

# Sorting out Speech: Understanding multiple methods of communication for persons with autism and other developmental disabilities

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**Abstract:** *This article presents a qualitative research study that descriptively documents multiple forms of speech experienced by participants who have historically been described as functionally nonverbal with noncommunicative echolalic speech, and whose primary and most reliable expressive communication occurs through typing. The authors have constructed a typology of participants' speech that includes two types of spontaneous speech—echolalic phrases and self initiated conversation and three types of scaffolded speech—reading aloud, the use of routine social scripts, and supported conversation. The communicative intent of these various forms of speech as described by the participants will be discussed. Four of these five forms of speech are characterized as dialogic, or potentially so, in that they allow the speaker to participate actively in meaningful communicative exchanges with others. As the data illustrate, the relationships among these various types of speech, and indeed the relationship between these various forms of speech and each participant's typed expressive communication, appears to be complex and dynamic. Implications for communication partners, in making decisions about supporting and responding to complex, multi-modal systems of communication are discussed.*

“Go home!” Sue shouted. I<sup>1</sup> had just arrived at her home and this apparent command to leave confused me. Did she want me to leave? Did *she* want to go? I decided to move forward with the conversation saying, “Good to see you Sue. How is school going?” Sue reached for her mother’s arm and tapped it quickly. Sue’s mother pulled out a small electronic keyboard and held it in front of Sue. Sue pointed her finger and, punching one letter at a time, typed out, “Echolalia at its worst. It is very embarrassing. I want you to stay.” I now understood that her verbal statement, “Go home,” was not what she intended to say. It has historically been quite difficult to interpret what meaning or intent (if any) echolalic speech such as Sue’s “Go home!” may or may not have for individuals described as functionally nonverbal (individuals whose speech is repetitive and not sufficient to engage in communicative exchanges with others). Had Sue not been able to make her intent clear through her typed language, I might never have known what she intended to communicate to me, or if, indeed, her speech had been intentional at all.

Sue Rubin has autism and for the past seventeen years has communicated through typing (i.e., pointing her index finger

of her right hand to strike a keyboard one letter at a time). Sue requires a communication partner, trained in methods of support, to coach her while she communicates. Sue refers to her method of communication as facilitated communication (FC) (see: Biklen, 1990, 1993; Biklen & Cardinal, 1997; Crossley, 1994, 1997, Mirenda, 2004 & 2008). FC (also referred to as Facilitated Communication Training [FCT]; see Crossley, 1994) is a method of augmentative and alternative communication (AAC) used by individuals whose speech is not reliable and who experience difficulties with intentional movement (see Donnellan & Leary, 1995; Donnellan, Leary, & Robledo 2006; Dziuk, Gidley, Larson, Apostu, Mahone, Denckla, & Mostofsky, 2007; Green, Charman, Pickles, Chandler, Loucas, Simonoff, & Baird, 2009; Leary & Hill, 1996; Ming, Brimacombe, & Wagner, 2007) that makes the ability to independently point to access a communication aid unreliable at the outset of the training process (Biklen, 1993; Biklen & Cardinal, 1997; Crossley, 1994, 1997, Iverson, 2006 & 2007, Mukhopadhyay, 2008). Physical support (e.g., hand stabilization, proprioceptive input, and resistance or backward movement away from the keyboard) to enable the communi-

ation aid user to access the alphabet, symbols, words, or pictures is provided at the outset of FC training, but fades as the FC user develops increasing motor control and becomes more confident and competent at typing. Many FC users, such as Sue Rubin and other participants in this study, have become independent of physical support in their typing, but may continue to need verbal and proximal assistance from a communication partner to stay focused, sustain movement, and gain confidence (Beukelman & Mirenda, 2005; Biklen, 2005; Blackman, 1999; Mirenda, 2004; Mukhopadhyay, 2000; Rubin, Biklen, Kasa-Hendrickson, Kluth, Cardinal, & Broderick, 2001; Wurzburg, 2004).

It should be noted that, historically, Facilitated Communication has aroused a good deal of controversy in the media and academic literature and research on the method has had mixed results (Bara, Bucciarelli, & Colle, 2001; Biklen, Saha, & Kliever, 1995; Cardinal, Hanson, & Wakeham, 1996; Sheehan & Matuozzi, 1996; Weiss, Wagner, & Bauman, 1996; Wheeler, Jacobson, Paglieri, & Schwartz, 1993). Although controversy regarding the use of Facilitated Communication continues, greater acceptance has built for those who have achieved independence in their typing. The goal for all who utilize Facilitated Communication, as a communication strategy, is to achieve independence in their typed communication (see: Facilitated Communication Institute (2000), *Facilitated Communication Training Standards*). Beukelman and Miranda (2005) in referring to Sharisa Kochmeister's keynote address at a TASH conference in 1994 comment on her ability to type independently stating,

Sharisa joins a small group of people around the world who began communicating through FC and are now able to type either independently or with minimal, hand-on-shoulder support. There can be no doubt that, for them, FC "worked," in that it opened the door to communication for the first time...for them the controversy has ended. (p. 324)

As increasing numbers of people who use FC continue to achieve independence in their typed communication (Biklen, 2005; Biklen & Burke, 2006; Broderick & Kasa-Hendrickson, 2001; Kasa-Hendrickson, Broderick, & Biklen, 2002; Mirenda, 2003; Rubin, Biklen, Kasa-Hendrickson, Kluth, Cardinal, & Broderick, 2001) Mirenda (2008) asks a thoughtful question, "What's going on here and what can we learn from it" (p. 229)? As qualitative researchers, interested in studying unique phenomena, this is our orientation. In this study we turn our attention, as researchers, to the careful observation and description of our participants' expanding forms of

speech, and to inviting our participants to share their own interpretations of their efforts to integrate their ever-expanding speech with their typing into a complex system of expressive communication that is ultimately useful to them.

All of the participants in this study have a history of experiencing speech similar to the example of Sue Rubin's "Go home!" described above—speech that has most often been characterized by professionals as "echolalic." Over twenty-five years ago, Prizant and Duchan (1981) and Prizant and Rydell (1984) asked what was, at the time, a ground breaking question—what might be the communicative function(s) of immediate and delayed echolalia? Their work indicated that in the context of naturally occurring events the echolalia of children labeled with autism did indeed seem to serve a variety of communicative functions. Prizant and Wetherby (1985) note the complexity of interpreting speech acts by saying, "When conventional acts, including speech, are used by autistic children, they may be used to convey a meaning different from the conventional one, or they may be used non-interactively, possibly for sensory stimulation, rather than for a communicative purpose" (p. 25). Prizant & Wetherby further suggest,

Rather than viewing intentionality as an all-or-none achievement, it would be viewed as a continuum with its roots in automatic, reflexive reactions with no apparent awareness of a goal to a coordinated plan invoking multiple schemes used deliberately to pursue a goal. (p. 26)

While this work added significantly to the complexity with which we regard the possible functions of echolalic speech, a significant limitation of this body of work is that none of the studies' participants had access to augmentative or alternative communication systems reliable enough for them to either suggest their own interpretations of the possible uses or functions of their own "echolalic" speech, nor even to confirm or deny the authors' hypotheses as to potential functions or ideas about "intentionality." Rather, the designs of this body of work necessarily offer what may be regarded as an "etic" (or outsider) perspective on functions and intentionality of echolalic speech; what remains missing from the literature is an "emic" (or insider) perspective on these very issues.

In an earlier study (Broderick & Kasa-Hendrickson, 2001), we sought to descriptively document our observations of a single individual (Jamie Burke's) rapidly expanding ability to produce speech that appeared to be reliable in communicative intent, and to explore the significance of that development in his life as interpreted by Jamie and his family.

While the design of this study did afford a partially emic perspective (through an interpretivist exploration of the meanings that these events held for Jamie and his family), we did not explore an insider's perspective on the range of forms and functions of Jamie's emergent speech, nor an emic perspective on issues such as communicative intentionality. Additionally, this earlier study focused on the experience of a single individual who had been previously regarded as nonverbal and his expanding use of speech. However, subsequent to (and in some cases, concomitant with) our data collection with Jamie, we noticed that a number of other individuals we knew who typed to communicate (while utilizing the support strategies provided by a communication coach or facilitator) were increasingly using speech in ways that were similar to Jamie Burke's experience. We broadened the scope of our data collection efforts, enlisting Jamie Burke and six other participants who were observed to experience or who self-identified as experiencing similar expansions of their own speech. The purposes of this study are thus (a) to provide a descriptive understanding of the forms of these participants' speech, (b) through solicitation of participants' own perspectives on their speech, to begin to understand how useful, dialogic, or communicative participants' speech may or may not be in enabling them to communicate with others in complex ways, and (c) to begin to explore the complexities of the work that communication partners must do in deciding how to support and interact with a person who experiences and uses a complex combination of spoken and typed expression.

## **Method**

This study is conducted utilizing qualitative methods of inquiry and analysis (Bogdan & Biklen, 2003; Denzin & Lincoln, 2005; Willis, 2005) and is grounded within the assumptions of an interpretivist worldview or paradigm, which seeks to "describe, interpret, and understand" (Ferguson, Ferguson, and Taylor 1992, p.6). Biklen (2005) explains the process of utilizing qualitative methods by stating,

The qualitative tradition involves spending time in the field; collecting data (e.g., interviews, documents) systematically; interacting with people; seeking multiple interpretations of events; coding, sorting, and analyzing data; interpreting data in relation to cultural ideas; ...and developing theoretical understandings. (p.3)

Within this interpretivist framework (Ferguson, Ferguson, & Taylor, 1992; Kemmis & McTaggart, 2005; Willis, 2007), we seek to understand how FC users themselves interpret and describe their experiences. We began this study with the as-

sumption that FC users' experiences, like any experiences, are not knowable in the objective sense. Biklen (2005) writes:

Qualitative researchers speak of multiple truths. That is, I can study what autism means at this time, to particular people, in given contexts, knowing that my understanding may change as I become aware of other perspectives and am affected by new experiences and contexts. I am obliged to welcome complexity, even contradictions, as they arise...I want to consider autism's layered and subjective identities. (p. 3)

Qualitative researchers seek to convey meaning that participants give to their experiences by staying close to the data. Janesick (2000) shares, "the researcher must find the most effective way to tell the story and to convince the audience of the meaning of the study. Staying close to the data is the most powerful means of telling the story" (p. 389). The participants' own words speak loudly, expressively, and with insight; their words tell of their experiences on their own accord. It is our hope that listening carefully to their words will expand the dialog for what it means to communicate through both the typed and the spoken word.

## *Data Procedures*

As researchers we conducted interviews and participant observation sessions with our participants while seeking to understand their experiences with using speech from their perspective; to understand their "sense and understanding of the world" (Cherryholmes 1988, p. 108).

During interviews (both individually and in focus groups), we posed questions to participants, seeking to gain deeper understanding of how they think about and use their spoken communication. Prior to the interviews participants were given a list of questions that asked them to describe how they used speech, what worked and when, what was difficult and when, and how they were engaged in practice. Although we would begin our interviews with set questions, events such as our participants engaging in echoed speech would lead us, in the moment, to shift our discussion to what was happening for them at the time.

Over the course of three years all of the authors worked as a team of researchers and collectively conducted a minimum of eight formal interviews with each of our participants<sup>ii</sup> in their homes and schools. Each interview lasted approximately two hours in length and was videotaped and subsequently transcribed. Further, we conducted six focus group meetings each lasting approximately 2 hours in length. In addition, we held numerous informal conversations with participants both

in person and through email. We also attended 35 public conference presentations where the participants gave talks discussing their communication strategies.

During observations we paid attention to the ways our participants were using their speech in action. The observations took place in participants' homes, schools, communities (i.e., at restaurants, parks, and stores), and at conference presentations. Each participant was observed a minimum of ten times with each observation lasting approximately 2 hours. As we observed and interacted with our participants we took notice of how speech was used and took time to ask participants about particular speech patterns they were using. We asked questions directly to participants regarding their communicative intent of utterances and about suggestions for the communication partner's interaction with them. Further, as we observed we were guided by questions that were not asked of participants, but that gave focus to our inquiry. Guiding questions were as follows: (a) When, and in what contexts, do participants produce speech? (b) What is the nature of the speech that participants are using? (c) How do participants use their speech? and (d) How might participants experiment with their speech or use speech in ways that may be novel to them?

To maintain anonymity we have used pseudonyms, except when participants have requested that we use their real names.<sup>iii</sup> Upon the completion of data collection we had conducted over 350 hours of interviews and participant observation. Transcription of the interviews were read and shared among researchers. Following each participant observation session we created detailed field notes and analytic memos. Transcriptions, fieldnotes, and analytic memos culminated in over 1500 typed pages of notes.

### *Participants*

When we decided to conduct this research we sought participants who had been typing for at least 5 years and who were beginning to speak or had become quite proficient at using their speech in some way. As researchers we have been studying facilitated communication for more than fifteen years and through this process have gotten to know many people who use FC. As we began to plan data collection procedures for this study we made a list of potential participants. The list was made based on our observations and professional recommendations of the person's use of speech and their engagement in developing their speech. As qualitative researchers we were specifically interested in the experiences of those who were working to use speech in concert with their typed communication. All participants in our original list ac-

cepted and were pleased to participate. As researchers we have presented at conferences and college classes with each of the participants. We have developed collegial relationships with each participant and continue to maintain contact with each in order to have on going conversation about their experiences with typing and talking to communicate.

All of the participants in this study use best practice strategies when typing to communicate (For a thorough discussion of independent typing see: Rossetti, Ashby, Arndt, Chadwick, & Kasahara 2008). Five of the participants type independent of any physical touch, one participant types independently most of the time and requires a light touch to the shoulder when he becomes tired or is in a stressful situation, and one uses minimal support of a hand on the shoulder or back of the elbow. Further, one participant who can type independently with one hand can also type using two hands when he had a light touch to the back of his shoulder. This support is given with his communication coach standing behind him and lightly touching the backs of his shoulder or grasping his shirt at his shoulders. All participants, regardless of their independence from physical support, continue to require a communication coach at their side who performs a variety of other supports (e.g., physical proximity, verbal encouragement, message monitoring, attention focus, and clarification, etc.) in order to be able to adequately express himself or herself through typing.

Thus we continue to describe each of our participants as "FC users," despite the fact that most do not require physical support in order to type (for a thorough discussion of the many types of support provided by facilitators see: Facilitated Communication Institute, 2000). All of the participants used the support described above during all data collection sessions.

Three young women and four young men participated in our study. Their ages ranged from 10 to 25. Table 1 provides specific information detailing each FC user's (a) name, (b) disability label prior to using FC, (c) current disability label, and (d) age when he/she began using FC, as well as (e) the number of years the participant has been using FC to communicate, (f) the level of physical support the participant was generally using during the period of data collection, (g) the number of facilitators who supported the FC user during the time of the study, (h) the facilitators' relationship to the FC user, and (i) descriptive characteristics of participants' speech prior to their use of FC.

Each of the participants had the ability to produce some spoken language prior to their being introduced to FC, yet none would describe their speech as communicative (i.e., useful in sharing thoughts, ideas, criticisms, or needs). Further,

FC USER	Disability label prior to using FC	Current Disability Label	Age when began using FC	Number of years using FC	Level of support at the time of the study	Number of facilitators who support FC user during the time of the study	Facilitators relationship to the FC user	Characteristics of speech Before FC
<b>Sue Rubin</b>	Autism/ Mental Retardation	Autism	13	17	No physical support	9	Mother Paid support personnel Friends	Echolalia with unintelligible words
<b>Jamie Burke</b>	Autism/ Mental Retardation	Autism	5	18	No physical support/ Touch to the backs of the shoulders when using two hands to type	5	Mother Paid support personnel Friends	Some echolalia limited speech from age 6-12
<b>Tyler Fihe</b>	Autism/ Mental Retardation	Autism	7	17	No physical support	4	Mother Paid support personnel Friends	Echolalia
<b>Blair Brown</b>	Multiply Disabled/ Mental Retardation	Multiply Disabled	10	16	Touch at the and shoulder or back of the elbow	4	Mother Paid support personnel Researchers	Echolalic talk /not useful for dialogic communication
<b>Franklin Wilson</b>	Autism/ Mental Retardation	Autism	15	15	No physical support	3	Mother Friends Paid support personnel	Echolalic talk /not useful for dialogic communication
<b>Nathan Guzman</b>	Autism/ Mental Retardation	Autism	6	13	No physical support/ Touch at the shoulder	4	Mother Researcher	Echolalic talk /not useful for dialogic communication
<b>Lucy Harrison</b>	Autism/ Mental Retardation	Autism	13	18	No physical support	5	Mother Friends	Echolalic talk /not useful for dialogic communication

Table 1. Participant Information

each participant has been labeled as “non verbal” in relation to their ability to use verbal communication in their lives. For example, Nathan Guzman, a teenager from southern California, describes his early speech as being cluttered by “lousy words;” Sue Rubin describes her early speech as consisting of “awful echolalia;” and Jamie Burke, a college student in New York, describes his early speech as consisting of many “words of annoyance.” Speech alone often left their communication partners, teachers, and others unsure about the meaning of the

exchange. When Sue first began to communicate through typing, she urged those around her to listen to her typing and not her talking, feeling that her echolalic and non-intentional speech would only confuse those she was interacting with. Several other participants shared this perspective. Franklin Wilson, a young man from California, insisted, “My spoken words are so confusing please pay attention to my typing.” Jamie Burke likewise advised his communication partners to “Listen to my typing; my voice is sadly unreliable.”

However, at the outset of this study, all participants had recently begun to acquire more reliable/intentional speech, although most continue to experience what they describe as “lousy words,” “awful echolalia,” or “words of annoyance”—speech that is not intentionally produced and which is not necessarily a reliable reflection of their communicative intent. The expressive communication of each of the participants in this study now consists of a complex mix of both typed and spoken language. Some of this spoken language continues to be echolalic and by participants’ own accounts, non-purposeful; however, they explain through their typed communication that more of their speech is becoming novel, spontaneous, purposeful, and reflective of their communicative intent. These individuals’ communication partners are thus increasingly faced with the dilemma that the first author faced in the opening paragraph when Sue said “go home” upon her arrival—how is one to respond to these individuals’

spoken language in a communicative exchange? How is one to interpret another’s communicative intent—that is, whether a particular utterance or series of utterances are intentional or not? Simply “not listening” to their talking, as they themselves once advised communication partners to do, is no longer a viable option in all contexts. Deciding how to interpret and respond to participants’ use of speech has thus become a much more complex challenge for our participants’ communication partners as participants attempt to use more verbal speech to communicate.

Parents of FC users also participated in data collection as their role in teaching FC users to type and communicate effectively informed our research questions. Parents were encouraged to comment during the interview process and observations. While parents were not primary participants, they played a supportive role in helping us to understand the use of speech for the FC user.

Spontaneous Speech		Scaffolded Speech		
Echolalic Speech – non-dialogic	Spontaneous conversational speech—dialogic	Reading aloud—potentially dialogic	Routine social scripts—potentially dialogic	Supported conversation—potentially dialogic
<p>Characteristics:</p> <p><i>Spontaneous speech that is echoed, not apparently relevant to the communicative context; FC users describe it as not being purposeful on their part, and as not being useful to them as it is generally not reflective of their communicative intent</i></p>	<p>Characteristics:</p> <p><i>Spontaneous speech that is novel and appears to be relevant to the communicative context; FC users describe it as purposeful (though not necessarily planned), and as useful to them in that it is reflective of their communicative intent, although often much more simplified in form than their typed expressive language</i></p>	<p>Characteristics:</p> <p><i>Speech scaffolded by visual and textual supports</i></p>	<p>Characteristics:</p> <p><i>Speech scaffolded by social/conversational supports and limited choices. Conducted in highly structured situations intended for practice.</i></p>	<p>Characteristics:</p> <p><i>Speech scaffolded by shared knowledge and experience with the communication partner.</i></p>
<p>Examples:</p> <ul style="list-style-type: none"> <li>• Saying, “baby hippos” while typing “So excited I am in need of a relaxing break.”</li> <li>• Asking repetitively, “What time is it?”</li> <li>• Shouting “Go home!” when someone you wish to stay has just arrived</li> </ul>	<p>Examples:</p> <ul style="list-style-type: none"> <li>• Alerting parents to item almost left behind</li> <li>• Initiating a conversation by sharing a new piece of information</li> </ul>	<p>Examples:</p> <ul style="list-style-type: none"> <li>• Reading aloud a sentence typed on a communication device</li> <li>• Reading aloud environmental print (road signs, familiar posters, books, etc.)</li> </ul>	<p>Examples:</p> <ul style="list-style-type: none"> <li>• Verbally responding to the question, “What is your homework to-night?”</li> <li>• Verbally answering question when given two choices (i.e., “do you want to eat in or go out?”)</li> </ul>	<p>Examples:</p> <ul style="list-style-type: none"> <li>• Negotiating activities for break time Telling a story about an event or shared experience (such as movies, plays, or school events) by responding to scaffolded questions provided by the partner who has shared knowledge of the experience</li> </ul>

Figure 1. Typology of forms of speech exhibited by participants

### *Data Analysis*

From the very beginning of this study, analysis of each participant observation and/or interview informed the questions posed at subsequent interviews; and researchers encouraged the participants to actively participate in the ongoing process of analysis. As we constructed and analyzed our field notes, memos, and interview transcripts, we shared the actual notes as well as analytic themes and categories with participants. Throughout the entire process of conducting this study, data collection and analysis occurred simultaneously using the constant comparative method as a strategy (Bogdan & Biklen, 2006; Charmaz, 2007; Glasser & Strauss, 1967)

As qualitative researchers we sought to deeply understand our participants' perspectives as we observed them and to query our participants regarding their understanding and interpretations of how they were constructing understanding of their use of speech in their life. We engaged in this research to understand the complex experiences of our participants, not to test hypotheses. Bogdan & Biklen (2006) remind us that,

Qualitative researchers ...tend to analyze their data inductively. They do not search out data or evidence to prove or disprove hypotheses they hold before entering the study; rather, the abstractions are built as the particulars that have been gathered are grouped together. (p.6)

As we proceeded in data collection and analysis we looked for coding categories and emerging themes (see Figure 1). Conducting a line by line analysis of the data we created codes for organizing the data pieces. As codes were identified we discussed and revised our coding categories. This process continued throughout data collection and after until no new information was emerging from the data. As a result of the coding process two major themes and subsequent sub-themes were formed. These are detailed in the findings as well as in Figure 1. These are the "big idea" (Bogdan & Biklen, 2006, p. 187) statements of the paper that emerged from the data through our analytic process.

### **Findings**

Speaking as a way to meaningfully communicate with others is a new development for all of the participants and is the focus of this study. Speech development from the perspective of people with autism is not widely written about. This research has the potential to contribute to the field of special education through presenting new ways to understand and support communication as experienced by people with autism themselves

The relationships among these various types of speech appear to be complex and dynamic, and the relative propor-

tions of each used by any individual at any given time appear to be affected by fatigue, anxiety, degree of familiarity with the communication partner(s) and context(s), and any number of other considerations. Each of these types of speech is described and illustrated below. In addition, the findings include a discussion of the pivotal role of practice cited by participants as being supportive of their ongoing development of more clearly dialogic and useful speech, as well as a discussion of the challenges faced by the communication partner in interpreting and responding to spontaneous nondialogic speech.

### *Spontaneous Speech*

Participants both demonstrated and talked about two forms of speech which we refer to as *spontaneous*, as they are described by participants as tending to "pop out" or "just come out" spontaneously, without any conscious effort or planning. The first of these, which we call *echolalic speech*, was not welcomed by participants when it occurred, as it did not support or enable them in any way to engage in meaningful communicative exchanges with communication partners. In fact, we further characterize this spontaneous echolalic speech as *non-dialogic* because it did not facilitate our participants' engagement in meaningful communicative exchanges with others and it frequently served to actively interfere with or undermine one's efforts to communicate meaningfully with others. The second form of spontaneous speech, which we call *spontaneous conversational speech*, may be described as purposeful (though not necessarily planned) in nature, and as useful to FC users in that they regard it to be reflective of their communicative intent, although often much more simplified in form than their typed expressive language. We have further characterized this particular form of spontaneous speech as *potentially dialogic* in nature, in that it may enable participants to engage in meaningful communicative exchanges with others through speech when it occurs, provided that their communication partners recognize and respond to it as such.

*Spontaneous speech: Echolalic phrases.* Echolalic phrases were the predominant form of speech that most study participants reported producing prior to their use of typed communication. This non-dialogic form of spontaneous speech continues to be experienced by most of the participants, and all expressed their frustration with its continuing presence in their communication processes. Franklin Wilson is a young man living in California. The following description of Franklin's speech is drawn from an analytic memo<sup>iv</sup> recorded early in our observations. His speech, at this point, was largely echolalic and non-dialogic:

*The questions from Franklin come rapidly, "What time is it?", "When will we go to the beach?", "Am I done?", "What's the score?" Giving him an answer often does not stop his questions. He may appear not to acknowledge the response at all in any clear way; indeed, he often responds by repeating the same question that was just answered.*

Listening to a string of questions that are apparently unrelated to the context of any given interaction might cause one to assume that Franklin has little of relevance to say. Yet, Franklin reveals through his typed communication that he is equally as frustrated by his non-dialogic speech as the listener might be:

I repeat the same words over and over. I don't want to ask questions all the time. I am almost never able to say what I want through talking. The speech is in my brain but I have to keep going with the typing to really be able to say what I want.

Franklin's experience with verbal communication for most of his life is not unlike most of the other participants in the study. Participants reported some ability to produce speech that consisted largely of repetitive words and phrases and echoes of others' spoken language prior to their use of FC. Virtually none of it was reported as being experienced as dialogic speech. While some may have experienced occasional isolated examples of dialogic speech production in earlier years,<sup>v</sup> often communication partners had a difficult time deciding what was meaningful and intentional and what was not when these FC users spoke. Only after FC users were able to communicate through typing to describe for others their communication styles and how they use speech (as Franklin does above) could people with whom they interacted begin to understand how uncontrollable and troublesome their speech has been and often continues to be.

Prior to her use of FC, Sue Rubin's verbal speech was almost entirely non-dialogic. For example, it was not uncommon for Sue to repeat, "99 cent store" numerous times throughout the day and her mother to repeatedly answer back, "We're not going to the 99 cent store." But that response would not end the conversation. Sue would utter the repetitive phrase, "99 cent store," again and again. Sue's mother describes how her understanding of Sue's non-dialogic speech has evolved over time:

We thought it was kind of cute when she did it at first. She had little phrases like, "donity" and people did it back and forth with her. Sue would say a part of it like,

"do" and someone else would say a part of it. We thought it was kind of interaction and I used to think that was good because she was connecting with people that way and people liked it and she endeared herself to them. But then I noticed that it would escalate and she would end up yelling it out, and then laughing uncontrollably and yelling and that interfered with any kind of interaction.

Sue's echoed phrases were a limited form of communication that did not allow for sophisticated give-and-take conversation or really for much interaction at all. Indeed, Sue's mother's observation indicates that Sue's non-dialogic echolalic speech actually actively "interfered with any kind of interaction." Sue's mother revised her understanding of this form of speech after Sue began to communicate by typing: "Now I see that it gets in the way and she's trying hard to stop those nonsense phrases and also echolalia in general." Reflecting on these exchanges Sue's mother says, "I used to treat these conversations as real. I don't think I would do that again."

Despite Sue's mother's eventual shift in her understanding of and response to Sue's non-dialogic speech, it continues to be a relatively common occurrence for non-disabled conversation partners to continue to commit themselves to a verbal conversation with an individual producing non-dialogic speech that may carry no meaning for either partner involved. Perhaps wanting to make connections, being interested in the person, or desiring to be polite (i.e., when one is asked a question it is generally considered polite to respond to that question) may explain why many partners will engage in and continue with a non-dialogic exchange of words. As Sue's mother noted, at first she thought that engaging in these non-dialogic verbal exchanges with Sue "was good" because it was a "kind of interaction," "she was connecting with people that way," "people like it," and "she endeared herself to them." It is likely there may be other, additional explanations for this common experience as well.

Jamie Burke, too, has considerable experience managing the spontaneous occurrence of non-dialogic speech (or what he calls, "words of annoyance") in his daily communication. For example, during an early focus group interview with other FC users one Saturday morning, Jamie sat with his mother and some friends talking about upcoming vacations. Jamie typed, "So excited I am in need of a relaxing break." Yet while he was typing he repeatedly said aloud, "baby hippos, baby hippos." In Kasa-Hendrickson, Broderick, & Biklen (2002) Jamie cites an additional example of his experience with these "words of annoyance":

In class today I was anxious and I was typing out an English assignment and I kept saying, “Mickey turns into Frankenstein.” But I was not typing that I was typing about Edgar Allan Poe, but all of a sudden out leapt, “Mickey turns into Frankenstein.” I call these words of annoyance.

In each of these examples, Jamie was surrounded by supportive communication partners with whom he has talked (through typed communication) extensively about his experience with words of annoyance, and in each circumstance, the supportive communication partners (i.e., parents, the researchers, his school-based facilitator) were able to reengage him in the relevant conversation and thus these particular occurrences of non-dialogic speech did not substantially disrupt the dialogic communication process. It was assumed by the communication partners that Jamie did not really want to talk about baby hippos or Mickey turning into Frankenstein, but rather that he wanted to continue with the established conversational threads of summer vacations and Edgar Allan Poe, and he was supported to do so through his typing.

These examples are perhaps more straightforward than many, and they illustrate, in fact, assumptions on the part of the communication partners that Jamie did not wish to have a conversation about baby hippos or Mickey turning into Frankenstein. However, it may not always be as clear or obvious to the communication partner whether the person’s speech is reflective of his or her communicative intent or not. Indeed, as these FC users have developed more and more spontaneous dialogic speech, making this sort of judgment is becoming an increasingly complex and ambiguous task for the communication partner.

*Spontaneous speech: Spontaneous conversational speech.* All of the individuals invited to participate in this study were asked to do so because they (or, in some cases, their parents) had reported experiencing (or observing) an increasing ability to produce spoken language, most often in the context of typed communication (i.e., reading aloud their own typed text). However, it was also clear to us as we began observing and interviewing participants that most were also experiencing an increasing ability to initiate and produce spontaneous speech that was appropriate to the context, and that enabled them to participate in a meaningful communicative exchange with a partner—that is, they were experiencing increasingly dialogic spontaneous speech as well.

Since Sue Rubin began purposefully trying to produce more speech, her spontaneous verbal communication has become increasingly meaningful with dialogic intent. Sue’s

mother shares a recent example of Sue’s use of spontaneous conversational dialogic speech:

Friday night Sue and I came back from synagogue and Bob [Sue’s father] was here and so I plopped down in a chair and started to talk and Sue walked over to me and said, “Want to go to bed” very clearly. It was beautiful.

Sue’s mother shared that she was startled and pleasantly surprised by Sue’s ability to convey meaning in this situation. Sue shared an additional recent example when this occurred:

We were flying and my mom put her purse and some other things on the security thing, and then left it there, and my mom started walking away and I noticed and yelled ‘purse’ absolutely perfectly.

In addition to being able to spontaneously share information or to make requests participants demonstrated the ability to have short conversations with family and friends about familiar topics and meaningful content and events in their lives. Lucy Harrison, a young woman from New York, comments on her ability to speak extemporaneously. Lucy reports:

I can use my voice well if I can deliver a message to my mom. I can succeed at the message because I care about the things I need in the house. [As an example, Lucy explains] I want to go on water slides and I think that I told my mom a lot.

Familiarity with Lucy and the ability to type with her to check on the intent of her speech would seem to be integral components of responding appropriately to Lucy’s spontaneous speech in this example. That is, an unfamiliar communication partner may be unaware of Lucy’s interest in water slides and immediately dismiss her spoken language on this topic as “repetitive,” “stereotypic,” or “echolalic.”

Blair Brown, a young woman who has been an FC user since the age of seven, and Tyler Fihe, a young man, who has been using FC since he was six years old, often present at conferences with each other. While attending a conference, the researchers observed as Tyler struck up a conversation with Blair at the breakfast table one morning without typing:

Tyler: Blair you like swimming?  
Blair: Yes swimming.  
Tyler: Let’s go swimming together.  
Blair: I have a swimsuit.

After observing this conversation the researchers asked Tyler about how this happened. He typed, “I wanted to talk to

Blair and no one was there to type with me so I went for it.” While Blair’s and Tyler’s spontaneous speech in this conversation is far less complex with shorter utterances than they each would have been able to produce if they both were typing, the self initiated spontaneous speech they did produce nevertheless allowed each of them to hold a short conversation with a friend—that is, it was dialogic.

As shown by these examples, participants demonstrate that shared experience and meaning, familiarity with contexts and communication partners, and sometimes sheer necessity (i.e., absence of any facilitators available to type) or even a sense of urgency (i.e., purse about to be left behind) at times can provide the necessary context for people to be able to speak, and through their speech to engage in dialogic communicative interactions.

### *Scaffolded Speech*

In addition to the *spontaneous* forms of speech described above, including both non-dialogic echolalic and potentially dialogic conversational speech, our participants also talked about and were observed to produce several forms of speech that we have described as *scaffolded*, in that they are produced in the context of a variety of types of purposeful and planned supports or scaffolds, including visual or textual supports, social or conversational supports including multiple choice or questions or questions with limited responses, and intimate and shared knowledge and experience with one’s communication partner. These scaffolded forms of speech include *reading aloud*, *supported conversation*, and the use of *routine social scripts*. We have further characterized each of these scaffolded forms of speech as *potentially dialogic* in nature, in that they may enable the FC user to participate in meaningful communicative exchanges with others.

*Scaffolded speech: Reading aloud.* The practice of reading text aloud<sup>vi</sup>, whether that text had been self-composed (i.e., on a communication device during a conversation or on a computer during composition of a written homework assignment) or pre-existed (i.e., road signs, advertisements, passages in books), was a common type of speech production demonstrated by the participants. There was considerable variation demonstrated in the range and complexity of their ability to read text aloud, both across the different individuals and within individual participants’ experiences (i.e., at different times and within different circumstances). For example, during a conference presentation very early in the data collection process, the researchers in this study observed Jamie whispering as he typed a greeting to a friend. Listening closely and upon reviewing the videotapes, we noted that he was whisper-

ing each letter before typing it. Jamie Burke typed, “Hi Lucy so good to see you.” As he typed his message he whispered, “H” and then typed the letter “H”. He then whispered “i” and then typed the letter, “i”. This continued throughout the entire session. It should be noted that Jamie was saying the letter before striking the keyboard on his communication device. This practice of saying the letter or word before typing it on the keyboard was a practice we observed five out of seven participants demonstrate over the course of our data collection.

Over time during the lengthy period of data collection, Jamie transformed this practice of saying the letters into the ability to say the entire word before typing it. And, eventually it became routine that he would read his own typing aloud after typing it. Throughout the period of data collection, we initially observed as Jamie practiced reading aloud familiar text (i.e., books he had read, descriptions on video boxes, and posters). He then moved on to reading aloud his own typing and finally to reading novel texts aloud. Being able to read out loud has changed how he participates in class and presents at conferences, and has given him a mode to practice using speech. At a recent presentation to a class of university students, Jamie prepared several pages of typed remarks and read them aloud to the class. His first paragraph began:

I communicate in most likely the arena of typed talking. It’s the best avenue suited for my travel and thought relaying. This is because my voice, while vastly improved since the first venture, still is not fully accessible as my typing allows.

Jamie’s speech, while increasingly useful for conversation, continues to be limited and not the most reliable method for him to communicate his thoughts. Jamie explains through typing, “Typing is still a more direct route to my thoughts. Speech is good, but ideas get lost and it is hard to say all that I want to say.”

Before Lucy Harrison began to type she was labeled as mentally retarded, unable to prove she was competent until she learned to type. She could speak, but invariably her speech was limited to echoed phrases or one or two word statements, not long sentences. Lucy began reading her typing out loud as a teenager. She typed, “I am feeling an urge to say the word when I see it. The urge is because I am different when I type. I have more confidence.” She reads her typing in a loud monotone voice. It is as if she is shouting at times. She often says a word on or before she actually has completed the act of typing the word and also often says the word several times, while she has only typed it once. Lucy explains through typing, “I really think that seeing the words when I

typed them made it easy to say the words and I feel that the typed words are more important than I should try to say them so I am heard.” Lucy describes her experience as one form of communication building on another as if the first was a kind of scaffold for the next:

When I type I am able to use the words better than before and I am a better talker. At first I was worried about the speech, but I noticed that the speech was getting better. Typing and the speech started to come at the same time and I could read the words as I typed.

Lucy now reads aloud all of her writing and has given speeches throughout the U.S. and in England, all from texts that she has prepared in advance. Upon completing a speech, she routinely takes questions from the audience and types out her responses at a furious rate, speaking the words aloud as she types them.

Learning to read text out loud has come more easily for some participants than for others. Sue Rubin describes herself as just now in the midst of learning to read her typing out loud. She refers to this work as, “Sweating out each word.” She has never had more than a few understandable words or short sentences that she can speak aloud, but she has been a successful independent FC user for many years (see Rubin et al, 2001; Wurzburg, 2004). Sue has recently begun working on reading her typing out loud with her speech therapist. She types and her speech therapist cues her to look at the printed message and then asks her to take each word, one at a time. The speech therapist prompts her to say each word. During an interview Sue commented on the usefulness of hearing her facilitator read the typing out loud first, explaining, “It is easier to read when I hear the word then am able to repeat it.”

Nathan Guzman types independently, and speaks each word as he types it out on his keyboard. Nathan comments on the difficulty of speaking aloud, and on the supportive nature of reading his own typing out loud:

I am having a hard time bringing the words from my brain to my mouth, typing organizes my thought process. When I type the words on the computer I can see what I want to say. I also must be comfortable with the person or persons I am speaking with. The harder time is when I am not focused, the word recall is not there, or my senses are bothering me. If I feel the person I’m talking to doesn’t believe me that also makes it harder.

Tyler Fihe reads aloud his typed communication, but this has not always been a part of his communication:

In 6<sup>th</sup> grade my mom decided that I should go to my first IEP meeting and read aloud what I wanted to work on in junior high school. I practiced reading what I typed over and over again and then I read it at the meeting. That’s when people started listening to what I had to say.

Many participants of the study are thus using speech that may be best described as “reading aloud” (whether they be reading aloud letters, words, sentences, paragraphs, or lengthy public addresses). We describe this speech as “scaffolded” in that the presence of the text as a visual support is an integral component of this particular form of speech. Several participants report that the visual scaffolding of a written text makes it easier to produce speech. For example, Lucy Harrison reports that, “seeing the words made it easy to say the words,” and Jamie Burke reports that, “seeing and hearing together” were very supportive of his learning to read his own typed text aloud.<sup>vii</sup>

*Scaffolded speech: Supported conversation.* A second type of “scaffolded” speech that many participants demonstrated was their engagement in conversations centered on predictable social verbal exchanges. In the previous section we discussed how reading out loud was supported by the text. Similarly, participants often used the support of a communication partner familiar with many aspects of their lives to scaffold their participation in an exchange. Within the conversation the communication partner often provided the topic of conversation as well as the supports to continue the dialogue. Further, the communication partner often relied on familiar events, areas of interest, and shared knowledge when supporting this type of scaffolded speech. For example, during summer focus groups we<sup>viii</sup> often had conversations with Lucy Harrison about her summer vacation. These conversations were purposefully structured to support Lucy’s continued, meaningful interaction. One day Alicia, second author, initiated the conversation by saying, “Lucy how was your vacation?” Lucy responded by saying, “Thousand Islands, swimming in the sun.” Alicia responded, “You went swimming; that must have been relaxing.” Lucy continued, “Yes yes relaxing vacation.” While this spoken conversation is much different (i.e., shorter and less complex) than Lucy would have shared if she had been typing her conversation it is an emerging method of communication that, when supported by a person familiar with Lucy and the events in her life, allows Lucy to meaningfully contribute to a conversation without typing.

Blair Brown, a college student from California, also uses both speech and typing to communicate. Blair is just begin-

ning to read her typing out loud, but has always been able to use scaffolded verbal conversations as a part of her communication. During an afternoon interview, Blair verbally initiated a conversation with the second author. She said, "I want to read." Alicia responded by saying, "You want to read a book?" Blair responded, "Ya." Alicia continued, "Go get a book." Blair replied, "Ok, I want a book." Alicia asked, "Do you want to read it to me?" Blair responded, "Yes, out loud." It was notable that Blair initiated this conversation and then carried out her wish to read a book out loud with Alicia. Alicia supported Blair to continue in this conversation in this situation, posing questions to Blair that allowed her to continue responding and further the conversation.

Nathan Guzman had similar supported conversations with his mother. During an interview Nathan negotiated break time activities verbally before getting back to his typing. Nathan's mother said, "When you are done, what do you want to do?" Nathan cut his mother off and said, "Then I will watch Fox Kids with Digemon?" His mother responded, "With Digemon, anything else?" Nathan continued to press her saying, "The Magic School Bus too, Mom?" His mother, at this point wishing to end the conversation stopped talking about the TV shows, stared at Nathan and said, "When you are ready let's get going. We need to get started." Nathan continued one more time, "Then I will watch the robot and action man on Fox Kids." Nathan's mother replied, "When you are ready I am here." Knowing that Nathan would have a break soon, his mother supported him to decide on his activities through using a familiar topic (i.e., his favorite TV shows) and a series of questions that would support his consistent communication in this situation. Nathan then finished the typed conversation with the interviewer and watched his requested shows during his subsequent break.

This type of scaffolded speech was useful for FC users to engage in short conversations about familiar events, topics, and interests in meaningful ways (i.e., not cluttered by echoes and repetitive talk), but this type of communication did not allow for FC users to express themselves as complexly as typing allows at this time. Intimacy and familiarity with the individual FC user, as well as the intimacy of having shared knowledge or experience between the FC user and the communication partner, both appear to be integral to providing this sort of conversational scaffolding to support FC users' meaningful participation in verbal social conversations.

*Scaffolded speech: Routine social scripts.* A final form of scaffolded speech that emerged from the data analysis is the use of routine social scripts. We describe this type of speech as purposefully practiced responses to typical social interac-

tions or exchanges that an FC user is likely to encounter in daily social communication.

In an effort to work on improving her speech, Sue Rubin purposefully practices answering questions verbally in daily social routines. These include responses to questions such as: "Do you want to cook or go out?", "Would you like to read or watch TV?", or "What do you want to wear?" Her support staff structures these questions so as to elicit routine and somewhat predictable responses. Thus, for example, although the question "what do you want to wear?" may appear to be an open-ended question, Sue most commonly responds from a fairly limited set of predictable responses (i.e., pants or a dress). Likewise, many of the questions are structured in such a way as to provide limited and even prescribed options for a response (i.e., yes or no questions, either this or that questions, or questions with a limited range of possible responses known to the questioner).<sup>ix</sup> Sue has requested that her support staff routinely engage her in this sort of routine, scripted verbal exchange in order to provide multiple opportunities to practice her use of speech.

In much the same way, Blair Brown's support staff engage her in the development of her verbal communication by asking her to respond to questions such as, "Do you want a quesadilla or a hamburger?" Blair will often take 10-15 seconds before responding, but her verbal response comes and her staff follows the choice that she shared verbally. Further, staff will often ask Blair to give her opinion of movies, food, or fashion by asking, "What did you think Blair? Was that good or bad?" Blair will again take some time before responding, but her verbal response does come and is the basis for further conversation between family, friends, and support staff.

Sue Rubin additionally practices routine, somewhat scripted verbal exchanges when she asks that her communication partners support her to communicate in full sentences, even after she has made her communicative intent known to her partner. For example, although it might be difficult for someone unfamiliar with her pronunciation to immediately grasp what she is saying, in the Oscar-nominated documentary film, *Autism is a World* (Wurzburg, 2004), Sue can be observed and heard speaking a full sentence aloud to her mother, "I want to go to grandma's." Sue's original spontaneous utterance had been, "Grandma, Grandma", and she generated the 6-word sentence in response to her mother's cue, "Sue, ok full sentence." In *Autism is a World*, as in our observations, most of Sue's spoken communication consists of single word utterances, for example "okay" and "alright." However, she continues to use these purposeful strategies to work on pro-

ducing lengthier utterances and reports that she wishes to speak even more, despite the fact that, “actually, it is very hard.” Indeed, Sue advises the authors to “assume all autistic people want really to speak.”

*Scaffolded speech: The importance of practice.* For each of these participants, working on speech has meant having practice as an ever-present companion. For example, during an interview Sue Rubin types, “It is easier to read when I hear the word then am able to repeat it.” In an effort to demonstrate the ways in which Sue practices reading aloud, her mother prompts Sue by saying, “Ok, let’s read that. Do you want to read it by letters first?” Sue responds by typing, “yes.” Her mother points at the message that Sue has typed and says, “Say the letter.” Sue says each letter as her mother repeats them “I-T,” then says, “Say the word.” Sue says, “It.” This continues: “Next, what letter is this?” Her mother urges her on. Sue says, “I.” Her mother says, “Now say the word.” Sue replies, “Is.” Again her mother prompts, “Next say the letters.” Sue says them, “E-A-S-I-E-R.” Her mother says, “Now the whole word.” Sue says, “Easier.” This continues until Sue has gone through each letter and each word of the entire sentence she typed. Then her mother continues, “Now say the phrase.” With this request her mother additionally reads the phrase out loud and again asks Sue to repeat it. Sue sits silently. Her mother reads it again and waits. After her mother reads the phrase a third time, Sue attempts the phrase, “It is easier to read when I hear the word then am able to repeat it.” Her articulation of many sounds is unclear, her pace is slow (she reads each word slowly with a pause between each one), and it would be difficult to understand some words if one did not know the content of the sentence she were producing. However, Sue is clearly making progress in wrestling with the complex oral motor task of producing spoken language.

Sue Rubin is not the only participant for whom speaking has been difficult. In fact, producing speech, particularly speech that is purposeful and enables them to participate in communicative verbal exchanges with others, has not come easily for any of the study participants. All reported that they had to commit to practicing both reading out loud and having verbal conversations. Each FC user has developed his or her own unique forms and routines of practice; however, each engaged to some extent in purposeful practice in at least two of the three forms of scaffolded speech already described: (a) reading text aloud, (b) supported conversation, and (c) routine social scripts.

While still a difficult activity for many of participants, most report that practice reading aloud (particularly their own

typed conversations) is helpful. Most practiced several of these forms of scaffolded speech on a daily basis. Lucy Harrison shares, “I really think that seeing the words as I typed made it easy to say the words.” However, lest anyone think that speaking has become an easy task for her, she further notes, “I think my speech is still careful and I have to work hard to get the right words to come out.”

When the participants practice reading aloud their own typing, for example, they not only see the message as it is typed out, they also hear an auditory model of what it sounds like to read those words aloud, as many either have a communication device that reads their typed words aloud for them, or have a facilitator who takes on that role and reads aloud the FC user’s words or sentences as or after they have been typed. Tyler Fihe explains that his device was an integral part of his practice; “I began hearing all the words I was typing over and over again and this repetition of the sound with the printed word really helped me to remember the words with their sounds.”

Each of these supports—access to a device with voice output or the support of a facilitator who reads aloud one’s words as one composes text—provide an auditory model for pronunciation and creates the opportunity to both see the text and hear the pronunciation of words together. For many, repeated opportunities for this type of practice—inclusive of the support of an auditory model as described—have been central to learning how to produce the sound on their own. Nathan Guzman describes the supportive nature of this type of practice: “Mentally the words are easier verbally it is harder. When my dad calls them out I can think about how to say them myself.” Similarly, Blair Brown explains, “Hearing the words helped me to keep focused on trying to say them. I want to read what I type.”

In addition to reading aloud his own typing, Jamie also reports that it was helpful to him to read aloud other familiar texts within his own home:

I chose to read video boxes because they were like family always available and I knew them well. I heard the titles being spoken. It made them constant.

[Researcher: What do you mean by constant?]

Meaning I could always hear the same word together. Together is necessary.

In addition to the time spent practicing reading a variety of texts aloud, participants also report that having multiple opportunities to practice routine social scripts is helpful for developing increasingly useful speech. For example, accord-

ing to Jamie, “I needed time to practice while having interesting conversations with family and friends.” At a support group meeting Lucy points to the value of having these opportunities to practice speaking: “I think practicing in a group typing and talking will help.” While each FC user developed his or her own way to practice, and utilized and practiced these forms of scaffolded speech in different proportions, what follows is a collective list of examples of some of the ways in which participants engaged in these forms of practicing scaffolded speech:

- Reading aloud a list of common words (often with the support of a family member reading the word first thus providing an auditory model to imitate if necessary)
- Reading aloud the backs of video boxes or titles of familiar books
- Writing grocery lists and then reading them aloud, again with the support of family members to provide auditory models as necessary
- Practicing reading words aloud that are written on flash cards and broken up into syllables
- Answering short questions related to daily routine (i.e., do you want to cook or go out? Do you want to wear a dress or pants?)
- Getting together with other FC users in a group to practice talking
- Asking others to daily engage the FC user in routine conversations (i.e., what subjects do you have for homework tonight?) and being supported to continue in that conversation by being provided any necessary cues to respond (i.e., going through one’s backpack together and seeing which folders are there)
- Practicing producing a full sentence, even after one’s communicative intent had been adequately expressed through a shorter utterance

In each of these practice activities, the necessity of communicating novel information to one’s communication partner, a task commonly referred to as “message passing,” is notably absent. Thus, we may conjecture that the act of producing spoken language may be considerably simplified for, and made more manageable for the FC user if one does not also have to convey novel communicative content. In the practice situations, the speaker can focus on the oral motor act of speech production of routine and predictable words, without having to devote thought and energy to the actual communicative content of one’s spoken message. This would appear to

be consistent with the experience reported by many FC users regarding their development of fluency in typing as well—practicing typing with these sorts of routine activities (i.e., copy typing previously composed sentences [analogous to reading aloud previously composed sentences], responding to yes/no, either/or, or multiple choice questions with a limited set of responses known to the communication partner, and engaging in routine social conversation with fairly predictable exchanges [e.g., “Hey, how’s it going?” “Not bad; how about you?”]) has been reported by many FC users to be supportive of developing improved fluency in the motor act of selecting keys on a keyboard. It makes sense that similar strategies would be supportive of developing improved fluency in the oral motor act of speech production as well.

### **Summary and Implications**

Based upon interviews with and observations of the seven individuals participating in this study, we have offered a descriptive typology of the types of speech that participants both demonstrated and talked about during the period of data collection. This typology includes two types of *spontaneous* speech—echolalic phrases and spontaneous conversational speech, and three types of supported, or what we call *scaffolded* speech—reading aloud, the use of routine social scripts, and supported conversation. Each of the types of speech is further characterized as either *potentially dialogic* or *non-dialogic*, indicating whether or not each particular form of speech lends itself to facilitating the FC users’ active participation in meaningful communicative exchanges with others. As the data illustrate, the experiences the FC users have with at times trying to use speech and at times trying to stop speech appear to be complex and dynamic.

A significant implication of this study regards the ways in which non-disabled communication partners need to support dialogic communicative interactions, facilitating the use of a complex array of communication modes and strategies of engagement on the part of the FC user (e.g., typing, reading typing aloud, responding to or initiating conversation verbally [in ways that may foster either dialogic or non-dialogic interactions], etc.). Non-disabled people often draw upon a number of rules and strategies of interpretation when communicating with others. Among these are the tendency to respond to another’s spoken language at face value, that is, with the assumption that when a person says something, it is because they intended to say it. For example, if someone were to say, “go home,” it would not be uncommon to interpret that utterance as a reliable indication that the person wanted to go home. Additionally, if a person either does not speak at all

when spoken to, or if a person uses speech that appears to the listener to be obviously unconnected to the thread of conversation (e.g., saying “baby hippos” repetitively, or asking “what time is it?” over and over again, despite having been told what time it was), it would not be uncommon to interpret these utterances (or lack thereof) as a lack of understanding or even of competence on the part of the speaker. But, as evidence from this study would suggest, such a conclusion would be contrary to the experiences of our participants.

While typing, FC users often use spoken language that includes repetitive chatter, continuous questioning, nonsense words, and other forms of non-dialogic speech. These “words of annoyance” (as Jamie Burke would call them) often leave the facilitator and communication partner to grapple with the questions, “How do I respond? How do I move this conversation forward?” If a communication partner or facilitator were to respond solely to verbal communication they might get caught in a tangle of responding to non-dialogic content such as Franklin Wilson’s endless questions about the time and when they will be going to the beach. This never-ending cycle would not only engage Franklin in a meaningless activity (i.e., responding to something he does not want to say), but it would place both participants in a meaningless conversation and leave the impression that Franklin does not have much to say. When faced with this context on a daily basis when Franklin first started to type with FC, Franklin’s mother describes their interactions in this way:

I would sit down to type and I would end up answering the 50 million questions he would ask verbally and we would do no typing. Early on Franklin said, “Pay attention to my typing.” So I thought ok I have to do that. I stopped answering the questions and then I started calling out the letters and words that he was typing. This stopped the questions and I think helped him to focus.

His mother’s decision not to answer when Franklin asked, “What time is it?” and continue to support him to type redefined Franklin as a meaningful communication partner. This assisted him in stopping the constant talking and allowed him to contribute to the conversation. Franklin’s mother’s strategy of simply not answering or responding to speech that is perceived as non-dialogic has been a fairly common one used by communication partners of the participants in this study.

However, the findings of the study indicate that strategies such as attending only to typed communication and ignoring spoken communication (i.e., strategies that have been articulated and advocated by participants of this study) are not complex or responsive enough strategies to meet the needs of

supporting many FC users in communicative interactions, particularly as the range of uses of their expressive speech expands to include more frequent occurrences of spontaneous, dialogic, conversational speech. Thus, the support strategy employed by Franklin’s mother and others (i.e., to respond to typed language as a reliable indicator of communicative intent, and to largely disregard spoken language as an unreliable indicator of communicative intent) may well prove to be inadequate to the task of supporting individuals to engage in dialogic communicative exchanges when they experience an increase in spontaneous dialogic speech.

Exploring and understanding these ever-shifting and ever-more-complex roles and responsibilities are integral to the ongoing process of continuing to support nonconventional communicators as their systems of expressive communication change, expand, and evolve over time. The dynamic nature of this growth process, and the dialectical nature of the communication process itself, necessitates that FC users’ facilitators and communication partners support strategies also change, expand, and evolve as well in response to FC users’ changing needs. Indeed, we have referred to many of the forms of speech we described as *potentially dialogic* speech, as FC users, as with all other communicators, are always engaged in interdependent exchanges with their communication partners. That is, an isolated speech utterance in and of itself cannot be characterized as dialogic; however, the speech acts contribute to an interaction that has the potential to be a dialogic one. It depends not only upon the communication skills of the FC user, but also upon the communication skills of the facilitator and communication partner to engage in and support reciprocal exchanges, using a variety of communication modalities, before a verbal communicative exchange may be characterized as truly dialogic.

Just as the strategy previously advocated by many FC users and employed by many facilitators (to completely disregard spoken language and attend only to typed language) now appears to be far too simplistic a strategy to be of consistent use in supporting meaningful communicative exchanges. So too would be the corollary strategy that some might be tempted to employ as FC users produce increasingly varied and more complex forms of speech (i.e., to attend to all speech at face value, minimizing opportunities to produce typed language). Clearly, the relationship between FC users’ typed language and their emerging forms of spoken language appears to be complex and dynamic, and adequately addressing complex questions of communicative intent would appear to necessitate that communication partners actively and explicitly engage the FC user in making these determinations.

## References

- Bara, B.G., Bucciarelli, M., & Colle, L. (2001). Communicative abilities in autism: Evidence for attentional deficits. *Brain and Language*, 77, 216-240.
- Beukelman, D., & Mirenda, P. (1998). *Augmentative and alternative communication: management of severe communication disorders in children and adults* (2<sup>nd</sup> ed.). Baltimore: Paul H. Brookes.
- Biklen, D. (1990). Communication unbound: Autism and praxis. *Harvard Educational Review*, 60, 291-314.
- Biklen, D. (1993). *Communication unbound: How facilitated communication is challenging traditional views of autism and ability/disability*. New York: Teachers College Press.
- Biklen, D. (1999). The metaphor of mental retardation: Rethinking ability and disability. In Bersani, Jr., H. (Ed.), *Responding to the challenge: Current trends and international issues in developmental disabilities: Essays in honor of Gunnar Dybwad* (pp. 35-52). Cambridge: Brookline Books.
- Biklen, D. (2000). Lessons from the margins, narrating mental retardation: A review essay. *Mental Retardation*, 38(5), 444-456.
- Biklen, D. (2005). *Autism and the myth of the person alone*. New York: NYU Press.
- Biklen, D. & Burke, J. (2006). Presuming competence. *Equity and Excellence in Education*, 39,166-175.
- Biklen, D., & Cardinal, D. (Eds.) (1997). *Contested words, contested science: Unraveling the facilitated communication controversy*. New York: Teachers College Press.
- Biklen, D., Saha, N., & Kliewer, C. (1995). How teachers confirm authorship of facilitated communication. *Journal of the Association for persons with Severe Handicaps*, 20, 45-56.
- Blackman, L. (1999). *Lucy's story: Autism and other adventures*. Brisbane: Book in Hand.
- Bogdan, R., & Biklen, S. (2006). *Introduction to Qualitative Research in Education* (5<sup>th</sup> ed.). Boston: Allyn & Bacon.
- Borthwick, C., & Crossley, R. (1999, October 17). Language and retardation: Target article on language and retardation. *Psycoloquy*, 10(038). Retrieved January 16, 2005 from <http://psycprints.ecs.soton.ac.uk/>
- Broderick, A., & Kasa-Hendrickson, C. (2001). "Say just one word at first": The emergence of reliable speech in a student labeled with autism. *The Journal of the Association for People with Severe Handicaps*, 26, 13-24.
- Cardinal, D., Hanson, D., & Wakeham, J. (1996). An investigation of authorship in facilitated communication. *Mental Retardation* 34, 231-242.
- Charmaz, K. (2006). *Constructing Grounded Theory: A practical guide through qualitative analysis*. London: SAGE Publications.
- Cherryholmes, C. (1988). *Power and Criticism*. New York: Teachers College Press.
- Crossley, R. (1994). *Facilitated Communication Training*. New York: Teachers College Press.
- Crossley, R. (1997). *Speechless*. New York: Dutton.
- Crossley, R., & Remington-Gurney, J. (1992). Getting the words out I. *Topics in Language Disorders*, 12(4), 29-45.
- Denzin, N., & Lincoln, Y. (Eds.). (2000). *Handbook of qualitative research* (2<sup>nd</sup> ed.). Thousand Oaks, CA: Sage.
- Denzin, N. & Lincoln, Y. (Eds.). (2005). *Handbook of qualitative research* (3<sup>rd</sup> ed.) Thousand Oaks, CA: Sage.
- Donnellan, A.M., & Leary, M.R. (1995). *Movement differences and diversity in autism/mental retardation*. Madison, WI: DRI Press.
- Donnellan, A.M., Leary, M.R., & Robledo, J. (2006). I can't get started: Stress and the role of movement differences in people with autism. In M. Baron, J.Groden, G. Groden, & L. Lipsitt (Eds.), *Stress and coping in autism* (pp. 200-225). New York: Oxford University Press.
- Dziuk, M., Gidley, J., Larson, J., Apostu, A., Mahone, E., Denckla, M., & Mostofsky, S. (2007). Dyspraxia in autism: Association with motor, social, and communicative deficits. *Developmental Medicine & Child Neurology*, 49, 734-739.
- Facilitated Communication Institute (2000). *Facilitated Communication Training Standards*. Syracuse, NY: Author. Available on-line at: <http://soeweb.syr.edu/thefci>.
- Ferguson, P. M., Ferguson, D. L., & Taylor, S. J. (Eds.) (1992) *Interpreting disability: A qualitative reader*. New York: Teachers College Press.
- Green, D., Charman, T., Pickles, A., Chandler, S., Loucas, T., Simonoff, E., & Baird, G. (2009). Impairment in movement skills of children with autistic spectrum disorders. *Developmental medicine and child neurology*, 51(4),311-6.
- Iverson, P. (2006). *Strange Son: Two mothers, two sons and the quest to unlock the hidden world of autism*. New York: Riverhead.
- Iverson, P. (2007). *The informed pointing method*. Retrieved January 17, 2008, from [www.strangeson.com/index](http://www.strangeson.com/index).
- Jacobson, J. W., Mulick, J.A., & Schwartz, A.A. (1995). A history of facilitated communication: Science, pseudoscience, and antiscience. *American Psychologist*, 50(9), 750-765.
- Janesick, V.J. (2000). The choreography of qualitative research design: Minuets, Improvisations, and Crystallization. In Denzin, N. & Lincoln, Y. (Ed.), *Handbook of qualitative research* (pp.379-400). Thousand Oaks: Sage Publishing.
- Janzen-Wilde, M.L., Duchan, J.F., & Higginbotham, D.J. (1995). Successful use of facilitated communication with an oral child. *Journal of Speech and Hearing Research*, 38, 658-676.
- Kasa-Hendrickson, C., Broderick, A., Biklen, D. (Producers) and Gambell, J. (Director) (2002). *Inside the edge*. (Video documentary). (Available from Syracuse University, 370 Huntington Hall, Syracuse, New York)
- Kasa-Hendrickson (2005). "There is no way this kid is retarded": Teachers' optimistic constructions of student ability. *The international journal of inclusive education*, 9(1), 55-69.

- Kasa-Hendrickson, C. (2006). Typing to Communicate: Understanding facilitated communication. *The Advocate*, 3(1), 14-22.
- Kemmis, S. & McTaggart, R. (2005). Participatory action research: Communicative action and the public sphere. In Denzin, N. & Lincoln, Y. (Ed.), *Handbook of qualitative research* (pp. 559-604). Thousand Oaks: Sage Publishing.
- Kliwer, C., & Biklen, D. (2001) "School's not really a place for reading": An analysis of the literate lives of people with severe disabilities. *The Journal of the Association for Persons with Severe Handicaps*, 26(1), 1-12.
- Leary, M.R., & Hill, D.A. (1996). Moving on: Autism and movement disturbance. *Mental Retardation*, 34(1), 39-53.
- Ming, X., Brimacombe, M., & Wagner, G. (2007). Prevalence of motor impairment in autism spectrum disorders. *Brain & Development*, 29, 565-570.
- Mirenda, P. (2004). "He's not really a reader...": Perspectives on supporting literacy development in individuals with autism. *Topics on Language disorders*, 23(4), 271-282.
- Mirenda, P. (2008). A back door approach to autism and AAC. *Augmentative and Alternative Communication* 24(3), 220-234.
- Mukhopadhyay, S. (2008). Understanding autism through rapid prompting method. Denver: Outskirts Press.
- Mukhopadhyay, T.R. (2000). *Beyond the silence: My life, the world and autism*. London: National Autistic Society.
- Mukhopadhyay, T.R. (2008). *How can I talk if my lips don't move: Inside my autistic mind*. New York: Arcade Publishing.
- Myers, L. (1998). Giving voice: Assistive technology and FC. *The Facilitated Communication Digest*, 6, 4-11.
- Prizant, B.M., & Duncan J. (1981). The functions of immediate echolalia in autistic children. *Journal of Speech and Hearing Disorders*, 46, 241-249.
- Prizant, B.M., & Rydell, P.J. (1984). Analysis of the functions of delayed echolalia in autistic children. *Journal of Speech and Hearing Research*, 27, 183-192.
- Prizant, B.M., & Wetherby, A.M., (1985). Intentional communicative behavior of children with autism: Theoretical and practical issues. *Australian Journal of Human Communication Disorders*, 13(13), 21-58.
- Rossetti, Z., Ashby, C., Arndt, K., Chadwick, M., & Kasahara, M. (2008). "I like others to not try to fix me: Agency, independence, and autism. *Intellectual and Developmental Disabilities*, 46(5), 364-375.
- Rubin, S., Biklen, D., Kasa-Hendrickson, C., Kluth, P., Cardinal, D.N., & Broderick, A. (2001). Independence, participation, and the meaning of intellectual ability. *Disability and Society*, 16 (3), 415-42.
- Schwandt, T. (2007). *The sage dictionary of qualitative inquiry*. Thousand Oaks: Sage Publications.
- Sheehan, C., & Matuozzi, R. (1996). Validation of facilitated communication. *Mental Retardation*, 34(2), 94-107.
- Weiss, M.J.S., Wagner, S., & Bauman, M. (1996). A case of validated facilitated communication. *Mental Retardation*, 34(4), 220-230.
- Wetherby, A.M., Prizant, B.M., & Hutchinson, T.A. (1998). Communicative, social/affective, and symbolic profiles of young children with autism and pervasive developmental disorders. *American Journal of Speech-Language Pathology*, 7(2), 79-91.
- Wheeler, D.L., Jacobson, J.W., Paglieri, R.A., & Schwartz, A.A. (1993). An experimental assessment of facilitated communication. *Mental Retardation*, 31(1), 49-60.
- Willis, J.W. (2007). *Foundations of qualitative research: Interpretive and critical approaches*. Thousand Oaks: Sage Publications.
- Wurzberg, G. (Producer/Director). (2004). *Autism is a world*. [Documentary]. Atlanta: CNN.

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### Footnotes

- <sup>i</sup> First author.
- <sup>ii</sup> During interviews and focus groups participant's communication was supported by a communication coach (also known as a facilitator). The communication coach provided attention focus and encouragement for those noted in table one as using no physical support. For those noted in the table as using minimal support to the back of the shoulder or elbow the communication coach provided this when needed, fading that physical support when the participant did not need that level of support. The communication coach did not participate in the interview, but served much as a sign language interpreter would in relaying messages communicated. At times the parents of the participant would be present and would respond to questions when directed at them.
- <sup>iii</sup> The majority of our study participants elected to use their real names.
- <sup>iv</sup> An analytic memo is a memo written while the researcher is in the process of collecting and or coding the data. The purpose is to provide a written record of analytical thoughts as one is steeped in the process of data collection and analysis (Schwandt, 2007). The excerpt regarding Franklin's communication is a part of an analytic memo written by the first author and is presented in italics to note that it has been directly taken from a memo.
- <sup>v</sup> For example, Jamie Burke's mother reports: "Kindergarten he hardly spoke at all the whole year. I remember his first grade teacher saying he spoke one sentence all year long, when a pile of blocks fell over and he said, 'Wow, what a mess.' She said, 'I nearly fell off my chair, that was the one sentence he uttered all year long.'"
- <sup>vi</sup> FC users involved in the study were all literate individuals prior to their development of the speech described in this paper--that is, they could read (decode text for meaning), but could not yet produce the speech necessary to read out loud. As reading aloud is a conventional means of demonstrating one's literacy skills, it was often difficult for these individuals to adequately demonstrate their existing literacy skills to others. For several participants, this process began with (and continues to involve) the ability to read (speak) aloud the names of individual letters, and is proceeding to involve reading individual words aloud as well. Some of our participants are currently able to read aloud

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lengthy passages with conventional inflection and fluency; others are currently struggling to reliably be able to read aloud individual letters and words. While learning to read out loud, many of the FC users stumble over letters and words and struggle to pronounce them correctly. While this struggle may create the appearance that they cannot identify letters or are unable to or are struggling to learn to read words, rather, they are engaged in the complex and challenging oral motor task of learning to pronounce and read aloud letters and words they are already able to read (decode for meaning).

<sup>vii</sup> In Jamie's situation, he also had the notable support of a communication device that not only provided text to look at, but

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also had a voice output feature that would read the words aloud which Jamie could then repeat in his process of learning to read aloud. For Jamie and others, the provision of a communication device with voice output was a significant scaffold in developing the ability to read text aloud (see Broderick and Kas-Hendrickson, 2001).

<sup>viii</sup> First and second authors.

<sup>ix</sup> For a detailed description of the "ladder of communication" and its support as a communication scaffold, please see Crossley (1994).