

Language is More than Speech: A Case Study

Morton Ann Gernsbacher, Ph.D.

***Abstract:** Some individuals face severe challenges with producing oral language (i.e., speech). In this article a case study of a child who experienced severe challenges with speech development is presented. Medical records, historical home videos, audio recordings, and photographs, in conjunction with an extensive journal maintained by the child's mother provide the basis for this report, which profiles the child's development from birth to age 8;0. This child's development demonstrates the necessity of distinguishing between language—the mental representation of concepts and their relations—and speech—one means for communicating mental representations.*

That the word language derives from lingua (“tongue”) betrays the common confusion about the relation between speech and language. (Schein & Stewart, p. viii)

Some individuals face severe challenges with producing oral language (i.e., speech). In this article a case study of a child who experienced severe challenges with speech development is presented. Medical records, historical home videos, audio recordings, and photographs, in conjunction with an extensive journal maintained by the child's mother provide the basis for this report, which profiles the child's development from birth to age 8;0. This child's development demonstrates the necessity of distinguishing between language—the mental representation of concepts and their relations – and speech – one means for communicating mental representations.

Neonatal Development

RH was the first and only child born to middle-age, professional parents. He was the product of an uncomplicated pregnancy, followed by a Caesarian delivery prompted by failure of labor to progress. During labor, RH's heart rate was observed to decelerate rapidly in response to larger uterine contractions. A Caesarian delivery was prepared for, but not executed, earlier in labor because of this precipitous heart-rate deceleration. An eventual Caesarian delivery was uncomplicated, and RH's birth weight was 7 lbs, 7 oz, with Apgar scores of 9/10 (1 min/5 min). RH's immediate postnatal behavior was remarkable, according to his mother, for demonstrating a calm, soothed demeanor, very early and natural nursing (i.e., within moments of being handed to his mother), and striking visual attentiveness. His mother recounts

that he fixated the ceiling mounted television while being held in his father's lap in the hospital bed to watch several minutes of a collegiate basketball game (the Final Four championship).

RH's first months of development were characterized by a calm demeanor, positive affect, and high visual attentiveness. RH began producing a social smile at 5 weeks, 5 days. RH greatly enjoyed leg extension activities, such as infant "kick gyms" (i.e., attractive stimuli dangling within kicking range, when RH was supine) and "Johnny Jump Ups" (i.e., a cloth saddle attachable to door openings with springs that allow an infant to bounce vertically using his legs). RH's mother reported that RH would remain exuberant about jumping in a baby jumper for nearly an hour. RH was also reported to enjoy watching commercial video tapes, beginning as young as two months of age when he primarily watched videos of other baby's faces (producing a range of emotional expressions), and later (beginning in the third month) when he began watching videos of children's educational shows, such as *Barney*. RH was able to sit unaided by his fifth month of life and began crawling at the beginning of his seventh month. Immediately upon beginning to crawl, RH was reported by his mother to cease enjoying the baby jumper.

RH was characterized by his mother and by other adults as a "very quiet baby." He rarely cried and had very limited babble, even by eight or nine months of age. He remained quite happy, playful, and curious, by his mother's report, but did not produce typical amounts of or a typical diversity of vocalizations. According to both his mother's report and recorded audiotape, RH produced little gurgling or cooing, and the sparse babbling produced was primarily vocalic (i.e., produced with vowels, not consonants). RH was reported to experience the onset of "stranger anxiety" at a developmentally typical point (around seven months) and passed the standard "a-not-b" object permanence task developmentally early (Smith, Thelen, Titzer, & McLin, 1999). RH could stand unaided by nine months of age, and shortly before his one-year birthday he began to walk. According to historic home video tape, RH's first succession of more than two steps unaided comprised 16 steps and a half-turn. According to medical records, RH's 'well baby visits' with his pediatrician were annotated with the phrases, "highly social" and "very active" at 6, 9, and 12 months.

Toddler Development

RH's mother reported that by the end of his first year of life, RH was particularly interested in numbers, letters, and colors—all interests that would maintain and strengthen through his second and third years of life. Indeed, prior to his second birthday, he arranged a set of large (8" x 4" x 2"), plastic alphabet blocks in perfect alphabetical order; he arranged correctly the letters in his name using large (12" high) foam letters, and he arranged in numerical order large, plastic numbers 1 through 20. He virtually always alerted to numerical or alphabetical stimuli, and he enjoyed watching videos about counting or spelling, in addition to videos portraying other toddlers or preschoolers playing. He was introduced, by one of his babysitters, to

videos starring the twin celebrities, Mary-Kate and Ashley Olsen, filmed when they were preschoolers, which he greatly enjoyed watching.

As a toddler, RH continued to be characterized by his parents and other care providers as cheerful and highly active, and an additional trait—an inordinate sense of physical balance—became apparent. RH's mother reported that he very rarely fell, despite his interest in walking in precarious environments (e.g., cobble stone streets) and his frequent climbing on furniture and other scalable structures. At 14 months of age, he began a toddler gymnastics program and was distinguished from the other same-aged toddlers by his agility in running quickly, without falling, down a 'tumble track' (a 40' by 10' trampoline). Despite RH's active mobility and agility, RH's mother reported in retrospect that his reaching and grasping were rare. She did not feel the need to remove, for example, fine china displays that were in his arm's reach because he never approached these objects or others with his hands. Materials on kitchen counters, his parents' work desks, or other surfaces that were within his toddler reach were never disturbed. Even earlier, during his first year of life, he rarely reached for anything (a desired toy, his mother's hair, or his father's or other care providers' eye glasses) with his hands. Because manual (e.g., index finger or flat palm) pointing is a developmental outgrowth of manual reaching (Hammes & Langdell, 1981), it is not surprising that RH did not develop or use any pointing behavior during the second year of life.

RH's vocal production remained severely limited during his second year of life; his mother reported, and historic home video suggested, that he was even more "quiet" (i.e., non-vocal) after his 13th month than he had been during the last half of his first year of life. RH communicated primarily with facial and other whole-body nonverbal expressions (predominantly those of positive affect, e.g., joy, satisfaction, curiosity, attention, and on rare occasions those of negative affect, e.g., distress or frustration). RH frequently led an adult to a desired item (e.g., a video) by either taking the adult's hand after RH began walking, or previously, when RH was only crawling, taking the adult's shirt bottom (as RH crawled along). RH's mother viewed this form of communication as highly adaptive for a child whose volitional vocalizations and distal arm and hand control were so limited, and this style of communication remained a core part of his communicative repertoire for several years, becoming more fine grained (e.g., leading an adult by the hand to a door, and then placing the adult's hand on the round door knob that RH was unable to open).

During his second year of life, RH enjoyed viewing visual stimuli upside down and would do so by facing backward to the stimuli, bending at the waist, and looking back at the stimuli between his legs. For example, often when watching familiar videos, RH would face away from the television, bend at the waist, and watch the video inverted by looking back toward the television between his legs. When a small, portable television was placed on the ground, RH stood behind the television and bent over it so that his head rested on the ground, only a couple of feet from the screen, and the image was inverted. RH's mother reported that RH resisted having books read to him, by grabbing the book out of the reader's hands and then studying intensely the bar code of the ISBN on the backside of the book. (His mother

reported that by 30 months of age, he was proficient in bar code; i.e., he could distinguish altered bar code from authentic bar code.)

RH appeared to be fascinated by looking through sheets of colored acetate, and indeed, according to his mother, a sheet of red colored acetate was the first object that he demonstratively shared with his mother, encouraging her (nonverbally) to also look through the acetate. RH's mother reported that RH was also very interested in door hinges, automatic doors, escalators, and the non-right angle caused by the family's vaulted living room ceiling. To this latter stimulus RH would lead his mother and indicate nonverbally for her to observe the unusual angle. RH's mother interpreted this act (RH's leading his mother by the hand to the floor underneath the non-right angle and directing with gaze his mother's own gaze to the angle) as an act of initiating joint attention. However, the communicative act, which RH's mother reported as quite successful, was accomplished without index finger pointing or verbalization.

Given RH's appreciation of visual stimulation during his toddler years, RH's mother reported introducing him to his first computer game when he was 19 months old. RH's parents purchased a child-sized trackball, which used a 4" wide surface and a slow tracking speed. With the child-sized trackball, RH needed to move only his arm, rather than more fine-grained movements of the wrist or fingers, to control the cursor's movement. RH experienced great success with the computer game; RH's parents report that adults who observed him playing this computer-based game would "stand in awe." One game involved a computerized version of a form board for which the child needed to bring the cursor to a puzzle piece and then drag the puzzle piece to the appropriate outline shape. Although at this time RH was completely unsuccessful at putting together even the simplest of physical form boards, he mastered the computerized version instantaneously. Another game was akin to a child's version of a conceptual slot machine. The goal was to click through several different options to select three of a kind. RH mastered that game without any adult guidance. RH's expertise with computer games kept his mother from assuming that his lack of speech was due primarily to cognitive limitations.

RH's stranger anxiety remained during his second year of life, although by all formal measures (e.g., Ainsworth, Blehar, Waters, & Wall, 1978) and informal assessments, RH maintained a secure attachment with his primary care provider. RH's mother notes that he was "less likely to make eye contact" with novel adults than other children his age and that he rarely oriented when his name was called (i.e., made the controlled movement to look up and orient to the direction from which the person was calling). RH's mother reported (and historic home video demonstrates) that RH was unable to follow with controlled vision a directional prompt, such as an adult pointing an index finger to a distal or even proximal stimulus. Thus, RH appeared to lack the traditional markers of receiving joint attention (Tomasello & Farrar, 1986).

After reviewing family photos and historic video tapes, RH's mother observed, in retrospect, that RH must have had extreme tactile sensitivity on the palms of his hands and in and around his mouth. In many photographs he was shown using fist

hands to grab seemingly innocuous objects, such as a soft, rubber therapy ball. In many contexts, he appeared highly reluctant to use his hands for exploration (such as with novel toys and novel food). In one family photograph he was shown retching after being encouraged to touch a “koosh” ball. RH’s mother reported that he was at this point in development highly resistant to having his teeth brushed, wearing hats and gloves (even in the winter), tasting novel foods, and trying on new shoes.

At RH’s 18 month ‘well baby’ visit, RH’s mother expressed concern to the pediatrician about RH’s speech delay. Records indicate that RH’s mother’s concern was not because she and her child could not communicate quite effectively, or that he was unable to communicate with others, but because comparing his expressive language development with typical milestones indicated a delay. RH’s pediatrician recommended an audiology examination, the first of which was conducted when RH was 19 months. According to records, the first behavioral audiology exam was completely unsuccessful with RH failing to alert to any of the auditory probes. Another behavioral audiology examination conducted at 20 months indicated that RH alerted slightly to one or two of the auditory probes; however, the test was far from conclusive. A third behavioral audiology examination conducted at 21 months was equally inconclusive with the exception of RH orienting rather strikingly to the audio track of a Barney videotape, which his mother had brought to the examination and which was presented auditorily at the conclusion of the examination.

At 22 months RH was evaluated via Brain Stem Auditory Evoked Response (also known as Auditory Brainstem Response), while RH was sedated as an outpatient at a hospital. The evaluation indicated no evidence of abnormal neurologic conduction through the brainstem auditory pathways. At 23 months, RH was evaluated by a multi-disciplinary team at a national clinic for developmental disabilities. With the exception of the Bayley Scales of Infant Development (Bayley, 1969), very few standardized tests could be administered, and even the Bayley was an approximation. A highly experienced developmental pediatrician observed and interacted with RH and his mother during a two-hour session. The result of the multi-hour evaluation was a diagnosis of pervasive developmental disorder.

Following this evaluation and diagnosis, RH was enrolled in occupational therapy and speech/language therapy. RH’s parents used as a guide to their interactions the “Communicating Partners” curriculum (e.g., MacDonald, 1987). They reported placing great emphasis on following their child’s lead, reciprocating his interaction, enhancing his strengths, encouraging all of his efforts toward communication (even those assumed by other programs to be ‘unconventional’ or ‘inappropriate’), and sharing mutual affect. In addition, RH began attending an integrated toddler program for two hours a day during the week. A speech-language therapist and occupational therapist were assigned to RH at the integrated toddler program, in addition to those professionals whom he saw in the community; however, after a few sessions with the occupational therapist assigned by the toddler program the parents declined her further services because she used ‘pull out’ sessions with tasks that were too frustrating for RH.

The speech-language therapist at the toddler program suggested developing sign-language, a decision, which in retrospect for RH's mother, seemed ill-conceived. RH's fine motor control was not developed well enough to promote even the simplest of signs. Nonetheless, the speech-language therapist worked for eight weeks with RH on the ASL sign for "more." When RH was unable to produce this sign independently after eight weeks, it was suggested to RH's mother that RH lacked the symbolic understanding needed for "developing language." RH's mother reported that she disagreed strongly with this assessment and asked the staff if they had any evidence that RH was able to produce the component motor plans for the sign (e.g., bring hands to the midline). They did not (e.g., RH had never clapped).

RH's mother later wrote in her journal the following entry related to this topic.

What a bias we as a society have against children who can't talk. This week RH was transitioning to a different classroom with different teachers in a different building at a different time of day. Before he left the house on Monday morning I asked RH if he wanted to take something special with him to school to serve as a transitional object, though I didn't use that term. RH chose two small dolls: one of his buddy, Bert, and the other of his buddy, Ernie [characters from Sesame Street]. As it turns out the teachers took the dolls away from RH, shortly after RH's father left for the day, because the dolls were "commercial." After looking around for them for 10 or so minutes, RH went to the art table and picked up two markers: one yellow and one orange. Because he then carried these two markers around with him the rest of the morning, always setting them down when he was playing with something else, but making sure that they remained with him, I was told on Tuesday during the first parent-teacher conference of the term, that we already had a problem. When I asked what the problem was with carrying around two markers, not even knowing the colors or the fact that the teachers had taken RH's dolls away, I was told that the behavior was 'weird.' Had RH been able to muster even just a "ehhee" or "buh buh" as he made the markers dance in his lap during music time, the teachers most likely would have figured out that RH was demonstrating the highest level of representational play (Ungerer & Sigman, 1981).

Preschool Age Development

According to RH's mother, during RH's preschool years he remained a delightful child, whose mood was almost always "off the charts" in positive affect. He sometimes seemed other worldly and frequently marched to his own drummer; however, he remained affectionate and engaging with persons he knew well, including his immediate family, his other care providers, and the speech-language and occupational therapists in the community with whom he worked after leaving the toddler program. He remained physically active, and he frequently sought out opportunities for proprioceptive feedback (such as jumping on beds and trampolines). According to RH's speech therapist, it was primarily while jumping on a trampoline that RH was able (during much of his preschool age years) to produce the phonation required for any vocalization, which remained quite primitive during this time.

RH developed a relationship with a surrogate sister, a neighbor, who was three years older than he, and with whom he spent one full day a week during the summer

and occasional days during the academic year. For over a year, when RH was 5 years old, he had a same-aged best friend (DW), a typically developing boy with whom RH played one-on-one for about six or more hours a week, always with support. By all observable measures, DW enjoyed RH's company as much as RH enjoyed his. RH taught DW as much about sand physics, water physics, and weather stripping, which was one of RH's fascinations during that period of his life, as DW taught RH about more typical 5-year old boy interests, such as water gun fights and rough housing. RH's and DW's very close bond of friendship appeared to require little speech. Unfortunately, according to RH's mother, the relationship ended abruptly the day that DW—with no malevolence or seeming premeditation—suggested to RH when they were dividing up who would play what that RH play a particular character, because—like RH—that character “would never talk.” RH appeared to be immediately heart broken and despondent, and the bond was never reparable.

RH typically avoided all mutual eye contact with strangers, although for a short period RH adopted the habit of squinting after he made brief eye contact with novel people. RH's fine motor skills remained severely impaired, including the bimanual coordination needed for sign language and conventional gestures, as was his eye-hand coordination. Because RH's manual motor skills were so severely challenged that he struggled to produce common gestures and conventional sign language, RH appeared to create his own gesture system, which drew on motions that he could perform. According to his mother and his speech therapist, RH had a repertoire of a dozen frequently used idiosyncratic gestures and was sometimes able to spontaneously generate novel gestures, which were typically iconic of motions or spatial relations about which RH was attempting to communicate. All gestures at this point in RH's development were produced bimanually. RH's mother reported that most persons not familiar with RH's gesture system interpreted his movements as being repetitive or erratic.

RH was unable to volitionally produce facial expressions, but his repertoire of spontaneous facial expressions was moderately sized. All of RH's vocalizations at this point in development were primarily vocalic; his consonant repertoire was limited to /m/ and occasionally /b/. Many of RH's vocalizations were produced in what his mother referred to as “squeal mode;” however, audio tape analysis demonstrated that many of these “squeals” carried the intonation of well-formed utterances. For example, during one session with his speech therapist, RH vocalized the intonational pattern of “I'm not yawning,” after his speech therapist teased him about looking a bit tired. As with RH's facial expressions and manual gestures, RH's vocal expressions were all spontaneous (i.e., he was unable to produce vocalizations on command or in volitional imitation).

Grade-school Age Development

When RH was 5;5, his mother watched a British Broadcast Company documentary (BBC, 2001) about an Indian mother and son who had worked together to

enable the son, minimally verbal, to develop handwriting as a communication medium; RH's mother then had the opportunity to visit with the mother and son in the United States (Mukhopadhyay, 2000). Although RH's mother was unwilling to go to the extreme measures that the Indian mother had used with her son, RH's mother was very motivated to explore the possibilities of RH using even a gross style of handwriting for augmentative communication. Realizing that RH had less control over the smaller muscles (such as those used during typical-sized handwriting) than he did for larger muscle groups, RH's mother designed a system so that RH could begin by using larger muscles, such as his shoulder girdle. She placed large sheets of easel sized pages on the wall at RH's shoulder height, and RH practiced marking (with a slash) using a wide felt-tip marker in large, designated regions. RH began with considerable physical support (hand-over-hand), which was slowly faded over the course of several weeks.

Once RH mastered the ability to mark independently within a several inch region of a designated target on the large easel-sized paper, RH was able to use this gross style of handwriting to demonstrate his literacy. For example, one of the first exercises accomplished by RH is shown in Figure 1; the goal was to mark through words in a list for which the vowel digraph 'oo' was pronounced /u/ as in "tooth." RH's success on this task demonstrated not only his self-taught literacy, but also his finely tuned phonemic awareness. Another task required identifying the correct verb tense, as shown in Figure 2, and another, as shown in Figure 3, required identifying the correct contraction (and verb tense). RH's mother reported being a bit surprised to observe RH's knowledge of prefixes and suffixes, as shown in Figure 4, in which only one prefix or suffix fits each stem word. RH scored perfectly on each of these activities and many more, all taken from a 3rd grade Language Arts workbook and all completed during the first week after RH mastered a marker, when RH was 5;10.

Upon RH's mastery of using a marker, this ability was used as a communication medium. For example, RH's mother reported that if RH woke up with a fever, she would make a list of body parts that possibly could be in pain (e.g., head, throat, ears). For presumed "yes" or "no" statements RH's mother originally offered only a "yes" and "no" response placed beneath the statement (e.g., "I am hungry. YES NO"). However, RH began sometimes to mark through both answer choices, as shown in Figure 5, and another time RH marked through both answer choices—and made a marking in between, as shown in Figure 6. Then he made only the marking in between the two answer choices, as shown in Figure 7, and RH's mother reported finally understanding his intention: RH wanted a maybe option, which he used in many politic situations, as shown in Figure 8. RH's mother reported that the "maybe" option was quite useful; she recounts an incident in which she was about to become angry at RH for pouring out a container of water she had asked him not to pour, and prior to scolding RH, she decided to find out if rather than RH doing this forbidden task on purpose, it was an accident. His answer was "maybe."

RH continued to use this gross style of handwriting (i.e., marking through options) as a medium of communication for over two years. During that time, RH was able to scale down from the easel-sized pages to more standard 8.5 x 11 typing

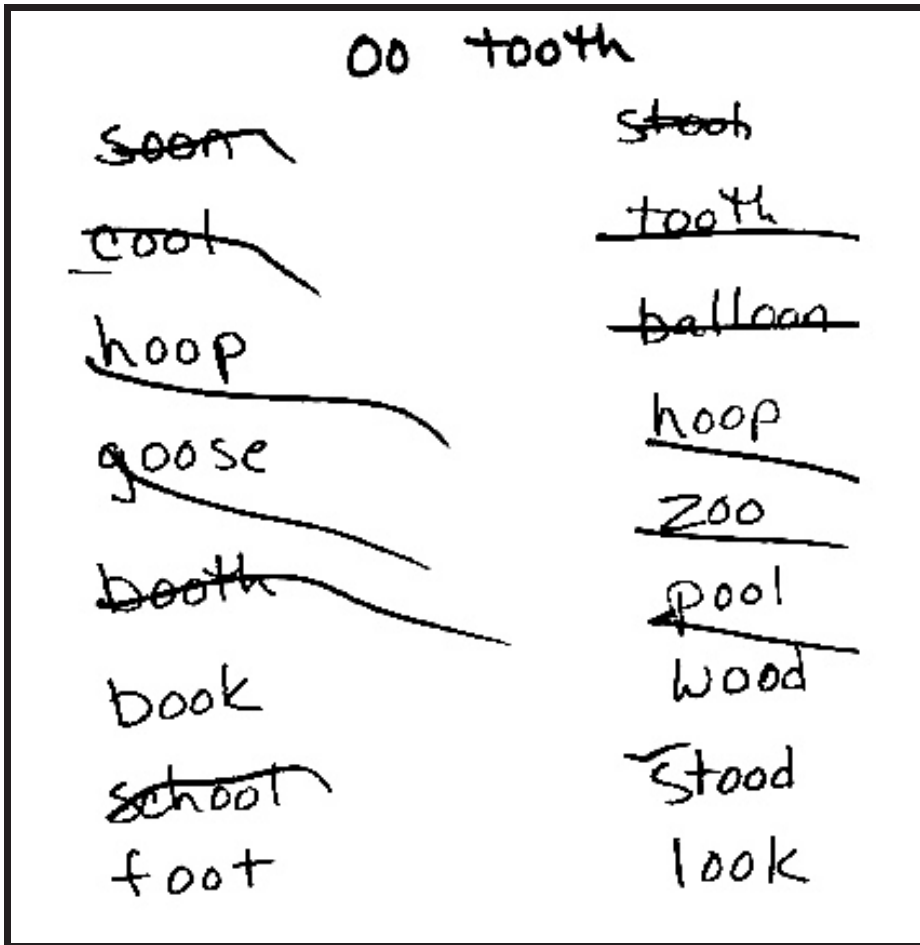


FIGURE 1. Handwriting by RH's mother with over marks by RH.

paper. When paper was not available (or necessary for recording academic work), RH used a magnetic writing toy (e.g., "magnadoodle"), which he carried in his backpack. RH was able to communicate about wants and needs, and to have extended conversations about abstract and complex topics, such as religion, death, and the societal versus medical definition of disability.

Only a few months after RH mastered holding a marker, he was administered the state-wide assessment of academic skills for fourth grade. This standardized multiple-choice test assessed skill in writing, mathematics, and reading, using a multiple-choice format. With the only modification being spacing the answer choices about four inches apart, rather than the mere millimeters that typically separate bubbles on computer-scored answer sheets, RH scored perfectly on the 150-item standardized test. A month later, he scored perfectly on the state-wide assessment for fifth grade. He was 5; 11.

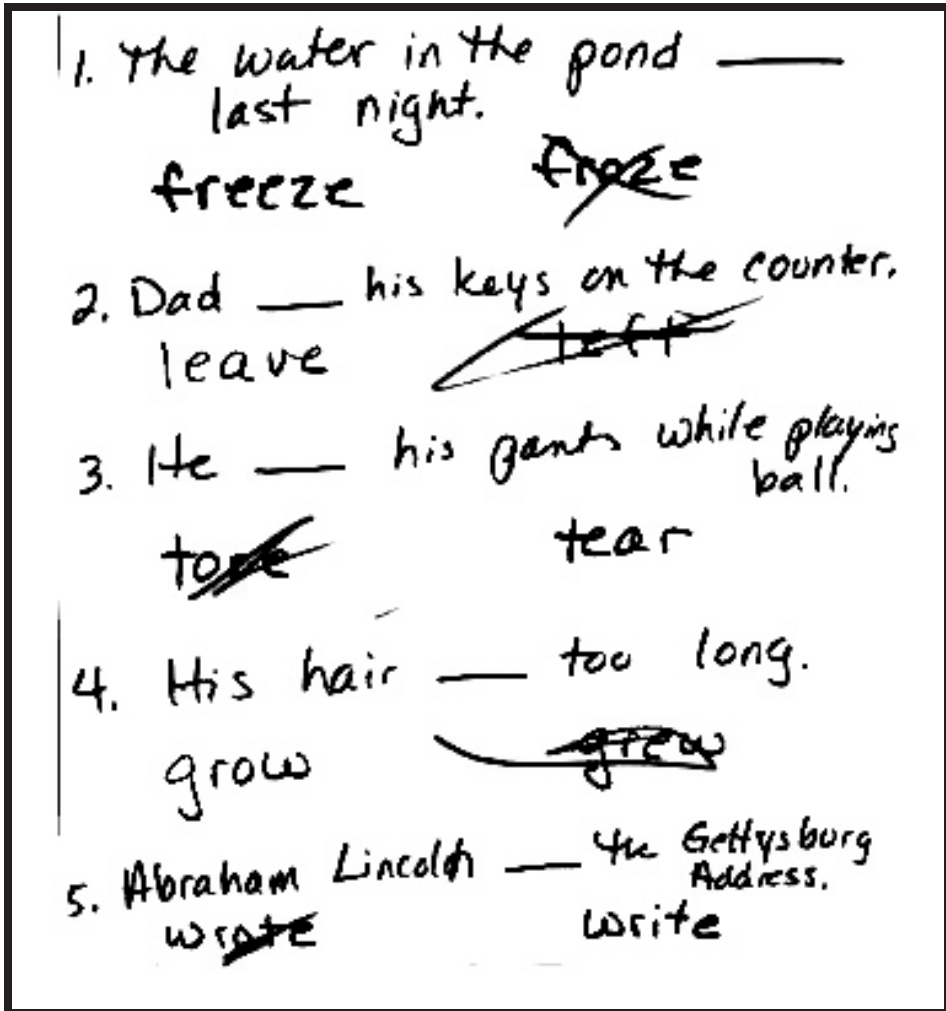


FIGURE 2. Handwriting by RH's mother with over marks by RH.

When RH was 6; 4, he was tested on the Peabody Picture Vocabulary Test (Dunn & Dunn, 1997), a commonly used verbal IQ test. RH would have been untestable with the standard requirement to point to the correct picture, because he still did not have a reliable proximal (or distal) point at that age; however, the picture plates were scanned into a computer, and RH was allowed to use his large, child-sized trackball to scroll to the correct answer. RH achieved a raw score of 181, which translated to a standardized score of 160, at the 99.9th percentile, with an age equivalence of 22 years. Similarly, RH's performance on the standardized Test of Receptive Grammar (Bishop, 1983), in which children select the picture that best represents the sentence, and the sentences vary in their grammatical complexity, was at the 95th percentile. At this point, RH's mean length of utterance (commonly known as MLU) was 1.5, and the intelligibility of his utterances was less than 20% to familiar listeners.

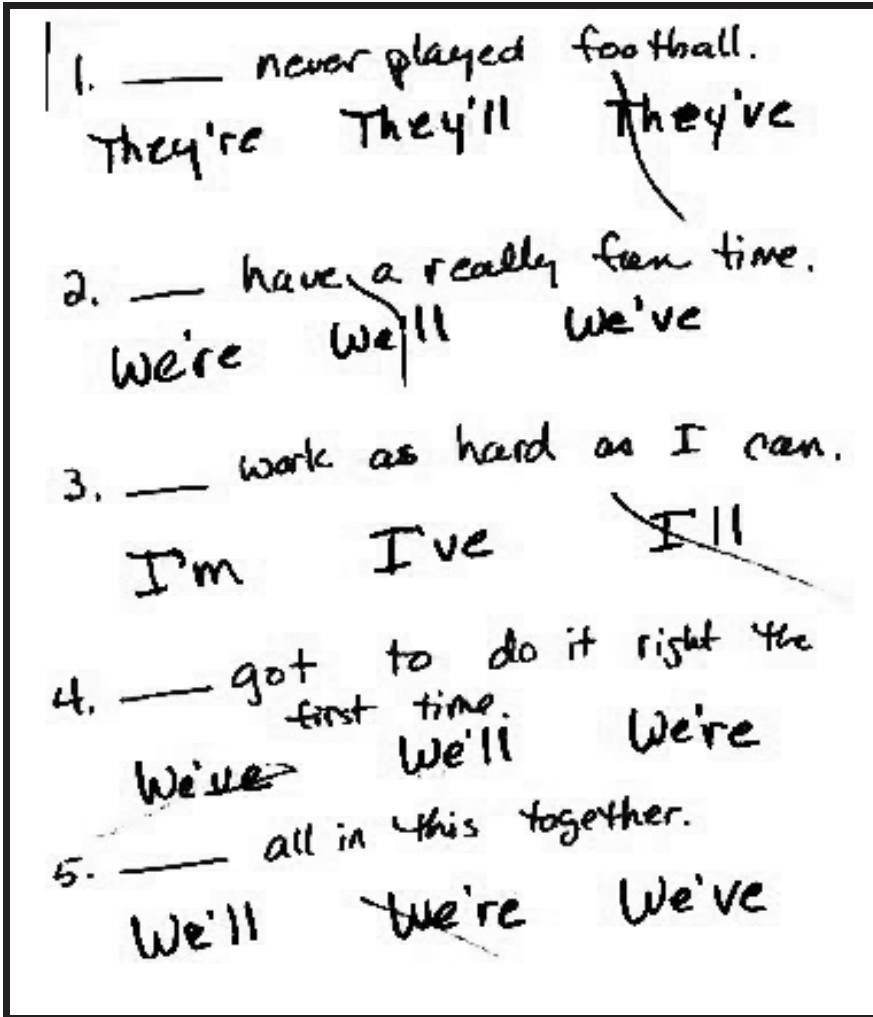


FIGURE 3. Handwriting by RH's mother with over marks by RH.

When RH was 7; 5, he developed a reliable index finger point. His mother reported that this development was a highly celebrated accomplishment; it followed development of his trunk strength and stability, coincident with development of his shoulder girdle strength and stability, and involved a range of finger motility and isolation that RH had not been able to achieve before. Indeed, the isolated index finger point was RH's first uni-manual—as opposed to bimanual—gesture. With his newly developed ability to point, RH and his mother considered whether RH might be aided by using a keyboard type augmentative communication device. They had considered a keyboard type augmentative device three years earlier, before they began the modified handwriting, but RH's body was not ready to support an index finger point at that time.

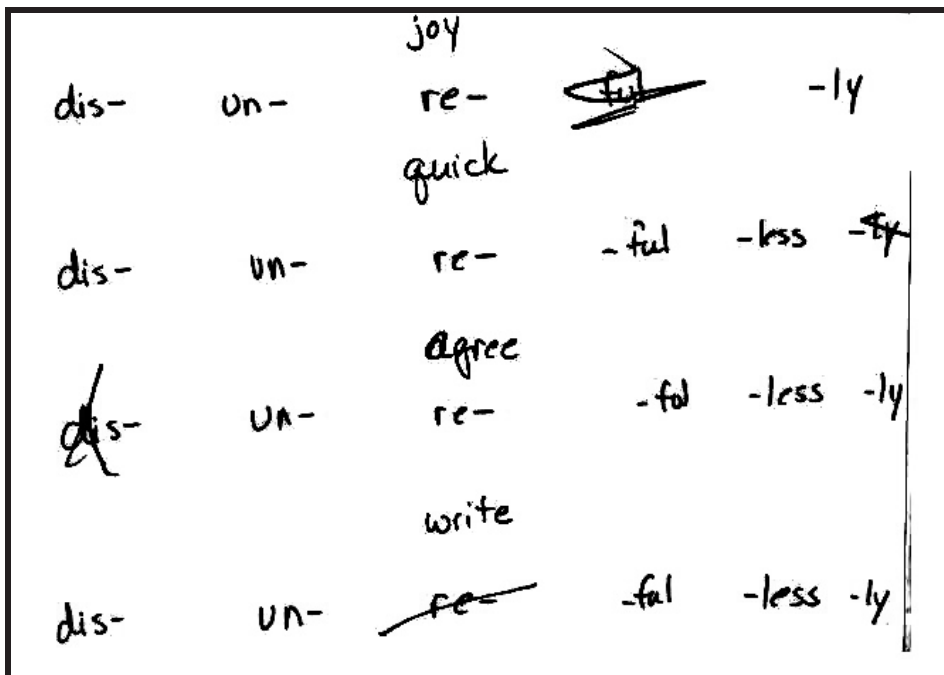


FIGURE 4. Handwriting by RH's mother with over marks by RH.

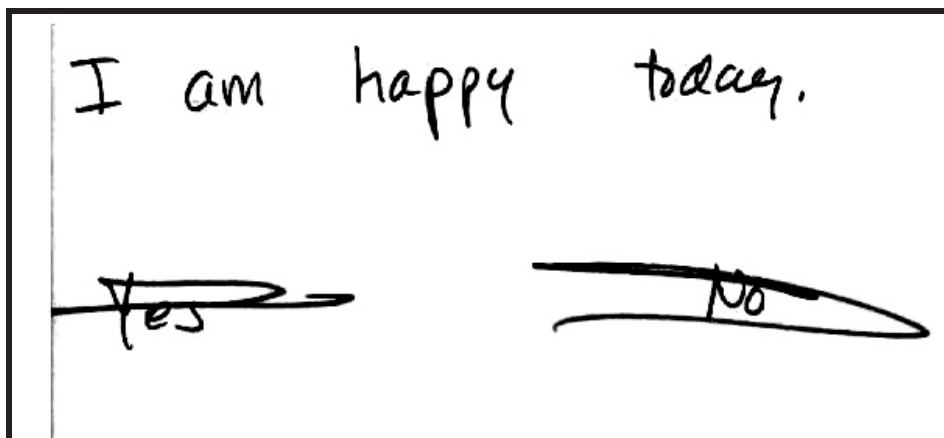


FIGURE 5. Handwriting by RH's mother with over marks by RH.

RH's mother began with the same strategy that she had used with the modified handwriting, namely, starting with an ample-sized target so that RH could use larger muscle groups while practicing to use smaller muscle groups. Thus, she produced a cardboard replica of a QWERTY keyboard with .5 inch-high letters spaced 1.5

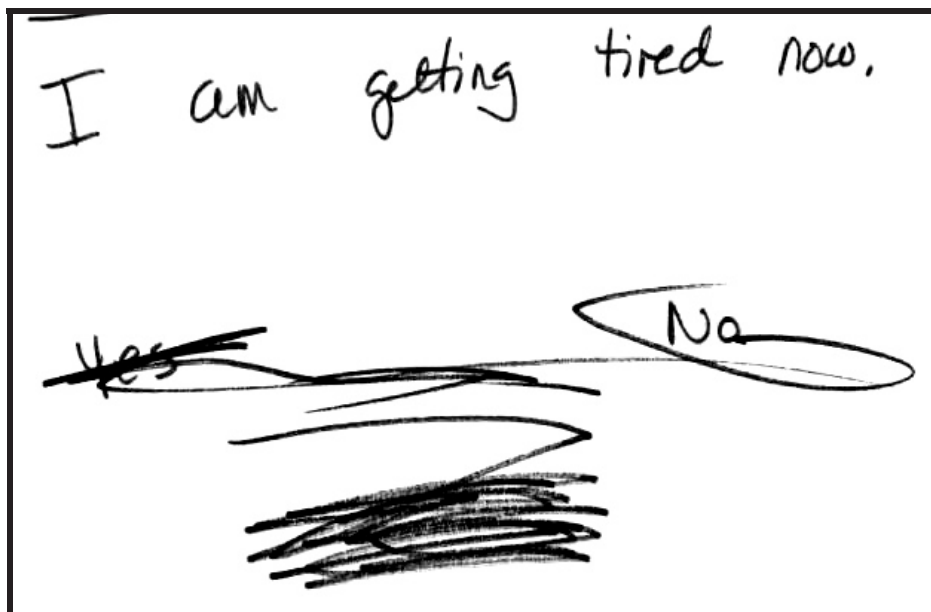


FIGURE 6. Handwriting by RH's mother with over marks by RH.

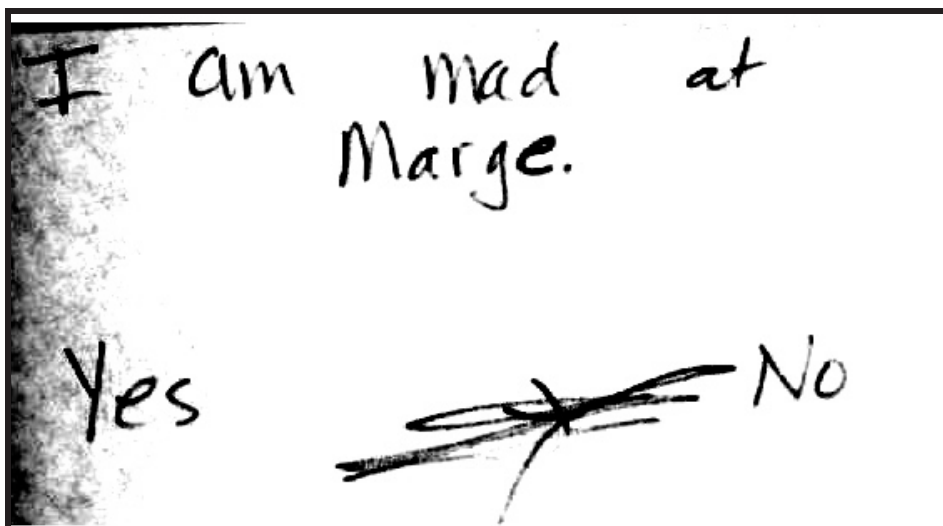


FIGURE 7. Handwriting by RH's mother with over marks by RH.

inches apart horizontally and vertically. RH began with physical support at the wrist while seated in a person's lap (for further proprioceptive input and support). The wrist support was faded to support at the elbow, and the lap support was faded to sitting beside the person providing support. The elbow support was then faded to a light touch on the shoulder, and then physical support was faded completely. With

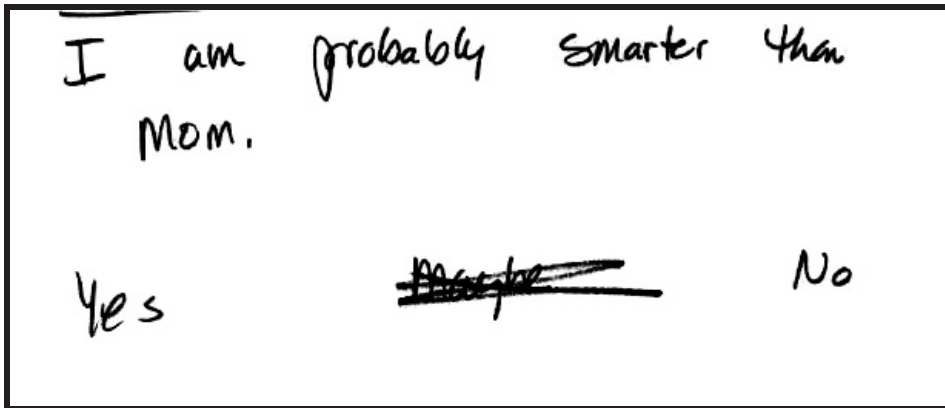


FIGURE 8. Handwriting by RH's mother with over marks by RH

RH's approval, the size of the keyboard replica was reduced two additional times, with the last adjustment approximating the size of a standard computer keyboard. RH and his mother reported appreciating the cardboard keyboard (i.e., the keyboard replica) because it was more portable and more durable; for example, it could be used when RH was in various physical positions, rather than seated with the keyboard on a flat desk-like surface.

As with the gross style of handwriting, which RH had mastered a couple of years earlier, RH also used the modified typing (i.e., index finger pointing to letters on the replica keyboard) both for academic work and for general communication (including email and postal mail, which was RH recorded manually by an observer while RH composed on the replica keyboard and then transcribed to other media). The modified typing demonstrated that RH's language skills included highly advanced expressive language, in addition to his previously demonstrated highly advanced receptive language. The modified typing also demonstrated how naturally and fluently RH could converse interpersonally when the output did not require vocalization.

For example, RH's mother wrote the following entry in her journal.

Just a week after RH began typing, we had the following exchange. The context was that we were talking about how mad it was making me that RH was at risk of ruining some of his videos because he wanted to flip the "lip" of the video off to see the actual tape (the thing I am calling the lip is the part that the video player does lift up, but people are not supposed to). RH had already broken two videos by too energetically lifting the lip up to see the tape. So I was having a pretty motherly moment in nagging him to not do this anymore. Actually I was telling him in no uncertain terms that I wouldn't do it for him because that's his clever way of getting something done if he knows he'll get into trouble for doing it—he coaxes someone else into doing it for him. So I was pretty steamed about this.

RH typed, "BUT THEY ARE MINE." I replied (in speech), "Yes, I know that they are yours, but I'm the one who spends my time and my money buying them." A note here is that RH's video collection, which is quite extensive, is also quite esoteric. I have to really search far and wide for

each one; it's not like going to ToysRUs and picking up what every other child is watching that week.

RH rebutted by typing, "BUT THEY CAN BE REPLACED," to which I replied, "Yes, I know they can be replaced, but that's more of my time and my money to replace them when I don't like your doing it in the first place." Realizing that I wasn't getting very far with my reasoning, I decided to try an analogy. I asked RH if he remembered the beautiful diamond earrings that he and his father had bought me for my birthday, and he typed, "YES." Then I asked him how it would be if I just flushed those diamond earrings down the toilet because, after all, they are mine and they can be replaced, so how would it be?

RH typed, "LAMENTABLE." At this point I was laughing too hard to be mad. And I confess I didn't really know that lamentable was a word until I looked it up later that night in a dictionary.

Later that night I was telling RH that it was definitely time for him to calm down and start trying to fall asleep, but he was still being a bit too animated. I had reminded him several times to calm down. Then I asked him, "Do you know why it's now time to start calming down and trying to fall asleep?" RH typed, "BECAUSE I AM JUST ABOUT TO PISS YOU OFF." So I then asked, "Do you want to piss me off?" And RH typed, "BETTER YOU THAN ME."

RH's use of the slang term, "piss off" prompted a discussion the next morning of slang and curse words, the bottom line of which is that I learned that RH was highly knowledgeable of an entire lexicon of slang and curse words. Indeed, his lexicon surpassed mine. He was also fully cognizant of which words were more slang-like compared with which words were downright verboten in formal company, and he could scale between those two extremes. I found this compelling, because my naïve conception was that children learn which words are taboo and how taboo they are by producing them—often without accurate knowledge of their full taboo status—and being reprimanded. At least that's how I remembered learning where on that sliding scale a few verboten words resided according to my own parents. However, RH had not only acquired an extensive vocabulary of slang and curse words, as he had with non-slang/curse words, he had extrapolated from what was likely very rare instances of each word's occurrence to know the word's shock value.

In addition to using modified typing for direct communication, such as conversations and email, RH also used modified typing for creative expression. At 7; 11, he completed a book of 30 poems. The first poem he typed was the following:

*When winter comes,
And snow has fallen,
Trees are barren no more.
Find me at your door.*

RH also used modified typing to clarify the words he articulated with his speech. An audio recording contained a repeated production of the utterance /KOO ki ki/ ('COO key key'), which RH's mother reported was produced while RH was playing with one of his troll dolls (referred to by his family as a "trollie," pronounced /troli/, rhyming with "holy"). RH typed that the target for this utterance, /KOO ki ki/

(‘COO key key’), was “cool trollie.” Another audio recording contained the production, /ga GA ga ga KI k^l/ (‘gah GAH gah gah KEY kuhl’), which RH translated through typing to be “[I] got the one that’s critical” (said in response to his mother asking if he wanted her to print out any more photographs after she had printed what seemed to be his one favorite). As a final example, an audio recording contained the production, /æ æ I i/ (‘aa aa aa EE ee), for which the target utterance, revealed through RH’s typing, was “that one is so neat.”

RH’s mother reported that RH’s ability to type also facilitated other people’s understanding of some of his other “atypical” behaviors. For example, even though through much of his toddler and preschool years, RH greatly enjoyed placing items and objects in linear arrangements (typically by color wavelength or other dimensions of importance to him), during his eighth year of life, he enjoyed making large piles or “nests” of favored possessions (such as CD insets, DVD covers, video cases, and books). As his mother reported, this free-flowing style was completely at odds with her own penchant for neatness and order. Thus, one morning when his mother was approaching one of his larger “nests,” she began uttering, “you know, RH, what about ...” She reported not getting any further in articulating her question when RH began giggling. To an outsider, one might think that RH was simply emitting some random outburst of laughter. However, when asked by his mother the basis of his laughter, RH typed, “I THINK IT’S FUNNY HOW YOU’RE NOW TRYING TO THINK OF WAYS TO ORGANIZE MY STUFF. GIVE IT UP MOM. IT’S FUTILE.”

Finally, RH’s modified typing provided a mechanism for him to share insights to the origin of his severe speech impairment. For example, when RH was 7;7 and his mother suggested that he try some oral motor imitation exercises, the following conversation ensued (with RH’s contributions being through modified typing and his mother’s, signified by “M” through her speech):

M: How about we try some imitation?

RH: [looks at his mother quizzically]

M: You know what imitation is, right?

RH: YES, IT IS THE HIGHEST FORM OF FLATTERY.

M: Funny. No, seriously, how would you define imitation?

RH: PURPOSEFULLY MIMICKING ANOTHER PERSON’S GESTURES OR BEHAVIORS.

M: Right. So, let’s try some.

RH: BUT IT MAKES ME SAD.

M: Why?

RH: BECAUSE IT’S SO HARD FOR ME TO DO. I CAN BARELY DO IT.

At another point, also during his attempts at oral motor exercises, RH expressed the following frustration, through typing: IT’S AS THOUGH MY MOUTH HAS A MIND OF ITS OWN.

Conclusions

Over 20 years ago, a document prepared for the federal Office of Technology Assessment, stated that “people of all levels of intelligence are found in the population with the inability to speak, which is one of several neurological or neuromuscular impairments. But, only rarely have distinctions been drawn between those incapable of thinking or comprehending and those who simply cannot express themselves. Lack of speech has been confused with lack of language and often been automatically equated with lack of intelligence” (OTA, 1983). The case study presented in this article has presented a profile of an individual whose struggle with speech should neither be confused with a lack of a language nor be equated with a lack of intelligence. Moreover, this case study has identified other challenges to well-accepted equations such as that between traditional manifestations of joint attention (e.g., pointing and following a point) and language development.

RH is clearly not the first individual to demonstrate the folly of equating language with speech. Others in the lay autism literature (e.g., Blackman, 2001; Eastham & Eastham, 1990) have done so before him, and it is very likely that others will continue to do so. These individuals and their lives demand distinguishing between language—the mental representation of concepts and their relations—and speech—one means for communicating mental representations.

References

- Ainsworth, M. D. S., Blehar, M. C., Waters, E., & Wall, S. (1978). *Patterns of attachment: A study of the strange situation*. Hillsdale, NJ: Erlbaum.
- Bayley, N. (1969). *Bayley Scales of Infant Development, Second Edition*. San Antonio, TX: Psychcorp.
- Bishop, D. V. M. (1983). *Test of Reception of Grammar (TROG)*. University of Cambridge, England: Medical Research Council Applied Psychology Unit.
- Blackman, L. (2001). *Lucy's story: Autism and other adventures*. London: Jessica Kingsley Press.
- British Broadcasting Company (May, 2000). *Inside story: Tito's story*.
- Dunn, L. M., & Dunn, L. A. (1997). *Peabody Picture Vocabulary Test—Third Edition*. Circle Pines, MN: American Guidance Service.
- Eastham, D. (1985). *Understand: Fifty memowriter poems*. Ottawa: Oliver-Pate.
- Eastham, M., & David E. (1990). *Silent words - Forever friends*. Ottawa: Oliver-Pate.
- Hammes, J.G., & Langdell, T. (1981). Precursors of symbol formation and childhood autism. *Journal of Autism and Developmental Disorders, 11*, 331–346.
- Health Technology Case Study 26: Assistive Devices for Severe Speech Impairments*. (1983). Washington, DC: U.S. Congress, Office of Technology Assessment. OTA-HCS-26.
- MacDonald, J. D., (1997). *Before your child talks: Practical guides for parents and professionals*. Columbus, OH: Communicating Partners Center.
- Mukhopadhyay, T. R. (2000). *Beyond the silence: My life, the world and autism*. London: NAS Publications.
- Schein, J. D., & Stewart, D. A., (1995). *Language in motion: Exploring the nature of sign*. Washington, DC: Gallaudet University Press.
- Smith, L. B. , Thelen, E., Titzer, R., McLin, D. (1999). Knowing in the context of acting: The task dynamics of the A-not-B error. *Psychological Review, 106*, 235–260.

- Tomasello, M., & Farrar, M. J. (1986). Joint attention and early language. *Child Development* 57, 1454–1463.
- Ungerer, J.A. & Sigman, M. (1981) Symbolic play and language comprehension in autistic children. *Journal of The Academy of Child Psychiatry*. 20, 318–337.

Contact Information:

Morton Ann Gernsbacher, Ph.D.
1202 W. Johnson Street
University of Wisconsin-Madison
Madison, WI 53562
MAGernsb@wisc.edu