

Some thoughts on communication, empathy, and sensory differences in autism¹

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What does it mean to be severely autistic, to be unable to communicate and to be dependent on others to meet your basic needs?

People with high functioning autism or Asperger Syndrome have often provided an insight into the lived experience of others who have severe autism and have minimal communication ability. But what can we learn from people who are on the opposite end of the autistic spectrum? Can we glean insights of a different kind? Unlikely as it may sound, I would argue that yes, we can.

I want to tell you about Liam, my teenage son. He has severe autism and is non-verbal, and although he doesn't know it he informs and broadens my understanding of life and relationships in a way that no one else does. When I meet clients on the autistic spectrum, holding Liam in mind helps me to remember that that they may be struggling with sensory differences and sensitivities. I see this as an opportunity to introduce you to Liam and to his world - one that is usually hidden away from the rest of society.

But first I would like to invite you to join me in thinking about how we relate to people on the autism spectrum – as parents, carers, counsellors and therapists. Autistic individuals are often described as having deficits in empathy and having “mind blindness” (Baron Cohen, 1997). In other words they may be thought of as being less able to infer the feelings and thoughts of others. When we spend time with someone in whom this ability is impaired, or seemingly absent, we may feel disorientated and unsure how to respond. But do we understand the challenges they are facing? Bogdashina (2014) suggests that “mind-blindness” describes only one side of the equation. The neuro typical person may be *also* be blind - to differences in perception of the autistic person, not understanding how autistic children and adults with a severely impaired sensory processing disorder experience a totally disordered sensory world. The author David Mitchell, whose son has autism, tries to imagine what it is like:

¹ Re-publishing this paper gives us an opportunity to honour the joy and learning Liam has given to his family, carers and others like us. Liam died unexpectedly in March 2019 at the age of twenty. Our thanks to Liam's parents, Ann and Paul Jinks, and to Ged Smith at Context for their support for republishing this writing.

...the floor keeps tilting like a ferry in heavy seas, and you're no longer sure where your hands and feet are in relation to the rest of you...your head feels trapped inside a motorbike helmet three sizes too small which may or may not explain why the air conditioner is as deafening as an electric drill, but your father –who's right here in front of you – sounds as if he's speaking to you from a cell phone on a train going through lots of short tunnels, in fluent Cantonese.

(Mitchell 2013, p.2)

Temple Grandin, an autistic writer and animal scientist, describes similar distortions in perception:

It is likely that he has no sense of his body boundaries and that sights, sounds and touches are all mixed together. It must be like seeing the world through a kaleidoscope and trying to listen to a radio station that is jammed with static at the same time. Add to that a broken volume control, which causes the volume to jump erratically from a loud boom to inaudible

(Grandin 1995)

These sorts of unusual or distorted sensory processes, even when less severe, would lead any of us to develop a range of coping and adaptive strategies. So what can we do? For the non-autistic or less autistic amongst us let us consider the systemic idea of positionality: having the benefit of coherent sensory integration and 'mind reading' abilities obliges us to recognise and be aware of our more privileged position and respond accordingly, whilst all the time remembering that because we are informed that someone is on the spectrum, or they tell us themselves, it does not mean they are like anyone else on the spectrum. In the April 2015 issue of Context John Shotter wrote about the ethics of attunement and how we can easily violate others' uniqueness "by fitting them into a diagnostic category, by assuming them to be a *kind of person* already familiar to us." Shotter talks about orienting ourselves towards the otherness of the other even when it is bewildering and confusing. I believe he means in the context of dialogue but I think the idea of attunement is also useful when spending time with someone who has impaired communication or no language.

Depending on their abilities, and ours, relationship with another person may be difficult, especially if speech is echolalic or absent. But if we are prepared to work harder on our own mind-mindedness we might enter further into their world and make a better connection. I am not suggesting this is easily achieved. Self-care is paramount; like driving on the opposite side of the road or drawing with our non-dominant hand, it will be tiring and all too easy to revert to old habits such as using too much language. It requires concentration and patience. David Mearns (2005) suggests that in order to offer a deeper relational involvement or engagement when we appear to be getting little or nothing back from another person, we need to sustain ourselves. One of the things that can help us to go on with someone who finds social contact and communication difficult is the feeling of resonance, however fleeting. As is using our imagination to "freshen up empathy" (2005, p106) and talking to others who understand, perhaps in clinical supervision or a parent support group.

And so back to Liam; he is a six feet tall, strong 17 year old with curly blond hair and blue eyes. He has what used to be called Kanner's or Classic autism. At age 10 he went to live in a specialist residential school. After years of observing his unusual and challenging behaviour, I believe Mitchell and Grandin are on the right track: Liam has sensory differences that we can only guess at, but what we do know is that he loves being in water and enjoys trampolining. He also loves eating but food is of obsessional interest and may be a sensory minefield. It can be a trigger for anxiety, aggression and meltdown. When this happens he will often throw things, bite and scratch and hit out, harming himself and others.

I am full of admiration for the teachers and care workers who look after him. They attend to Liam's personal hygiene needs, such as bathing, showering and teeth brushing. He builds trusting relationships with certain members of staff over time and even though he has always been terrified of the process, he was able to have his hair cut again recently. Six people were involved: four were ready to restrain his arms and legs, one cut his hair, and another gave Liam grapes and cherry tomatoes to help him through the ordeal.

In the same grounds Liam has his own classroom and a version of National Curriculum activities that would hardly be recognisable in other schools. "Lessons" are creatively adapted for someone who will never know or care where London is or what 2+2 equals. It is not expected that he



will ever live, work, study, or travel independently. He can go outside and trampoline or swing when he becomes frustrated and angry with tasks that most toddlers would find easy such as threading beads or matching pictures. Liam shows no imaginative play skills. He has however learned to ride on the back of a tandem for a few minutes at a time within the school grounds and (with the closest possible supervision) he is currently learning how to make toast - without eating the bread first.

When Liam acts aggressively, and hits out, it can seem completely out of the blue and without reason. But thinking systemically can help us "make sense of behaviour that otherwise would seem to be insane or malicious" (Jones 1993, p17). Let us for a moment freshen our empathy as Mearns suggests and imagine coping with the systemic environment and its sensory overload: people are using incomprehensible language around you, loud screeching, shouting noises come from other students, doors beep loudly as people enter your flat. You are hungry and can smell food cooking but don't know when it will be ready to eat: is it for you, or someone else? Imagine the difficulty of

communicating what you want, unable to use words or pictures. Imagine not knowing what you want in the first place. The only choice you are able to make is between a red drink and an orange drink. If someone is available and willing you can take him or her to the cupboard to get a DVD, but the one you want is not there. What would you do?

Going for a drive with Liam

Ideally I would like you to have Beatles' songs playing as you read this...

I was alone, I took a ride

I didn't know what I would find there

Another road where maybe I could see another kind of mind there

McCartney, P. (1966) Got to Get You into my Life. Revolver. EMI Records.

It's Sunday afternoon and I am sitting in the back of the car with Liam. His dad (Paul) is driving. The Beatles are playing on the car music system. Liam rocks backwards and forwards and occasionally gives a little smile.

Paul and I have travelled for an hour and a half on very familiar roads to see him. Turning onto a driveway from a country road we announce our arrival over the intercom and the large iron gates swing slowly open. Through a series of locked doors we are escorted to Liam's flat. We most often find him waiting in his bedroom, usually naked. Clothes are cast aside, presumably because he is more comfortable without them. There are no greetings from him. He rummages through the bag we bring and finds fruit, magazines, iPad, and sits on the bed munching his way through an apple or a pear whilst whizzing through photographs on the small screen. He occasionally pauses and flicks back to familiar faces. Some are pictures of members of staff who he liked but no longer sees because they left to work elsewhere. There is no way to explain to him that they are not coming back. He likes to rub squashed up chewed pieces of food into the screen. If we are not fast enough to stop him he posts the iPad through the window when he is finished.

Liam then takes us by the hand to his wardrobe, which is locked (he posts clothes through his window if they are left out) and we find a member of staff to open it up. I help Liam dress. He can dress himself but usually put socks on with the heel at the top. I twist them around and into place if he will let me. He doesn't mind if his clothes are back to front or inside out, or someone else's. He pulls us both by the hands and back down to the car park, through a series of beeping doors, waiting for them to be unlocked again in turn. He pushes members of staff away so we borrow the keys to open locked doors and gates and throw them back. We need to act fast. Like all transitions, leaving the flat is a potential flash point where any confusion or delay can lead to anxiety, meltdown and injury. Liam recognises the car, and looks inside, including the boot, to see if there is any more food. He takes off his shoes and socks and sits in his usual place on the back seat. We click red plastic "Angel Guards" into place to

prevent Liam unfastening our seatbelts en route. Two members of staff appear behind us in another car so they can help and support if needed... and we're off!!

As the car begins to move, the music begins. The first track is "I Feel Fine" by the Beatles and on its distinctive buzzy feedback intro Liam starts to relax. The iron gates swing open again and we pull out onto the country roads.

We drive for at least an hour. Every now and again Liam will take my hand and get me to scratch the back of his head or occasionally he holds my hand for a second or two. These are the best of times. I get to sit close to Liam and take a good look at him. This is also the time we learn from Liam what it is like to enjoy the moment – without talking. Words are for schmucks. Conversations are passé. We don't talk because Liam may become irritated, angry even. Imagine waiting all week to meet a friend or see a film you were looking forward to, then someone enters your space and starts talking, and in words you don't understand. We have learned not to talk. We just want to *be* with him. Liam's dad has compared the visit with being in love or having a new baby; it's enough to just to see him, to look at him, and be in his company.

Liam takes his shoes and socks off, more clothing may be removed in a while. As we ride, the flat green and brown Lincolnshire landscape now becomes particularly soothing. These country roads have probably been the same for decades. The sky is huge, expansive, like a grand master, the clouds majestic. We have our own motion picture soundtrack. To Liam, the lyrics are probably irrelevant, incomprehensible, but to me they seem unusually apt. We are *on* The Long and winding Road, we *are* Let(ing) it Be, and we have *always* Got to Get You Into My Life. These are probably not the songs other teenagers would be listening to in 2015 but Liam enjoys them just the same. He rocks. He smiles. We're happy.

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