



CONVERSATION WITHOUT WORDS



We refer to some autistic children as 'non-verbal', yet this is a misleading label, implying that they are not sending us clear messages. In fact, children who don't use verbal language are often sending us many signals loud and clear, says Dr Barry Prizant, author of *Uniquely Human: A Different way of Seeing Autism*.

On a beautiful autumn morning, I entered a school in a small town in Massachusetts to do what I have done for three decades as a Speech Language Pathologist* and educational consultant.

This time, I was asked to observe James, a bright-eyed four-year-old child with red hair and rosy cheeks. Only a few months earlier, he had received a diagnosis of autism spectrum disorder following an evaluation at a hospital. James was beginning his third week in his inclusive pre-school programme, and my role as a consultant was to observe him for an hour in routine activities in school, and then meet with the school team and his parents to summarize my observations and provide recommendations.

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As I've experienced so many times before, this youngster was described as non-interactive and non-communicative with significant problem behaviours. Staff added that he sometimes blurted out short phrases that they could not decipher as meaningful, as they could not see any connection to the ongoing activities.

For example, when approached by an unfamiliar adult, he would cock his head to the side and say "Are you a good witch or a bad witch?" I was also told that he used people 'as tools' to get his needs met, by pulling their hands or pushing them to closets that contained his favourite play things such as Lego™ or musical toys. Staff noted with some frustration that he engaged in tantrums to get his way if he

did not wish to co-operate – screaming and sometimes dropping to the floor.

As I began to observe James in his classroom, it did not take very long for me to witness some of what staff had described. He pushed one of the classroom assistants to a tall cabinet and exclaimed twice with great excitement, "It's coming down the tracks!" His speech was barely intelligible.

The assistant looked at me quite perplexed, and I suggested that she opened the cupboard to see what he would look at or reach towards. James immediately shifted his gaze to a plastic box of miniature trains just out of his reach, pushing the assistant's hand towards the box while rapidly repeating "...down the tracks!"

After a few minutes of playtime, when James sat by himself lining up train cars on floor, his teacher helped all the children

stand in line as they prepared to go to a small gym in the school.

As we approached the gym door, I peered through the small glass window and noticed it was filled with mats, climbing equipment and very active, noisy children. As the teacher opened the gym door, a cacophony of sound filled the air, and James immediately dropped to the floor, rolling, grimacing and covering his ears.

With arms flailing and legs kicking, he resisted his teacher's attempts to have him stand up, as he rolled up in a foetal position whilst sucking his thumb. The rest of the class was brought into the gym while one of the assistants sat with James until he calmed down. She then brought him for a drink as he pulled her to the water fountain.

After a full hour of observation, it was crystal clear to me that this youngster, described as non-communicative and



SPEAKING VOLUMES: Non-verbal signals can be very obvious, but in children who don't talk we have to watch more carefully for them.

uncooperative, was attempting to communicate and express his intentions in so many ways. However, because his signals were subtle, unconventional and not always socially desirable, school staff found it difficult to understand what his goals or intentions were.

His teacher felt that she should not allow such behaviour in school, but admitted that her attempts to get him to behave more appropriately had not been successful.

When we met with his parents, I described some of my observations and they smiled and shared that he was enthusiastic about playing with trains. They added that he often repeated sentences they had said or he had heard from videos to request his toy trains or to comment while playing.

His father commented that he often repeated lines from movies, such as "Are you a good witch or a bad witch?" to greet others, which came from *The Wizard of Oz*.

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I noted that this is called echolalia or speech that is repeated from others, and it is a path to language development for many autistic children due to their strong memory and their unique learning style.

His mother added that since he was a toddler, he physically directed them to specific locations to request objects or assistance. When I described the scene at the gym door, they knowingly shook their heads stating that this behaviour is his language for protesting or refusing when he is unable to speak when confronted with a potentially overwhelming situation.

His mother added that when this occurs, it causes great distress for them in public situations as onlookers believe he is simply a poorly behaved, spoiled child. However, they knew that because he had so little spoken language, especially when upset, he used behaviour to communicate. In this case, he was communicating "there is no way I am going into that overwhelming, chaotic room".

His parents had great insight into how much James was trying to communicate and WHY he engaged in such behaviour, but admitted they needed support and guidance to help him develop more language so that he could communicate in ways that other people could understand.

For too many years, the behaviour of autistic children and adults has been

viewed through the lens of pathology. They have been described as non-communicative, non-interactive and uncooperative, terms that emphasize only what they cannot do, leading to interventions that too often try to eliminate behaviours without understanding WHY the person is behaving that way.

This 'deficit-checklist' approach is not only unhelpful, but it is disrespectful and too often blames individuals whose challenges are based in neurological differences.

What we have learned through decades of research, clinical experience, and from people on the spectrum who can talk about their experiences, is that professionals and parents, and indeed, society in general must change our attitudes and how we view and understand their behaviour.

Ultimately, this will help us provide appropriate and comprehensive support to develop the language and communication abilities that results in successful participation in everyday activities, and that prevents the development of so-called problem behaviour.

Rather than simply trying to change behaviour and 'fix' children on the spectrum, we must support success in communication through the development of trusting relationships.

This requires that we understand that behaviour and all kinds of speech is communication. We must make the effort to listen, watch and ask WHY, and then provide appropriate support. In this way, we will be able to discard the lens of pathology to see autistic people as Uniquely Human rather than broken, by focusing on strengths, abilities and unlimited potential.

*Speech Language Pathologist is the US equivalent of the UK title Speech and Language Therapist

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DE-CODING THE SIGNALS

A Personal Experience



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Very often parents know exactly what their children mean by a phrase or a gesture, but teachers and professionals often miss the context when these signals were first formed. Parents have a great advantage in that they were often around when the child first learnt their own signal.

For example, I once thought that my son Alec had something in his eye. Gently pulling down his lower lid, I expressed concern and sympathy. Since then, Alec pulls down his lower lid when he wants sympathy and we now call it 'The Sad Eye'. It's no longer anything to do with something in his eye but is very effective. But if you missed that early distress signal, you'd be in for it!

My other son Bobby knows Toy Story off by heart. When he's upset, he can't find the right words and blurts "I'm lost - Andy is gone!" So-called meaningless echolalia here has a clear purpose, which is to communicate distress and panic. So it sometimes helps not to listen to the actual words spoken, but the emotion behind them.

All autistic behaviour is motivated by a hidden message. However random or nonsensical it may seem, the message is there. Try your best to look at clues within the environment for what that message could be.

Tori, our co-editor, taught me to extend a child's communication ability by interpreting their message and then giving them a more effective means to communicate it. Fine if the rest of the world understands 'sad eye', but they don't.

So, if your child uses their own message to demonstrate fear, show them a symbol or a sign for fear and label that emotion for them, saying: 'I'm afraid'. Use those symbols or signs a lot as your child is giving their own signal, and gradually they will learn to use them spontaneously as a more effective replacement.

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