in terms of observable behaviors, locating deficiencies within individuals labeled with disabilities (Illich, Zola, McKnight, Caplan, & Shaiken, 1977; Linton, 1998). However, it is inaccurate to say that some people are independent and others are not:

Few, if any, people are completely autonomous, and few of us would choose to meet all of our daily living demands independently and without the assistance and support of others: autonomy includes interdependence of families and others with whom we interact. Educational and behavioral interventions should acknowledge this interdependence and focus on supporting people with severe disabilities to become more autonomous within the context of interdependence. (Brown, Gothelf, Guess, & Lehr, 1998, pp. 10–11)

Within this context of interdependence (Kennedy, 2001), the agency of individuals labeled with

autism can be recognized and supported by their families, friends, colleagues, classmates, and teachers.

In this study, we conceptualize *agency* as describing the opportunity to initiate a topic or agenda, participate in a dialogue, move a conversation in a particular direction, interpret others, affect the person with whom one is in dialogue, make a point, interact as a peer, and be seen as a person with ideas to contribute and a personality to inject into the conversation. Being supported to express agency is similar to Fogel's (1993) co-regulated communication, largely based on research with mothers and infants, in that it is a *continuous process communication system* in which "both partners are continuously active and continuously engaged in the communication" (p. 27). Agency emerges out of social interaction and communication and is, therefore, not something someone can possess. Expressions of agency require contexts in which communication partners believe that an individual has something to say, provide communication supports, and possess the listening skills to hear them.

Mackay (2003) provided a theoretical formulation of agency based on his own experiences with aphasia and interviews with 18 individuals experiencing aphasia. He described the process of doctors interpreting individuals with aphasia who performed "voicelessness" (p. 813) as incompetent. This is similar to the experiences of individuals labeled with autism who do not speak and rely on others for support in daily-living activities. Rather than valuing independence, Mackay (2003) explained that people with aphasia can be seen as competent when others recognize and value interdependence, supporting individuals with aphasia to express their agency.

Mackay (2003) described a situation at the hospital in which a doctor was assessing Mackay's competence by asking him to point to various objects in the room. The doctor missed a quick movement Mackay made to point at the carnations, confidently declared that he missed it, and quickly remarked that he would help Mackay recover his cognitive functioning. Mackay and his friend Paul exchanged knowing glances when the doctor left the room. Mackay explained, "My friend honoured my experience and the agency I possessed . . . The doctor was oblivious to my ability to express my thoughts nonverbally, as well as through the signal specific system I developed" (p. 815). Although Mackay's use of the term *agency* included his sense

that it was something he possessed, we conceptualize it as opportunity. Without the opportunity to express ideas, opinions, or preferences, an individual's ability to do so may be reduced or eliminated. Implicit in our conceptualization of agency is the belief that all people can communicate or express agency in some form, when given the opportunity.

Literature on self-determination stresses that people who have what are perceived to be even the most severe of disabilities live self-determined lives (Brown et al., 1998; Rock, 1988; Turnbull & Turnbull, 1985, 2001; Wehmeyer, 1998; Wehmeyer & Schwartz, 1998). Olney (2001) noted that "communicative initiative, or agency, leads to self-determination only when others in the environment understand and respond appropriately" (p. 88). Similarly, Bremer, Kachgal, and Scholler (2003) reported that students who have self-determination skills—even strong ones—can be thwarted in their efforts toward self-determination by people who present barriers or do not provide needed supports. Thus, in this study, we were not only interested in the participants' conceptualizations of and progress toward independent communication but in how they interacted with their communication facilitators during this work.

Method

During an academic school year, September to May, a research team engaged in participant observation and conducted open-ended interviews with 9 individuals labeled with autism who typed to communicate in training–strategy sessions, at school, and at home. The research team included six disability studies–school inclusion researchers and one speech–language pathologist. The purpose of this interpretivist, qualitative study was to explore the development of greater independence for individuals who type to communicate. We identified the concept of agency during data analysis. Therefore, we began this work with the following research questions as guides: What training methods are effective in reducing and/or eliminating physical support for someone who types to communicate? How do the participants and their communication facilitators conceptualize independence? How do the participants and their communication facilitators interact with each other—and perceive their interactions—as they work toward independent communication?

Participants

Three of the 8 participants were adolescent boys in secondary schools, 2 were adult women, and 3 were adult men; all were labeled with autism. Seven of 8 participants completed the study. One participant joined the study shortly after it had started. All names used in published materials are pseudonyms.

In this study, we engaged in purposeful sampling (Bogdan & Biklen, 1998; Merriam, 2002). Merriam (2002) explained that, "Since qualitative inquiry seeks to understand the meaning of a phenomenon from the perspectives of the participants, it is important to select a sample from which the most can be learned" (p. 12). All participants typed as their primary means of communication and desired to develop greater independence in their communication. Although there was no requirement in terms of the length of time that each participant had been typing to communicate, participants were required to work regularly with more than one communication facilitator and to have expressed an interest in working toward independent communication.

Procedure

Each participant began with an initial session for the purpose of gathering background information and developing communication goals. Participants identified through supported typing one or more of the following general areas to work on: typing with faded physical support; typing without physical support; reading aloud what was typed, speaking, and initiating communication, either typed or spoken. These goals reflect methods commonly accepted in the field of validating supported typing through fading or eliminating physical support (Biklen, 2005).

The initial session concluded by establishing a schedule of strategy sessions every 2 to 3 weeks throughout the academic calendar year that lasted between 1 and 2 hr per visit. Each participant attended 10–12 strategy sessions. These strategy sessions included the participant, the participant's communication facilitator, a graduate student paired with each participant, and the speech–language pathologist. Strategy sessions made up the bulk of the study and were designed so that the participants were in control of their work because their communication was the focus of these sessions. Because each participant established the parameters and goals of their work, strategy sessions were dynamic, flexible, and varied. Typical activities during strategy sessions included rehearsing

greetings, practicing conversations, connecting spoken and typed words (e.g., typing a letter and then saying it, or pointing to a word and reading it), experimenting with faded physical support during typing (moving from the hand or wrist to the forearm and then shoulder), typing with a metronome, trying out various physical and sensory supports, working on different angles for the communication device, typing with new communication facilitators, and striving to type without any physical support. Between sessions, participants were asked to practice techniques and explore the ideas discussed.

Data Collection and Analysis

Qualitative methods allow for a detailed understanding and descriptive analysis of such a complex phenomenon as supported typing, which includes both communicative and interactive (between communicator and communication facilitator) components. Data were collected by multiple methods (Bogdan & Biklen, 1998; Denzin & Lincoln, 2000). Olney (2001) argued that “competence appears to be best revealed when an individual’s activities are studied through extended observations and interactions” (p. 89). In addition to participant observation, strategy sessions were videotaped and audiotaped with permission and were available as data for microanalysis and review. We accumulated more than 60 hr of videotape and more than 70 hr of audiotape during these communication strategy sessions.

Observations in the participants’ home and school settings, which were more sporadic, were not videotaped. Each participant was observed at least twice in a home or school setting. All observations were recorded in detail with field notes and analytic memos by individual researchers, and these materials were periodically reviewed and discussed by the research team. Individual researchers met with the speech–language pathologist after each strategy session to discuss key ideas and important aspects of the preceding session. We generated more than 500 pages of field notes and memos.

The research team began with deductive analysis of the data, independently coding field notes using the research questions as a guide. Emphasis was placed on methods to reduce physical support during typed communication as well as on how participants and their facilitators interacted during this work. Researchers extensively discussed agreements and disagreements in working to identify emerging themes related to independent communication and

the interactions between the participants (communicators) and their communication facilitators. The full research team met weekly to discuss and reach consensus on these codes (e.g., *typing and talking*, *typing rhythm*, *independence*, and *participation with support*). Those initial codes were combined, collapsed, and refined through discussion with all research team members. During this process, and specifically through discussing the independence and participation-with-support codes, we recognized that participants viewed independence on several levels in potentially conflicting ways and conceptualized independence as much more than simply typing without physical support. For them, independence could include various supports if it led to their full participation and decision making—in other words, if it led to expressions of agency.

The research team identified agency as a concept that encompassed the juxtaposition of working toward independent communication while citing the need for particular supports to enable the communicator to express his or her needs, desires, and ideas. The researchers began a second round of coding that was more inductive and included the emergence of the theoretical framework of agency. Researchers independently engaged in line-by-line, open, and axial coding (Strauss & Corbin, 1998) rather than coding with the preconceived research questions as a guide. Again, we met as a research team to discuss and reach consensus on codes related to agency. This process included extensive discussions of key interactions and scenarios that defined agency. The findings contain these defining scenarios and detail the identification of agency as a theoretical framework for understanding this work. Specifically, we offer detailed interpretations based on close readings of interactions between 5 participants and their communication facilitators in strategy sessions ($n = 5$), at school ($n = 1$), and in general life situations ($n = 1$). By closely reading a limited number of brief interactions in terms of agency, we hoped to define agency in detail and to identify some of the conditions necessary for the demonstration and recognition of expressions of agency by individuals labeled with autism. As this article focuses specifically on this notion of agency, we chose not to include the specific strategies that helped the participants move toward independence in communication.

Results

Through phenomenological analysis of the data, we identified three findings from this research.

First, the participants troubled traditional notions of independence by including dependence on various supports in their perceptions of independence. Second, researchers recognized the concept of agency in the interactions of participants and their facilitators. Third, participants conveyed their thoughts, determined the course of interactions, and took control through these expressions of agency. Though the study was originally designed to explore the process of working toward independent communication, the participants demonstrated the importance and necessity of depending on others for opportunities and supports to express their agency as they worked on independent communication.

Troubling Independence

The following examples illustrate the complexity of working toward independence in communication and dealing with larger concepts of becoming independent in life while depending on some supports to communicate and to complete daily tasks. We identified this complexity with 7 out of 8 participants. Communication supports allowed them to express independent thought, though they did so through supported typing. Daily supports were necessary but were provided in a way that embraced and allowed for self-determination through expressions of agency. Michael likes to play video games, has an older sister, and is labeled with autism. He is a 12-year-old, sixth-grade student. He speaks some words intentionally, whereas others seem automatic or less intentional, and he types to communicate with backward physical support or pressure from a facilitator under his forearm. His project goals were to type without physical support and to increase his speech. However, Michael challenged traditional concepts of independence. While discussing goals at the beginning of a strategy session with the speech–language pathologist (SLP), Michael typed while receiving backward physical support underneath his right wrist from his mother, “INDEPENDENCE TO ME IS ONLY PLEASING MYSELF AND NOT OTHERS.” (Note: In this article, we use a system in which uppercase letters represent typed messages and lowercase letters represent spoken messages.)

With this statement, Michael clarified that the determining factor of our research, and his life, needs to be him. The conversation continued:

SLP: Are you trying to tell me that when you are here it is too hard to say no to anything I suggest?

Michael: YES.

[He made increasingly more high-pitched, siren-type vocalizations as he continued to type. The vocalizations continually increased during this message to the point where they were almost constant.]

Michael: “INDEPENDENCE ISN’T DOING YOUR IDEAS.”

SLP: “Independence isn’t doing your ideas.” Gotcha. Gotcha. So, maybe I should stop suggesting things.

Even while trying to promote and support his independent communication in participant-led strategy sessions, Michael clearly felt that the research team was in control of the session. The SLP’s ideas of what to work on to develop Michael’s ability to type without physical support, something he had identified as one of his goals, conflicted with his idea of independence as “doing” his ideas. Independence meant much more to Michael than typing without physical support. For example, Michael requested more physical support for his typing in school, although he still desired ultimately to develop the skills to type without support. Being able to demonstrate what he knew in time-pressured class situations among other students with physical support was more important at that time than achieving his goal of typing without physical support.

John’s experiences in the project also revealed to us a more complex notion of independence. John, a poet and a writer who is labeled with autism, joined midway during the study. He is 31 years old and speaks some words, but they are often very difficult to understand. His communication includes typing with backward physical support at the forearm, speaking some words, and making sounds. John’s project goals were to type without physical support, increase his speech, and type with multiple facilitators. John often experiences anxiety in public settings, suddenly wringing his hands and bolting up to walk around or leave a room. In addition to communication support, John relies on his facilitators, friends, and family to provide supports related to his anxiety, as well as with his compulsion of grabbing food that he sees. He described not wanting to grab food but being unable to control this on his own.

Struggling with anxiety and compulsion often left John feeling helpless. This feeling, coupled with his support needs, presented a costume of dependence. Yet, John conveyed to us a strong determination to control his life. He convinced his family to move to this college town specifically for support in his communication. He symbolically changed his

name from a childhood nickname. He still depended on many supports, but he was in charge of these supports. He commented: “ALTHOUGH I AM BESET BY THE DRUDGERY OF AUTISM I LIKE OTHERS TO NOT TRY TO FIX ME. I LIKE TO DECIDE WHAT I WANT FOR MYSELF.” This element of choice and control represents a driving force of independence that was difficult to ignore when observing John, even though he depended on the supports he chose to receive.

Recognizing Agency

This section details the development of our framework of agency. The following examples illustrate commonalities across all participants. When we focused on agency, we recognized expressions of control, personality, and self-determination that might otherwise go unnoticed. When individuals labeled with autism do not have opportunities to express agency and when expressions of agency are overlooked or disregarded, individuals remain at risk of being misinterpreted as incompetent. Like the doctor in Mackay’s (2003) example, we had missed opportunities for recognizing and supporting agency. The most dramatic example of a missed opportunity occurred during one of Denise’s strategy sessions.

Denise is a 28-year-old, disability rights advocate and college student who is labeled with autism. She makes sounds but does not speak words and types with backward physical support under her forearm and while holding onto one end of a marker that her facilitator holds at the other end. Her sole project goal was to type without physical support. Her primary facilitator is her mother, Maureen. During the session, the SLP was trying a faded level of support (specifically, fading support from the wrist to the elbow) with Denise and asked Maureen to walk over and observe the support from a different angle. As Maureen stood up, Denise immediately made agitated sounds of protest, “Ooh, ooh, ooh,” and pointed to Maureen’s chair. Both the SLP and the graduate student operating the camera told Denise that it was okay and explained that they just wanted Maureen to take a closer look at the support. Denise repeated the agitated sounds once more. Maureen told her it was okay and walked closer to the SLP and Denise. The conversation returned to the specifics of the faded level of support.

Through repeated viewing of the videotape, researchers recognized that Denise clearly expressed

herself in relation to Maureen standing up, but the SLP, Maureen, and the graduate student did not listen to her. They attempted to calm her by redirecting her to what they wanted to do, explaining their intentions as if she did not understand them, even though this is what she reacted to in the first place. They misinterpreted the meaning of her non-verbal communication, effectively disallowing her the opportunity to express her agency. Even with such a clear and intentional protest of Maureen standing up, Denise required someone to support the expression of her agency by recognizing her intentions or supporting her to type to clarify her intentions. Absent this recognition of intentionality, she was not only denied agency but risked being misinterpreted as incompetent with the assumption that her noises were meaningless.

Of all the participants, Isaiah may have been at the greatest risk of being misinterpreted as “incompetent” because of his unintentional actions and intense support needs. Isaiah has two brothers, enjoys running, and is labeled with autism. He is a 15-year-old sophomore in an urban, public high school. He makes lots of noises and hums but does not speak words. Isaiah requires emotional, verbal, and a variety of physical supports while typing, although he was specific during his initial session in wanting to fade the support. His project goals were to type without physical support, to increase his speech, and to improve supports for his sensory distractions.

A large part of Isaiah’s support consists of helping him to calm his body and to remain on task because of almost constant sensory distractions. In many ways, he might be identified as the least independent because of his intense support needs and relative lack of typing. However, had we assumed that he was too dependent to be a competent communicator, we would have missed opportunities to recognize his agency. During one of his later strategy sessions, Isaiah struggled settling in to type and required a great deal of support from Jason, who served as both his communication facilitator and high school special education teacher. Isaiah sat down at a chair pushed away from the table, with his facilitator Jason to his right. They were trying out the SLP’s suggestion that Isaiah type on a downward angle with the communication device on top of two milk crates in front of him.

Isaiah looked around the room and made loud laughing sounds. Jason said, “Okay, Isaiah, I am going to give you some deep pressure.” Jason stood up

behind Isaiah and pressed down on his shoulders. “Okay, stretch your arms.” Isaiah reached both arms out to the sides, stretching his whole body back as well. Jason explained, “That’ll make it a little easier maybe.” Isaiah made two loud “Oh” sounds. Jason responded, “What, are you a good singer?” Jason held out his right hand in front of Isaiah. Isaiah reached up to grab it, grasping Jason’s index finger with his right hand. He extended his own index finger and began typing. Jason’s left hand applied pressure on Isaiah’s shoulders. Jason read what Isaiah typed: “YES.” Jason responded, “Yes, you are a good singer. I agree.”

Then he asked, “Now, is there anything you want to say to [the SLP]?” Jason held out his right hand once more in a ready position to support Isaiah’s typing. Isaiah moved his legs back and forth and then leaned forward slightly and glanced quickly at his right shoe. Jason noticed this and said, “You’re distracted by your shoe. Why don’t you fix your shoe.” Isaiah leaned forward and adjusted his right shoe. Jason watched and then pulled Isaiah’s legs toward him so he was centered on the chair, moving Isaiah’s right foot so it was flat on the floor. “All right. Comfortable?” Simultaneously, Jason applied pressure to Isaiah’s shoulders again and then extended his right hand to Isaiah for typing support. Isaiah reached out, grabbing Jason’s hand in the same manner and began typing. He hummed in a rhythmic pattern as he typed. Jason read what Isaiah typed: “HI. HOW ARE YOU?” The SLP replied, “I’m glad it’s Friday.” Jason held out his hand again and Isaiah grabbed it in the same manner and then began typing, humming the same rhythmic pattern. He paused and made the loud laughing sound again. Jason said quietly, “Go ahead.” Isaiah began the same rhythmic humming and finished typing his statement. Jason read what Isaiah typed, “I LIKE FRIDAY, TOO.”

Understanding this interaction within a framework of agency was important because it directly affected how we interpreted both Isaiah’s and Jason’s actions during their interaction. Jason provided extensive physical and emotional support in the form of verbal prompts, questioning, and a (literally) hands-on approach. It would be easy to interpret the need for this support as evidence of Isaiah’s incompetence. However, this conclusion constitutes a misinterpretation of both Isaiah’s and Jason’s behavior, a missed opportunity for agency, and evidence of competence through supported communication.

When we use the framework of agency we pre-

sume competence (Biklen, 2005). We interpreted Isaiah’s behaviors as meaningful and necessary for communication, reading the interaction in a way that understands him as a competent communicator. What could easily be interpreted as Jason’s physical manipulation of Isaiah, almost like maneuvering a puppet, is actually a mutually agreed on and invited *physical regulation* so that Isaiah can get his body to the point that he can type all that he wants to say.

Jason read, or interpreted, Isaiah’s body and behavior very closely, using his local, personal understanding (Kliewer & Biklen, 2001) based on years of supporting Isaiah, looking for ways to support Isaiah with his sensory distractions to calm his body. Jason was consistently respectful to Isaiah, collaborated completely with him, and did not determine the direction of the conversation. He sought to support him rather than to control or manage him. In short, Jason acted as a sensitized listener: “The sensitized ‘listener’ knows how to respond to nonverbal communication. He or she considers shared knowledge, environment, time, and location when attempting to interpret the communicative intent of the other person. A sensitized listener collaborates, seeking feedback and clarification from individuals who use primarily nonverbal methods” (Olney, 2001, p. 92).

Although this support may seem intensive and time consuming, it eventually resulted in Isaiah quieting his body; developing his focus on typing, manifested and/or assisted by the rhythmic humming; and getting his words out so that he could engage in a casual conversation.

Expressing Agency

This section contains detailed descriptions of various ways that agency was expressed when it was recognized and supported. Though none of the participants achieved independent typing, they all demonstrated agency in numerous ways. We observed several examples of expressing agency: sharing in an interaction, making a choice, taking a stand, regulating someone’s behavior, and adding one’s self, through personality or humor, to an interaction or conversation. Often, expressions of agency are complex and dynamic and include more than one of these elements.

One of the most important manifestations of agency is making a choice. Choice making for the participants required a sensitized listener, various communication supports, and a context in which

others believe they have something to say. Jason exemplified the sensitized listener with Isaiah when I (the first author) visited them at school on a day when Isaiah was to take two tests. Furthermore, because of this opportunity, Isaiah expressed agency through sharing an interaction, regulating Jason's behavior, adding humor, and, ultimately, making a choice.

I followed Isaiah and Jason to their separate classroom after lunch. Isaiah sat down on the bean bags in the front left corner of the room. Jason said, "Not now, Isaiah. We have to get started on some work. You have those two tests. Get up." Isaiah stood up and looked around the room. Jason closed the door, and the choice board on the back of the door swung into full view. The choices were: Walk, Exercise, Work, TALK, Rest, Bathroom, Something Else. Isaiah stood in front of the door, looking at the choice board. Jason saw this and said, "Okay. You can make a choice for an activity, and then we are going to do some work. What do you want?" Isaiah reached straight across with his right hand and slightly downward to point to "Rest" in the lower left corner of the choice board. Jason laughed and said, "Sorry, Isaiah. Nice try. Are you being funny?" Isaiah smiled and sat down in the bean bags. Jason looked at him for 3 s and then turned and pulled the testing materials out on the desk.

There are several important aspects to this quick interaction. First, Jason offered the choices to Isaiah, something that may be read as being "soft" on discipline or being manipulated by Isaiah. However, Jason's goal was not to control Isaiah but to support Isaiah so he had control over his life. In this case, it meant making the choices available to Isaiah, knowing that Isaiah could not plead his case to rest or ask for the choices as another student who can speak might. Second, Isaiah made the choice without any physical support. When asked about this, Jason described that Isaiah often did that with these choices, possibly because they were high-interest choices and because the board hung at a lower level on the wall that he could reach more easily. Third, Jason respected Isaiah's choice, though he clearly did not want to because of the need to administer the tests. Jason explained that allowing Isaiah to take a brief break was not that big of a sacrifice and that by respecting Isaiah's choices he hoped to support Isaiah to communicate more. When he asked Isaiah to get up a few minutes later, Isaiah joined him at the table and began his first test.

Taking a stand is sometimes difficult to do. When someone does not speak and depends on a communication partner to accept the stand while continuing to support his or her right to disagree, it may be much more difficult. Michael made a choice and took a stand regarding the word he wanted to practice typing and speaking during one of his strategy sessions. He was supported by his mother, Jennifer, during this session in which he was to type a word, read it, and then practice saying it spontaneously (without reading it).

Michael typed, "HIPPOPOTAMUS." The SLP then prompted, "Okay, let's say it." With Jennifer breaking down the word into sounds to support him, Michael said, "Hip-po-po-ta-mus." Jennifer re-read the word slowly, clearly pronouncing each sound. Michael looked directly at his mother and said some of the sounds. Jennifer then said, "Let's type it again." Michael typed it again, faster this time. His mother supported him at the wrist, applying backward pressure. They repeated the process two more times. Each time Michael waited for his mother to supply the consonant sounds, but he produced the vowel sounds more quickly. After the third time, Michael stood up and walked over to the bookshelves on the right wall. Jennifer asked, "How about the nickname just for starters? Let's do 'Hippo.'" Michael returned to his seat and typed "HIPPO" with backward pressure applied underneath his wrist. Jennifer prompted him, "Okay, now say it." Michael said, "Hippopotamus." Jennifer asked, "Do you want another word?" Michael immediately typed with the same type of support, "NO MORE." He then repeated several times without any prompting, "No more, no more, no more, no more."

The key aspect of this interaction was the agency Michael displayed by saying "hippopotamus" when his mother suggested he practice with the shorter "hippo." The unintended challenge to his agency could have been his motivation to say a long word on his own. His desire to stop practicing after this may or may not have been related to this challenge to his agency, but we read this as part of his taking a stand with his word. The second key to this interaction was that Jennifer continued to support his communication and did not persist in trying to urge him to use "hippo" or another word or to continue practicing when he said, "No more." She recognized his agency, supporting him to continue communicating even when he disagreed with her suggestion.

Demonstrating a combination of taking a stand and regulating someone else's behavior, Megan was 1 of 2 participants who asked that she not be filmed during the strategy sessions. Megan is a 26-year-old woman labeled with autism who speaks both functional and automatic phrases. However, her most reliable form of communication is typing with physical support. Her project goals were to type without physical support and to receive increased or improved support with sensory-based emotional issues. During an early strategy session, Megan walked in the room and seemed anxious as she slowly began to take out her communication device. The SLP asked Megan if she would like some help with the bag. Megan replied vocally, "I'll do it." She partially unzipped the bag but then stopped and seemed to be stuck, which was uncharacteristic for her. She typically managed such tasks independently and smoothly. Guessing that Megan might be reacting to the presence of the cameras, the SLP asked Megan what she wanted to do with them. Megan replied vocally, "Get them out of here." As soon as the cameras were gone, Megan put her slant board on the table, took the communication device out of the bag without difficulty, and placed it on the slant board, ready to begin the session.

Again, we observed that the role of the communicative partner was crucial to whether Megan's expression of agency was recognized. The SLP was not sure what Megan was thinking, but rather than interpreting her difficulty taking out her communication device as evidence of incompetence, she knew to look for external factors causing difficulty with the physical task. She eventually recognized and tried to predict normative reasons for her anxiety. By attributing her difficulty with the bag to anxiety and not any assumed deficiency that was due to autism, the SLP supported Megan to continue the conversation by allowing her the opportunity to do so. Similar to Jennifer in the example above, the SLP listened to and complied with Megan's requests, although she would rather have videotaped the session.

Discussion and Implications for Practice

We began this study with the goal of exploring how individuals labeled with autism who type to communicate conceptualize and work toward independent communication skills. Each of the participants made progress toward independence in their communication by either decreasing physical

supports from their communication facilitators or increasing their speech. Most participants faded physical support to some degree and all were practicing typing with less physical support, although none of our participants typed independently, without any physical support. One of the key factors to their successful participation in these strategy sessions was that the participants shaped their own paths toward communicative independence. Participants had various opportunities after the study ended to continue individual training sessions with the SLP if they chose to do so.

A significant finding of this study is that the participants troubled traditional notions of independence as typing or completing a task without support. More important, they challenged the view that dependence in some tasks can be read as incompetence. We found that the concept of agency is a useful frame with which to understand social and communicative interactions between those labeled with autism and their communication facilitators. Focusing only on independence would prevent the recognition of expressions of agency while people work toward independent communication as well as expressions of agency by individuals who may never type independently or who may continue to require support in some daily tasks. The framework of agency accounts for the complexity of one's participation in the world when that participation includes various supports. Although someone may be seen as dependent in many ways and may never achieve independence in certain tasks—including typing to communicate—she or he can demonstrate control over, make choices about, and determine the course of her or his life through expressions of agency.

For the participants to express their agency, they required the opportunity to do so, the necessary supports provided by others, and communication partners who recognized, or "heard," them. The findings of this study present several implications for practice. The following specific recommendations reflect keys to recognizing and supporting expressions of agency by individuals labeled with autism:

1. *Believe that all people can communicate.* Because recognizing and supporting expressions of agency require the provision of opportunities to do so, it is important to believe that all individuals labeled with autism can communicate their intentions in some manner. For some, this may involve an attitudinal shift to resist the automatic assump-

tion that individuals labeled with autism who look or act certain ways are incompetent and incommunicative. It also requires a broadening of the concept of communication to include nonspoken and supported communication.

2. *Provide constant and consistent opportunities to express agency.* We should try to support people to control their lives rather than supporting them to “act appropriately” or comply with behavioral norms. This may also require an attitudinal shift. The communicative intent of various behaviors and nonspoken communication may be misinterpreted or overlooked when the focus is on curbing or controlling them. Furthermore, it may be tempting to disregard an expression of agency when it is difficult to abide by one’s request or when it conflicts with one’s intentions. The examples of Jennifer, the SLP, and Jason recognizing expressions of agency in this study demonstrate both the potential for such expressions and the imminent risk of overlooking, ignoring, or misinterpreting them.

3. *Recognize subtle and multiple forms of communication.* As in this study, it is important to recognize and support expressions of agency even while someone may be working to develop independent communication skills. Validation of communication and competence should not be a necessary first step to being afforded the opportunity to communicate and be heard. Communication partners need to hone their observational skills because agency is often expressed through various fleeting and nonspoken forms of communication such as facial expressions, emotional reactions, sounds, blinks or subtle glances, and other quick physical actions. Another rule of thumb is to look for the communicative intent in all actions and behaviors, such as in Denise’s protests to her mother that we initially overlooked in this study. One must also understand the purpose of various behaviors and physical actions. Some behaviors are unintentional, such as some repetitive actions, automatic responses (John grabbing at any food he sees), and some echolalic language. These would need to be differentiated from intentional actions expressing agency.

4. *Give people the time to respond.* As stated in the introduction, many individuals labeled with autism take longer to respond to others through communication or action. Performing on demand and/or within a quick conversational give and take can be difficult but not impossible. However, if one does not wait for a response, then he or she will not get it. Thus, it is necessary to provide this time for pro-

cessing, initiating, and combining the physical actions required for communication and interactive behavior.

5. *Recognize that goals and needs will change.* For all of the participants in this study, their communication goals and needs fluctuated depending on the circumstances and the demands placed on them. One of the most important lessons we learned was to recognize those fluctuations in need and respond in kind. Just as some people might need additional support in stressful or new situations, individuals who type to communicate may need more or different supports at certain times. This should not be seen as a setback but a natural expression of agency. Sometimes, more support enables someone to express an important thought or need.

Conclusion

What started as a study of independence in communication led this research team to challenge our socially constructed notions of independent performance. Considering these data through a framework of agency opens the door for other possibilities. What else can we learn from people labeled with autism (and other disabilities) by broadening the lens of “normal” to include a focus on interdependence rather than independence?

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