

Amber Communicates – Just Listen

Introduction Communication occurs in many different ways and includes: the use of spoken language, gestures, eye contact, facial expressions, body movements, patterns of behavior, manual signs, vocalization, in writing or typing, pointing to items and pictures, and natural, synthesized, or digitized speech.

ODP supports the right of all persons with communication challenges to receive needed supports and services so that they can effectively and more fully communicate.

The Office of Developmental Programs (ODP) is proud to share the story, “Amber Communicates – Just Listen”. Amber’s story focuses on the communication journey taken by Amber and those who love her. As you’ll experience in the story, communication is an essential part of an “Everyday Life”. Effective communication is the key to leading self-determined lives, being part of communities, being healthy and safe, and having healthy relationships.

Amber’s story illustrates the importance of communication. **Here is *Amber Communicates – Just Listen*.**

Amber doesn’t say much, at least in strings of words that most people would understand. “She likes to think she is speaking in sentences, but,” says her mom, Debbie, “we have to use alternate modes of communication and she is quite cooperative.”

Amber is 24 years old. She was born three months prematurely following her mother’s difficult pregnancy. The infant spent four months in the neonatal center and her weight dipped as low as one pound. “I could hold her in the palm of my hand.” Amber survived seizures, brain bleeds, heart problems, and there were several episodes where medical personnel “bagged” Amber to restore her breathing.



Debbie visited her baby every day at the hospital. She talked to Amber, read to her, and played classical music for her. Every Tuesday, Amber underwent scans which revealed ever-more injuries to her brain. Debbie began to think of brain scan days as, “dreaded Tuesdays.” When Amber’s parents were allowed to take her home, she was four months old and diagnosed with cerebral palsy. Her parents were told that it was likely that Amber would never walk independently. “That’s all I was told, which was probably good.”

“I started reading books on the brain. A baby’s brain is like a sponge. Even when it is injured, it can take in information and language. I began a quest of beating cerebral palsy. I became obsessed. I was determined that Amber was going to walk, feed herself, and talk. I learned everything I could from books and magazines. I would have been really dangerous if the Internet was available then!”

“I did her therapies, and learned to use adaptive equipment. I tried to stimulate crawling – moving Amber’s arms and legs to mimic the motion. I tried to teach her to feed herself.”

Acceptance

Eventually, Debbie realized Amber would never have the coordination to crawl. Over the years, she came to understand that, “Amber knows what needs to be done, but the harder she tries to do something independently, the harder it becomes because of the spasticity.”

Instead, she decided, “We are going to adapt, adapt, adapt her world. Amber will do it her way. Her success will be doing it hand over hand.” (With another’s hand assisting Amber’s hand) “I think in some ways, Amber was relieved. She is very happy, and has a wonderful attitude.”

Amber may have accepted her complete physical dependency before her mother did. Because of her tiny size while in preschool, the other children treated Amber like a living doll. “She learned that when the kids helped her, it made life easier.”



At three years old, she also demonstrated some of the feistiness that allowed her to survive infancy. “No more!” she scolded the psychologist who asked the same question after Amber correctly answered it the first three times.

“Amber is strong in her receptive language skills – taking things in. I taught her to read. I wrote words on big cards with huge letters. She could pick out words, like Amber and mom, but we couldn’t expand on that once we realized she has vision problems. But it told me that Amber is capable of learning anything.”

Bucking the System

Amber had proven over and over again that she is very bright. So at an annual IEP meeting with her teachers, Debbie was frustrated that her daughter continued to receive zeroes on her IEP goals. Amber was required to press a switch to select the correct answer when it was spoken to her and she failed to do so. “Did you see her try to connect at the appropriate times?” Debbie asked the teacher. “Yes,” was the response. Well, Debbie explained, the attempts were Amber’s answers. Her motions demonstrated

she knew the correct answers but was prevented from completing the connection because of her muscle spasticity. Debbie made her point and Amber's attempts were recognized as correct.

There were other times when Debbie has had to buck the system. At three years, Amber still couldn't hold her head up without support, effectively forcing her to watch the world at a tilt, so Debbie inquired about using a cervical collar. No, the experts told her, she'll become dependent. For awhile, Debbie toed the line, but eventually decided, "She needs to see life." She purchased the collar, put it on her daughter so she could view the world the way most people do. Today, Amber only needs the cervical collar when horseback riding.

Amber has no physical independence and requires 24-hour care. During the week, she lives in a group home. "Her roommate is a year older than Amber. Even though neither of them speaks with words, there is a secret communication that goes on. I've walked in on them and both were giggling and laughing."

Essential Lifestyle Plan

Thanks to the Essential Lifestyle Plan Debbie prepared, her daughter lives her everyday life at the home based on Amber's likes, dislikes, and activities she enjoys. The 25-page Plan helps the staff understand details of Amber's life, her habits, her family and friends, things that are important to her and not important to her. It is a vital tool in developing mutual communication. "If I am not with Amber to interpret her body language and vocalization, someone could read her Essential Lifestyle Plan and respond to her wants and needs."

Alternate Communication

Amber uses an electronic device, the DynaVox, to aid in her communication because her speech is unreliable. ("One day it is clear, the next day — complete garble," says Debbie.) Whisper Wolf was the first device she tried twenty years ago. "It was hi-tech at the time and had a robotic voice. It was an auditory listing of many things for her to say, but she had to get the right physical timing. When she got to the right place, she'd activate the device to repeat the message she heard." Debbie remembers Amber choosing the message, "I'm hungry." "Yes," Debbie responded, "I'm getting your breakfast." Amber would have the Whisper Wolf repeat the message over and over. "I just wanted her to talk but the robotic voice was driving me insane!" Still, it showed Debbie that her daughter had a strong desire to communicate.



In addition to electronic devices, Amber has several ways to communicate without speaking. Like most children, she learned that facial expressions could convey a world of meaning and now an adult, she continues to put them to use in her daily life. Amber smiles for yes, frowns for no, and pouts when she is

dissatisfied. Debbie's favorite? "Amber has this expression. I call it her, 'What you talkin' about, Willis,' face," says Debbie, referencing the phrase actor Gary Coleman made famous on *Different Strokes*. The Willis face means a sassy, "Yea, right," or "You've got to be kidding."

Actions, too, get the message across. While still a baby, Amber showed she liked her food or wanted more by smacking her lips. That evolved into the action she still uses. "Amber smacks her lips if there is a conversation taking place regarding food and it is about something she likes . . . when we talk about pizza, as an example." She also does it to let you know she is thirsty. On the other hand, says Debbie, "She hates vegetables. You mention broccoli or green beans and she will wrinkle up her nose and gag."

"When she was very young, I would put her hand up to her mouth and say, 'Blow grandma kisses.'" Now blowing kisses has become an Amber mainstay. "She uses it to say I love you, just to be cute and get attention, and sometimes to say thank you."

A man complimented Amber on the jewelry she wore one day and she blew him a kiss. Her gesture affected him deeply. As a father of a daughter with developmental disabilities, he confided that Amber's simple action became an inspiration to him. "I've been so depressed ever since we've learned of my daughter's disabilities," he told Debbie. "But I realize that I've been looking at the glass half-empty. We need to really focus on ways my daughter can communicate."

Amber made an impact at a fundraiser in 2010 when she and her mother were presenters on the topic of Amber's everyday life. While photos were projected on a screen behind them, Amber spoke by activating her DynaVox communicator which had been programmed earlier with a speech she and her mother had discussed and prepared. Throughout the speech, Amber vocalized the word, "Okay," emphatically agreeing with the recording. It was obvious by the standing ovation she received that the listeners were deeply affected.



Amber also got her point across when she and Debbie spoke at a legislative breakfast in 2009. The topic was waiver funding and the goal was to educate legislators on the importance of waivers. After an introduction from Debbie, her daughter, using the DynaVox explained how waivers allowed her the support to live in her community and help pay for staff so that she can have an everyday life.

Learning to Listen

Communication is a two-way street – a message has to be both sent and received in order to be effective. Amber works hard to send messages; receiving Amber's messages requires that Debbie really pay attention. In the process she has developed listening skills and is happy to share these. "It doesn't take a rocket scientist. You just need to be in tune."

“You have to pay attention to every little thing,” Although control of her body is rare, Amber takes advantage of what she can control – in particular her eyes. Recently, at bed time, her caregiver asked whether she wanted to change into pajamas or a nightgown and displayed both, one in each hand. Amber directed her eyes toward the nightgown, exercising her power of choice.

“Assume everything means something.” To a casual observer, Amber might seem to be zoned out when she fixes a steady gaze on the hallway. But her caregivers understand that is Amber’s non-verbal way of telling them she wants to leave her room.

“Dissect what they are doing.” There are a very few words or phrases that Amber can often form. Okay, all gone, ice cream, and good girl, are some, most of them learned as a child and years of practice have made them somewhat easier to produce. And then there is the word Auga. Auga is the name she gave to a Precious Moments collector’s doll given to her years ago that occupies a special place on Amber’s bed. “At first, it didn’t register with me that she was connecting the word, Auga with the doll. Then one day, it clicked.”

Amber brought Debbie along on the next step to understanding. While in the living room one evening, Amber said, “Auga.” “Do you want me to get Auga?” Debbie asked and then suddenly, had an Ah-ha moment: She realized that Amber always asked for Auga when she was tired. She didn’t want the doll brought to her; rather, she wanted to be brought to the doll. “Auga” was Amber’s shorthand for ‘I’m tired and want to go to bed.’ To this day, her daughter retains that verbal shortcut and her caretakers understand that “Auga” means time for bed.

“Don’t just consider something random behavior, trust your gut instinct.” Debbie advises parents of children with disabilities to, “Follow your intuition. Tune into what is happening to your children’s emotions – if their personality is changing. Understand that behavior as a form of communication. If something doesn’t feel right, it probably isn’t.” For instance, typically Amber is a happy person, but like some women, hormonal changes affect her mood. Debbie and her family, as well as Amber’s other caretakers, have learned to tell the difference between Ambers sounds of monthly discomfort, discontent, agitation, fear, and physical pain.

“Help professionals help your loved one.” Debbie understands that the staff who work with Amber want to successfully communicate with her. “I’m not the only one who has learned to listen to Amber’s nonverbal cues. I have found that the professionals around her appreciate all the information they can get. They’ve read her Essential Life Style Plan and do a great job paying attention to all the details.” She credits their work for how well Amber has adapted into the greater community.

“Use respectful guessing.” The strongest part of Amber’s enunciation is at a word’s end. “It would be much easier if you got the beginning of the word,” admits Debbie. Nonetheless, the listener can make guesses as to what Amber is trying to say using context and watching her reaction.

“There’s so much we don’t know if she knows,” notes Debbie. “Does she understand danger? Does she understand money? We were never able to figure out a good way to tell because the cerebral palsy is so involved.

“For instance, it’s fine that she can identify exit signs, but she can’t get to the exit herself. She understands, but there is absolutely nothing she can do without intervention. All we can do is expose her to experience and knowledge. I think she understands everything, but I didn’t always know. I just gave her the respect and treated her as if she did.”

Debbie wasn’t sure Amber understood the concept of death and what it means to lose a loved one. When a relative passed away, “I took Amber to the funeral home. She was very close to my great Aunt Ginge who called Amber her ‘little darling.’ I explained that she had gone to live with Jesus but that she was still with her. I took her to Aunt Ginge’s casket, and Amber looked at her and said, ‘All gone.’

“That tugs at me in a very powerful, positive way. She gets it like the rest of us do. I don’t question her anymore.”

Amber's Everyday Living

Thanks to the Essential Lifestyle Plan, shared with all her caregivers, Amber can lead her everyday life whether or not her parents are available to help her communicate.



1. Amber takes horseback riding lessons, a recreational activity that also helps develop her balance.



2. Enjoying a sail on Lake Erie with a volunteer during the MOVE Community Day Program



3. Amber volunteers at the Erie Veterans Hospital, working hand over hand doing office tasks



4. Bowling in a League