



How to Speak Up When You Have No Voice

*(This post is the second in a series featuring Indianapolis' **Outside the Box**, a nonprofit designed to empower individuals with intellectual and developmental disabilities. To read the first installment, visit <http://bit.ly/1Z015VX>. While in this article I refer to people as "verbal" or "nonverbal," I use these labels to simply make a point in a way you might better understand. I want to illustrate that not all people communicate the same way. The names of all participants in this post have been changed.)*

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An unstoppable beautiful spirit describes Jason, one of my new "verbal" friends at Outside the Box. When I see Jason he asks, *How ya doing Gerry?* and quickly adds, *How was your weekend? What'd you do last night? Did you like the Star Wars movie?* He repeats my answers.

I ask him, "How are you today, Jason?" (*How am I today? I'm fine, I'm fine.*) Did you sleep well last night? (*Did I sleep well last night? Yes, yes I did sleep well last night.*) Could you eat a dozen pancakes right now? (*Could I eat a dozen pancakes right now? Yes, yes I could eat a dozen pancakes right now. How about you?*)

This is how we communicate.

For the past two months, I have been weaving in and out of OTB's 18 adult group rooms listening and learning. I've spent large blocks of time with a wide range of participants (ages 18 to 80) who call OTB home through the workweek. Because of the challenges of communicating with some in this group, many outside of OTB would throw up their hands, turn their backs, and flee. But not OTB's 52 full-time and nine part-time workers.



After visiting groups with intellectual and developmental disabilities, such as Down syndrome, Autism Spectrum Disorder and cerebral palsy, I've often wondered how staff members cope with the emotional challenges they face five days a week.

So as I began my third month of observation I asked:

- How do you communicate with nonverbal participants?
- How do you know they understand you?

I can look at OTB's Zeppelins Group and bunch them together as mostly *Style 1* (an OTB term meaning "nonverbal to minimally verbal individuals"). But even that

definition is inaccurate and politically incorrect. And it's something OTB's Co-Founder Kelly Hartman quickly pointed out. "Saying someone is *verbal* is simply saying that person uses intelligible words with thoughtful sentence structure in what many of us think of as daily communication. *Nonverbal* indicates that the individual does not use traditional verbalizations to share how he or she is thinking or feeling. At Outside the Box we're very intentional not to label people."

Because at OTB, each adult has unique needs that require specific, individualized attention – and each one receives it.

So now when I walk into the Zeppelins or Grasshoppers or Dolphins Group rooms, I try to awaken my sense of respect for the participants who have the difficult task of communicating with me, a novice at listening carefully to those who cannot speak. I assume it must be frustrating for them. And I'm reminded: **Just because some participants are nonverbal doesn't mean they don't communicate. It is me who can't communicate effectively.**

"We're not giving up on helping them."

One OTB participant uses a digital tablet to communicate. The day I visited, Glen pressed the square icon that spoke the phrase: *I want to wear a dress*. A dozen times. He had other options on his tablet: shorts, pants, shirt. Socks, underwear, hat. Mitten, shoes, coat. However, he chose: *I want to wear a dress*. I looked at his facilitator and shrugged. "Glen's got jokes," the facilitator told me.



Another participant said only one word, but said it appropriately and repeatedly while being pushed down the hall in his wheelchair at checkout: “Bye-bye-bye-bye-bye-bye-bye...” (17 times). I noticed those around him from other classrooms joined in the cadence: *Bye-bye-bye-bye-bye-bye-bye...*

Another nonverbal participant offered a high five or a hand to tap every time I saw her. She giggled then she pointed back and forth between her friend and me, indicating that she is a friend to both.

Some participants have never spoken a syllable recognizable to most of the world outside of OTB's doors. That doesn't dissuade their facilitators, who, in the absence of words, look for the smallest detail to indicate understanding. It's the batting of an eyelash. A twitch of a lip. A jerk of a single finger. **Maybe the answer is in a vacant stare.** Vacant maybe to you and me...but not to OTB's trained staff. Sometimes a vacant stare is enough for them.

Anjala Dick, facilitator of the Grasshoppers Group, works each day with six nonverbal participants. Everyone in this group is prone to seizures, and one individual is deaf.

“I like it that we're a small, nonverbal group – it makes us learn how to communicate differently,” Dick said. Just then, she joins the song playing on her laptop: *If you're happy and you know it clap your hands...* And one individual claps.

Group participant Claire used to speak words, but she doesn't use them anymore. She will touch. If she wants more water, she'll carry her cup around until she gets more water. Claire used to live in Spain and learned Spanish in six months. She doesn't speak Spanish now, but she understands what is being said.

***Of all human communication
60 percent is nonverbal body language and
30 percent is tone. That means 90 percent of
what you're saying isn't the actual words.***

Lila, another participant, comprehends words, but she doesn't talk. "Lila's smart as a whip and she smiles a lot," Dick said. "Earlier when she wanted to listen to *Barney* music, she clapped. Sometimes she'll touch. She lets us know whether or not she likes something. If she's had a bad day, if she's not feeling well, she'll yell. That's one way we work together to communicate. When I first joined this group, I used to take Lila's hand and put it up to my throat, so she could feel what's going on when I talk. Today Lila communicates pretty well."

Robert, another Grasshopper, has spoken one word in his entire life: "Gump." He and his brother Larry, who is also part of this group, do not use sign language, but they do have their own form of communication. **Robert doesn't speak or point, but he will look at something to show he understands.**

Larry knows pictures. He's really good at it. And they both play a slow motion peek-a-boo from behind a blanket.

Dick uses a lot of American Sign Language in the Grasshoppers Group. Randy is hearing impaired and has taught some ASL to Dick. "When I worked in the Zeppelins Group, Brady created his own sign language," she said. "That was OK, because it was teaching Brady that he needed to use his own words."



I learned that when Brady is with his mom, he can speak a full sentence. But why?

"Different expectations," said Adam Reuss, the Zeppelins Group's facilitator. "**With some of the guys it's more of a preference than an ability not to communicate.** A lot

of times if the participant is nervous or doesn't know how to answer the question, he falls back on saying things he already knows," Reuss said.

Brady is big into the holidays. He's not going to say the word Christmas, but he will verbalize *Ho-ho-ho*. And Easter is coming, so he'll change it to *Hop-hop-hop*.

Where you and I might see desperation of a soul trapped within a non-cooperating body, OTB staffers see hope. Each day they arrive with visions of breakthroughs and milestones. **It's what makes them special – superstars** in this outsider's eyes.

The day I visited the Zeppelins I sat opposite Curtis at a table. Curtis tapped a plastic doughnut rapid-fire against the inside surface of a Frisbee. Then he rattled it around and around, circling the rim time and again. Usually, when he's done with whatever he's holding on to, he tosses it to the floor. It's not a behavior issue. Curtis is not throwing stuff to cause trouble. It's just his way of telling his facilitator he's done with it.

I also had to take this into consideration: Having someone unfamiliar enter their group and observe could be a pretty big change and potentially overwhelming for the participants. It could upset them and this could lead them to communicate differently. Others may call these "behavioral incidents" but I am learning that it is just a different message.

After 10 minutes, Curtis slid the Frisbee across the table to me. I glanced at Reuss, Curtis' facilitator, and he nodded for me to accept it. I did. I held it and looked at Curtis, unsure how he would react to me holding his possession. Anything could happen, and I wasn't prepared for any of it. After a moment, Curtis stood and walked around the table to where I sat. I became nervous. I drew in a deep breath and waited. **Curtis opened his arms and gave me a solid embrace.**

"This is how it feels to be believed in!"

In the Zeppelins Group, we sang nursery rhymes as if it were common to sing nursery rhymes to other adults. "Singing is something a lot of the guys really enjoy," said Reuss. "It's getting them used to words and what they mean. The songs are usually basic, with repetitive lyrics. We have individuals now who will sing along with us a little. They kind of know what comes next."

When one of the participants screamed or acted out, Clyde Shovan, Facilitator Assistant to the Zeppelins Group, said, “Use your words, because we don’t know what you mean when you holler. I’m right beside you. Use your words. Because we love you!” Then Shovan turned to me and said, “I never rush them. I always take my time.” During my visits to the Zeppelins Group, I noted that **Shovan said “I love you” many times.**

Taylor Perme, OTB Support Staff Specialist, said, “If you say *Brady, it’s time for lunch*, Parker will slap the chair next to him, because that’s where Brady sits. Except for a few words, Parker doesn’t talk, but he’s telling Brady it’s time for lunch. When talking to or about Travis, another participant, Brady points to where his bag goes. When Brady goes *Unnn*, and points to Travis’ bag, we’ll say, *Yes, Travis will get it when he leaves*. Brady wants to make sure his buddy will take his backpack with him.”

Luke will walk up and point to a drawer that contains his yarn; that lets his facilitator know he’s ready for it. He pulls on the yarn throughout the day. It calms him. If he wants to go for a walk, Luke will make his way toward the door and look back at the facilitator.



Reuss told me he always talks with the participants, even if he’s just narrating what they are doing. *I’m going to get up and go get our coats for the outing.* “We have a couple of our guys who might not understand that the word coat and the actual garment go together,” Reuss said. “But when I say *I’m going to grab our coats* and then I come back with their coats, we hope they will eventually start to make that connection. And it might take months.”

“It’s an art form getting to know individuals and learning how to communicate with our participants,” said Allie Shaw, Staff Support Specialist. “That’s why they come to OTB. **We have the patience, the interest and the yearning. We have those things that most don’t. We treat individuals with respect and we treat them like equals.**”

While the Zeppelins may have mobility limitations, as participants become more communicative and outgoing, OTB staff may move the participant, at least in a part-time capacity, to another group where he or she is able to become more involved in the community.

“*How do you know Dean understands you?* I asked Dolphins Group facilitator Candi Shepherd. “It’s time and trust,” she said. “You’ll pick up on things they’ll do when they’re frustrated – like hitting themselves or breaking something.”

Dolphins participant Dean uses a digital tablet, mostly to communicate his emotions at any particular time: happy, sad, mad, tired. “Sometimes I ask him, *What’s Dean look like today?* and sometimes he’ll point to a happy face,” Candi said. “But usually Dean picks sad. And I’m like, *Really? You look happy to me.* He smiles.”



In music therapy with the all-male Dolphins, the group forms a semicircle. The leader introduces tambourines, paddle drums, and a cabasa to engage the participants. *Everybody’s here so it’s time to say hello*, the instructor sings while playing an acoustic guitar. She stands before each participant and encourages him to participate.

Brady has joined the Dolphins Group for this activity because of his interest in music. **He stops bouncing on a large, inflatable therapy ball long enough to strum the guitar.**

Chris, in the same group, stands and pantomimes playing a keyboard while his requested song – *Phantom of the Opera* – plays through a tiny smartphone speaker.

Dean, who wants a turn, lifts both hands in the air. “That took a long time,” Candi said, in reference to Dean’s unlikely action.

When presented with a tablet, Dean folds it up. I didn’t realize it, but he was sliding into a 10-second seizure. Candi gently calms him.

David Martin, OTB’s Coordinator of Day Programming and Therapeutic Planning, said, “I am overjoyed that I get to work with such inspiring people, many of whom I have the honor of calling my friends! I love Outside The Box and the people who make it what it is, because without them it would just be a place. Instead, **it is a place where transformation of the heart and mind happen.**”

***“Just because I don’t talk doesn’t mean
I don’t have something to say.”***

At first I definitely wasn’t confident that everybody was getting what I was saying,” Perme said. “I always assume that they have receptive understanding. You’re doing them a disservice by not giving them information. Even if an individual doesn’t understand you, you’re treating him or her as an equal and as an adult by offering that. If you don’t take the time to get to know a person, you’re never going to understand what each person is trying to say.” This is called “presumed competence” a concept some strive for – at OTB it is ever present.

“If Terrance is vocalizing in an agitated way, and yawning and falling asleep, he’s probably not feeling well, because Terrance doesn’t fall asleep,” Perme said. “You and I can say, There’s no way I’m going to work today, but many of our participants can’t say that. Almost all of them come no matter what. **So we become the advocate for them**, to call their staff and say, *He’s been falling asleep all day. He’s agitated. We know he’s not feeling well.*”

I attended a bowling outing with the Zeppelins Group at Pinheads one day. I didn't know if the Zepps would be able to understand much of it (like who won or what their individual scores were), but the visual stimulation of being able to see the ball in the various colors, moving away from them on the beautifully polished lane, tapping the bumper rail and knocking a pin down was thrilling to watch.

“For someone with Autism Spectrum Disorder, going to a bowling alley or sitting in a busy coffee shop may upset them,” said Shaw. “Lights might flash. They might hear conversation from everyone. It can be a sensory overload. Most individuals can zone out the background noise and pay attention to the person they are talking to, but for someone with different abilities, that might be really tough, maybe intolerable.”

Stares and jeers never helped anyone.

The Style 1 groups have pictures of themselves on the wall, so the facilitator might say, *You're here, let's find the rest of your friends that are here.* Stephen points to Artie, because they used to be together in group. They started having Artie and Stephen time at the end of the day. They go out into the hallway and visit. They don't really talk to each other; they just sit together. And visit.

Katy Bird, OTB's Executive Director, said, “OTB is where – no matter who you are – you fit in, because it's a place where everybody fits in. That's a unique beautiful thing that OTB offers the world. I would love for everyone to be able to experience that feeling and that opportunity.

“We recognize that part of what's so special about what we do at OTB is not even so much about the service; it's about the environment that is created here,” Bird said.

“Individuals have this experience in high school – whether it be good or bad – and then they have the opportunity to create their own relationships and friendships and their own social opportunities. But if they didn't have the skill sets to do that, or the means to do that, wouldn't it be great if that existed somewhere?”

It does. At Outside the Box.

How you can help

For more information, contact OTB's Executive Director Katy Bird at kbird@otbonline.org. Or contact her at (317) 253-6658.

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