You Can Know Me Now If You Listen: Sensory, Motor, and Communication Issues in a Nonverbal Person With Autism

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KEY WORDS
- autism
- communication
- effectiveness
- movement
- sensory processing

This case report describes an intensive approach to treating autism and provides an intersection between a first-person narrative paired with intervention and outcomes. In-depth conversations between a person with autism and an occupational therapist provide insight into understanding differences and difficulties in sensory processing and regulation, praxis, and communication. Individuals with autism may be intellectually and emotionally intact but hampered by deficits that interfere with the ability to move the body efficiently. These sensorimotor deficits underlie the ability to communicate with others and to develop relationships. This article illustrates the benefits of an intensive therapeutic program designed to address sensory and motor differences underlying communication, as well as the vital role the occupational therapist plays in addressing these underlying differences to improve functional communication and social participation.

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> *What do we* believe *versus what do we* know *about people who do not speak and who cannot tell us about themselves?* (Donnellan & Leary, 1995, p. 97)

There is growing evidence to suggest that the high prevalence of mental retardation reported in people with autism is not supported by empirical data and that measures of intelligence are inadequate to take into account "the interfering symptoms of autism on the process of assessment" (Edelson, 2006, p. 74). Autism self-advocates who have gained access to communication after being classified as mentally retarded have articulated the power of misassumption. As Rubin stated, "I was sadly assumed to be mentally retarded. No one made the distinction in real life if I was labeled mentally retarded or was mentally retarded" (Rubin et al., 2001, p. 418).

When David, the key informant in this case report, gained access to communication at age 14, he vividly described the experience of living with a sensory regulatory disorder, dyspraxia, and having no means of communication despite his intelligence. David is an 18-year-old student diagnosed with pervasive developmental disorder not otherwise specified, apraxia of speech (a neurological motor speech disorder), and dyspraxia (a sensory-based movement disorder).

> *I began so angry typing and never had dreamed to be having dreams ever, then the typing here in OT freed my little voice to be heard and I could release anger finally, and I could need no more to hold in all my thoughts because I can tell in real words finally all I needed, and little by little through years of daily struggle of working the muscles and trying to focus to stay still and really learning to feel my body move when I walk or talk and control movements.*

David attends a private school for students with language disorders, autism spectrum disorders (ASD), and apraxia of speech. The curriculum is characterized by an emphasis on speech and language using the Association Method, intensive speech therapy, intensive occupational therapy, and the rapid prompting method (RPM; Mukhopadhyay, 2007). The association method is a multisensory, phonics-based curriculum that systematically teaches children with language disorders to speak, read, and write fluently (DuBard & Martin, 2000). Speech therapy is provided intensively to develop precise articulation, oral motor control, and verbal fluency. Intervention is specifically designed to reduce or alleviate the student's difficulties in decoding, organizing, associating, storing, and retrieving information pertinent to the production of clear, articulate speech. Occupational therapy is provided using a sensory integration approach, a relationship-based approach, and principles of motor learning and motor control. Sensory integration focuses on somatosensory, proprioceptive, and vestibular experiences to improve sensory modulation and establish body scheme as a foundation for praxis and motor planning. A relational approach is based on respect for people and building a relationship on trust, which leads to the student's desire to be engaged in learning and relationships (Greenspan & Wieder, 1998, 2005). RPM, developed by Soma Mukhopadhyay, focuses on the initiation of responses without physical support using tactile, visual, verbal, and auditory stimuli (Mukhopadhyay, 2007). RPM focuses the student's attention on written alphabetic and numeric symbols to provide a communication method for people who are primarily nonverbal.

After several months of using these methods, David learned to independently communicate through typing. Through this newfound ability to communicate, David has shared many insights, including his difficulties with body movements, his sensory challenges, and his love of life by having found a means of communicating with others. Through these descriptions, occupational therapists can gain insight into guiding effective interventions. Like people with cerebral palsy, Parkinson's disease, or stroke, those with autism may be intellectually and emotionally intact, even though their bodies do not reliably allow them to demonstrate who they are and what they know. The importance of occupational therapy cannot be overstated. In David's words,

> *We want to be heard but it's hard and in here being [in] OT has helped me tell my story of [a] happy life that's come since being able to talk, but before that I had to be cautious because I was so much overlooked to be ignorant and to be able to share.*
>
> Occupational therapist: *What was it like for you to finally be able to communicate?*
>
> *It was heaven.*

Assessment Results

Occupational therapy is based on the principle that engagement in occupation includes the subjective (emotional or psychological) aspects of performance and the objective (physically observable) aspects of performance (American Occupational Therapy Association, 2002, 2003). David's goals, based on a thorough evaluation, were to address the developmental parameters of sensory processing and modulation, motor/praxis, emotional/relational, and communication/cognition. Table 1 displays initial evaluation results for David as well as the current results of the Sensory Profile (Dunn, 1999). Administration of standardized testing revealed significant difficulties with balance, strength, gross and fine motor skills, visual motor skills, and motor planning/praxis skills. Although David was unable to complete these assessments in 2002, he was able to complete them in 2007 after intervention, and the results are summarized in Table 2. Clinical observations provided further evidence of both difficulties and progress in these areas, as described in

Table 1. Sensory Profile Test Scores for David

	Difference Rating	
Category/Section	2002	2007
Sensory Processing		
Auditory processing	Definite	Definite
Visual processing	Typical	Typical
Vestibular processing	Definite	Definite
Touch processing	Definite	Typical
Multisensory processing	Definite	Probable
Oral sensory processing	Definite	Typical
Modulation		
Sensory processing: endurance/tone	Definite	Typical
Modulation: body position/movement	Definite	Probable
Modulation: movement/activity level	Definite	Probable
Modulation: sensory input/emotional	Probable	Typical
Modulation: visual input/emotional/activity	Definite	Typical
Behavior and Emotional Responses		
Emotional/social responses	Definite	Probable
Behavioral outcomes of sensory processing	Definite	Probable
Thresholds for response	Definite	Definite
Factors		
Sensory seeking	Definite	Typical
Emotionally reactive	Definite	Probable
Low endurance/tone	Definite	Typical
Oral sensory sensitivity	Definite	Probable
Inattention/distractibility	Definite	Definite
Poor registration	Typical	Typical
Sensory sensitivity	Definite	Definite
Sedentary	Definite	Definite
Fine motor/perceptual	Definite	Definite

Note. Typical = within 1 *SD* from the mean; probable = within 1–2 *SD* from the mean; definite = ≥2 *SD* from the mean.

Table 2. 2007 Test Scores for David

Sensory Integration and Praxis Tests (Ayres, 2004) Subtests	*SD* from the *M*
Postural praxis	–3.00
Sequencing praxis	–3.00
Oral praxis	–3.00
Bilateral motor coordination	–2.66
Praxis on verbal command	–3.00
Bruininks–Oseretsky Test of Motor Proficiency, 2nd edition (Bruininks & Bruininks, 2005)	**Age equivalents**
Fine motor precision	<4.0
Fine motor integration	<4.0
Manual dexterity	<4.0
Upper-limb coordination	6.3–6.5
Bilateral coordination	4.6–4.7
Balance	4.10–4.11
Running speed and agility	5.0–5.1
Strength	4.10–4.11
Beery–Buktenica Developmental Test of Visual–Motor Integration, 5th edition (Beery & Beery, 2004)	**Age equivalents**
Visual perception	2.11
Motor coordination	3.3
Visual–motor integration	3.6

Table 3. Clinical Observations and Functional Skills

2002	2007
Significant difficulty motor planning to imitate body positions	Able to imitate body positions with close approximation
Significant difficulty motor planning to gesture during conversations	Emerging use of gestures, such as reaching out to touch a person's shoulder and pointing to indicate desired objects during conversations
Required facilitation to manage and don clothing; difficulty buttoning shirt	Able to dress independently; able to orient to the front of the shirt and don independently; buttons shirt independently
Unable to perform smooth projected action sequences; slow responses	Able to demonstrate smooth projected action sequences such as catching a ball when thrown to the side, away from midline
Often displayed rigid and jerky movements; decreased balance and slow responses	Smooth and fluid movements; improved balance, for example can stand and balance to tie his shoe
Difficulty with visual attention and eye contact; significant difficulty integrating vision with whole body movements	Attends visually with greater ease; engages in eye contact easily for several seconds at a time during conversations; improved integration of vision with whole body movements, such as to walk on uneven surfaces while looking at the visual environment
Initial typing began by pointing very slowly to one letter at a time using large movements from his shoulder	Types using small hand and finger movements; learning to isolate and individualize each finger with increased speed and accuracy

Table 3. The primary therapist who obtained these clinical observations is certified in the Sensory Integration and Praxis Tests from the University of Southern California/Western Psychological Service and has extensive experience providing occupational therapy using a sensory integrative frame of reference. David's behaviors and skills were analyzed by administering specific observations that include those originally defined by A. Jean Ayres as "clinical observations" (Blanche, 2002). His present levels were documented in his individualized education plan each year. Annually, David participated in occupational therapy evaluations involving standardized and nonstandardized assessments to document changes over time. The evidence indicated sensory processing difficulties involving modulation of his sensory system and dyspraxia, a sensory-based movement disorder.

Goals and Plan for Intervention

Specific goals and interventions were designed according to David's needs for functional performance and engagement in meaningful occupations at school and at home. David has been an active participant in an intensive academic language program and intensive intervention during speech and language therapy (8 hr weekly) and occupational therapy (6 hr weekly). Table 4 details David's daily schedule at school, including academic instruction and specific therapeutic interventions. Occupational therapy intervention occurs at the school in treatment rooms fully equipped with numerous ceiling hooks for suspended equipment, therapy balls, mats, fine motor activities, visual motor activities, and a variety of gross motor equipment. Occupational therapy involves a sensory integration approach using key constructs that demonstrate fidelity to occupational therapy–sensory integration intervention. These include ensuring physical safety, presenting sensory opportunities, maintaining appropriate level of alertness, challenging his postural and bilateral motor control, collaborating in activity choice, and challenging his praxis and organization of behavior (Parham et al., 2007). Although David's challenges can be recorded as severe and his progression slow, he has demonstrated tremendous improvement in his adaptive responses and functional progress in all areas over a 5-year period.

Sensory Processing

The prevalence of a sensory processing disorder in the general population (5%–14%) is significantly less than in the population with ASD (80%–90%; Ahn, Miller, Milberger, & McIntosh, 2004; Huebner, 2001; O'Neill & Jones, 1997). Through his typing, David described his sensory processing disorder:

Table 4. Example of David's Schedule: Academic Areas and Therapeutic Interventions

Occupational Therapy: Individual therapy sessions focus on the developmental parameters of sensory processing/modulation, motor/praxis, emotional/relational, and communication/cognition.

Example of a typical session:

Sensory diet/body wakeup: Sensory diet provided according to his individual needs and may include brushing and "buzzing," body awareness activities providing proprioception and joint/skin compression with active muscle contraction such as wall push ups or prone wheelbarrow walks over peanut. Therapeutic listening provided before therapy session.

Active sensorimotor activities: Activities such as prone in net swing, holding dowel horizontally and bilaterally, reaching in front or to side to knock down targets, walking down a balance beam while focusing visual attention across the room to read a sentence.

- A primary focus of each activity is developing a trust relationship between the therapist and individual.
- Each activity is adjusted and fine tuned to provide a "just-right challenge" in each of the five developmental parameters listed previously mentioned. Each activity focuses on combining language and body action.

Association Method: The Association Method (DuBard & Martin, 2000) is a systematic, multisensory, phonics-based method used to develop fluency of reading, writing, and oral language skills. Speech and language pathologists work in the classroom with the teachers to collaborate on his specific needs and learning process. The occupational therapist provides ideas to adapt the classroom environment and materials based on his needs as well as to provide intervention for regulation, sensory support, and writing or typing abilities.

Snack Time, Sensory Diet According to His Needs, and Motor Group: Motor planning activities are coupled with language. For example, jumping rope while counting by 10 or basketball drills involving passing, dribbling, or shooting while naming capital cities in the United States (concepts from a history lesson).

Language Group Lesson: Language groups such as calendar or journal discussions are taught by teacher or speech and language pathologist. These language groups are important for the motor memory and auditory memory practice of sequencing sounds into syllables, syllables into words, and words into sentences, ultimately developing automaticity of speech and language.

Lunch Time

Recess: Group activities coordinated by occupational therapists and teachers, such as baseball, kickball, or gross motor activities on playground equipment.

Sensory Diet According to His Sensory Needs

Speech Therapy: Individual therapy sessions focus on articulation, proper rate of speech, breath support, volume, the development of auditory memory, and the automatic recall of language.

Academics From Curriculum: Math, science, and history units are taught according to his academic level. Language components from the Association Method are targeted and reinforced during this time to increase verbal communication, and Rapid Prompting (Mukhopadhyay, 2007) principles are used to enable him to express his true level of comprehension of the subject matter through typing.

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

Intervention, Progress, and David's Response

David is actively engaged in an individually designed sensory diet (Frick & Hacker, 2001) four times daily with specific sensory experiences to facilitate regulation and to increase his body awareness. Intervention includes a "brushing and buzzing program" (tactile input and deep vibration massage to skin, muscles, and joints) and "heavy work" (involving active proprioception, such as pulling and pushing with added resistance). David also participates in therapeutic listening, a modified program specifically designed to desensitize sound sensitivity and to improve auditory processing (Frick & Hacker, 2001; Hall & Case-Smith, 2007). Because his auditory system is highly sensitive, his program was scaled back, slowly increasing listening time as he was able to accept more auditory input.

> *The OT helps my body move better. OT much improved my senses. They used to need more controlling me, but OT has made my body calm, and now OT helps me use my body how I want instead of it controlling.*

In response to his sensory diet:

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

David is able to discuss his "self-stimulative" behaviors, which are common in people with autism. He indicates that these "behaviors" serve a purpose beyond simply stimulation of the body and can be better described as "self-regulatory." Although self-stimulative behaviors have been viewed as atypical or disruptive, it is important to understand the underlying reasons for these actions and fashion an appropriate therapeutic intervention (Koenig, Stillman, & Kinnealey, 2006; Stillman, 2003). David's self-regulatory actions frequently involve vocalizations, moving around the room, and

stroking his face. These actions appear to be used for different purposes at different times—sometimes to assist with calming and decreasing anxiety, sometimes to block out bombarding sensations, or sometimes to organize his thoughts. Regardless of their importance, David is self-conscious about these actions and would like to stop.

> *Really they help me to calm and be watchful really around the room and feel better, We need them and can't control always like breathing.*
>
> Occupational therapist: Are there things someone could do that might help you with these behaviors?
>
> *Yes to let me get really a lot of movement breaks before sitting and concentrating for a long time.*
>
> Occupational therapist: How do you describe what it looks like when you are attending to something?
>
> *Always aware, never secure.*

Motor Skills, Praxis, and Movement Differences

Praxis is defined as the ability to have an idea of what to do, plan and sequence the action, and execute the action (Ayres, 1979; Miller, Anzalone, Lane, Cermak, & Osten, 2007). The idea, plan, and ability to act are based on the sensorimotor understanding of our bodies and what they can do. When we give our bodies "commands," they should respond in the way we intended. The inability to do this is dyspraxia, a sensory-based movement disorder in which people have difficulty with volitional and controlled body movements (Miller, Cermak, Lane, Anazalone, & Koomar, 2004; Miller et al., 2007). Dyspraxia can also be found in the face and mouth, which interferes with facial expressions and speech. In spite of movement differences and dyspraxia, receptive language and cognitive ability can be intact (Davis, 2001; Donnellan & Leary, 1995; Leary & Hill, 1996.)

Donnellan and Leary (1995) described movement differences in people with ASD, Parkinson's disease, and catatonia as an interference or shift in the efficient or effective use of movement occurring when a person is starting, stopping, executing, continuing, combining, or switching movements. There is ongoing research on movement differences and motor challenges for people with autism (Davis, 2001; Donnellan & Leary, 1995; Greenspan & Wieder, 1998, 2005; Leary & Hill, 1996; Mostofsky et al., 2006; Teitelbaum, Tietelbaum, Fryman, & Maurer, 2002). For people like David, developing and executing a motor plan efficiently is difficult and frustrating. He explained,

> *Moving my body is impaired and I can't move and think at the same time. My body feels like cement and moving takes so much hard concentration.*

Intervention, Progress, and David's Response

David's therapy program has been designed to incorporate body awareness with motor planning and use of each of the senses: to look, speak, hear, and move at the same time.

> *To type I move one hand, but to speak takes my mouth which always never moves right, I have words I want to share all the time. Teach me how...Really just moving is hard.*
>
> Occupational therapist: How is it different now than before OT?
>
> *Absolutely much easier.*

Communication and Behavior

> *In OT there's happiness, in [this school] there's happiness because here I find my place . . . learning only lessons of hope necessary like air for lungs and learning lessons of kindness to myself, seeing me not as retarded, forgotten, less than human, but as a smart mind trapped and slowly pushing through the dismal body to show my brilliant mind.*

From an educational background and knowledge of the human body, the sensory systems, and psychosocial concepts, the occupational therapist has the preparation to be able to provide a safe place to voice emotions, difficulties, and accomplishments. Occupational therapists must have a primary focus on intervention that enables the individual to develop volitional control of his or her body while presuming intellectual competence. David is an example of a student for whom a team of professionals was willing and able to provide intensive intervention and support. His improved motor abilities enabled him to communicate and participate more fully in his daily life.

The enhancement of therapy when ongoing communication is incorporated can be multifaceted. As Rubin et al. (2001) stated, "Our view is that competence should be presumed, with the burden on the teachers and others around the person to find ways of helping the person communicate" (p. 427).

> *I am able to type out all my thoughts and feelings about autism and being a boy struggling and really enslaved by it and then [this school] gave me the ability to type and be heard after 14 years of no one hearing me or knowing that I had any intelligence and now I'm working on speaking and being confident with my voice and having friends. I only secretly dream for independence and for love and to have friends that see the real me and that want only to be nice to each person in the world no matter how difficult or how they struggle in life to be or what they look like in physical appearance because it's the heart that lives and love for the inside is all each person really wants in life and it's all I want and it's all autistic kids dream about.*

Discussion: Shifting Our Thinking

Learning how to interact and respond to the world is often extremely difficult, frightening, and intimidating for people with autism. Personal narratives from people with ASD, coupled with their responses to interventions, can give the therapist insight into how significantly a person's sensory processing, motor challenges, and communication difficulties impede independence. Occupational therapists can play a key role in reducing the interference of ASD on occupational performance. David's narrative highlights the following key principle: Always presume intellect and believe in the potential for competence (Koenig et al., 2006; Stillman, 2003).

It is important to demonstrate belief in the student's intelligence through daily interactions. Edelson (2006) highlighted the inability to accurately empirically test the intelligence of people with ASD and suggested that autism may be a performance deficit rather than a cognitive deficit. David's narrative, in conjunction with previous intelligence testing that wrongly placed him in the mentally retarded range, highlights the danger of not presuming intelligence. The "least dangerous assumption" suggests that when there is no absolute evidence, it is essential to make the safest and most respectful assumption that would be the least dangerous to the individual if proven to be false (Rossetti & Tashie, 2002).

Conclusion

David continues to receive occupational therapy services with the goal of greater self-regulation and freedom of movement, with full participation in relevant occupations and independence as primary goals. He often discusses his goals for making friends, going to college, teaching about autism, and living independently.

> Occupational therapist: How do you see yourself?
>
> *A teenager who has a lot of struggles but determined to conquer.*
>
> David has dreams and goals for the future:
>
> *Here the dreams mean taking my hand to help me to walk and talk and invite someone into my life and thoughts and to know each other like life friends. Those are my dreams. I dream for the world to be hearing my voice, to change people's ideas about some struggles of autism, and for hope to be realized by others with autism.*

Personal narratives provide insight into a process that goes beyond what can be measured (Jones, Zahl, & Huws, 2001). What does it mean to listen to David's voice? David's narrative contributes to a new understanding of what it means to be a nonverbal individual with autism. It does not mean that David speaks for everyone on the autism spectrum. By their nature, single case reports inevitably raise questions of whether conclusions can be generalized to a larger population. Nevertheless, important elements from this study are supported from existing literature, including the motor and performance difficulties that may be mistaken for a generalized cognitive deficit (Davis, 2001; Donnellan & Leary, 1995; Edelson, 2006; Greenspan & Wieder, 1998, 2005; Leary & Hill, 1996; Mostofsky et al., 2006; Teitelbaum et al., 2002); the frustration that may be observed and misinterpreted; and the need for professionals to initially presume a higher intelligence than is readily apparent in people with these disorders. Rubin's narrative highlights that full participation for people with autism "includes having a stake and effect in redefining the notion of ability and diagnostic classifications associated with presumed ability or disability" (Rubin et al., 2001, p. 426). Professionals have an ethical obligation to seek methods for communicating with people with ASD that will access their intelligence and free their voices. s

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