

Now Communication

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Thousands of adults with severe and profound intellectual disabilities are now, through the NDIS (The National Disability Insurance Scheme – Australia’s funding scheme for people with disabilities), having access to speech pathology services. In many ways this is new territory for therapists. Experienced therapists are being flooded with referrals and new therapists are entering the field.

For many therapists, the traditional way of working may have been to examine present skills and recommend the next level of complexity. There is a logical impetus to work towards expanding a person’s communication repertoire and teach symbolic systems which will be more easily understood by partners. Particularly with the rise of electronic communication systems, devices are recommended with the hope that partners will model the systems rigorously until the person can then use it both for comprehension and expressive communication.

What is sometimes missing, however, is a deep examination of what the person understands now and what they express now. What a person does now is their “now communication”. It is how they connect, share, and relate to the world and people around them. It is their strongest neurological network.

Speaking neurologically, what a person does while they are sitting by themselves tells us much about their understanding – what they are doing by themselves is where their attention is focused. It may be tiny movements of fingers, shaking of a foot, sucking movements at their mouth, rhythmic rocking. Some movements may be voluntary, some involuntary but triggered by particular conditions. These movements are the textures that permeate the person’s day, either with a connection to the environment outside of the person’s body or mediated by internal factors. If we are sincere about interacting with a person, then these movements are part of the language that we must use with them.

Firstly, let’s consider what the person understands. Understanding what a person understands necessitates a grasp of the person’s sensory functioning. The more severe a person’s cognitive impairment, the greater the likelihood that they will experience sensory impairments, though, sadly the more likely their sensory impairments will not have been diagnosed. Unfortunately too many people may have not accessed assessments of vision and hearing, and those who have may have findings of “non-compliant with testing”, “not assessable”, or a polarised diagnosis of deaf or blind versus hearing or seeing. Few will have a quality low vision assessment that addresses

what the person can see, the colours, the settings, and the distances which best enable them to use the vision they have, and avoid painful visual stimuli like glare or particular colours. Few will have hearing aids, a description of which ear functions best, or a diagnosis of hyperacusis (heightened sensitivity to particular sounds) and its distressing affect when the person is in particular auditory environments.

Subsequently, our assessments of what a person can understand requires creative problem solving. We examine the person’s responses to sounds, including our voice, at different positions, pitches, and volumes. We watch the person’s responses to sounds, from turning, leaning, or attempts to cover their ears either with their fingers or through self creation of sounds that can block out external sounds. We watch for how the person uses their eyes: looking at people across the room or only when a person is sitting next to them. Their response to colours: reds, yellows, fluorescents, bright on dark on an iPad, light tracking in a darkened room, or light gazing (all giving some clues around potential cortical vision impairment).

Most importantly we examine how the person responds to our, and others’, engagement with them. What do they respond to: words, tone of voice, presence of a person, touch of a person? Do they demonstrate anticipation in an activity, memory of an action? Do they smile on your smile, laugh with your laugh, or demonstrate fear or indifference? If you ask them, “can I sit down?” and gesture to a spot, do they minutely nod, shift their posture, or demonstrate tensing muscles? How close will they accept your presence – a gaze from across the room, two metres away, on the couch, sitting with knees together? A deep curiosity for what a person may or may not understand is needed. For some people, with the possibility that they understand speech, you may preface your assessment with “I have just met you and I want to learn what you understand and how you express yourself; you can learn about me too”.

We need to accept, with seriousness, that we need to communicate with the person in a way that they can understand; to not do so compromises shared meaning.

It is inauthentic. For some people, this means our first language directed to them needs to be impressions on their skin at different body parts - firm, soft, quick, tickly, slow, tiny, broad, clapping, tensing - a rich language of sharing of the feelings of life. Some will need a rich language of non contact gestures such as pointing, along with our face expressing happiness, frustration, tiredness, shared excitement. For others, single words with gestures will be their way of understanding; acknowledgement is needed that a multiword sentence may result in many words floating into the air and the words that land at the person's comprehension may not be the ones intended (e.g. "don't hit Santa" may only be understood as "hit").

Our next challenge is to see how the person expresses themselves. Again, we observe the movements that the person makes when alone. What is their face expressing, their hands, their feet, their torso, their sounds. Often the expressions are best translated not into words, but word qualities: languid, excitable, considered, heightened, restless, attentive. In presence with a partner, what expressions do you see: leaning in proximity, reaching, retracting, caution, lingering gaze, smile, lip smacking, pointing, eyebrow raising. We look for any signals indicating levels of arousal. For some people, in parallel to typical infants, turning away, grasping hands together and wringing, may be used to reduce a feeling of being overwhelmed in an interaction. They are signals for a partner to slow, soften, and wait for reengagement, but are too often interpreted as signals for the partner to leave the person alone.

Everyone is expressing themselves in some way. Their moves and stillness are all expressing a state of being. We need to observe with our eyes, ears, and touch senses to capture the expressions that can share a meaning about what the person is thinking or feeling in the present moment. Much like the act of mindfulness, we need to be aware of all that is happening now.

Sometimes the way a person expresses themselves can best be seen by looking at a video recording of an interaction. Transcripts of interaction, describing the moves beyond words, allow the dialogue to be observed. Watching the video, in different ways, allows you to change your lens for meaning. Watching without sound will reveal another story. Watching in slow motion will illuminate how two people are responding to each other microscopically; the proposition of who initiated and who responded will become blurred. As a therapist, you can write down this transcript to help other people see what you are seeing, and explore alternative interpretations to what you see, including acknowledging when you are not sure what a person is expressing with particular movements or sounds. Setting this scene of curiosity and willingness to be right, wrong, and explore alternative

interpretations is an essential stepping stone in quality planning, goal setting, or supported decision making.

Combining an understanding of a person's comprehension and expression lays the foundation for an authentic conversation with the person using what they can do. Feelings can be shared and heard, expanded or softened. To be shown that you've been understood by another person is the blossom of a flower: "I express my feelings and my partner shows me they've understood (or tried to understand) by repeating my feeling in the same way".

To respond to a person's feeling by only using words, for example the person laughs and you say "You're happy" may be a speckle of meaningless word dust to the person. But for you to laugh back, lands on the person's brain: "I can hear my partner knows what I know".

The same is true for expressions of sadness, pain or frustration. It is important to hear and let the person know you've heard their expression before being tempted to try to change their state. For example, a person growls, grasps their chest and writhes suggesting possible reflux – you can respond by making the same sound to let them know they are heard. You will often find that people will gaze towards you or pause if you repeat their action, showing that they have noticed you noticing them.

In the area of mental health we know that validating a person's feeling is essential. To have your feelings ignored, invalidated, leads to feelings of isolation, exacerbation of the feeling, and fails to support a person in developing their resilience or problem solving for responding to the feelings. Holding someone's hand, metaphorically, with the feeling, allows you to meet the person where they are, and gently guide them to a resolution – even if that resolution is that pain, frustration, anger, and sadness happen, they will know they are not alone in those feelings.

Topics of "How about we do this with our hands", or "Let's drop these objects" form the basis of turn-taking and anticipation. Often our perception of whether a person is truly understanding turn taking is at first tentative; "I'm not sure if they do understand it... but we go with it", admits its exploratory nature. Simple sharing or games build rapport and a desire to be with another person.

It is essential to acknowledge that turn taking is only possible if two people have access to the same behaviour. You can not turn take in a clapping hand if one partner cannot move their hand. You can not turn take in a song if one partner has no voice. But if you both have access to a movement or sound, then you have

what is needed for a turn taking interaction – subsequently using what you’ve observed about what the person can already do is needed, is the starting point, for this mutually imitative engagement.

Unfortunately, what is missing from many of our service systems and communication interventions is the essential ingredients of two people who want to authentically engage with each other.

Here lies the challenge in assessments and interventions for adults with severe and profound levels of intellectual disability – two people who want to authentically engage with each other.

Our assessment reports need to take the ingredients and spell out the recipe. The recipe for authentic engagement with a person with the most complex communication needs is rarely obvious. It is rarely an adaptation of an old family favourite that you’ve used for years. It is a thoroughly unique combination of understanding what the person understands, being receptive to every expression that the person makes, creating a bridge of sharing meaning using these ingredients.

Every time we meet a person, they already have a language. The sad thing is, too often, others are failing to use their language with them. Others are often trying to pull the person to use a different language, perhaps speech or pictures. Second language learning is of value; don’t get me wrong. But failing to use the person’s now communication, even as a foundation for building their second language, leaves the person in a communicative abyss. Alone. Not understood. Not shared.

Our reports and interventions need to teach partners the person’s rich now communication. The reports and interventions need to give permission and overcome systemic barriers that may try to stop us from using the person’s language. Our reports, interventions, and interactions need to acknowledge the complex ethical issues, and the dynamic way that we need to explore how to be with a person authentically where there will be points where we are unsure of meanings or what the right thing to do is. People with severe and profound intellectual disabilities are complete people now, they are communicative and relational now... we need to be willing to meet them.

Contact Details

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