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# Language to Communicate Abstract

Intensive Interaction is an approach that uses body language to facilitate positive engagement with non-verbal or semi verbal children and adults with intellectual disabilities and or autism and with whom communication is often difficult. Positive outcomes include a deepening of emotional engagement as measured by increases in eye contact and social responsiveness and a reduction in distress (challenging) behaviours.

**Intensive Interaction: Using Body** 

[Note: *Intensive Interaction* is being used all over the world in groups of individuals. It is strong in Australia (Barber, 2008) and also used in Scandinavia and Europe. It has been taught in Bulgaria and other Eastern European countries, and used by people as far widespread as Tasmania and Saint Helena. In the UK it is used by schools, the National Health System, social services, private providers, therapists and families. Intensive Interaction is a communication approach that is not generally familiar to those in the field of intellectual and developmental disabilities in the United States, where interventions tend to be behavioural and medical in nature. Because this approach is a key tool in two other articles in this special issue on innovative approaches, and has recently been introduced in Ontario, it is important that it be introduced to Journal readers. This present article by Dr. Caldwell is an edited version of a related article first published in 2011 by www.intellectualdisability.info, a Health Alert initiative jointly managed by the Down's Syndrome Association and St. George's, University of London (SGUL). This adaptation of the original article is published with permission from the editors of this website initiative.]

This article introduces an approach called *Intensive Interaction* that allows us to engage with children and adults with intellectual disabilities with whom we find it hard to get in touch. They in turn find it hard to communicate and are often distressed. Many are on the autism spectrum. This review discusses using body language to align ourselves with the affective state of our communication partners and the part played in this by the mirror neuron system. It questions the idea that autism is a problem of motor neuron deficit. As illustrated in the article, persons with autism are able to copy if their stress level can be reduced and our initiatives and responses are already part of their repertoire. Sometimes if they are particularly relaxed they will also copy actions that are not part of their normal repertoire.

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### Communication

We communicate in two different ways. Most of what we are consciously aware can be called functional communication, informing each other of our needs, on the level of "Do you want a cup of tea?," or sharing more sophisticated information. In people with intellectual disabilities or autism who are non-verbal, functional communication may be assisted by sign systems such as Makaton (Grove & Walker, 1990) or PECS (Picture Exchange Communication System) (Bondy & Frost, 2001). What we are all less aware of, is how we inform and monitor each other's emotional states all the time. This emotional engagement is expressed through our body language, not so much by what we say or do, as how we do or say it. For example, in people who are non-verbal, there is a difference in the affective state of someone who is flapping their hand gently and one who is thrashing the air with it: the same gesture, but in the first instance we know they are relatively calm and in the latter that they are expressing severe distress.

The paradigm underlying Intensive Interaction is that of the infant-mother interaction: the infant initiates a sound or movement or rhythm and the mother responds in an imitative way. Once the baby's initiative is sufficiently confirmed, the infant is able to move on and try out something else. It is crucial to emphasise that in using Intensive Interaction we are not in any way infantilising our conversation partners. For all of us, this non-verbal dialogue is a primary communication pathway, laid down in babyhood but remaining with us all our lives. Based on imitation, it has recently become clearer why Intensive Interaction is so successful in attracting the attention of a conversation partner. Much research is now devoted to the mirror neuron system, a network of nerve cells in the brain that recognises actions made by other people and fires off a sensory motor response (Hamilton, 2013; Hamilton, Brindley, & Frith, 2007; Molenberghs, Cunnington, & Mattingley, 2009; Rizzolatti, Fabbri-Destro, & Cattaneo, 2009; Rizzolatti, Fadiga, Gallese, & Fogassi, 1996; Rizzolatti, Fabbri-Destro, & Cattaneo, 2009). Seeing another person yawning triggers a tickling sensation in one's own jaw, even if not an outright yawn. It is speculated that this mechanism can also apply to emotions: it is easy to feel dragged down in the company of someone who is depressed.

### **Intensive Interaction**

People who are unable to communicate develop ways of interacting with themselves in such a way that brain and body engage in an internal conversation through self-confirmation. Each individual develops their own personal language of stimuli that have significance for them and to which they "listen." The first question we have to ask ourselves is, "How is this person talking to themselves?"

We start with "observation" but need to think of observation as the development of an ongoing picture of what our conversation partner is doing now, this minute. We are looking for the feedback they are giving themselves so that we can join in and build up a conversation using their body language as a basis. We need to avoid the pitfall of drawing up a list of activities we "do" with them: our responses need to be contingent, not only to their initiative but also, how this initiative is made, since it is this that will allow us to tune into their affective state. We have to empty ourselves of any behavioural expectations and learn to "be with" this person as they are at present, using their initiatives to respond in ways that have meaning for them.

We need to approach our interaction in terms of a "listening" with all our senses, tuning in to any minute movements, gestures or sounds, focusing on what this person is doing at this particular moment. This will be our way in to our partner's inner language, our aim being to draw their attention from their solitary inner world onto ourselves in the world outside, so that their sensory monologue becomes a dialogue, an interactional conversation that we can now share. At the same time we need to be aware that a person's attention may be focused on as little as their own breathing rhythm, an activity we overlook since it does not have significance for us.

Below are two case studies which document the successful application of Intensive Interaction. Case studies descriptions provided are of individuals in the authors' practices. Permission to publish the studies has been obtained from these persons and/or their families. Pranve's name is his real one, others have been changed.

#### Case Study 1: Debbie

Debbie, has cerebral palsy and severe intellectual disability. She sits in the day centre with her head down, staring at the floor, apparently uninterested in any form of activity. The physiotherapist has been trying for two years to get her to sit upright since her current posture is likely to cause her spinal problems. When I listen carefully she is making small but regular sounds sucking her saliva. We begin to answer her minute sounds. Within a few minutes Debbie's head has come up and she is looking from one of us to another for responses and smiling. Her supporters continue to interact with her as demonstrated. Within three weeks she sits with her head up on a regular basis, looking around her to see what is happening. The world outside her has become sufficiently meaningful to have drawn her attention from her inner world onto her surroundings

This simple interaction not only claims Debbie's attention (she raises her head) but also encourages her to engage with us, in the sense that she refers back to us, deliberately making a sound and waiting for our response. No longer self-confirming, she has developed an expectancy from the world outside herself.

Using Intensive Interaction, we are not just imitating or mimicking, even though this is where we may start. But in order to move from attention to engagement, we need to be aware of our partner's entire body language: so we may answer a sound with a relevant touch or vice versa but always keeping within their repertoire. Sometimes, the way that people without speech express how they feel is complex.

#### **Case Study 2: Pranve**

Pranve is on the autistic spectrum and hypersensitive to sound. He attacks people to the point where it has become difficult to find care staff who will support him. I am warned when I arrive he will probably either attack me or run away.

He lives on the edge of an airport and is distressed by high frequency engine whines lifting his head and rolling his eyes towards the sound. When he is anxious, he touches the fringe of the lampshade beside his chair and runs his hand down the stand. When he is angry he will sit in the hall banging the door with his fist.

Pranve self-confirms by rubbing his fingers; he carries a ball of strings underneath his armpit and spends time sorting them.

Pranve makes sounds, a particular rhythm, "er-erer," which turns out to be a pre-verbal version of "Where's Charlene?," his sister who no longer lives with the family. This is the only thing he has ever been known to say.

When I arrive, I take care not to invade his personal space before making contact with him. So when his mother opens the door I listen ? and from another room hear, "er-er-er," I respond, "er-er, er-er-er?," with a lift at the end, rather in the way one might say, "Hello, how are you?" He comes straight out and takes my hand and leads me to the sitting room. I ask him if I may sit down and he responds by pointing to the chair.

I sit beside him and respond to each of his small sounds, tuning into how they make me feel, but altering the rhythm or pitch occasionally. I am answering rather than copying. At first he is half-turned away from me but he gives me his hand which I shake in time to the sounds we are exchanging. He becomes more interested and turns round to face me, laughing. He introduces new sounds and movements to which I respond. We are soon engaged in a complex non-verbal interactive conversation.

I draw the shape of his different sounds on his forearm and he leans forward and looks with interest, then tries a different sound to which I respond with a shape that reflects its rhythm and pitch.

At one stage I become over-confident and move in when he is not looking. Immediately Pranve thumps my arm, but quite gently. He is telling me that he cannot cope if something happens unexpectedly. Now he is anxious he goes into his lamp stand routine, a feature of his language that I do not fully understand until I revisit our interaction on video. He wants me to confirm this sequence of touching the fringe and running a hand down the stand and tries to guide my hand to meet his need. He is clearly disappointed when I miss this. However we are able to return to using his sounds to interact. Eventually our session comes to an end when I fail again to pick up on his anxiety routine. *He pushes me away gently and we have a break. Then* he goes into the hall and bangs the door. I respond by banging my feet on the floor. He laughs and throws his ball of string into the sitting room, a strategy which means he has to come back to us to retrieve it. He comes in, spots his mother and goes over and hugs her.

He drags a spring-backed chair over in front of me and bounces on it, turning round to me inviting me to bounce him. I do this every time he makes a sound. He

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begins to hum four notes, as it turns out, the first line of the nursery rhyme, "Baa Baa Black Sheep." After trial and error he gets the words and then goes on to produce the tune and rhythm of the second line, his face and jaw working for some considerable time before he can make the necessary muscular movements. As he places his head at different angles one can see the meaning of the phrase "getting one's head round something." His jaw wobbles with the effort but eventually he sings these two lines confidently. His family and the speech therapist who is present are astonished: while he must have heard this song when he was younger, to their knowledge he has never before said anything before except the phrase, "where's Charlene?"

During the three hours I am with Pranve, apart from the one time that I startle him, he shows no aggressive intent and is clearly delighted with our interactions. But also, after about twenty minutes, he is no longer reacting to the scream of the planes passing over the house, so close their wheels are down for landing. His interest in our conversation is overriding his hypersensitivity to the high frequency whines of the jet engines (Caldwell, 2006).

I have presented this intervention in detail because it illustrates some of the interwoven subtleties of a body language interaction. I am not just working with repetitive behaviour but more with what might be thought of as the total ecosystem of a person's life and how they interact with their surroundings.

When using their body language, people with autism start to engage. They relax, their whole demeanour and posture change. Eye contact increases, they start to look round, they can generalise and copy and are interested in their conversation partner in a way that is not generally accepted to be typical of people on the autistic spectrum (Zeedyk, Caldwell, &Griffiths (2009). And contrary to the idea that people on the spectrum have a deficit in their mirror neuron system (Ramachandran, 2011) which might account for their communication difficulties they have, they always recognise and respond to gestures and sounds, provided they are already part of their significant repertoire.

Intensive Interaction can be applied across a wide field of disability. For example, Hart uses Intensive Interaction to work with people who are deaf-blind (Hart, 2008). He highlights the need for care staff to learn the capacity to "feel"

the world from a tactile perspective, developing "communicative landscapes" to capture the attention of their deaf-blind partner in order to negotiate joint activities.

Each time we use Intensive Interaction we are beginners, in that we have to learn the significant language for a specific individual from our conversation partner. Inevitably there will be some trial and error: our partner will latch on more quickly to our using certain aspects of their language than others. For example, David who is biting pieces of jigsaw may be unmoved when we try replicating his activity, since the feedback he is giving himself is that of pressure in the area of the mouth rather than visual. In this case he responds very quickly to the application of vibration in this area (Caldwell, 2009).

Intensive Interaction is particularly effective with people on the autistic spectrum who are struggling with a sensory environment that is behaving like a kaleidoscope, where the pattern never settles. This instability can appear as life-threatening: responding in terms that are meaningful to the brain confirms what the person is doing. Donna Williams, who was diagnosed with autism as an adult, says that it is like having a life belt thrown to her in a stormy sea (Williams & Magnus, 1993).

When engaging with people with behavioural distress, we need to ask two questions. The first asks, "What do I do now when I am being attacked, or my partner is self-harming?" The second is, "Why does he or she feel the need to do these things?" So when I use Intensive Interaction, it is as part of a dual approach: I am looking to reduce the triggers to sensory distress such as the sensory hyper- and hyposensitivities, emotional overload and the difficulties caused by failure to process speech. On the other hand, I am looking to increase signals that the brain can process easily, such as use of body language combined with strong proprioceptive input.

### Using Intensive Interaction to Construct an Autism-Friendly Environment

People with autism live in a sensory maelstrom (Ramachandran, 2011). It is difficult for them to

know what they are doing. Pranve is confirming himself by activities that are hard-wired-in elements of his body language such as hand movements and string sorting, which help him construct a landscape that has meaning for him. In the dual autobiography written by Judy Barron, we learn that when Sean repetitively switched the lights on and off it gave him a wonderful sense of security since it was exactly the same each time. In an unpredictable world he knew what was going to happen (Barron & Barron, 1992).

One of the reasons Pranve attacks people is because something has happened that he has not foreseen. He becomes sensorily overloaded and his autonomic nervous system tips him into an "autonomic storm" (Ramachandran & Oberman, 2006), an experience that is both confusing and can be extremely painful. As Pranve becomes more relaxed his brain finds it easier to organise his muscular responses and he says clearly, "Where's Charlene?" instead of muttering the rhythm and then goes on to astonish his family and speech therapist by singing a nursery rhyme.

Over the next two months, Pranve's parents use his body language to communicate with him. His behaviour calms and he is able to return on a part-time basis to the day centre from which he had been excluded. His mother says he has the odd off-day but on the whole they can now interact with him and manage his behaviour.

A teacher using Intensive Interaction with her students sums up the effects. "They want to be with people now." Wanting to be with other people, desiring relationship is what I hope to achieve for my conversation partners.

### How Well Does Intensive Interaction Work?

Intensive Interaction is not a "cure" for autism, in the sense that if we discontinue using their body language to engage with them, their distressed behaviour will return. We have to use it as a continuing way of communication exploring, and building on the emotional engagement and relationship it fosters. When the brain is no longer under processing pressure it begins to work more effectively on its own account, within the limitations of its intellectual disability if this is present. This is especially true for people with autism who are so vulnerable to environmental stress.

Success is dependent on maintenance. Since Intensive Interaction holds our partner's attention, we can sometimes use it to guide them through activities they would otherwise find threatening by constantly supplying sounds or movements or gestures that are part of their repertoire. These act as landmarks that the brain can focus on and exclude the avalanche of stimuli that threaten to overwhelm them.

While there are a massive number of anecdotal studies from practitioners all round the world as to the effectiveness of Intensive Interaction there is rather less empirical evidence. However, in spite of the difficulties presented by standardisation, Zeedyk, Caldwell, and Davies (2009) have analysed filmed Intensive Interaction interventions frame by frame and shown that, although the time-line may vary, there is always a significant increase in eye contact, in social responsiveness and an increase in the desire for proximity. Nind and Kellett (2002) show a significant decrease in disturbed behaviour in adults with learning disabilities when their support staff engage with them through corresponding actions. In a survey commissioned by Mencap and the Department of Health, UK, on communication with people with profound and multiple disabilities, Goldbart and Caton (2010) find that Intensive Interaction is one of the approaches most widely used. Over 85% of speech therapists in the survey were using it.

Fundamentally, Intensive Interaction is straightforward. Laying aside our own agendas, we start by looking and listening to what our conversation partners are doing, the physical feedback they are giving themselves and how they are doing it – at the same time, tuning in to how they feel, using our own body language to respond and building up non-verbal conversations and emotional engagement.

## Key Messages From This Article

*People with disabilities:* "Just because I cannot speak it does not mean I have nothing to say."

"Talking to me through my body language is like having a delicious conversation." "I like it when people tune in to me."

**Professionals:** Intensive Interaction facilitates getting in touch with people with intellectual disabilities/autism in a way that is accessible and meaningful to them, by engaging them through their personal repertoire including their body language.

**Policymakers:** Genuine communication with people with intellectual disabilities should inform all policy decisions relating to their support and empowerment.

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### References

- Barber, M. (2008). Short Report. Using Intensive Interaction to add to the palette of interactive possibilities in Teacher-pupil communication. *European Journal of Special Needs Education*, 23(4), 393–401. Retrieved from http://drmarkbarber.co.uk/usinginte nsiveinteractiontoaddtothepalette.pdf
- Barron, J., & Barron, S. (1992). *There's a boy in here*. New York, NY: Simon & Schuster.
- Bondy, A., & Frost, L. (2001). The Picture Exchange Communication System. *Behavior Modification*, 25(5), 725–744.
- Bradley, E. & Caldwell, P. (2013). Mental health and autism: Promoting Autism FaVourable Environments (PAVE). *Journal on Developmental Disabilities*, 19(1): 8–23.

- Caldwell, P. (2006). Finding you finding me: Using intensive interaction to get in touch with people whose severe learning disabilities are combined with autistic spectrum disorder. London, UK: Jessica Kingsley.
- Caldwell, P. (2009). Training Film: Autism and intensive interaction: Using body language to get in touch with children on the autistic spectrum. London, UK: Jessica Kingsley.
- Goldbart, J., & Caton, S. (2010). Communication and people with the most complex needs: What works and why this is essential. London, UK: Mencap. Retrieved from http://www. mencap.org.uk/node/6185#node-6185
- Grove, N., & Walker, M. (1990). The Makaton Vocabulary: Using manual signs and graphic symbols to develop interpersonal communication. *Augmentative and Alternative Communication*, 6(1), 15–28.
- Hamilton, A. F. (2013). Reflecting on the mirror neuron system in autism: A systematic review of current theories. *Developmental Cognitive Neuroscience*, *3*, 91–105. doi:10.1016/j.dcn.2012.09.008
- Hamilton, A. F. de C., Brindley, R. M., & Frith, U. (2007). Imitation and action understanding in autistic spectrum disorders: How valid is the hypothesis of a deficit in the motor neuron system? *Neuropsychologia* 45(8), 1859–1868. doi:10.1076/j.neuropsychologia.2006.11.022
- Hart, P. (2008). Sharing communicative landscapes with congenitally deaf blind people: It's a walk in the park! In M. S. Zeedyk (Ed.), *Promoting social interaction for individuals with communicative impairments: Making contact* (pp. 66–83). London, UK: Jessica Kingsley.
- Molenberghs, P., Cunnington, R., & Mattingley, J. B. (2009). Is the mirror neuron system involved in imitation? A short review and meta-analysis. *Neuroscience and Biobehavioral Reviews*, 33(7), 975–980.
- Nind, M., & Kellett, M. (2002). Responding to individuals with severe learning difficulties and stereotyped behaviour: Challenges for an inclusive era. *European Journal of Special Needs Education*, 17(3), 265–282.
- Ramachandran, V. S. (2011). *The tell-tale brain: A neuroscientist's quest for what makes us human* (1<sup>st</sup> ed.). New York, NY: W. W. Norton.

Ramachandran, V. S., & Oberman, L. M. (2006). Broken mirrors: A theory of autism. *Scientific American*, 295(5), 62–69.

Rizzolatti, G., Fabbri-Destro, M., & Cattaneo, L. (2009). Mirror neurons and their clinical relevance. *Nature Clinical Practice Neurology*, 5(1), 24–34.

Rizzolatti, G., Fadiga, L., Gallese, V., & Fogassi, L. (1996). Premotor cortex and the recognition of motor actions. *Cognitive Brain Research*, 3(2), 131–141.

- Williams, D. (1995). Jam jar. Channel 4 TV in association with Fresh Film UK.
- Williams, D., & Magnus, E. (1993). My experience with autism, emotion and behaviour (an interview of Donna Williams aired on *Eye to eye with Connie Chung*). New York, NY: CBS Television.
- Zeedyk, M. S., Caldwell, P., & Davies, C. E. (2009). How rapidly does Intensive Interaction promote social engagement for adults with profound learning disabilities? *European Journal of Special Needs Education*, 24(2), 119–137.

### **More Resources**

### **Intensive Interaction Training Courses**

There is a problem with training, in that being highly intuitive, laying down rules tends to box it in an unhelpful way. The best training inspires people so that they go away and try it. Since it normally works first time, trainees usually want to go on with it. Some will need long-term support. In the UK, training is provided by the author. More formal courses are run through the Intensive Interaction Institute based in Leeds by Dave Hewett. Others who run courses include: Cath Irvine (cath@intensiveinteraction.co.uk); Pete Coia at Fieldhead Hospital, Wakefield; and Helen Beltran, speech therapist in Glasgow.

While there is no formal training as yet in Ontario/Canada, there is now a serious interest in Toronto and several clients with intellectual disabilities are being supported in this way.

#### **Intensive Interaction Training Films**

Caldwell, P. (2002). *Learning the language* [DVD]. Brighton, UK: Pavilion Press. (Follows a three-day intervention using Intensive Interaction to get in touch with a young man with very severe autism, using his body language, followed by discussions with Care Staff)

- Caldwell, P. (2004). *Creative conversations* [DVD]. Brighton, UK: Pavilion Press. (Intensive Interaction being used with people with multiple disabilities, mainly severe cerebral palsy)
- Caldwell, P. (2007). Reaching Ricky [Teachers TV made by Available Light Productions Ltd., Bristol, UK]. Retrieved from http:// www.tes.co.uk/teaching-resource/ Reaching-Ricky-6084099/ (Working with a child with autism in school)
- Caldwell, P. (2009). Autism and intensive interaction: Using body language to get in touch with children on the autistic spectrum [DVD]. London, UK: Jessica Kingsley. (This three-part film includes a twenty minute uncut Intensive Interaction intervention with an eight-year old child, whom staff cannot make contact with and whom Caldwell has never met before. The film moves from initial rejection to total attention.)

Clips from these films and other interventions with children aged 3–18 may be viewed at http://www.phoebecaldwell.co.uk/films.html

### **Radio Interview**

Ledgard, C. (producer). (2013, January 15). [Interview with Michael Rosen]. *Word of mouth, autism and learning difficulties*. [Radio broadcast]. Bristol, UK: BBC Radio 4. Retrieved from http://www.bbc.co.uk/ programmes/b01pty43 (In this interview, Phoebe Caldwell talks about the principles of "Intensive Interaction," and why listening and non verbal communication are central to her work. Parents, researchers and carers also discuss with the host the ways we communicate with people with autism or profound learning disabilities.)