

“SAY JUST ONE WORD AT FIRST”: The Emergence of Reliable Speech in a Student Labeled With Autism

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This article presents a qualitative, interpretivist research study that documents the emergence, in the context of typed expression, of increasingly useful and reliable speech for a young person labeled with autism. The authors construct a descriptive narrative of the process of this young man's emergent speech development and organize the data around four components of this complex, dynamic, and nonlinear process: (a) echolalia or "unreliable" speech, (b) reading out loud, (c) using reliable speech, and (d) integrating speaking and typing. Additionally, the authors identify three categories of supports that this young man and his family experienced and interpreted as being supportive of his emergent speech. These categories include (a) the importance of taking risks, (b) the importance of seeing and hearing words together, and (c) the importance of an inclusive academic education including rich literacy experiences. Throughout, this inductive analysis constructs an understanding of how this young man and his family have experienced and interpreted his emergence as a reliable speaker.

DESCRIPTORS: qualitative research, interpretivist research, autism, speech development, language development, facilitated communication

Jamie Burke is 13 years old, and he is labeled with autism. Throughout his life, his speech has not been terribly useful to him. As recently as a year ago, Jamie was considered to be functionally nonverbal—what little speech he had was sporadic and consisted largely of echoed words and phrases. People around him could not be certain if his words reflected what he thought or intended to say at any given time. It was not uncommon to hear Jamie repeat short phrases over and over again, including titles or lines from favorite books, songs, or

films, such as “*The Magic Tollbooth*,” “*Everywhere I Go*,” or “*Flash Gordon*.” Jamie’s limited speech did not allow him to verbally answer a direct question, to ask a friend how the weekend was, or to offer comments during a class discussion. To express himself in these kinds of situations, Jamie has relied for the past 8 years on facilitated communication (FC), a method of supported typing, as his primary means of expressive communication (Biklen, 1990, 1993; Biklen & Cardinal, 1997; Crossley, 1994, 1997).

However, over the past year, Jamie Burke has emerged as a reliable speaker,¹ someone for whom speech has become an increasingly useful form of expression. When we began this research, we could not have anticipated how quickly and almost explosively Jamie’s speech would emerge. Virtually every time we saw Jamie over the course of the research, he used his expanding speech in novel ways. How might we describe the emergence of Jamie’s increasingly reliable speech? What did Jamie experience as supportive of his emerging speech? And how have Jamie and his family

¹ The authors and Jamie struggled over selecting terms that would most appropriately describe Jamie’s emerging speech: *intentional* seemed inappropriate as an observer’s description of Jamie’s emerging speech, as only Jamie could make the determination (on an utterance-to-utterance basis) as to whether his speech corresponded to his expressive intent; *useful* seemed an appropriate descriptor as it connotes a mutually constituted assessment of Jamie’s speech within the context of communicative exchange and social interaction with other(s); however, Jamie elected to describe his echolalic speech as “unreliable” and his emerging speech as more “reliable” again, an assessment that only Jamie is capable of making as the reliability of one’s speech depends to some extent on the speaker’s intent in producing speech. The authors chose to use the term *reliable* most often in this article to describe Jamie’s emerging speech, as it is a self-selected descriptive term chosen by the primary informant. However, the authors also use the term *useful speech* to describe and interpret their observations of Jamie’s emerging speech. The term *useful* is not meant to connote any assessments of reliability or intent; rather, it is meant to signify that Jamie’s emerging speech is “of use” to him inasmuch as it permits him successful access to and participation in communicative exchanges with others.

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experienced and interpreted this emergence of reliable speech at the age of 13? These questions are the focus of this inquiry.

This is a descriptive, qualitative study conducted in the tradition of interpretivist inquiry in disability studies (Bogdan & Taylor, 1989; P. M. Ferguson, Ferguson, & Taylor, 1992; Goode, 1992, 1994). This study not only utilizes qualitative methods of inquiry and analysis (Bogdan & Biklen, 1998; Denzin & Lincoln, 2000; Taylor & Bogdan, 1998), but is also grounded in the assumptions of an interpretivist worldview or paradigm. Although interpretivism does not represent a single monolithic position or school of thought, the variations of interpretivist thought do share a number of broad underlying assumptions or tenets. According to Ferguson et al. (1992, pp. 5, 6), these tenets include (a) a theoretical orientation that holds that reality and knowledge are socially constructed and (b) a research agenda that holds the goals of interpretivist research to be best characterized as to "describe, interpret, and understand" (p. 6).

This study focuses on the experience of one adolescent student, Jamie Burke, as he developed increasingly reliable speech between the ages of 12 and 13. The emergence of spoken language at this age is particularly significant in that Jamie is a student with a label of autism who had very little useful speech prior to this point. Additionally, Jamie's primary means of expression has historically consisted of typed language produced through FC. His speech has emerged in the context of a complex and ongoing incorporation of both typing and talking in his expressive communication.

FC is a form of augmentative and alternative communication (AAC). It is used by individuals whose speech is not reliable and who experience difficulties with intentional movement (Donnellan & Leary, 1995; Leary & Hill, 1996) that may make the ability to independently point to access a communication aide unreliable (Biklen, 1993; Biklen & Cardinal, 1997; Crossley, 1994, 1997). Over the past decade, research on the method has centered primarily around the issue of validating authorship in FC. This question stems jointly from the supported nature of the method itself (i.e., the provision by a facilitator of physical, emotional, and other supports in order to type) and the often presumed lack of competence of the individuals communicating via the method (i.e., individuals with labels of autism, mental retardation, Down syndrome, and other developmental disabilities) (Calculator & Singer, 1992; Green & Shane, 1994; Jacobson, Mulick, & Schwartz, 1995; Wheeler, Jacobson, Paglieri, & Schwartz, 1993).

However, as Beukelman and Mirenda (1998) noted, there is "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. . . . For them, the controversy [of authorship] has ended" (p. 327). As an increasing number

of individuals has developed the ability to type independently or with minimal physical support (i.e., a light touch to the shoulder or to the back of the neck), it has become more widely recognized that the issue of validating authorship need not be the central form of inquiry around FC (Biklen, 1999; Biklen & Rice, 1999; Blackman, 1999; Rubin et al., 2001). These individuals, for whom "the controversy has ended," have compelled us to broaden our inquiry around FC and to begin to ask fundamentally different questions about FC: What impact has our understanding of FC levied on the meanings of the constructs of mental retardation and other disability labels (Biklen, 1993; Blackman, 1999; Borthwick & Crossley, 1999; Rubin et al., 2001; Smith, 1999)? How might we support increasing levels of independence in typing (Broderick & Kasa-Hendrickson, 1999)? How might typing with facilitation support the development of spoken language (Meyers, 1998)?

Jamie Burke is among a handful of FC users who have learned to type independently; however, his independent typing is not the central focus of this inquiry. This article describes Jamie's recent and concomitant development of useful speech and explores the nature of the relationship between his typing and his speaking in expressive communication as experienced and interpreted by Jamie himself. There are many reports in the literature of individuals who use FC and some form of spoken expression, which may range from intermittently saying letters and words aloud that correspond to the content of typed language to reading aloud entire passages that have been composed through facilitated typing (Attfield, 1998; Biklen, Saha, & Kiewer, 1995; Meyers, 1998). However, Jamie's experience allows us to document the emergence and development of useful speech for one FC user as it unfolded over the past year. The purpose of this study is to describe the process by which Jamie has emerged as an individual who incorporates both speech and typing in his expressive communication. The study also explores the significance of this development in the contexts of his life.

Background and Method

In the spring of 1999, several researchers from the Facilitated Communication Institute (FCI) organized a discussion group of six FC users. They met monthly to discuss issues such as how they think about independence, supports, school, and other issues relevant to their lives. During these discussions, it became apparent that one of the participants, Jamie Burke, was just beginning to use speech in ways that he had not previously been able to (i.e., Jamie began saying letters and words aloud as he typed and began to read aloud portions of what he had typed). Another participant used a complex combination of speech and typing in her expression. When the discussion group dissolved for the summer, she and Jamie continued their conversations

around issues of talking and of increasing independence in typing through the summer. The authors facilitated these discussions as a small focus group, which provided the opportunity both to conduct open-ended interviews with participants around issues of talking and of independence and to observe and document Jamie's ever expanding use of speech in his expressive language.

This research was conducted using qualitative research methods (Bogdan & Biklen, 1998; Taylor & Bogdan, 1998). We did not begin this research with any intent to test hypotheses about why Jamie was beginning to speak. Our intention was to descriptively document his development of speech as we observed it and to construct an understanding of how Jamie and his family experienced and interpreted his emergence as an intentional speaker.

In an attempt to capture the dynamic, fluid, and complex nature of Jamie's speech development, multiple sources of data were drawn upon throughout the process of inquiry including the words (both typed and spoken) of the primary informant, Jamie Burke; data gathered through interviews with his mother and primary facilitator, Sheree Burke; and the researcher's videotaped observations of Jamie typing and speaking in a variety of contexts. The researchers conducted in-depth, open-ended interviews and engaged in participant observation (Bogdan & Biklen, 1998), totaling more than 35 hours of data collection over a 9 month period. Interviews were videotaped and subsequently transcribed. Detailed observers' comments and analytic memos were constructed by the researchers/authors throughout the data collection process. Transcriptions coupled with notes constructed following participant observation culminated in over 350 typed pages of field notes. In addition, these data were gathered across multiple contexts including the FCI discussion group, the subsequent focus group conversations about talking and typing between Jamie and another FC user, interactions and conversations with Jamie and his family in his home and in the community, and ongoing e-mail correspondence between Jamie and the researchers. Due to the lengthy amount of time that it takes for FC users to type out complex answers to questions, the researchers also gathered written material that Jamie had composed outside of the context of the interviews and observations (i.e., essays he had written for school assignments and presentations) whenever the content of his writings was relevant to his development and use of speech.

Several design decisions were purposefully made with the intent of supporting the specific needs of Jamie and other FC users in participating in the research process. The locations and times of the interviews were mutually chosen and agreed on by Jamie and other FC users. Locations were carefully negotiated and selected

to ensure that all participants would feel comfortable with the physical space, seating, lighting, and ambient noise. Most of the interviews took place in the home of Jamie or another FC user, spaces that were both comfortable and familiar.

The focus group interviews were held every other Saturday morning throughout the summer and averaged an hour and a half in length. Although these interviews were open-ended and conducted in a conversational style, the researchers wrote discussion questions and e-mailed them to Jamie and the other FC user prior to each interview. Thus, the opportunity existed for prior consideration of each question and for prior composition of one's thoughts. In addition, the written questions were available for reading during the interviews in the event that the processing of auditory information became difficult or overwhelming.

We took many breaks during the interviews and observations to move around, listen to music, and have food and drinks. The topic, pace, and length of each session were directed by Jamie and the other FC user. Breaks were initiated by our informants either typing or verbally asking for a break or by one of them getting up and leaving the table. Our informants routinely supported one another in continuing with the interviews either by verbally calling each other back to the table by name or by typing or verbally offering direct questions or comments to each other, thus encouraging the other's return in order to reply.

Analysis of the data proceeded inductively (Bogdan & Biklen, 1998) and was integral and ongoing throughout the research process, from the early stages of data collection through the writing process itself (Richardson, 2000). From the very beginning, analysis of each participant observation and/or interview informed the questions posed at subsequent interviews, and researchers encouraged the participants to actively engage in the ongoing process of analysis. Researchers shared their analytic themes and categories with participants throughout the data collection process and invited participants to expand upon, refute, or otherwise shape the interpretation of themes in the process of inductive analysis. Although Jamie was an active participant in the research process, he was not a collaborative partner. His role was not equitable to that of the other researchers, primarily due to his status as a minor and his limited research experience.

We have constructed and presented our findings in two sections. The first is a descriptive narrative of "The Emergence of Reliable Speech" for Jamie. This was based on data gathered through interviews with Jamie's mother, in which she describes her own observations of this process, and the data gathered through the participant observations of the researchers. The second section draws on the content of interview data from both Jamie and Sheree. It identifies and analyzes several "Categories of Supports," elements that Jamie and

Sheree report experiencing and interpreting as supportive of Jamie's emerging speech development.

The Emergence of Reliable Speech

In an attempt to narrate Jamie's experience of developing increasingly useful speech, we struggled with and ultimately rejected presenting the emergence of Jamie's speech using a chronology or otherwise linear representation of its development. We struggled with using the term *development* at all, given the multitude of potentially conflicting theoretical orientations in which the term may be grounded and conceptualized. Also, the inference often made in common usage is that development implies a linear or hierarchical process. Our own observations coupled with Jamie's and his mother's accounts and interpretations of his emerging speech clearly illustrated a complex, overlapping process of growth. Each component expanded yet encompassed the previous components, with Jamie's emerging speech integrally and complexly intertwined with his typed expression. The theoretical model of human development that seems to best account for our research data is Thelen and Smith's (1994) work on a dynamic systems approach. According to Thelen (1995), a dynamic systems approach to development "emphasizes the multicausal, fluid, contextual, and self-organizing nature of developmental change" (p. 79). Within this theoretical framework, we describe the complex and dynamic development of Jamie's emerging speech and its fluid and dynamic integration with his typing.

We have constructed Jamie's emergence of increasingly reliable speech around the four descriptive components of (a) echolalia or "unreliable" speech, (b) reading out loud, (c) using reliable speech, and (d) integrating speaking and typing. None of these components is discrete. In Jamie's experience, considerable overlap exists among them in a complex, dynamic interplay.

"Tremendous Echolalia": Unreliable Speech

In 1990, at the age of 3 1/2 years, Jamie was labeled with autism. His language was described by the consulting psychologist as "delayed and/or deviant" including the presence of "echolalia" with "very little spontaneous language" apart from his "spontaneous labeling of objects." Jamie's mother, Sheree Burke, describes his early language development in this way:

He met basic words on time, like "mama, dada, book, ball." Single words. When he got to be two, that's when we found a little concern, 'cause he wasn't stringing more than 2-3 words together to make sentences. . . . That was at two, and three, and even at four. . . . [He also showed] tremendous echolalia. Everything we said was echoed back.

Sheree also reports that Jamie was reading books at the age of two. He routinely took books to bed with him and would select his own books off the library shelf by scanning the spines of the books and selecting books on his current topics of passionate interest. Jamie entered an inclusive preschool program with supports when he was 4 years old.

When he was 5 years old, Jamie was introduced to FC and quickly began typing to communicate his thoughts. For example, in 1991, shortly after he began typing with FC, Jamie wrote, "I LOOK TO YOU. ME IS LOVING EVERY MINUTE OF THIS. LOOK AT ME MY NOEISESE [noises] ARE STUPID BUT MY NINSID [inside] IS SMART."² Sheree reports that after Jamie started typing:

We would see a little bit more expansion in sentence structure, through his speaking. . . . [for example] "Jamie go store," but that seemed to drop off tremendously when he really got into the typing. Even the 1, 2, and 3 words just sort of disappeared. The typing was the main mode of communication. . . . 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."

According to this report, once Jamie had a system of communication in place through which he could express complex thoughts, his use of his limited speech seemed to diminish as his use of typing as a favored mode of communication expanded. He continued to echo others' words or favorite phrases or movie titles, but he used typed language as his primary means of reliable expression. Jamie states, "I COULD NOT DO BOTH. MY BRAIN FELT CONFUSED BY SPEAKING SO TYPING WAS CORRECT FOR ME." During this time, Jamie occasionally directed his teachers and family to pay attention to his typing, rather than his speech saying, "LISTEN TO MY TYPING. MY VOICE IS UNFORTUNATLY UNRELIABLE." He occasionally produced speech during this time, but it was not a reliable form of communication for him. When asked about wanting to speak, Jamie says, "SADLY I WAS NOT FEELING THAT MY VOICE WAS NORMAL SO EVEN THOUGH WORDS WERE VERY EASY TYPING WAS CLEARER." Typed language became a useful means of expression for Jamie, in ways that spoken language had not been.

² For the purposes of this study, words that were typed by Jamie are indicated in ALL CAPITALS, words that were spoken aloud are indicated in *italics*, and words that were read aloud after being composed through typing are indicated in *ITALICIZED ALL CAPITALS*.

“Open[ing] the Floodgates”—Reading Out Loud

Jamie now types using a conversational device called a Lightwriter™. It can be programmed to say each letter aloud as it is typed, read each word aloud when the space bar is pressed, and read whole sentences or paragraphs aloud when the “speak” bar is pressed. When the speak bar is pressed, the sentence scrolls by on the bright green visual display as the device reads it aloud. Jamie initially began incorporating speech that seemed related to his typing by intermittently repeating aloud individual words after the Lightwriter. Shortly thereafter, he began repeating aloud phrases and eventually whole sentences as they scrolled by. Within a matter of weeks, Jamie was able to read aloud his own sentences from the visual display as they scrolled by, without the added support of repeating after the Lightwriter’s voice output. Sheree describes Jamie’s reading aloud as beginning “once he got the Lightwriter and the use of the computer . . . and all of a sudden [he] started reading back, and repeating after the machine had said it, that just opened the floodgates.”

When Jamie was just beginning to read aloud what he had written, he required extensive supports from his facilitator to be able to do so successfully. During the early focus group interviews, Sheree provided a number of different supports to Jamie while he was reading. She held his wrist and guided his finger along the text that he was reading; she placed her hand on Jamie’s shoulder and periodically pointed to a word when he seemed to get “stuck”; and she would sit close at his side and direct her own visual attention to the text as he was reading, providing encouraging verbal feedback such as, “um-hmm,” “keep going,” or “ok.”

In addition to these supports, Sheree also provided auditory models by occasionally saying words aloud in order for Jamie to repeat them. For example, when Jamie was asked to describe what it felt like for him to begin to use his speech he silently typed: “IT FELT LIKE FREEDOM FROM AUTISM. HAVE YOU EVER BEEN TRAPPED AND THE DOOR WAS OPENED AND YOU RAN OUTSIDE AND SHOUTED YEA! THAT IS HOW IT FELT FOR ME.” When Jamie had finished typing, Sheree asked, “Do you want to read what you said?” She then pointed to the first word of the message on the Lightwriter’s visual display. Jamie began to read, “IT,” but then paused and looked up at his mother. Sheree directed her eyes back to the screen and said, “felt.” Jamie then repeated, “FELT,” read, “LIKE,” paused, and looked up from the screen again. Sheree continued to direct her attention toward the screen and again placed her finger under the word on the visual display that Jamie seemed to be stuck on, saying, “freedom.” Jamie repeated, “FREEDOM,” continued to read, “FROM AUTISM. HAVE YOU EVER BEEN,” and then paused again. Sheree quickly said, “trapped.” Jamie repeated, “TRAPPED,” continued reading, “AND THE

DOOR WAS,” then paused again. When Jamie paused, Sheree said, “opened.” Jamie repeated, “OPENED,” and continued to read, “AND YOU,” then paused. Sheree read, “ran.” Jamie repeated, “RAN” and continued to read, “OUTSIDE AND SHOUTED YEA! THAT IS n/a! n/a!” [these last two words sounded like a repetition of the word “not” with the final consonant sound, /t/, omitted.] Sheree modeled “sounding out” the word by saying, “h/a!, how.” Jamie repeated, “HOW” and read on, “IT FELT FOR ME.” In this example, Sheree provided Jamie with auditory models by reading aloud the words when he hesitated, a strategy that appeared to support him to read aloud the word. Jamie comments on this type of support when he writes, “SOMETIMES IT IS HARD TO REMEMBER THE RIGHT SOUND AND MAKE IT CORRECT IN MY VOICE SO I AM LOOKING TO OTHERS FOR ASSISTANCE.”

As Jamie grew more comfortable reading aloud words that he had written himself following an auditory model (provided either by his facilitator or by his Lightwriter), he began reading aloud printed texts that he had not written, but with which he was very familiar, such as the text on the boxes of his favorite videos. While reading aloud these familiar texts, Jamie would occasionally misread a word by saying a similar familiar word having the same first few letters as the word he was reading from the box. For example, on one occasion when reading the word *preside*, Jamie said “*present*,” and when reading the word *begin*, Jamie said “*beside*.” In the former case, Sheree provided the verbal model of the correct word, *preside*, which Jamie repeated and continued reading; in the latter case, she simply prompted him by saying “*be-/g/-*,” and Jamie corrected himself, saying, “*begin*,” and continued reading. Errors of this type appear to be related to difficulties with word finding and automatic completions (for a thorough discussion of these difficulties, see Crossley, 1997).

Several weeks after Jamie began reading aloud familiar texts such as video boxes, Sheree reported that he had begun to read texts that he had never seen before (e.g., pages out of a novel, street signs). She observed that his fluency with these novel texts was considerably less than the fluency he had achieved in reading aloud his familiar texts and texts that he had composed himself. For example, during one of the focus group interviews, one of the researchers presented Jamie with a piece of paper with a question written on it. Jamie had seen the question once before in an e-mail correspondence. The question read, “You once said that FC means freedom. Now that you are both talking and typing, do they mean the same thing to you or are they different somehow?” Jamie read aloud the text as follows: (Sheree’s comments and supports are indicated by [S:]): “*You once sight* [S: ‘said’] *said that FC more* [S: ‘means’] *means from* [S: ‘free—’] *freedom* [S: ‘Um-

hmn.']. *Now that you are* [S: 'both talking'] *and talking* [S: 'ty—'] *typing* [S: 'Um-hmn'] *do they mean the same* [S: 'same'] *the same thing to you or one* [S: 'are'] *or are they* [S: 'different somehow'] *somehow.*" After reading aloud the question, Jamie silently typed his response, "NO, NO THE SPEAKING IS PARAMOUNT. TO SAY WORDS IS TO LIVE LIFE AS OTHERS," and when he had finished typing, he read aloud, "PARAMOUNT. THE SPEAKING IS PARAMOUNT. TO SAY WORDS IS TO LIVE LIFE AS OTHERS." Jamie continued to experience difficulties with automatic completion errors in reading the unfamiliar text of the question (e.g., reading "freedom" as "from" and "typing" as "talking") and required a good deal of verbal encouragement and auditory modeling of words from Sheree. In contrast, the sentences that he had typed himself were read clearly and fluently with no verbal supports from Sheree. At this point in Jamie's reading aloud, his fluency when reading self-composed or otherwise familiar texts was clearly greater than it was when reading novel or unfamiliar texts.

"Two Way Conversation"—Using Reliable Speech

As Jamie was learning to read aloud his typed communication more fluently, he also began to use more speech to communicate when he was not typing. For example, during one of the focus group interviews, we had been engaged in a discussion about fears:

Jamie said verbally, "*Is Jessie afraid?*"
 Sheree responded, "*Jessie is afraid—she said she was afraid of storms.*"
 Jamie said, "*Sick.*"
 Sheree said, "*Yeah, like what happened to you.*"
 Jamie said, "*Jamie got throw up from—Tina's.*"
 Sheree said, "*From—? Which storm?*"
 Jamie said, "*Tina's house. Labor Day storm.*"
 Sheree nodded and said, "*The Labor Day storm. Yeah, we went to go to Aunt Tina's and poor Jamie—*"
 Jamie said, "*Went to have a cookout.*"
 Sheree nodded and said, "*And what were we doing? Where were we rushing? We kept saying, 'Hurry!'*"
 Jamie said, "*To the sink!*"
 Sheree laughed and said, "*Yeah, to the sink!*"

In this example, Jamie not only verbally asked a conversational question, but also contributed to the discussion about fears by sharing that he, too, was scared of storms, and he shared a story in which he was so frightened during a storm that he got physically sick in the sink. Although Sheree carefully scaffolded parts of the story for Jamie by asking questions like, "Which storm?" and "Where were we rushing?" to elicit more information from him, Jamie verbally initiated the story and offered most of the central elements of the story on his own.

Recently, Sheree reported that Jamie had bumped into his old school principal in the hallway at school. When he spoke to Jamie, the principal was pleasantly surprised to find that Jamie could respond verbally. The two chatted in the hall for a few minutes. Sheree said of this encounter:

He actually had a two-way conversation. You know, minimal, but give and take. Functional . . . and that's what I see. He's able to have a give and take conversation, with a little bit of echo. With, you know, verbal prompting. We've still got to do some verbal cueing.

The verbal cueing that Sheree refers to consists largely of asking Jamie questions to encourage him to respond further. In many situations, Sheree is able to facilitate Jamie's verbal expression by asking him questions based on her own familiar knowledge of Jamie's experience, as in the above example. In this instance, if Jamie had said, "sick," to an audience entirely unfamiliar with his experience that day, it may quite possibly have been more difficult for him to verbally share as much information as he did with Sheree's verbal support.

It is still quite challenging to hold a reciprocal verbal conversation with Jamie without some degree of shared knowledge of the topic, as in the prior example, or without the opportunity for him to supplement his speech with typing. However, Jamie is becoming better able to verbally offer information that is unknown to his conversational partner, especially when that information is in the context of fairly routine and familiar events. For example, upon coming home from school one day, Jamie joined his father in the living room. His father, Mike, asked Jamie where a particular homework assignment was. Jamie replied, "*In my backpack.*" Mike then asked Jamie where he had left his backpack, as he did not have it with him. "*It's in the kitchen.*" Jamie replied, and when asked to, retrieved it from the kitchen table where he had left it. A year ago, responding reliably to routine questions such as these would have been difficult for Jamie without the opportunity to type his response. Jamie states that his speech is more reliable for him "WHEN THE NEED IS FAMILIAR."

Recently, Jamie initiated a telephone conversation with one of the authors. He used a number of specific strategies in order to express himself verbally in the context of the conversation. One of the authors had called for Jamie's mother, and as Sheree was being called to the phone, Jamie picked up the phone himself and said, "*Hello, Alicia!*"

"Hello, Jamie! How are you?" Alicia replied.
 "Good," he said. "*Flash Gordon.*"

[Alicia had recently shared with Jamie videotapes of several old *Flash Gordon* movie serials, which Jamie

said he had enjoyed tremendously. Over E-mail, Jamie had requested a copy of the photograph on the front of the tape box, along with a list of the individual episode titles. Alicia interpreted his words, "*Flash Gordon*," to be an initiation of a topic of conversation.] "Oh, yes, the videos," she said. "Did you like them?"

"Yes," Jamie replied.

"Did you want to ask me about the photocopies I promised you of the tape boxes?" Alicia asked. [Sheree had previously shared with Alicia that Jamie had been asking about the copies of the boxes.]

"Yes," Jamie replied.

"Well, I just made the copies this afternoon. I can bring them over to you tomorrow. Which episode was your favorite?"

"*Captured by Shark Men, Battling the Sea Beast, Shattering Doom . . .*" Jamie said, listing about 6 of the 13 episode titles from the video Alicia had shared.

"Wow, sounds like you liked them all!" Alicia said. "Hey, did you perform your play at school yet?" [Jamie had recently shared with Alicia that a play that he had been writing for speech class was due to be performed at some point.]

"Yes—no!" Jamie said.

"You did, or you didn't?" Alicia asked. Jamie did not reply. "What did you want to tell me about?" There was a several second pause in the conversation.

"*Pilgrims*," Jamie said.

"Oh," said Alicia, "Did you do something about the pilgrims this week?"

"Yes," Jamie said.

It was, in fact, the week before Thanksgiving. Jamie later clarified in a typed conversation with Alicia that he had wanted to tell her about the Thanksgiving program his class had put together about the pilgrims. He had not yet performed the play he had been composing, but he had recently performed in the Thanksgiving program.

During this verbal conversation, Jamie used his speech to initiate a conversational interaction ("*Hello, Alicia!*"), to initiate a specific topic of conversation ("*Flash Gordon*"), and to respond to Yes or No questions that were rhetorically posed to him, presuming an affirmative response based on the questioner's prior

knowledge of the context. For example, Alicia knew that Jamie had loved watching the videos, as he had already typed as much through e-mail. She also knew that Jamie had been asking his mother whether Alicia had made the copies of the boxes yet. These Yes or No questions were constructed (as is common in conversational speech) with the expectation of a "yes" response, which Jamie provided. When Alicia asked a question that she had no prior knowledge of ("Did you perform your play at school yet?"), Jamie briefly faltered, answering, "Yes—no!," then remaining silent when the question was posed again. When an open-ended question was posed ("What did you want to tell me about?") coupled with several seconds of wait time, Jamie verbally offered a piece of information unknown to the questioner, "*pilgrims*." However, without the opportunity to clarify or elaborate on his thoughts through typing, it was unclear at the time of this conversation whether "*pilgrims*" was what Jamie had intended to say, and if it were, exactly what Jamie had intended to convey by that comment. In this example, Jamie participated in a reciprocal, although limited, verbal telephone conversation, an activity he would have been unable to participate in a year ago. However, the complexity of this verbal exchange is significantly limited in comparison with the complexity of Jamie's typed conversation.

"I WANT TO USE MY OWN VOICE"—Integrating speaking and typing

For the first months of the summer, Jamie had been silently typing his communication first and then reading it aloud afterward in what appeared essentially to be two separate processes of expression. However, as the summer progressed, Jamie began to incorporate his speech into the typing process itself, sometimes saying letters and whole words aloud before he typed them, and sometimes talking himself through word-finding, self-correction, or message clarification processes. For example, on one occasion Jamie said, "*What's that? Two 'i's.*" in the midst of typing a word, verbally prompting himself to backspace and remove the extra 'i,' he had just typed. On another occasion, Jamie slowly composed "*SO NICE TO HAVE,*" typing each word, then reading each word aloud. Then he quickly said aloud, "*friends gathered here together.*" and continued typing the latter half of the sentence much more fluidly and quickly. In these examples, Jamie's use of speech appears to support the accuracy, fluidity, and speed of his typing as he integrates the two in his expressive communication.

As Jamie gained more experience with his reading and speaking aloud, in most situations, he no longer needed his facilitator to model the words to allow him to continue with his reading. Jamie presently reads unfamiliar texts aloud with little support from his facilitator. Sheree's assistance now consists largely of standing

or sitting near Jamie as he reads, occasionally placing her finger at the beginning point of the text that he is going to read and providing reassuring verbal feedback (i.e., "keep going," "um-hmm") as Jamie reads. By the end of the summer focus group, Jamie was able to read his own typing aloud fairly fluently and consistently and he typed a request that the voice output on his Lightwriter be turned off. As he stated, "*I WANT TO USE MY OWN VOICE.*"

Jamie's ability to read aloud and to speak has been continually expanding over the past year. However, we wish to reiterate that this has not been a simple linear process for him. Although Jamie has experienced increasing independence in reading aloud and in speaking (as well as in typing without physical supports), he continues to experience occasions when it is more difficult for him to read aloud fluently, to speak purposefully, and to type without physical supports. When Jamie is feeling tired, ill, or anxious, or when he finds himself in an unfamiliar or challenging environment or situation, he continues to require additional supports from his facilitator (e.g., the provision of auditory models of words that he can repeat when necessary, or the provision of a light touch to the back of his neck or shoulder to support his typing) in order to fluently compose and read his thoughts. We understand these fluid and variable needs for support not as a progression and regression of Jamie's skills, but as an indication of the variable and often unpredictable ways that Jamie experiences autism (including difficulties with anxiety, processing of sensory information, and sensory overload). As Thelen (1995) remind us:

[M]ovements are always a product of not only the central nervous system but also of the biomechanical and energetic properties of the body, the environmental support, and the specific (and sometimes changing) demands of the particular task. . . . Every movement is unique; every solution is fluid and flexible. (p. 81)

Although his speech has become increasingly reliable and useful to Jamie, it remains a limited form of expression for him under many circumstances. Jamie is continually constructing an integrated system of communication for himself wherein his speech and typing support one another. The vulnerability of relying on either of these forms of communication alone is clearly evident to Jamie, as he discusses the keenly felt limitations of each:

I AM THINKING THAT SPEECH IS ASSININE THAT THEY LAUGH AT MY VOICE BUT TYPING MAKES ME A SMARTER STUDENT. . . . TYPING IS DEARLY DIFFICULT FOR OTHERS NOW FEELING LIKE I AM BETTER AT PLACING ANSWERS BUT NOT

FOR FUNNY TALKS IN HALLWAYS THEY DO NOT SEE ME AS A MOSTLY ENVIABLE FRIEND THAT BOYS WANT.

Jamie acknowledges the benefits of his typed expression, saying it "**MAKES [HIM] A SMARTER STUDENT**" and allows him to be "**BETTER AT PLACING ANSWERS.**" He also recognizes the limitations of typed expression as typing does not allow him to participate in "**FUNNY TALKS IN HALLWAYS.**" Even though speech could potentially offer him greater access to participation in this aspect of school life, he grapples with sometimes "**THINKING THAT SPEECH IS ASSININE**" as "**THEY LAUGH AT MY VOICE,**" and with his concern that he is not perceived as an "**ENVIABLE FRIEND THAT BOYS WANT.**" Jamie continues to struggle with integrating these two modes of expressive communication in his life in complex ways that will best enable him to participate socially. Despite the ambivalence and the many difficulties that he faces in this process, he continues to want to use his own voice.

Categories of Support

In analyzing our descriptive observations of Jamie's emerging speech, as well as the reflective comments of Jamie and Sheree on their own experience and interpretation of that process, three themes emerged from the data that describe elements that Jamie and Sheree experienced or interpreted as supportive of his emerging speech. We have organized these themes into the following categories of support: (1) the importance of taking risks, (2) the importance of seeing and hearing words together, and (3) the importance of an inclusive academic education, including rich early literacy experiences. These categories, each of which is described and illustrated below, are formative, not exhaustive. Each indicates potentially rich avenues for further inquiry beyond the scope of the present study.

"SAY JUST ONE WORD AT FIRST"—

Taking Risks

Sheree describes Jamie's beginning use of speech:

When he started speaking, he would whisper, and . . . he'd say, "I'm embarrassed of my voice," because it sounded different. It still sounds immature comparatively, so he's really taking a risk. So I think it's confidence in himself. I just feel he's more comfortable risk taking, too. . . . And then turning the voice off . . . the reading of the letters, and then the risk taking of repeating the word, and then asking to have it turned off was incredible. . . . I think it has to be a huge drive within, to speak . . . This is his drive.

Sheree locates much of the impetus to begin speaking within Jamie himself, referring to his "drive" to speak,

his "confidence in himself," and his increased comfort level with "risk taking." Jamie also acknowledged the roles of developing confidence in oneself and taking risks in learning to speak, when he encouraged a non-speaking friend labeled with autism to try to speak by advising him, "SAY JUST ONE WORD AT FIRST," and "FEARS MAY HOLD YOU BACK BUT YOU NEED TO CHALLENGE YOURSELF." Similarly, Attfield (1998), a man labeled with autism in Great Britain who learned to communicate through facilitation and who later learned to speak, wrote:

I came to a decision that I was going to try to talk more because I realized that I needed to be able to communicate verbally to live my life to the fullest extent. . . . I decided to try to talk a few sentences each day. . . . So from that day to this, that is the decision I came to, and I have tried to stick with it despite the anxiety I feel every time I try to join in the conversation both verbally and nonverbally. (pp. 1-2)

Attfield's belief that he "needed to be able to communicate verbally to live [his] life to the fullest extent" is reminiscent of Jamie's assessment that "THE SPEAKING IS PARAMOUNT. TO SAY WORDS IS TO LIVE LIFE AS OTHERS."

Other elements that Jamie experienced as supportive of his willingness to take risks and to speak more include the strong support of his family and school and the many long hours of practice that have helped him to improve his speaking skills. Jamie says of his family:

THEY ARE KIND AND DEVOTED. MOM IS MY DEVOTED FRIEND AND FACILITATOR. SHE IS HOLDING MY DREAMS SAFE FOR ME IN THAT I FEEL I NEED HER GRACE TO HELP ME THROUGH THE WAR OF AUTISM. POP IS THE GREATEST. HE HELPS ME STAY LIKE I NEED TO BE IN ORDER TO REACH MY QUEST OF SO GOOD GOALS THAT I AM NOW MEETING.

One of the ways that Jamie's family supports him is by providing a safe and supportive place for him to take risks, practice, and build his confidence. For example, in the family's kitchen, there is a poster hanging on the wall of the hundred most commonly used words in the English language. Sheree describes how Jamie used this poster to practice speaking in a safe context:

He would come all summer and stand in front of it and read those words out loud, you know, "in," "about," "out," just all the basic stuff, and he'd come back 3 or 4 times a day, and there were some that he couldn't get, and they were the wh- words. He would get very confused and he kept coming back to them until he got those down. It's a re-

hearsal type thing. . . . Maybe he just had to hear and hear and hear and practice, practice, practice until he felt confident.

Attfield (1998) also reported that reading aloud was a helpful stepping stone to communicating verbally:

I decided to go half way between the two [typing and speaking] again—the lesser of two evils I told myself—and so I took two steps backwards and began by repeating back to myself each word as I typed it to gain some confidence. (p. 2)

Thus, encompassed within the broader category of "taking risks" as being supportive of Jamie's speech development, we also see illustrated the significance of having a strong drive or desire to speak, having or developing the confidence in oneself to take a risk and make the attempt to speak, and having supportive opportunities for the practice of reading words aloud.

"SEEING AND HEARING TOGETHER"— Connecting Sounds and Meaning

When asked to name the supports that have helped Jamie to read aloud and to speak more purposefully, the second category of support that emerged from both Jamie's and Sheree's accounts points to the primacy of seeing and hearing words together. Jamie describes it in this way:

MY LIGHTWRITER IS A WONDERFUL TOOL TO HELP MY BRAIN FIGURE OUT THE CONNECTION BETWEEN WORDS SOUNDING AND MEANING. . . . ITS SEEING AND HEARING TOGETHER.

Similarly, Sheree says:

Once he got the Lightwriter and the use of the computer . . . and it seemed to be the large screen, where he could see the letters, you know, [that] really started kicking things in. . . . The computer seemed to really hook him into looking. With the Lightwriter . . . when he saw it and heard it, and all of a sudden started reading back, and repeating after the machine had said it, and that just opened the floodgates . . . and the fact that it would scroll back, it wasn't just gone, really seemed to cement things in his mind. When I asked him one time, he said the words and the letters make sense, they're coming together It's the sounds, that's what Jamie's telling me, he's connecting words with sounds . . .

For Jamie, and for Richard Attfield, obtaining a communication device with auditory output and a clear visual display appears to have played a significant role in supporting their emergent speech. There have been reports in the literature of students who have difficulty

speaking whose speech production has been supported through the use of assistive technology devices with voice output (Romski, Sevcik, & Adamson, 1999). Additionally, others who communicate through facilitated typing have expressed similar sentiments about the importance of having a communication device that provides voice output. Meyers (1998) reported on the significance of "giving voice" to people who communicate through assistive technology. In Meyers's account, Ryan, a nonspeaking young man, wrote, "Technology gives me speech. It's very important because I have to talk" (p. 5).

"LIKE WATER TO THE DESERT"—Inclusive Academic Education and Rich Literacy Experiences

Lastly, the data illustrate that both Jamie and Sheree experienced or interpreted Jamie's ongoing access to an inclusive academic education and to rich literacy experiences from an early age as being supportive of his development of reliable speech. Jamie began his schooling career in an inclusive preschool and has been a member of the general education classroom ever since. Currently, he is an eighth grade student attending eight academic classes a day. Although he types without physical support, he still requires conversational prompting (i.e., "Do you have any comments on that topic, Jamie?") and logistical guidance (i.e., moving between classes, gathering books), and receives these supports from a one-to-one facilitator while at school. An entire team of committed educators (i.e., a special education teacher, a speech pathologist, an occupational therapist, eight general education teachers, and a facilitator) works together to support Jamie throughout the day. For example, the special education teacher may team teach with the science teacher, planning lessons and working with small groups of students during science class. In addition, the special education teacher is a resource to all of the teachers when considering how Jamie will participate in specific lessons, assessments, and class projects. Jamie is well supported in having full access to and participation in an eighth grade academic curriculum.

When asked about the role that his academic and literacy experiences have played in his ability to communicate, both through typing and through his emergent speech, Jamie responded: "EXPOSURE TO THE PRINTED WORD IS LIKE WATER TO THE DESERT. ONLY BOOKS COULD LEAD THE WAY TO GAIN UNDERSTANDING HOW TO SAY SOUNDS."

In describing elements that she interprets as supportive of Jamie's emerging speech, Sheree states:

Just being in an inclusive classroom. I still think being in a classroom where everybody is reading, speaking, and I think the use of overheads, seeing print and not have everything read to the class, but

the use of a big visual display. . . . I'm thinking too, probably his drive to be like the other students, that's such a huge motivator for him. . . . He's had speech therapy since he was three. He thought it was futile, he said, "I take speech five days a week, yet I cannot speak." I don't think just speech and language would have done it. If a child is nonverbal. I don't think you're going to get it without the support of typing, personally. I don't think you're going to get the speech. I think the printed word supports the spoken word, because I think they need to see what it looks like, and like Jamie says, the letters and the sounds are now making sense, and if you don't see the letters . . . ? [She shrugs her shoulders and shakes her head.]

Sheree does not complete her final sentence, "and if you don't see the letters . . . ?" but her implication seems clear. In a follow-up interview, Sheree confirms that she has often wondered if Jamie would have learned to speak if he had not had opportunities to see letters and age appropriate texts.

Conclusion

This inquiry provided the opportunity to descriptively document the emergence of reliable speech for Jamie Burke, a student who previously had been considered to be nonverbal. In documenting the emergence of useful speech, we initially observed an expansion of Jamie's echolalic speech as he began reading aloud his own typed letters, words, and sentences following the auditory models provided either by his facilitator or by the voice output of his communication device. Shortly thereafter, Jamie began to read aloud other texts (that he had not typed). His need for the support of auditory models has increasingly diminished. Throughout this process, Jamie used his speech as a useful and reliable mode of expression and integrated his emerging speech with his typed expression. The emergence of reliable speech did not present as a simple linear progression of skills. Rather, it was a complex, dynamic, and fluid expansion of Jamie's expressive communication system, a system in which he continues to integrate both speech and typing in complex and novel ways.

One of the most significant implications of this study emerged as we searched for theoretical tools to interpret the data. For example, many theoretical models of development are conceptualized as linear and hierarchical (i.e., cognitive development theory, behavioral learning theory), which are inadequate or inappropriate as frameworks for interpreting Jamie's experience. Interpreting these data within a linear theoretical framework of development might have predisposed us to conceptualize Jamie's emergent speech as a linear process. We might also have conceptualized it as a somewhat deviant process because it has not followed the traditional, linear, conceptual sequence of language

development (i.e., listen, speak, read, write). Instead of using linear models that might have led us to conceptualize Jamie's experience as deviant or otherwise as anomalous or exceptional, we sought a theoretical model that would better account for Jamie's experience as we understood it inductively (i.e., the dynamic systems model reported by Theien & Smith, 1994), and thus a model that might more broadly and complexly illuminate our understanding of speech and language development generally. Because our analysis proceeded inductively, the categories of supportive practices that we identified were in many ways similarly incongruent with traditional linear developmental models and their underlying assumptions.

We constructed three categories of support that we and Jamie or Sheree have interpreted and experienced as supportive of the dynamic expansion of Jamie's expressive speech. These categories include (a) taking risks (including having a strong drive or motivation to speak, having the confidence to take risks, and having supportive opportunities for practice), (b) seeing and hearing words together, and (c) having access to an inclusive academic education, including rich literacy experiences. These findings suggest that a number of different elements have blended through a complex, dynamic process in support of Jamie's emergent speech and of his integration of that speech into his expressive communication system.

Jamie has obviously been integral to this process. He had a strong desire to speak ("to say words is to live life as others"), he developed the confidence necessary to take the risk to try speaking ("say just one word at first"), and he made the commitment to engage in the hard work and ongoing practice of learning to speak. These have all been necessary to Jamie's emergence as an intentional speaker. Jamie has maintained his desire to integrate speech with his typing, and is committed to pursuing this difficult work, in spite of the ambivalence he feels about the ways that his speaking affects others' perceptions of him. Jamie has been supported in this process by his family's and his teachers' consistently high expectations of him and their ongoing encouragement of and confidence in Jamie as a learner.

In addition to the crucial role that Jamie has played in this process, these findings also suggest that there are a number of key supports that have been provided to Jamie that have contributed to his development of useful speech. Key among these supports have been the provision of opportunities for supportive practice of both his speech and his typing (and the integration of the two), the provision of adaptations and of technology that simultaneously present language both auditorially and visually, and the opportunity to participate in a challenging and supportive academic environment in which Jamie is understood to be an active participant and a competent and literate learner. The provision of each of these supports is embedded in assumptions that

recognize the complexity of Jamie's individual experience and which derive from a fundamental posture of presuming competence (Biklen, 2000). As a nonverbal child, Jamie was provided with a text based system of communication, presuming that he could and would become literate in reading and writing. He has. As a nonverbal child with a label of autism, Jamie was provided with rigorous, age appropriate, academic curricula and literacy experiences, presuming that he could and would achieve academically. He has. And as a nonverbal child, Jamie was provided with AAC technology that supported his integration of auditory and visual information, presuming that he could and would become not only a reader and a writer, but also a speaker. He has.

Jamie's experience presents a challenge to us as researchers, theoreticians, and educators to broaden the theoretical and conceptual frameworks that we use in order to account for the complexity of this young man's experience. We are challenged to account for Jamie's experience by understanding it not as a model, nor as an exceptional or anomalous case, but as a vision of possibility that may illuminate the experiences of others whose language development falls outside of our current conceptual models. Their experiences collectively may better illuminate and broaden our understanding of language and speech development in individuals labeled with autism.

Recently, Jamie reflected on his thoughts on his emerging speech in a poem that he wrote, *I used to be*:

I used to be a silent boy
 Living in walls of mostly moving lips
 My ears were senseless, but now,
 I am living in the world of words and speech

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