

"Nothing Never Happens!"



**A New Look at Communication, Language,
Speech, and Literacy**

ASSET Center for ASD/DD

Autism Spectrum Disorders and Developmental Disabilities

Services, **S**upports, **E**ducation and **T**raining

Youth Advocate
PROGRAMS, INC.

Table of Contents

Introduction

What is Communication?

What is Language?

What is Speech?

What is Literacy?

A Few Final Thoughts

Introduction



What are the first words we think of when we think of developmental disabilities? Maybe the answer is “words” themselves. Since parents tend to anticipate and pay close attention to their child’s first spoken words, the process of arriving at many developmental diagnoses may be triggered by a child’s unusual use of language or delayed use of speech. Parents may report to their pediatrician that “she doesn’t have many words, for her age” or that “he always gets his pronouns reversed.” The accurate observation of speech and language differences can, however, lead to highly inaccurate observations about a child’s other activities and abilities. A child’s awareness and intelligence may be unfairly called into question. Parents of a child who does not speak may be told that he or she “is not able to communicate,” despite their insistence that their child has found *many* highly effective ways to make needs and feelings known!

Communication is always happening all around us, yet may be overlooked when it does not happen through typical forms of spoken language. *Communication, speech, and language are often lumped together as if they were the same thing, when in fact they are not.* This confusion can lead to serious underestimations of what people with disabilities know and can do. For example, children who do not speak fluently may be treated as if they do not comprehend language. Adults may unintentionally cause them distress by making negative comments in their presence or allowing others to do so, or by failing to recognize their basic need to be given information and explanations.

Parents of such children often worry that their son or daughter will not grow up enjoying the benefits of literacy; understandably, they cannot conceive of childhood without the rich imaginative experience of books and stories. These parental concerns are legitimate, since students who are presumed to lack language or communication tend to be given fewer and fewer options to engage meaningfully in what the curriculum calls “language arts.” Schools may decide that it is not worthwhile or even possible to help

them access typical literacy experiences such as listening and responding to stories. Teachers may forget that literacy is not just about decoding symbols on a page, and may overlook the fact that it exists fundamentally as a participatory learning experience. In fact, *all* human beings can and must learn about the world, themselves, and others by participating in shared stories. Children with developmental disabilities can always be included in this process if we respect their capacity to understand and to communicate in a wide variety of ways.

Nowadays many outdated beliefs about disabilities are being replaced with positive information. We know that people with communication challenges should be recognized and supported as language users, even if the receptive ability of some individuals works better or faster than their ability to process information, retrieve words, or produce a response. We agree that all children should be encouraged as speakers in their own right and their own ways, sometimes with the assistance of technology, keyboards, letter or picture boards, sign language, or other forms of support. We are becoming much more aware that people can speak out and speak for themselves without actually creating sound waves in the air.



We are getting better at recognizing that everyone communicates all the time, in countless ways: how we act, the things we choose, how we move, and what we pay attention to. And we say that there is no such thing as a person who does not communicate, or a time when someone completely stops communicating. That is why this publication is called “Nothing *never* happens!” It’s not an error of grammar, not a double negative, but a reminder that communication is always available to those who look and listen. We are never stuck with “nothing,” and that is doubly positive.

This guide was created to explore the nature of communication, language, speech, and literacy, so that we can more effectively recognize and support their development in the lives of all children and adults. It is dedicated to people with communication challenges in their capacity as teachers, in the hope that we will all become more sensitive and observant learners.

I. WHAT IS COMMUNICATION?



Communication: *a process by which information is exchanged between individuals through a common system of symbols, signs, or behavior; personal rapport*

~Merriam Webster Dictionary

We live in the Communication Age, in a constant stream of media and messages. But while computers have become our model of how information is exchanged, it's important to remember that information must first be *created*. The only way for that to happen is the old-fashioned way: through relationships or, as the dictionary defines it, "personal rapport."

Communication starts at birth - for everyone!

Every time an infant comes into the world, eager parents and caregivers immediately begin to draw him or her into the world of human communication. They observe closely and start to pick up many cues about what the baby wants and feels. They notice the fussiness that means "time to eat" or "time to sleep" and respond appropriately. They notice changes in behavior and investigate them as possible signs of distress or illness. They speak to the baby and comment on the things he or she does, whether kicking or cooing or startling at a nearby sound. They follow the baby's gaze and name the person or thing at which the baby seems to be looking.

Of course, an infant may not have very well-defined intentions about these interactions at first. Adults know instinctively that it is up to them to take advantage of baby's every action to build little stories about how the world works and what sorts of possibilities it contains. Babies and caregivers work together to create shared meanings and shared patterns of activity in which there are actors, actions, and people or things acted upon. They rehearse patterns of giving and taking, leading and following, seeking and finding, and all the other basic categories



of human interaction. In turn, these become the foundations for making sense of language. This is the universal process by which all of us become increasingly intentional participants in a family and a community. The raw material of our first basic communications about what we need and how we feel is slowly shaped into larger and more defined expectations about the world, how it works, and our place in it.



It is the same for children who will one day be diagnosed with a variety of developmental differences, including intellectual disability or autism. Like all infants, they come into the world communicating important cues about how their bodies feel and operate, and how caregivers should approach them. Since these babies tend to

experience differences in the perception and regulation of sensations and movement, however, parents and other caregivers may find themselves learning and adapting to a different system of communication. Their child may be telling them, through her reactions to toys, that she finds certain sounds, colors or movements distressing. Or he might be communicating deep attachment to his parents by watching them closely out of the corners of his eyes, even though he finds being held and hugged overwhelming. He or she may develop intense interests in certain activities or things. Those interests need to be appreciated and shared by others, even if their purpose seems puzzling at first. They are sure to tell a great deal about the strengths and emerging personality of the child, and participating in them creates a motivating basis for further communication. As the child grows older, caring parents, teachers and friends will continue to assume that his or her behavior has meaning, and that this child is communicating all the time. ***Nothing never happens!***

Communication can be intentional or unintentional

A person who does not speak may be trying hard to send us a message by other means. For example, a child who wants to have a story read may return expectantly to a special chair where that activity has taken place before. By observing that she is interested when we approach with a book,

we are confirming the intent of her communication. As she sees us respond appropriately to the meaning of her action, she will be encouraged to reach out and interact more. However, it is important to remember that while some communication is intentional, some is not. If that same child later walks past us without stopping when we call her name, she is not necessarily communicating a wish to ignore or avoid us. We need to investigate further rather than make assumptions about her intention and take it personally. That pattern of action may be an *unintentional* communication that informs us about the child's difficulties with auditory processing or her inability to transition to a different movement pattern once she is in motion. Unintentional communications are the clues a good detective looks for. They can lead to an explanation of what really happened and why. But if we jump to the conclusion that they contain a personal message - or a rebuke -- just for us, we will become so distracted by our own feelings that we will never solve the case.

Communication involves relationships

When our communication is understood and reciprocated, we are in a relationship. Relationships are essential to human development, not optional or an "added extra." We need relationships to give structure and purpose to our actions. Who hasn't observed what happens when a young child is left too long to his or her own devices? The baby in the playpen or the car seat who hasn't had much attention for a while becomes aimless, disorganized, and may eventually lose control in what parents call a "meltdown." At this point adults will intervene by interacting, and the child's equilibrium will eventually be restored. Not surprisingly, children who experience long term, intense deprivation of supportive relationships are at high risk for the development of mental illness and problems with learning and attention.

The relationships that best promote communication and personal development are *reciprocal*, with both parties respecting and learning from each other. Psychologist and researcher Morton Ann Gernsbacher



characterizes reciprocity as “a two-way street”¹ and suggests that many parents and professionals “have neglected the reciprocal nature of reciprocity.”² While one-way relationships based on controlling the actions of others can provide a type of organization, their usefulness seems to be limited by their rigidity. Developmental psychologist Alan Fogel expresses this limitation with great insight:

Information becomes available only through active engagement... When relationships evolve into patterns in which participants perceive them as sequences of discrete exchanges of reward and cost it is quite likely that the creativity has gone out of them. They are no longer dynamic systems in which individuals grow, they have become prisons of the soul.³

Dr. Gernsbacher, herself the parent of a child on the autism spectrum, suggests that when we relate to children whose means of communication is challenged we may

...need to enact *even more* reciprocity, need to share *even more* of the child's world, need to follow *even more* of the child's lead, and need to become something of a detective to discern the ways that the child is expressing joint attention and social and emotional reciprocity.⁴



Sharing, following, and playing detective can lead to amazing results. One young boy, diagnosed with developmental disabilities and unable to speak, had long been a puzzle to his family and teachers. They expressed great frustration over not knowing what was on his mind. Then one day, a support person trained in communication noticed that this child would listen intently when any of three particular songs came on the radio. He would try to

¹ Morton Ann Gernsbacher (2006). Toward a behavior of reciprocity. *Journal of Developmental Processes*, 1, 139-152, p. 139. Online at http://psych.wisc.edu/lang/pdf/Gernsbacher_reciprocity.pdf

² Ibid, p. 140.

³ Alan Fogel (1993). *Developing Through Relationships*. University of Chicago Press, pp. 89-90.

⁴ Morton Ann Gernsbacher (2006). Toward a behavior of reciprocity. *Journal of Developmental Processes*, 1, 139-152, p. 145 Online at http://psych.wisc.edu/lang/pdf/Gernsbacher_reciprocity.pdf

silence everyone around him, and no one was allowed to touch the radio dial until the song ended. Not satisfied with labeling this behavior perseverative or meaningless, this support person researched the song lyrics and found something remarkable: all three songs were laments about being “locked up inside” and not understood by others. Taking this clue in a spirit of reciprocity, he thanked the child for sharing this personal message and made him a CD of the songs to play whenever he wished. A way was now open for this child's family and teachers to approach him as a communicator, begin to recognize and respond to his messages, and help him to expand them. The willingness to look and listen, and the belief that everyone communicates, were the first steps in supporting this child to connect and make his feelings known.



II. WHAT IS LANGUAGE?

Language: the words, their pronunciation, and the methods of combining them used and understood by a community; audible, articulate, meaningful sound as produced by the action of the vocal organs; a systematic means of communicating ideas or feelings by the use of conventionalized signs, sounds, gestures, or marks having understood meanings; the suggestion by objects, actions, or conditions of associated ideas or feelings; the means by which animals communicate; a formal system of signs and symbols

~Merriam Webster Dictionary

Some people with disabilities have been referred to as “non-verbal.” This term is a misnomer: these people *do* have verbs, and nouns too! Whether or not a person can retrieve the words they need when they need them, or form readily intelligible words with their vocal apparatus, it is wise to start with the assumption that he or she has the capacity to understand language.

Receptive language is different from expressive language

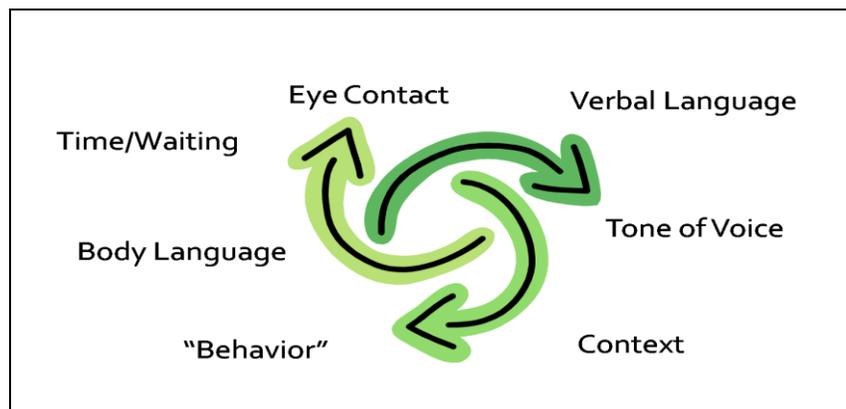
There can be a vast difference between *receptive language* - what people can “take in” and understand - and *expressive language* - the words they can fluently and reliably produce to share their thoughts with others. People can understand language perfectly well without necessarily being able to retrieve or speak the words they want, on demand. Most of us have known people who experienced a stroke or brain injury and lost, for a time or permanently, the ability to speak. Others may retain the ability to speak but have great difficulty in bringing forth words appropriate to the situation. There may be long pauses while they try to find the word they want; to their great frustration, unwanted and unintended words may pop out instead. Yet we continue to presume that these friends or family members understand

language, and we speak to them as if they do. Often they give us a nod, blink, or other gesture that lets us know they are following what we are saying.

It may be easier for us to keep our ideas of "speech" and "language" separate in cases like these, where we knew the person as a language user before he or she lost the ability to speak. When children or adults have experienced a developmental disability from birth or an early age, people are much quicker to jump to the erroneous assumption that they don't understand much or any of what is said around them. Yet when they are given opportunities to demonstrate their understanding by means other than speech - such as making choices, demonstrating skills, sharing personal interests, typing or pointing to answers, or expressing their awareness through music or art - such individuals have given evidence of their language comprehension time and time again.

Body language and vocal cues can impact comprehension

Children and adults with developmental differences may have difficulty interpreting body language, including gestures and facial expressions. This can be a significant challenge to comprehension, since communication experts estimate that anywhere from 50% to 80% of the meaning of the words we speak is found in the body language or vocal cues (such as tone of voice, speech rate, pauses, and timing) that accompany them, and not in the words themselves. To help a person understand what we are saying, it can be helpful to keep our words clear and precise, avoiding figures of speech, jokes, sarcasm, double meanings, or other messages that depend on body or vocal cues. Until you know a person well enough to feel in sync with their sense of humor and understanding of body language, it is best to say what you mean and mean what you say.



Not looking does not mean not listening

Another common misunderstanding is the presumption that a person is not paying attention to a speaker if they are not looking at the speaker's face, and especially if they are not making eye contact. Yet for many people, looking at a speaker can be so distracting that the speaker's words fail to register. One student, who was corrected for sitting with his face to the window during class, explained to his teacher, "If I look at you, I can't understand your words. If you want me to understand your words, I can't look at you." For this child,



watching the teacher to prove he was paying attention would mean *not* attending to the lesson she was teaching! Fortunately, the teacher "got it" and this student went on to enjoy good grades as well as an unobstructed view out the window. Unfortunately, many people continue to mistake the listening needs of children and adults with certain disabilities for lack of attention, reinforcing the mistaken belief that they are not attuned to language.

Not speaking does not mean not intelligent

The assumption that speech and language are the same thing, or that the absence of speech means the absence of language, has led to underestimates of the abilities and feelings of many people with developmental differences. Doctors or teachers may talk negatively about a child while he or she is nearby, failing to realize that children who do not speak can nevertheless understand and be hurt by the things they overhear. One mother recalls being given her young son's diagnosis and prognosis while he was seated on her lap in the doctor's office. The doctor spoke in dire terms of his presumed "retardation" (a term no longer in use) and of all the things he "would never do." As soon as they returned home, this typically cheerful and energetic child curled up into a ball on the floor and would not respond for the rest of the day - something he had never done before. His intense reaction had all the signs of shock and despair; it took a long time and a lot of encouragement before her child was able to smile and act like himself

again. Experiences like this remind us that medical professionals should take special care never to talk negatively about a child under any circumstances. In fact, the Hippocratic Oath to "do no harm" should extend to all the professions, including teaching and parenting, that so strongly impact the lives of children. Children's self-esteem and acceptance by others is sure to be affected even when the communication of negative opinions, labels, and predictions is indirect or unintentional.

People who do not speak have too often been assumed to lack intellect. They have too often missed out on access to everyday cultural experiences - such as being included in the general curriculum at school, participating in the ceremonies and activities of their family's place of worship, or attending community events and celebrations -- on the grounds that they would not understand them. Now we know that people with developmental differences can have receptive language and powers of observation that far exceed their ability to express themselves in speech. They are, as Douglas Biklen emphasizes in *Autism and the Myth of the Person Alone* -- a book largely composed by self-advocates who communicate in various ways -- "thinking people with ideas about their lives and their relationship to the world."⁵

Self-advocates are using many different kinds of assistive and alternative communication to speak out and get together



Not surprisingly, many people who have difficulty vocalizing find alternatives to the spoken word. They may use keyboards and computers, sometimes with voice synthesizers that allow them to speak out at the touch of a button. Others may prefer various kinds of picture systems or sign language. In some places, groups of alternative

⁵ Douglas Biklen, Richard Attfield, Lucy Blackman, *et al.* (2005). *Autism and the Myth of the Person Alone*. New York University Press, p. 1.

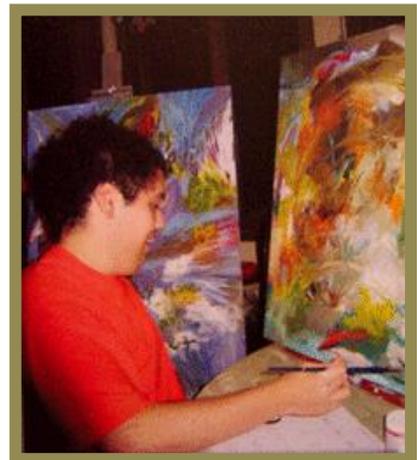
language users have found each other and get together for mutual support and self-advocacy. Pennsylvania is home to a group that chose the poetic name of The Lonesome Doves. Many of the self-advocates who organize and run advocacy groups and web sites "let their fingers do the talking" on their keyboards. A quick search of YouTube will turn up numerous contributions by self-advocates who do not speak, but use technology remarkably well. A t-shirt that has become popular with many self-advocates sums up the message succinctly: "Not being able to speak is not the same as not having anything to say."⁶

Assistive and alternative communication can support or "back up" speech

Sometimes fears are expressed that introducing a child to assistive communication technology will discourage him or her from learning to speak. To the contrary, helping people to start communicating - by any means - appears to increase the likelihood of speech development. There are even instances in which adults who have never spoken began to do so after first establishing an alternative communication system. It appears that using any motor system in the service of language helps "wire" and prepare the brain to maximize language efficiency. Some people also may rely on assistive technology when they are too tired or overwhelmed to engage in spoken words. For them, having more than one communication option is very important. It serves as an essential "back up" when their speech system is down.

Learners may be gifted in different kinds of languages

There are many more languages than the ones represented by words and sentences. Music and art - in which many people with disabilities are highly talented -- are often called "universal languages." They too are systems that represent and relate concepts in the mind. Temple Grandin writes that she and many others with autism are talented in



⁶ Slogan from the Human Policy Press: <http://thechp.syr.edu/HumanPolicyPress>

understanding the language of animals; by reading their “body language” they are able to communicate with animals to a remarkable degree.⁷



Many people with developmental differences seek order and coherence in their worlds through mastering other systems of representation that are not usually thought of as languages, but are like languages in that they symbolically structure and relate aspects of the world, often with vast detail and precision. These systems may include road maps, train schedules, star charts, calendars, or any of the numerous symbolic structures that people with autism have used to organize and tame everyday experience. These systems are complex and demand great mental energy, focus, and motivation. Instead of discouraging such interests as perseverative or odd, we need to

appreciate their power as organizing systems. We need to honor them as manifestations of the very human motivation - the language motivation -- to “read” and make sense of our complex world.

⁷ Temple Grandin and Catherine Johnson (2006). *Animals in Translation: Using the Mysteries of Autism to Decode Animal Behavior*. Houghton Mifflin Harcourt.

III. WHAT IS SPEECH?

Speech: the communication or expression of thoughts in spoken words

~Merriam Webster Dictionary



It is not unusual to find a range of speech differences among any group of young children. Some will speak much sooner or later than others; some will be using huge vocabularies while others prefer action to words. Some will have difficulty hearing and pronouncing certain speech sounds, or will experience dysfluency (such as long pauses or a stutter). Some will think long and hard before they speak; others will tend to speak first and think later. All of these differences can apply to children with developmental disabilities as well; what distinguishes them is that their range of different speech challenges and adaptations can be especially wide.

Movement differences may underlie speech challenges

In recent years many child development researchers have turned their attention to the study of movement to explain differences in the ways children with various disability labels adapt and communicate. Anne Donnellan and Martha Leary draw our attention to "difficulties some people have in starting, stopping, combining, executing, continuing and switching movements."⁸ Movement differences involve variations in the type and amount of direct voluntary control that people have over parts of their bodies, as well as to the creative adaptations they make and the accommodations they need to get about and accomplish their goals.

Sometimes movement differences are present early in life, as when a child develops the motor or vocal tics associated with Tourette Syndrome.

⁸ Anne Donnellan and Martha Leary (1995). *Movement Difference and Diversity in Autism/Mental Retardation*. DRI Press, p. 35.

Sometimes they are due to losses or changes in the power of voluntary movement later in life, as with the onset of Parkinson's Disease. Some individuals experience an over-abundance of movement (called hyperkinesia, dyskinesia, or involuntary movement), while others experience difficulties in initiating or sustaining voluntary and automatic movements (called hypokinesia, bradykinesia, or akinesia) which are unrelated to motor weakness or muscle spasticity.

Movement differences mask competencies and can be misinterpreted as signifying cognitive or intellectual disability. As Donnellan and Leary explain,

A non-speaking person cannot show knowledge on an oral test. A person with delayed response cannot show actual ability on a timed test. A person with movement difficulty cannot perform adequately on a test requiring dexterity, handwriting, or typing. A person with any or all of these characteristics cannot be tested using conventional instruments.⁹

Movement differences don't reflect a lack of awareness or capacity; they reflect the different ways that different people's sensorimotor systems perceive and navigate the environment. A person's body may sometimes have "a mind of its own" over which their mind has very limited direct control. A person may find ingenious ways to "outsmart" such a body; such solutions need to be better understood and appreciated rather than devalued as self-stimulatory or odd.

Apraxia and aphasia can affect speech production

Some challenges to the fluent use of speech are in the muscles themselves, while others are in the larger system of motor planning by which we sequence and carry out multi-step actions. Still others are in the brain systems that retrieve the connections we need when we need them. An understanding of these challenges can help us to accommodate the difficulties that people may experience. It can also help us reassure everyone that these problems do not reflect a lack of intelligence or a lack of interest in communicating with and relating to others.

⁹ Anne Donnellan and Martha Leary (1995). *Movement Difference and Diversity in Autism/Mental Retardation*. DRI Press, p. 27.

Apraxia and aphasia are two relatively common movement difficulties that can affect a person's ability to speak or otherwise communicate when and how they want:

Apraxia (sometimes called "dyspraxia" when the form is mild) is a neurological condition characterized by loss of the ability to execute or carry out skilled movements and gestures, even when the person has the desire and the physical ability to perform them. Apraxia usually arises in the left hemisphere of the brain, and can have many different causes.

There are several kinds of apraxia that may influence speech in particular and communication in general. The most common is oral-facial apraxia, which results in an inability to carry out facial movements on command (e.g. licking lips, whistling, coughing, or winking). When there is difficulty coordinating the very complex and finely-tuned system of human mouth, lips, tongue, throat, and breathing that produces speech, the person is said to have verbal apraxia.

Other types of apraxia can also affect the ability to communicate with ease. For example, they can impact the ability to perform the fine, precise movements of the arm needed for printing, writing, or for using certain communication devices. Other forms of apraxia affect the ability to make the proper movements in response to a verbal command; the ability to coordinate activities that require multiple, sequential movements; and the ability to copy, draw, or construct simple forms. All of these challenges can get in the way of particular communication methods and systems.

Aphasia is a language condition that sometimes accompanies apraxia. Unlike apraxia, it creates problems with language comprehension as well as expression. Aphasia is generally diagnosed on the basis of a reduced comprehension and use of speech due to difficulty in recognizing and using the names of things. It may be limited to certain categories of words, or it may be more global in its effects. Aphasia also makes it difficult to read and write. However, it is important to know that aphasia may affect language only, leaving thinking and generalized intelligence unimpaired. A person who develops aphasia suddenly, perhaps after an injury or stroke, may feel like he or she has been transported to a foreign country and asked to learn a new language. Children who grow up with aphasia may use their

intellect and their senses to investigate the world in many meaningful ways, yet continue to struggle with language-based tasks.

Speech can be inhibited by proprioceptive and vestibular challenges

We are all familiar with the five senses of vision, hearing, smell, touch, and taste. Nowadays we recognize that people with sensorimotor differences can receive too much or too little input through these sensory channels. However, there are two more sensory channels that are often overlooked, but are turning out to be very important: the proprioceptive and vestibular systems.

Proprioception refers to body awareness and the feedback we need to maintain it. The proprioceptive system tells us where our body parts are in space and in relation to each other, so that we can plan and carry out effective, coordinated movements. One common experience that can help us understand proprioception occurs when we get Novocain for dental work. Without feedback from that area of our face, we feel very strange. That part of our body may seem to be many times larger than it is; we keep touching our face to reassure ourselves that we are okay. While this sensation wears off soon, it can leave us with some sense of what proprioception entails. Many people with developmental differences report proprioceptive processing that is unreliable; some tell us that at times their body seems to "go away."

Vestibular processing refers to the ability to adjust and maintain balance and posture, and to manage neck, head, and eye movements. Many people with disabilities report feelings of instability and lack of balance due to lack of accurate vestibular feedback. Using stairs, or even maintaining certain kinds of sitting postures, can be very difficult. The visual field in particular may seem unstable and the movement of people and objects in the environment may be hard to track. The vestibular system, centered on the inner ear, can malfunction in ways that make it difficult to unite looking and listening into one seamless perception.

An inefficient system of body awareness and feedback can have a major impact on the ability to speak. So can problems in processing sound, especially in conjunction with difficulties in using the head, neck, and eyes for effective visual tracking movements, such as following a line of print

across a page. Some people may benefit from various therapeutic systems of sensory stimulation and integration that enhance bodily feedback. They may also benefit greatly from *accommodations*, which involve changing the way a task or activity is set up and carried out to minimize the impact of sensorimotor difficulties. For example, receiving a gentle touch while using a keyboard may help a typist obtain much-needed proprioceptive feedback, or using a reading device which blocks out text above and below the line being read may help prevent a person's gaze from making confusing jumps among lines. The kinds of accommodations that can be created are limitless; the key is to individualize by working *with and not on* the person for whom they are being created.

Speech can be influenced by setting and physical state

Stories are sometimes told of children with developmental differences who seldom speak at all, only to occasionally surprise their families with a fully-formed sentence. These speech occasions are usually times of high emotion, such as a sudden emergency. This leads to an interesting insight: many "occasional speakers" seem to maximize their ability to speak when their senses and motivation reach an optimal state of arousal. There is something about those moments that is highly organizing to the brain and nervous system, even if only temporarily. Of course, it is never a good idea to deliberately stress or distress anyone in the hope of setting the stage for speech - in fact, that is likely to increase problems by raising anxiety. But experts suggest that speech can be encouraged through the use of natural, desirable, highly-motivating situations. A person is more likely to be able to access speech when he or she is deeply interested in what is occurring, and when it is chosen by and meaningful to that individual.

Music can be a route to communication, language, and speech

Many parents have noticed that singing to a child, or speaking in a sing-song voice, can promote language comprehension. Children with developmental differences typically have no impairment in their musical appreciation, and can use music to build a bridge to areas of experience they might not otherwise access. For example, if children do not pick up nuances in facial expression such as distinguishing between a happy and sad face, they are still likely to pick up emotional nuances in music and to distinguish happy from sad music. Studies have found that some individuals may exhibit a high level of preference for music and show little deficit in processing musical

components even when they have processing difficulties in non-musical areas. Recent research has determined that the interpretation and appreciation of music is highly diffused across brain areas, which may help account for the ways that music seems to bypass specific and localized processing problems.

It is also well known that people who speak with a dysfluency or stutter may be free of it while singing. Occupational therapists sometimes use musical rhythms to help a person initiate and sustain speech. A strong, regular beat may give a speech interaction the structure it needs -- one which the person's motor system has difficulty providing on its own. Some people may find it easier to initiate singing than speaking, and may enjoy increased attention, motivation, and emotional engagement during music activities. Last but not least, many individuals have a highly accurate memory for song lyrics and may try to use them to let others know what is on their minds. Paying close attention to the music and lyrics that a person wants to hear can be very enlightening.

Picture systems can be effective, but need not be "the last word"

Many people with developmental differences acquire their first formal communication system by using picture boards and picture cards. These can be a simple and effective way for people to make their wants and needs known. As these systems become more developed, "icons" - which are more abstract and symbolic representations of broader concepts - are often introduced. Many people with autism become very proficient in the use of these systems, and rely on them to express a wide array of thoughts. However, other learners reach a "glass ceiling" beyond which they cannot move because expressing more complex ideas involves the organization of too many pictures. Some people find that the motor planning skills involved in using picture systems are very challenging, especially when they are tired or in a high emotional state.

Just because a person does not use, or has had limited success with, picture systems does not mean that he or she will not be able to use a standard letter-based system. Use of pictures to communicate should not be made a prerequisite to the use of words. Some people who become frustrated by picture boards and picture cards do well with the letters of the alphabet

and happily learn to arrange them into words. Trying picture systems can be useful, but accessing nonpictorial systems should always remain an option. Unfortunately, those who select communication systems often do so with a hierarchy in mind: people with no speech are offered simple "yes/no" systems, those with a few spoken words are given sight word cards and basic signs, while those with speech dysfluencies may be given computer-based speech generation equipment. If the person succeeds, it is too often assumed that they have reached the limits of their communication abilities; if they fail, it may be suggested that they should be demoted to a more limited, more generalized system.¹⁰ With our improved knowledge of sensorimotor differences, we can see why this method of matching the *most challenging* physical symptoms with the *least precise and expressive* communication systems does not make good sense. It is important to experiment with all options for each individual communicator.

Interpreting unusual speech calls for awareness and sensitivity

What about those children and adults who speak, but the meaning of their speech is not clear to families and friends? There is no one simple answer, but a variety of possibilities to consider:

- Echolalia, sometimes called "scripting" – the repetition of whole "chunks" of speech that a child has heard – is often a concern, and sometimes behavior plans are written to halt it. However, typically developing children also repeat or echo on their road to independent speech. Some language experts have pointed out that children with developmental differences may memorize and use complex language structures before figuring out how to break them down into their simpler components, reversing the typical process of language development.¹¹ While the typically-developing child is building up from "Cookie, Mommy!" to a more complex argument about why they deserve one, the child who is developing differently may need to build

¹⁰ Chris Borthwick and Rosemary Crossley (1999). Language and Retardation. *Psychology* (an online refereed journal sponsored by the American Psychological Association: 10(038), # 16. Available at: <http://www.cogsci.ecs.soton.ac.uk/cgi/psyc/newpsy?article=10.038&submit=View+Article>

¹¹ Michelle Dawson, Laurent Mottron, and Morton Ann Gernsbacher (2008). Learning in Autism. In J. H. Byrne (Series Ed.) & H. Roediger (Vol. Ed.), *Learning and memory: A comprehensive reference: Cognitive psychology*. New York: Elsevier. Online at: http://psych.wisc.edu/lang/pdf/Dawson_AutisticLearning.pdf, p. 11

down from a snack request expressed as "Bert and Ernie would like everyone at their big birthday party to enjoy a delicious cookie" to something much simpler. But both children are using language to ask for a cookie.

- When a person uses memorized words and phrases, it is important to avoid jumping to the conclusion that these have no meaning or are "just self-stimulatory." Often a little detective work will reveal a very appropriate message or comment. One mother recounts that her child, who had very little independent speech, was playing nearby while she discussed with her friend the challenges of parenting a child with a disability. Finally he came over and assertively broke into her conversation to recite Kermit the Frog's famous observation, "It's not easy being green!" Was his surprising use of speech on this occasion an attempt to remind his Mom that she wasn't the only one facing challenges and trying hard? She assumed so, and resolved to be more aware of his feelings and of her words when he was nearby.

- Sometimes, however, speech may not have meaning for the speaker. It may be unwanted and unintended, what medical science calls a "vocal tic." A good example of this is the words sometimes spoken by Sue Rubin, a young adult with autism who uses a keyboard to communicate. Sue is a bright, college-educated person who frequently advises those around her to ignore the unrelated and repetitive words she calls out and concentrate instead on what she is typing. It can be very instructive to view Sue's award-winning video, "Autism is a World," which aired on CNN in 2004, and consider what she has to tell us about her complex relationship to language and speech. The last thing we want to do is interfere with a developmental process that represents a step on the way to more fluent speech. Nor do we want to draw attention to, and risk intensifying, speech that is tic-like in origin. Even if it is not meaningful, and the person readily agrees that it is not meaningful, noticing it or targeting it for "extinction" may produce the opposite effect. Vocal tics, like motor tics, tend to increase in number and strength as anxiety increases, and there is no surer way to increase anxiety than to insist that someone get rid of a behavior that is not under their direct control.

Creative accommodations can support language use

Many people with disabilities have used writing, typing, signing, gesturing, or the use of other assistive and augmentative communication strategies and

devices to demonstrate their knowledge of language. However, low muscle tone, muscle weakness, and motor planning problems can sometimes affect a person's ability to do so successfully. While sign language can be a useful tool for some children, others seem to have difficulty configuring their hands and lower arms and carrying out the motor sequences involved in producing signs as well as typical communicative gestures. It is typical of some disabilities, including autism, that the person will experience better gross motor skills (meaning strength and agility of those parts of the arms and legs that are near their trunk) than fine motor skills (the ability to control movements farther from the trunk, e.g. elbow to hand to finger). Writing may be laborious and frustrating; in some cases, even marking off "yes" or "no" on a test may be extremely challenging or impossible.

As with difficulty making speech sounds, difficulty in writing words can be mistakenly interpreted as evidence that a child does not understand language. Insightful parents and professionals have found many individualized strategies to overcome this obstacle. For example, one mother taped large sheets of paper to the walls and used them to write out the questions she wanted her young son to answer. Under each question, in large print, she gave him a choice of two or three possible answers. Her inspiration was to make use of her son's gross motor ability so that, by simply moving his arm from the shoulder, he could mark his choice of answer. By using this method, language skills that had previously been untapped were revealed and his literacy and communication abilities finally began to flourish.¹² Knowing a person well, and using the skills of patience and observation, can lead to a surprising variety of creative solutions.

¹² Morton Ann Gernsbacher (2004). Language is More Than Speech: A Case Study. *Journal of Developmental and Learning Disorders*, Vol. 8, pp. 81-98. Online at: http://psych.wisc.edu/lang/pdf/gernsbacher_case_study.pdf

IV. WHAT IS LITERACY?

Literacy: the state or quality of: being educated, cultured; being able to read and write; being versed in literature or creative writing; having knowledge or competence, as "computer-literate" or "politically literate"

Merriam Webster Dictionary

At this point, we've considered many reasons why people with developmental differences might not test well by conventional methods. There's nothing wrong with being unconventional! The methods and the expectations, not the person, need to change. Standard types of tests, including IQ testing, only tell you the *least* a person can do - often under very adverse conditions. They can never tell you the *most* a person can do. They show you the floor but not the ceiling. As Anne Donnellan and Martha Leary put it:

Let us have the humility to say how little we know and the courage to be wrong as we begin to ask better questions.¹³

With literacy too we need to ask much better questions and hold higher expectations, starting with the presumption that everyone can have access and can respond meaningfully to literacy experiences.

Literacy skills need careful observation and cultivation

We now know that many of the typical ways teachers probe and assess literacy skills don't work well for students who are developing differently. For example, a teacher may point to letters and ask students to supply the sound. One particular child may not be able to make the sound at all, or be unable to make it on demand each time the teacher asks. The teacher may not know that the child requires extra time to process and answer the question. Perhaps this exercise will work better in reverse: if the teacher makes the sound, and the student is given plenty of time to indicate a picture of the correct letter. It is very important to explore many different ways of approaching and examining literacy skills, and never to

¹³ Anne Donnellan and Martha Leary (1995), *Movement Difference and Diversity in Autism/Mental Retardation*. DRI Press, p. 92.

assume that an autism diagnosis or IQ number makes the acquisition of reading and writing unlikely. It is also very important not to make specific "pre-literacy" tasks like producing letter sounds a prerequisite for participating in and enjoying everyday literacy activities!

It is often said that we live in a "language-rich environment." With endless episodes of Sesame Street, readily available computers, the Internet, a huge and ever-growing children's book industry, more magazines and newspapers than most families can keep up with, omnipresent electronic games, texting, email, tweets, slogans on t-shirts, labels and directions on products, and signs and advertising everywhere, children swim in a sea of letters and words every day. Is it any wonder that many of them start to figure it all out even before the adults know that they have?

Here again, good detective skills are the key to exploring what a person can really do. It is important to read to children often, modeling the pleasure of sharing stories as we observe a child's responses. Does the child look at the book as we read? Does he or she sometimes follow the correct line with a finger? Turn the page at the right time? React if we miss a word or line? Does the child like to page through books and magazines? Pick out books he or she wants at the library? Explore children's Internet sites? Identify and record favorite TV shows? Use menus, maps, and schedules? Watching a child navigate in these language-rich environments may suggest a level of capacity and awareness that does not show up on standardized testing, and give us ideas about how to support the child's growth in literacy skills and experiences.

Literacy is a shared experience

Literacy is about much more than "reading and writing." It is about the shared experiences that precede, grow beyond, and can flourish independently of those specific skills. As the dictionary definition says, literacy is about being educated and cultured, having knowledge and competence. It involves us in the types of interactions that Anne Donnellan, David Hill, and Martha Leary identify as central to learning:

Learning happens within a social context, within a dialogue with others. We acquire cognitive skills, knowledge and *behavior regulation*, not simply through memorization of facts or actions, but through our

interactions in the social world where this knowledge has function and meaning.¹⁴

Students can be included in typical, age-appropriate literacy experiences in their schools and homes in many ways: they can make choices and selections, enjoy listening, respond with applause or laughter, act out or perform exciting episodes, dress up like a favorite character, create music or art in response to the topic, cook and taste the foods mentioned in a story, visit historical sites related to the time period, explore the culture in which the events take place, and much more. All of these methods are well known to teachers as ways to motivate and engage non-readers. There is no reason to leave out students of any age, with any type of learning differences, who can benefit from the many types of literacy experiences.

Paula Kluth, in her classic "You're Going to Love This Kid!", objects strenuously to the way students with developmental disabilities such as autism tend to be left out of certain classroom activities:

Although students with autism are increasingly being educated in general education classrooms, they are often excluded from rich and meaningful literacy experiences such as reading and writing stories, joining book clubs, acting and performing, journaling, and participating in whole-class and small-group discussions.¹⁵

She suggests that teachers must abandon the readiness model, or "literacy ladder," which has kept many students stuck on a bottom rung of isolated and uninteresting tasks (e.g. letter-sound production, sight words, vocabulary memorization), and "reject the notion that literacy skills develop in a linear fashion."¹⁶ Instead of withholding literacy activities until "prerequisites" are mastered, teachers can broaden their understanding of literacy to fully include all students in accessing stories, subjects, and themes that are creative, engaging, and age-appropriate.¹⁷

¹⁴ Anne Donnellan, David Hill, and Martha Leary (2009). *Rethinking Autism: Implications of Sensory Movement Differences*. Disability Studies Quarterly (in press). Available online.

¹⁵ Paula Kluth (2003). *You're Going to Love this Kid! Teaching students with autism in the inclusive classroom*. Paul H. Brookes Publishing Company, p. 136.

¹⁶ Ibid., p. 138.

¹⁷ Paula Kluth and Kelly Chandler-Olcott (2007). *A Land We Can Share: Teaching literacy to students with autism*. Paul H. Brookes Publishing Company.

Access to literacy gives access to shared meanings

Every culture and every period in history involves shared stories that give meaning to events. Calling someone a Romeo, a Robin Hood, or a Rosa Parks is a way of using our access to literature, legends, and history to make sense of our own lives and times. Every stage of life is also illuminated by shared stories. For example, the second-grader who is introduced to books with surprise endings is able to explore the developmentally appropriate idea that it's fun and okay for things to turn out differently than expected. And adolescents who feel inconsolable over lack of popularity, siblings who tease, and parents who "just don't understand" can find solace and perspective in novels carefully selected by middle school teachers for just that purpose. For students to miss out on these shared literacy experiences because they are presumed "not ready" or "not able" is to close the door on culturally vital and age-appropriate information and awareness. It is to remove those students from the common ground they need and deserve to share with their peers. Access to literacy - and to all the many ways of experiencing and responding to it -- should be considered a birthright for everyone.

A few last words...

Communication, language, speech, and literacy have turned out to be broader, more various, and more accessible than many people think. Children and adults, with disabilities and without, are always communicating, all the time. Receptive language may come to some individuals far more easily than expressive language. Many people are skillful in other kinds of organized communication systems, such as the languages of music, of art, or of animals. More and better pathways to supporting speech development are opening up as we learn more about the sensorimotor challenges that may arise; we are also learning that people can speak out eloquently using instruments other than their vocal cords. And literacy turns out to be not only more widespread than we probably assumed, but accessible to all in the form of shared experiences and shared meanings. People with disabilities are taking the lead in helping all of us to redefine terms and expectations that were once too narrow, and to appreciate that "neurodiversity" can enrich our schools, our communities, and our lives.

Pat Amos

March 2009; updated October 2015, April 2016

©Youth Advocate Programs, Inc., Harrisburg, PA

