

[Approaches to the autism spectrum](#)” - Dr. Ava Ruth Baker
2015 Update of Keynote presentation given at Kolisko Conference “Connecting
with Today’s Children” Cambridge, New Zealand July 2010

Origins of this article: To my surprise and trepidation, I was asked at short notice to present the keynote address on the autism spectrum to the 2010 Kolisko Conference in Cambridge, New Zealand, when our wonderful leader of the worldwide Medical Section, Dr. Michaela Glockler, was no longer able to come. My intention to convert the talk afterwards into an article encountered numerous delays while coping with the Christchurch earthquakes, cancer, and the resulting shifts of home. Here it is finally, thanks to the questions of the new wave of autistic individuals, families, teachers and therapists that I’m privileged to encounter through my work with the Aurora Wellspring group, Raphael House and Te Ra schools. While the original presentation was addressed to an audience of teachers, therapists and doctors, it’s also relevant to all of you who meet autism at home, work or the wider community.

Terminology:

The following terms are used somewhat interchangeably, by me and those quoted, to refer to *the whole autism spectrum* and to individuals identified as being *anywhere along that spectrum* (to all of whom this article pertains):

- *autism / autistic / autist / on the spectrum*
- *ASD* (which I encourage you to think of as ‘*Autism Spectrum Difference*’ rather than the medical term ‘*Autism Spectrum Disorder*’)
- *Asperger’s Syndrome / PDD / PDD-NOS* (terms now superseded by ‘ASD’ but still in common use)
- *AS* (an abbreviation used by some authors for ‘*Autism spectrum*’ and others for ‘*Asperger syndrome*’ – distinctions now of diminishing relevance)
- *aspie* and *autie* (names some folk on the spectrum give themselves – but, like any nickname, advisable for others to use only of individuals who self-identify thus)

NT (Neurotypical) and Nypical refer to people whose nervous systems work in more typical (non-autistic) ways

Autistic community: Yes, there is such a thing - a worldwide network of autistic people, meeting online and in real-life, with its own culture, events, communication style etc.

[Meeting individuals on the autism spectrum:](#)

Can you imagine what it might be like to be an autistic child at school? Clare Sainsbury writes in her introduction to “Martian in the Playground” (a collection of personal accounts by twenty-six autistic adults of their experiences as schoolchildren):

“Here is one of my most vivid memories of school: I am standing in a corner of the playground, as far away as possible from people who might bump into me or shout, gazing into the sky and absorbed in my own thoughts. I am eight or nine years old and have begun to realize that I am different in some nameless but all-pervasive way.

I don’t understand the other children around me. They frighten and confuse me. They don’t want to talk about interesting things. I used to think that they were silly, but now I am beginning to understand that I am the one who is all wrong. I try so hard to do what I am told, but just when I think I am being most helpful and good, the teachers tell me off and I don’t know why. It’s as if everyone is playing some complicated game and I am the only one who hasn’t been told the rules. But no-one will admit that it’s a game or that there are rules, let alone explain them to me...

I think that I might be an alien put on this planet by mistake; I hope that this is so, because it means that there might be other people out there in the universe like me. I dream that one day a spaceship will fall from the sky onto the tarmac in front of me, and the people who step out of the spaceship will tell me, “It’s all been a dreadful mistake. You were never meant to be here. We are your people and now we’ve come to take you home.”” (1, pp. 8-9)

How teachers (or any of us) meet such children can play a pivotal role in their experience. As Clare continues

“We don’t need ramps or expensive equipment to make a difference for us; all we need is understanding. ...

Good experiences with teachers, though much fewer than bad experiences, shone in people’s recollections with extraordinary vividness. ... Their thoughtfulness made an overwhelming difference to my life ... [As] stood out from many different stories ... the presence of even one teacher who was willing to approach a student with Asperger’s with insight and respect could make a dramatic difference to the whole of their school career and even to their life as a whole (even though that student might not have been able to express their gratitude ... at the time). Conversely, ignorance and intolerance could scar a child for life.” (1, pp 97 & 130)

When meeting such children, ponder Rudolf Steiner’s words about those considered ‘abnormal’ (terms like ‘autistic’ not yet coined when he wrote in 1924):

“The only possible grounds we can have for speaking of the normality or abnormality of the child’s life of soul, or indeed of the life of soul of any human being, is that we have in mind something that is normal in the sense of being average. There is no other criterion than the one that is customary among people who abide by ordinary conventions; such people have their ideas of what is to be considered reasonable or clever, and then everything that is *not* an expression of a “normal” life of soul (as they understand it) is for them an abnormality. At present there is really no other criterion. That is why the conclusions that people come to are so very confused. When they have in this way ascertained the existence of “abnormality”, they begin to do – heaven knows what! – believing they are thereby helping to get rid of the abnormality, while all the time they are driving out a fragment of genius! We shall get nowhere at all by applying this kind of criterion, and the first thing the doctor and teacher have to do is to reject it and get beyond the stage of making pronouncements as to what is clever or reasonable, in accordance with the habits of thought that prevail today. Particularly in this domain we must refrain from jumping to conclusions, and simply *look at things as they are.*” (2, pp 16-17)

And from anthroposophist Georg Kühlewind:

“I have learned more about the human being from what people with autism have communicated than from any other source. I am also sure that many of them live in a world that is more real than the one we live in, and that their so-called disturbed perception offers a world picture that is not poorer but much richer than ours. ... If we understood them, they would be our teachers for our own self-knowledge.”(3, pp 209-210)

Three very different perspectives from which to view and approach autism are:

‘OUTSIDE’ (most professional and lay) perspectives, reveal behaviours. From this vantage, it’s not obvious what causes those behaviours, or which might actually be ingenious coping strategies, rather than behaviours to get rid of. For example, repetitive behaviours (like jumping, spinning, pacing) can often help an autistic person to process information; as can fidgeting, repeating things out loud, or averting the eyes. This is one of many reasons for first listening to

‘INSIDE’ perspectives: accounts by those on the spectrum of their experience, of what autism means to them – individually, as well as ‘pooled’ experience and meaning as shared by the wider community of autistic people.

Could ANTHROPOSOPHICAL perspectives further enhance our understanding of autism? Or even of ourselves? Individually, and as families, communities, society, humanity?

I find myself translating constantly between these perspectives (hence various switches in perspective in this article) as I live all of them daily myself: the inside perspective familiar all my life, through my own place on the spectrum alongside friends and family; anthroposophical because it's the basis of my life and work; the outside perspective as a common language when talking with those unfamiliar with the other two perspectives, and to describe diagnostic conclusions – since a diagnosis using currently accepted medical terminology is the main gateway to services, and signpost to helpful literature.

A HISTORICAL PERSPECTIVE offers clues to how 'outsider' perspectives have evolved, how 'insider' voices have been heard (or not), and what we might learn anthroposophically from such shifts.

A common 'outside' perspective has been that autistic people are 'broken' people who need 'fixing' or 'changing.' Professionals and caregivers are often keen to help in this way. But I'd like to suggest as a first step, before even considering how to help, that you take a step back, try to get a sense of what it's like to be autistic, and only then start exploring how to 'connect' with the autistic person(s) in your life. Such an approach is in keeping with anthroposophical work: to observe carefully before judging what appearances may mean, and how best to respond. This is particularly important in autism, because 'behaviours' as seen from the outside can seem so bizarre and be so misleading if you don't know what the autistic person may be experiencing on the 'inside'. In this article, you will need to observe through the words of those quoted: Try to *listen deeply* to their words, to *'live into'* their worlds.

Christopher Gilberg, one of the more insightful autism experts, stresses just how hard it can be for non-autistic people to *really* understand:

"Rationally we may understand what it means to suffer from social blindness, but we do not really understand what it means with our heart or guts. We are born with too much social intuition, we simply miss the experience. Helping people with autism requires an extraordinary, almost impossible, effort of imagination." (4, p. 71)

['INSIDE' Perspectives](#)

As you read the following accounts by autistic writers, I invite you to exercise that 'almost impossible effort of imagination':

John writes

"When I was a toddler ... my grandmother would pick me up and make faces at me ... I wasn't sure what to make of her ... I stared back, more puzzled and worried with each strange face she made. Was it funny? Was it dangerous? I could never tell. Finally, she'd had enough. "Why won't you smile at me? You're just a mean little boy!" And with that [she] plopped me down on my stubby feet and marched away ...

I was not able to fully grasp what had just happened, but I got the message that she didn't like me very much. .. A little bit sad. A little bit puzzled. Eager to return to the comfort of my imaginary wooden-block world where strange and scary grown-ups did not suddenly appear out of nowhere to pick me up and menace me ...

The inability to read the unspoken signals from other people added up to a childhood filled with anxiety." (5, pp 79-80 & 89)

John then describes life as an adult (a parent himself now) - progress bringing new pain:

"Reading about and studying body language and expression have been a big help. But there's still a gap between me and many nypicals because our responses are often very different even when we both understand the same message ... [For them] it's a gut thing, instinctive ... It's more of an intellectual process for me. ...

Yet it still hurts when people notice my different behavior ... 'You're not paying any attention to me' and 'You don't even care' are two refrains I've heard all too often. Even today it just crushes me to hear words like that, because they show the huge gap between the feelings inside of me and how the outside world perceives me. I can be crying for someone inside, and he or she thinks I'm laughing or indifferent." (5, p 95)

Sean recalls his experience as a five-year-old:

"People bothered me. I didn't know what they were for or what they would do to me. They were not always the same and I had no security with them at all. Even a person who was always nice to me might be different sometimes. Things didn't fit together to me with people. Even when I saw them a lot, they were still in pieces, and I couldn't connect them to anything ... They made me sit on a chair sometimes. It made me so very angry! I recall that they said words to me, but that's all they were, just words. I don't think I ever knew what they meant, but it didn't matter. They were interrupting me and interfering with me, and I wasn't doing anything wrong." (6, pp 20-21)

As well as having no idea what 'people' or 'words' were for, Sean had no idea that the 'rules' he'd come up with were not universal, or that others couldn't possibly know his 'rules' or 'feelings' unless he communicated them:

"I had an intense interest in dead-end streets ... Most streets just keep going on forever, but I loved the dead-ends because they made me feel safe. Every time we approached one my anticipation would skyrocket. Then what happened? Our car would pass right by! My parents would refuse to turn into the street. ... This was the message I got: They won't take me up this street because they think that something I love is somehow wrong. It didn't take me long to feel that there really was something wrong with me. After all, what harm could it do to drive up a dead-end street?" (6, pp 89-90)

Sean is now a college graduate, living independently, working as a journalist, with friends, and a close trusting relationship with his parents.

Donna describes three stages of grasping and responding to her differences:

"My first idea that there was any problem was that the problem wasn't with me, it was with the thing that was stuck on me that I came to know as my body. It was with the intangible, uncontrollable and overwhelming assaults I came to know as emotions and it was with the unpredictable, incomprehensible, illogical actions of what I came to know as people and their expectations. But me ... I figured that I wouldn't have had any problems if I could have got rid of all of those things. ...

[Later on, I learned] to feign the emotions I was expected to have ... to communicate with a copied voice and to move with mirrored movements in the absence of personal connection to my own and to learn to look as if I understood even if I didn't ...

By my teenage years, I began to be too aware of the feeling of being alien. Unable to have even consistently shared true self-expression ... I grasped the absolute emptiness of what the world held for me. My answer to this was to follow and mimic anybody who would take me along for the ride and to move through life as fast as possible so I didn't have to stop to feel how bad and out of control it all felt." (7, pp 2-3)

Donna finally started to make sense of herself and life, and to forge a way ahead with them, through her twenties and thirties. Some of what she's written since about autism makes a lot more sense than any professional text I've read. One such insight is the central role 'processing' differences play – as many on the spectrum agree:

Most autistic people can only process information slowly and consciously (although some with Asperger's speak very fast, but when doing so are usually not fully processing what they're saying). Also, most autistic people can only process one type of information at a time ('monotropism' or 'mono') - so *can't simultaneously*

-express *and* understand

-be aware of self *and* other

- be aware of thoughts *and* feelings
- process *and* monitor *and* access
- coordinate *all* the components of a process

even if capable of each of those tasks on its own, one task at a time.

Donna explains the effect of such issues on speech, and the impact on social life:

“People who are mono may access the words they intended to say -but then when they access the physical means to say [them], they may lose the thought they intended to express. Even if they can recall the words they intended, they may not be able simultaneously to access the purpose or intent behind these ... [so] the motivation of speaking gets lost so nothing is said or what was to be said comes out but sounds personally detached ...[or] whilst monitoring facial expression, they may lose track of the volume of their speech or its intonation or pace [or] whilst monitoring [those], they may lose track of their word order, or even lose track of the words ...[Then while struggling with their own attempt to communicate, they] may then have little or no ability to process simultaneously the listener’s or viewer’s response to them ... The worst part of all this is that the concept of ‘social’, which requires simultaneous ability to process and monitor and access, becomes a shattered and intangible one and, at best, an evasive, undependable and inconsistent one.” (7,pp 96-98)

Imagine having to accomplish each of those steps separately and consciously! Isn’t it miraculous that autistic people manage to speak and socialise at all?

So getting one’s system to work as a cohesive whole can be a challenge:

“I sometimes feel as though I was issued a kit instead of a ‘ready-to-use person’, and some of the components in my kit, anyway, leave me scratching my head and muttering about who decided which parts I got, but I do this with at least half a smile on my face ... daily life becomes more of an adventure than most nonautistic folks probably experience. The combination of great ability in some areas and great difficulty in others makes it quite a task for me to sort them out: “these will work as-is ... these will work with some modification ... what on earth do I do with these?” (Dave, 8a)

But beneath these processing problems, autistics often have a healthily intact sense of their inner being. As Frank describes (9):

“When I say, ‘I know where I am going’, I am referring to my spiritual being ... As an autistic, the central processing core of my physical brain is a bit catastrophic. You might compare the human physical brain to an extremely high-tech computer. My computer brain has a few bugs and several loose connections in its logic-control unit. Input gets misinterpreted, output is vague and ambiguous, and the “artificial intelligence” unit (the thinking mechanism) gets really screwed up. The physical side of me (tied in with the autistic brain) is bizarre, unpredictable, weird and out of focus with reality. On the contrary, my spiritual being is “full of fire”: joyous, undaunted, persevering, and full of life. Perhaps it is the constant conflict between my “fiery” spirit and my “desensitised” autistic body that makes my life so excruciatingly painful. I am being constantly torn apart between what I sense spiritually and what I ache autistically. It is like planning a wonderfully exciting vacation trip, and then discovering that your car has a dead battery.”

An important effect of these processing differences, is that the autistic brain is easily overloaded by too much input (sensory, social, emotional, cognitive or even (bio)chemical - household chemicals, food intolerances etc; including others’ emotions unrelated to the ASD individual, and sounds or smells too subtle for others to perceive).

School – both playground and classroom, however well managed - is often an overloading experience for autistic children: not only *sensory* but also *social* overload, as Carol and Clare describe (1, pp 52, 88 & 90)

“I was constantly on edge and aggravated when I tried to focus on language and other people talking. It was kind of like having ten radios blaring with each of them slightly off the station and trying to listen to each one of them. On the other hand, when my mother would try shutting everything off and try to get me to focus on her and what she was saying, that too was overwhelming. I would hear her words, but they just didn't make any sense. I felt like a deer caught in the headlights.”

“In particular, avoidance of eye contact causes problems, often leading a teacher to assume mistakenly that a child is not paying attention or is deliberately refusing to meet their gaze. This leads to what I have mentally classed as the “look at me” routine, where a teacher ... will repeatedly demand “look at me”, getting more and more vehement as the child becomes more overloaded and less able to do so (or finally manages to make eye contact with a blank stare, thus usually ensuring that they are incapable of attending to or absorbing the message which the teacher is trying to give them).”

“Children with Asperger's often have a real need for solitude, which at times may be much stronger than their need for contact with others. Social interaction even when desired, is still work, not “break”, for children with Asperger's, and breathing space and opportunities for escape are vital.”

Overload can cause processes to shut down, as Donna describes

“A patterned carpet or wallpaper ... floods my senses and shuts down a lot of the ability to understand what I hear.” (10, p 97)

Autistic individuals differ as to which processes work best and which shut down when overloaded. It could be thinking that shuts down, or emotions, or body awareness. (Remember how Donna called her body the “thing stuck on me”? Sometimes the only way she could identify thirst was by touching her mouth to see if it felt dry; or the need to urinate by pressing over her bladder and observing what happened).

Such ‘shutdowns’ can be fleeting or last for hours, weeks or even years, making it even harder for the autistic child to make sense of the world. The human world in particular may make little sense, as for those quoted earlier, who experienced even loving family members as ‘things’ and human speech as meaningless ‘sounds’. Some, like John, Sean and Donna, gradually learn to make sense of it all; others may not, or may need much insightful help to do so.

For some, meaningful connection began by connecting with animals or objects. Dawn describes how gorillas were for her that bridge to understanding the human world. After years living homeless and lost, her ASD unrecognised, her social breakthrough began with the following chance encounter with gorillas at a zoo:

“Through the rain and a lifetime of waiting, [the gorillas] did not look at me, but they knew I was there. I sat still. I sat still. I sat for an hour, two, and three. I sat still. They didn't look at one another, and they didn't look at me. Instead, they looked at *everything*. They were so subtle and steady that I felt like I was watching people for the first time in my whole life, really watching them, free from acting, free from the oppression that comes with brash and bold sound, the blinding stares and uncomfortable closeness that mark the talk of human people. In contrast, these captive people spoke softly, their bodies poetic, their faces and dance poetic, spinning conversations out of the moisture and perfume, out of the ground and out of the past. They were like me. ... [then after many further visits to them] ... As I learned their language, I began to have a context for human communication that made it meaningful to me in a whole new way. Very cautiously, I tried to apply the things I'd learned from the gorillas in social situations.” (11, pp 93 & 136)

Dawn went on to become an eminent 'interdisciplinary anthropologist' and author of books, including a moving account of her own path to parenthood.

Why do autistic folk learn so differently about the world in the first place? Is it because direct human interaction is so confusing, overwhelming ('brash and bold' as Dawn put it)? Or lack of that 'instinct' by which the human world is automatically central to the infant's world, such that non-human foci may become central instead? As Daina, co-editor of our collaborative book 'Women from another planet?', suggests:

"One of my earliest memories... is of a texture that communicated an infinite softness to me and was very, very important. I also remember that this love of this texture somehow caused people to be angry with me, and to punish me. Their anger did not make me love the texture any less, but it did teach me, early on, that what I perceive and love and what other people perceive and love, are two different incompatible things. I learned to be a quiet, private child ...

Most people who see my work as an artist/filmmaker notice the textures, but they assume ...that I am like them with this added fixation on textures. It is not that way. My world is organized around textures ...This way of seeing things replaces the neurotypical way of seeing things. All emotions, perceptions, my whole world and how it has been created in my mind have been heavily influenced by textures ...

A pattern started to form in my mind-wiring when I was a baby ... The most important ... [were] visual things, textures particularly, but also shapes, colours, movement ... Secondary things, like people's faces, were not that important. ... As a child I was constantly aware that my perceptions were different from everyone else's around me. Most normal or NT children's way of organizing ... information is either inherently similar to their parents or, perhaps by watching and perceiving their parent's reactions to things, their mind wiring comes into line with that of their parents. This did not happen with me, and I knew that my world was not the same *literally not the same*, as anyone else's. This was, and is, the absolute, constant truth that underlies every moment of my life. ...

I was always blamed for this. People would say, "If you could just enjoy the same things that other little girls enjoy, you would be much happier."... I knew it was possible to do things you don't want to do, but how do you make yourself perceive what you don't perceive, or feel what you don't feel? And yet people seemed to think this would be possible for me, like turning on a light switch." (12, pp 85 & 87)

An autistic child may respond in a variety of ways to this sense of confusion, of being somehow 'wrong' in others' eyes. Some like Daina continue to pursue the objects of their passion behind a 'quiet private' façade.

Others dissociate, as Joseph describes

"At the age of five or six I felt that my soul was dying and I couldn't stop it or even make anyone understand that anything was wrong. I think I learned to 'pass for normal' as was expected of me, by dissociating severely." (1, p 85)

Some try a succession of ways to manage their social confusion. Susan writes:

"I realized that if I asked to be the *servant* or *child* in pretend play, that someone would always direct me. That way I didn't need to figure out what the game was all about. It was the first of many ways I learned to hide my social confusion ...

I had language skills, but it didn't do me much good ... It was better to remain silent. As long as I was being *good*, people left me alone. I learned that life was easier for me that way. ... less painful ...

Social skills did not come naturally or easily. I was overwhelmed with trying to figure it all out on a cognitive level ... I went robotic. I allowed others to direct and control me ... and I hid what remained of 'me' deep inside a world of my own, where no one else was allowed

... I still experienced emotions, but only when I was in *my* world, not when in *the* world. I built a wall between the two and it made life simpler for me.” (13, pp127-130)

“As the demands on me grew, I developed different ‘characters’ that had specialized knowledge and skills to ‘perform’ as others expected me to perform.” (14)

Quiet compliance comes at a cost though, as Clare comments

“Some children with Asperger’s adopt a strategy of robotic compliance, passively obeying every instruction, never initiating anything or volunteering information, because it makes it more likely that people will leave them alone ... The teacher may believe they have “won” because a child does not disobey them; in fact they have lost any opportunity for the child to learn from them.” (1, p 94)

For some, lack of playmates can be deeply distressing, as John describes

“Many descriptions of autism and Asperger’s describe people like me as “not wanting contact with others” or “preferring to play alone.” I can’t speak for other kids, but I’d like to be very clear about my own feelings: *I did not ever want to be alone.* ... I played by myself because I was a failure at playing with others. I was alone as a result of my own limitations, and being alone was one of the bitterest disappointments of my young life. The sting of those early failures followed me long into adulthood, even after I learned about Asperger’s.” (15, p 211)

By adulthood, John had learnt to relate by observing and analysing:

“What I’m lacking with regards to the nypical gift of reading people instinctually, I compensate for with good observation skills and logical analysis... It’s as if I have to build a behavior data-base for every single person I meet in life.” (5, pp 99 &102)

Some experts consider this drive to consciously make sense of the world in terms of ‘systems’ is *the* fundamental difference between autistics and NTs. In fact, autistic thinking may differ from that of NTs in many ways, also differing from one autistic to another. Each way of thinking has its advantages and disadvantages – whether thinking in pictures, textures, numbers, spatially, or, as Sola describes, ‘branches’:

“*Branched* thinking happens when an idea bears several possibilities for development. It is hard for me to choose one and discard the others, till I have examined all of them. So, after dwelling some on one possibility, I have to go back to the original idea and do the same with the other possibilities. This way of thinking ... may be a disadvantage, as it is slower than purely linear thinking. Normally, a person would choose only one possibility, the most probable one, or the one commonly agreed among other people, and then follow only this one linearly and never come back to the others (or never even realize that there may be other possibilities). This is usually hard for me to do, as I do not always know what should be more probable, or ... [how] to prioritize and give up the other possibilities. This way of thinking can be very annoying to other people if I try to employ it in a conversation, because it seems as if I am breaking the continuity of the subject. It also makes multiple-choice questions extremely annoying for me. But branched thinking makes me a very good programmer and is conducive to science. I use it for problem solving in my own life.” (16, p.24).

So if an autistic child is slow to answer you, or goes off on tangents, they may be busy ‘searching the branches’ – and if you’re patient, they may come up with an unexpected but brilliant idea from exploring a ‘branch’ that others overlook.

However hard an ASD child tries to apply social rules, social skills training etc., it’s unlikely they’ll ever ‘seamlessly fit’ in an unstructured social group, even though they may manage topic-based conversations and structured games, or relate well 1:1 or with those of a different gender, culture or age-group. Jane describes this difficulty of ‘fitting’ with her peer-group:

"I was enrolled in a Girl Scout Camp one summer when I was about eight. I was a cheerful child ... I looked forward eagerly to the one night at the end of the term when, instead of going home at the end of the day, we would be camping out in tents overnight Every day I participated in whatever activities the staff had programmed. ... I helped write a little song for my group (Bluebirds) to sing. I went where I was told, did what I was told to do, never objected or fussed. It was only on the final night, inside the tent with the other Bluebirds, that I became aware of something odd ... Something had happened to them, individually and as a group, during the weeks of the camp, that had not happened to me ... The other girls had become friends with one another. Alone there, with no adult present to direct us, they chatted and whispered and laughed and interacted with seamless ease. How did they know what to say? They weren't talking about anything, and yet they talked constantly. My conversation was limited to specific subjects, not including anything as nebulous as girtalk or smalltalk. Moreover, they seemed to know each other in a way they didn't know me -- and I certainly didn't know them. I had been with them as much during the summer as they had been with each other. I had done everything they had done (as far as I could tell). And yet I was a stranger there. The only stranger in the tent. ... It was as if everyone else had studied a script and learned their parts beforehand. In fact, of course, they were improvising brilliantly, thanks to the social code capacity programmed into their brains." (16 p 41; 17 pp 158-159)

Lack of such 'social code capacity' affects more than friendship – as Clare writes:

"[We] seem to be particularly vulnerable to the effects of bullying, often being genuinely traumatized by what others would class as "mild" teasing ... Most [NT] children can interpret a comment like "You're an idiot" in terms of the other's motives ("he's just being mean", "they're saying that to upset me," "she's lying") and so deflect it at least partially from a direct impact on their self-esteem. Often unable even to name what is happening to us as "bullying" ... [we] just absorb it, and either feel that we *are* idiots or end up expressing our pain by lashing out." (1, p.86)

Teachers' attempts to help may even add to the confusion, as Clare recounts

"A teacher's attempt to "reach" a child with great kindness usually appears, to a child with Asperger's, as the teacher mysteriously talking in a strange, "syrupy" voice and insisting on patting them on the arm or shoulder. When people behaved like this to me, my only thought was how to escape as quickly as possible from this baffling and therefore perhaps dangerous behaviour. ([Despite high IQ] it wasn't until the end of my teens that I worked out what the intention behind it was). In particular, for a teacher to respond in an emotional "comforting" way when a child is stressed is often disastrous; a child with Asperger's who is upset or anxious will be having enough trouble handling their own emotions without being expected to process and respond to someone else's."(1 pp.96-97)

Conversely, the child on the spectrum is commonly misunderstood by teachers:

"Asperger's could be described as the most invisible of all invisible disabilities; even when a child has been diagnosed, many teachers, however well-meaning, find it hard not to interpret their behaviour as they would that of another child and see them as being intentionally rude, etc. ... This perception can be due at least in part to manner: My tendency to ask difficult questions in a flat voice that sounded as if I was being sarcastic ... [My] literal understanding ... I had been told by everyone that I should tell the truth ... so I couldn't understand why people got upset when I told them they were stupid. Literal understanding of instructions was typically interpreted as sarcasm or "trying to be clever." ... Many teachers react with hostility when they see a child apparently usurping their authority by telling off another child who has misbehaved (often in language and tone which may be an uncomfortable mirror of the teacher's own behaviour). It is hard for them to understand that this is logical behaviour for a child who has no innate understanding of hierarchy, and who therefore has learnt by observation that this is what is to be done when rules are broken. ... Yet these behaviours arise from a sincere belief in the rules

and an anxious concern that they be kept. ... [Furthermore] a pupil with Asperger's will not be able to distinguish between "important" and "unimportant" breaches of rules. ... My major memory of primary school, basically, is of spending a huge amount of time being told off and having no idea why, especially as it seemed to happen when I thought I was being most helpful." (1, pp 90-92)

'Social radar' and 'executive function' (grouped here with 'insider' perspectives, being among the most problematic issues for adults on the spectrum, and discussed extensively within the autistic community, though little mentioned in professional autism literature – in fact 'social radar' is a term coined by 'insiders').

Most NTs can 'wing it' through the ever-changing social nuances of a day, unaware they're continuously using both 'social radar' to detect social signals, and 'executive function' to monitor, predict and adapt. Without those tools, autistics depend for navigation on a predictable environment and consciously planned scripts (18, pp 20-27), and are likely to feel lost and anxious if the 'what, when, where and how' are unclear or change without warning – as Dave describes

"When several unpredictable things happen one after the other, I feel like my understanding of the world is collapsing ... as if I am trying to hold onto something very important and it is becoming slippery in my hands ... Or imagine standing in the ocean, with the water almost up to your mouth, and seeing waves coming at you, and feeling the sand beneath your feet shifting." (8b)

What's usually needed when losing grip of that slippery reality, is not a hug or "don't worry dear, it'll be alright", but concrete information to hold onto, that's not slippery - like the details of what's going to happen when.

'Social radar' depends on the ability to detect and interpret non-verbal signals, and to 'read between the lines' of verbal messages. 'Executive function' (EF) refers to certain complex brain functions achieved – comparable to conducting an orchestra - by skilful coordination of its component 'instruments'. Examples are

- Alertness: It's thought some 90% of ASD children are either too under- or too over-aroused for optimum brain functioning.
- Memory
- Initiation (carrying out an action without being prompted by another person or by the familiarity of one's own rituals or routines): problems with which make it hard to respond; or to start, stop or shift from one thing to another
- Self-awareness, self-monitoring and self-management (such as controlling impulses and managing strong emotions like anxiety, frustration or excitement)

Executive function issues thus make it difficult to organize, plan, sequence, multitask, navigate busy situations, make sound judgments and decisions (by knowing what options one has, weighing them up, prioritizing etc), solve problems, resolve conflict etc.

In other words most aspects of modern daily life are difficult for those on the spectrum, except tasks requiring singular focus, where they may excel; and planned practised routines. Perhaps one of the reasons they usually cope best with structure, rhythm, repetitive tasks, familiar pastimes etc is that these may be their only 'break' from constant effort (even 'social time' being effortful) and from the associated fatigue, stress, meltdowns etc.

Clare and Dave describe some of these difficulties:

Attention-shifting:

"I could not shift my attention from one subject to another by an act of will; it seemed to take a sort of mental "wrench" to manage it at all and the level of effort required meant I could only sustain it for short amounts of time before I switched off and was unable to take in any more information." (1, p 62)

Remembering without prompts:

"I couldn't think of anything I had done at the weekend, although I know that if someone had prompted me with specific question such as "Did you...?" I would have been able to answer accurately. I just couldn't access my memories on demand and I was terrified and frustrated at not being able to do what the teachers were telling me to do. Although I was very verbal, I didn't have the communicative skills to spontaneously say that I couldn't remember, so I made up stories instead." (1, p 63)

Modulating emotions

"If anyone has used a drinking fountain which is either completely off or completely on, that's a decent model for my emotional responses. It's very difficult to get a reasonable amount of water from the fountain – it takes a very delicate touch, and the slightest disturbance can either shut it off or have it stream all the way to the ceiling." (8a)

[The invisible end of the spectrum](#) (a term coined by me in a presentation to the Inaugural World Autism Congress) refers to those whose autism is not obvious on the surface, so often missed or mis-diagnosed (20). For a variety of reasons, this applies particularly to those who are female, gifted, or adults.

For instance autistic features may not be obvious beneath

- coping or compensatory strategies
- another condition dominating e.g. anxiety (even when triggered by autism)
- advanced skills belying 'deficits': for instance eloquent vocabulary but poor comprehension of social-emotional language; or social skills that are merely copied or rote-learned, without grasping the nuances of when, where or how to use them

As Gunilla Gerland (counselor and educator, on the spectrum herself) writes

"The real paradox here is that the more the person [on the spectrum] learns to 'blend in', to 'behave' or 'seem' like others ... the smaller the chances are that he or she will be met with an understanding of their difficulties." (21, p154)

And autistic presenter Dave Spicer (8a):

"Having a good interface, means that the amount and scope of an individual's efforts at conformity would go undetected until they either failed spectacularly or led to the person breaking down under the accumulated stress ... What is especially frustrating to hear is the opinion that some of us, rather than being autistic, merely have a few "autistic-like traits". Well, suppose a wheelchair athlete came to a stairway and managed to get up it by dragging himself or herself with upper-body strength. Would it be reasonable to say to the person, "You are not disabled; you only have a few disabled-like traits"? I think not."

Thus, the terms 'low-functioning' and 'high-functioning' are best avoided. Based on superficial impressions, these risk ignoring both the hidden potential of autistics deemed 'low-functioning' and the subtle difficulties of autistics deemed 'high-functioning'.

Furthermore, functioning

"commonly varies in the same person both across functional areas and over time (short- or long-term) ... We believe that all autistic lives are worthwhile, and even those who face more difficulties may lead a meaningful life, if given appropriate supports" (22).

The autistic community and 'neurodiversity':

Like the deaf community, autistic adults, embracing their neurological difference, began from the 1980s on to build an emergent 'autistic community' (22, 23), welcoming and accommodating individuals diagnosed or self-identifying anywhere on the spectrum. By the 1990s, this community had developed a unique 'culture' and begun to hold its own conference-retreat events such as Autreat in the USA www.autreat.com and later Autscope in the UK www.autscope.org. Meeting fellow-autistics for the first time was for many like a life-line: as one man, diagnosed at the age of 70 after seeking relevant help in vain from over 20 psychiatrists and psychologists, describes his first meeting with fellow-autistics as "like coming ashore after a life of bobbing up and down in a sea that seemed to stretch to infinity in all directions." (24, p247)

Autistics had begun to write books too – individually and collectively – initially autobiographical, but now on many aspects of autism, including what I for one find to be the most insightful books on the nature of autism, coping strategies, etc.

The term 'neurodiversity' was coined in the late 1990s for the movement whereby members of the autistic community, together with self-advocates representing other developmental conditions such as ADD and dyslexia, more openly celebrated and promoted their difference from neurotypical peers as a positive identity, not necessarily a disability (25). Neurodiversity as a concept considers atypical neurological development a normal human variation to be accepted and respected – just as differences defined by gender or race are (or should be). From this perspective, ASD is considered not something to be cured, but rather a way of being, with both disadvantages needing accommodation, and advantages that can make a unique and positive contribution to society – and have in fact already contributed to the evolution of human culture and technology.

The new millennium sees the autistic community increasingly reach into other fields such as advocacy on matters of public policy, and autism research which is, in some places at least, beginning to welcome autistics as equal partners with academics at all stages of autism research, from choice of topic and design through to interpretation.

Jim Sinclair, one of the first pioneers of autistic community and self-advocacy, coined the phrase '*self-narrating zoo exhibit*' to describe the role autists were often expected to play in NT-centered autism forums and conferences in the 1990s (23). Now two decades on, 'autists' and 'aspies' are finally starting to gain respect as leaders in the understanding of, and approach to, autism spectrum conditions –as Michael John Carley writes:

"Their worth was becoming redefined ... Suddenly it wasn't the experiences of people on the spectrum that were of importance and insight, it was also their *opinions*. They were figuratively moving from existing as zoo exhibits, to becoming *talking zoo exhibits*, and then to themselves becoming the zoologists." (26, p40)

For parents too

"the emergence of the neurodiversity movement has offered ways of fighting for a better future for their children that don't depend on hopes of recovery. It has also made something available to young people on the spectrum that previous generations of autistic people never had: role models of happy, creative, and socially engaged autistic lives ... able to translate [their child's] world into terms they can understand." (24, p464)

Current 'outside' views of autism

Bearing in mind how dramatically this has changed over the past eighty years, and how much it may yet change in the future, the current prevailing 'outside' view of autism is of a spectrum of conditions, ranging from obvious to subtle, having in common a so-called 'triad of social impairments' (or 'social differences' as many on the spectrum prefer to call them) – though in the latest diagnostic manual (DSM-5) the first two are now grouped together and 'sensory issues' have been tacked on. This 'triad' refer to

- *Social interaction* and *Social communication* (verbal and nonverbal – particularly those aspects involving reciprocity and 'social radar')
- *Social Imagination* or *social cognition* (as measured for instance by the degree of flexibility of thinking, interests and behaviours: the ability to 'imagine' what another person's thoughts and intentions are, to predict social consequences, to think of alternative perspectives or solutions, to adapt to new situations, to share imaginative play etc)

Disguising or colouring those underlying differences, are the various adjustment strategies an ASD individual may have adopted to cope with being 'different'. Dr. Tony Attwood describes the four most common as (27, p23):

- *escape into imagination* – for instance to create a fantasy world in which one is more successful, or simply to escape everyday reality
- *reactive depression and / or self-blame*
- *denial and arrogance, blaming others* - a response often held as the stereotype of autism, but it's only one of the possible ways of coping, albeit a troublesome way; perhaps the reason these cases are most easily noticed and diagnosed; perhaps also behind some of the negative autism stereotypes.
- *Imitation*: adopting others' attributes or even whole 'personas' as a way of passing as normal (often hiding how lost one's 'real self' may be)

Common myths and stereotypes still prevalent in some circles today (including some professionals) portray autism as a condition primarily of childhood; its 'sufferers' as nearly all male, not wanting friendship; and incapable of feelings, empathy, humour, imagination, being caring or cooperative – all of which, however, are inaccurate (as quotes in this article suggest), hurtful, and contribute to ASD being missed. Fortunately the more shockingly dehumanising views of the last century are only occasionally echoed now, as for instance the highly respected medical specialist who in 2001 described autism as "a terminal illness . . . a dead soul in a live body" (24, p431).

Causes and models

Of the many 'outsider' theories about cause, none fully explain ASD. The most touted are (10, pp.97-133):

- deficits of 'theory of mind' and / or empathy (theories now being increasingly challenged)
- 'executive function' deficits
- differences in cognitive style e.g. lack of 'central coherence' (the predisposition to focus on details at the expense of the whole); or the tendency to 'systematize'
- social-developmental theories (e.g. 'dyscultural' children; impaired emotional relatedness, impaired intersubjectivity)

As evident in the terminology, the above theories come from what's known as the '*medical deficit model*.'

Completely different is the '*social model*' of disability, which considers a given condition as a 'difference' that only becomes disability because of society's response to it. Under this model "AS is a neurological difference that often *turns clinical* in a culture that doesn't value AS strengths" (28, p xix): one of a cluster of conditions linked under the umbrella term 'neurodiversity.' In such conditions the brain is considered 'differently wired' compared to the NT brain. The value given to such differences will vary with context and perspective:

A simple shift of perspective from the usual 'medical' stance, can depict ASD as an advantage, and NT a pathology. For instance the 'Diagnostic criteria for Asperger's Disorder' have been reframed as the 'Discovery criteria for Aspie' (29), defined by a triad of autistic strengths and talents instead of a triad of impairments, as this extract shows:

A qualitative advantage in social interaction, as manifested by ...

- peer relationships characterized by absolute loyalty & impeccable dependability
- interested primarily in significant contributions to conversation; preferring to avoid 'ritualistic small talk' or socially trivial statements ... etc

Fluent in "Aspergerese", a social language characterized by ...

- a determination to seek the truth
- conversation free of hidden meaning or agenda ... etc

Cognitive skills characterized by ...

- original, often unique perspective in problem solving
- avid perseverance in gathering & cataloguing information on a topic of interest ...etc"

Conversely, 'neurotypical syndrome' could be defined as a disorder – as manifested by

- "delusions of superiority: assuming their experience of the world is either the only one, or the only correct one
- intolerance of difference in others
- rigid adherence to apparently meaningless social conventions
- thinking determined by social acceptability rather than truth
- social dependence: difficulty coping with being alone... etc."

This website for the 'Institute for the study of the neurologically typical' (30), created by autistics, is a playful reminder that it's all a matter of perspective!

HISTORICAL perspectives:

A newly-published book *NeuroTribes* by Steve Silberman (24) tells of the fascinating – often horrifying – evolution of attitudes and ideas about autism, its causes and management over the past 80 years, as shaped by the quirks of politics and personalities, fact and fiction, historic events and trends in medical / psychiatric thinking – a journey through dark times and false hopes to a hopefully more enlightened present that is only slowly throwing off the stigma and stereotypes of the past. [NB Quoted text in this “historical” section of the article is all from this book unless otherwise referenced].

Surprisingly, though the concept of autism as a broad spectrum of neurodiversity affecting all ages, bearing gifts as well as challenges, is only now receiving widespread recognition, it turns out to be a very old idea, proposed by Hans Asperger some 80 years ago, but till recently “forgotten, along with “the story of a brave clinician who tried to rescue the children in his care from the darkest social engineering experiment in human history.”.

Asperger (described as a “gifted, eccentric and solitary” child himself) was an Austrian physician who identified strongly with the puzzling boys that “noone else wanted to deal with”, coining the term *autismus* (or alternatively *autistic psychopathy*) for the condition we now know as ASD, the focus of his work from 1931 onwards. He regarded this condition as a

“natural entity [whose] distinctive characteristics were already familiar in stock characters from pop culture like the “absentminded professor”... [that persisted] throughout the whole life-span... [and] encompassed an astonishingly broad cross section of people, from the most gifted to the most disabled. [He considered] the innate gifts of these children were as central to the condition he was describing as their social difficulties ... [Their] potential to become innovators in their fields of interest [was] precisely because they were constitutionally unable to take things on faith ... This distinctive cluster of aptitudes, skills, attitudes, and abilities [he called] *autistic intelligence* ... making the bold suggestion that autistic people have played an unappreciated role in the evolution of culture.”

In fact several of these children Asperger followed up right through to their adult lives, achieved outstanding success – one going on to win a Nobel Prize for Literature; another becoming a brilliant scientist, who, soon after starting university, “proved a mathematical error in Newton’s work.” (10, p.10).

Asperger worked with these children as one member of a team of teachers, therapists and doctors at the *Heilpädagogik Station* in Vienna (24, 31), a clinic founded in 1911 by physician, schoolteacher, and social reformer Erwin Lazar, with the mission

“to find individualized approaches to education that would enable these children to make the most of their innate gifts while ensuring that they had the resources to cope with the challenges of their disabilities ... Instead of seeing the children in his care as flawed, broken, or sick, he believed they were suffering from neglect by a culture that had failed to provide them with teaching methods suited to their individual styles of learning. He had an uncanny knack for spotting signs of potential in every boy and girl no matter how difficult or rebellious they were alleged to be ... [and] developed an approach to helping each child attain his or her potential based on the nineteenth-century concept of Heilpädagogik (“therapeutic education”), for which Asperger considered ‘his boys’ to be in the most urgent need (31).

[Individualized ‘treatment’ involved] “an integrated program of music, literature, nature study, drama, art, speech therapy, and athletics”

“Diagnosis was based on a method of intensive observation ... ‘down to their very toes’ ... the criterion for classifying behavior as normal or abnormal [being] the challenges that it created for the individual child, not whether it strayed from an idealized template of psychological health ... [and going beyond diagnosis] to determine the innate capacities

of the child ... what will best assure his personal happiness, security and social welfare, what his right place is in the family, society, what are his personal goals and ambitions, and how these can all be realized.”

Near the end of Asperger’s 1943 thesis, he wrote

“Possibilities of social integration which one would never have dreamt of may arise in the course of development. This knowledge determines our attitude towards complicated individuals of this and other types. It also gives us the right and the duty to speak out for these children with the whole force of our personality.”

In the historical and political context written, one might well surmise that “Asperger was speaking out [thus] for the sake of children all over Europe who had not yet been murdered by a monstrous idea of human perfectibility— an idea that his supervisors, who were fervent Nazis, had imported from America.”

Silberman describes the eugenics movement, with its views on disability as well as race, as “not fringe science ... [but] the perspective of a broad swath of the scientific mainstream in America after World War I, backed by ongoing research in the United States and Europe funded by major foundations.” Campaigns to sterilize the disabled “received a significant boost from experts who declared that people with developmental disorders were not only cognitively but morally impaired”. Some American eugenicists, considering sterilization too slow, advocated euthanasia as “a practical, merciful and inevitable solution ... [to be] applied to an ever widening circle of social discards” – an idea readily adopted by the Nazis. As one Vienna neurologist urged his colleagues, “It is our duty ...to exterminate everything that is morbid, impure, and corruptive.”

It was in this “climate of rabid fanaticism”, in 1938, that Asperger gave “the first public talk on autism in history.” After paying lipservice to the regime, he proposed “a radical way of thinking about cognitive disabilities that was in direct opposition to the dogma of racial hygiene:

““Not everything that steps out of the line, and is thus ‘abnormal,’ must necessarily be ‘inferior. ... The good and bad in a person, their potential for success or failure, their aptitudes and deficits— they are mutually conditional, arising from the same source ... Our therapeutic goal must be to teach the person how to bear their difficulties. Not to eliminate them for him, but to train the person to cope with special challenges with special strategies.” Outlining how the special gifts of these children were inextricable from their impairments, he asked “Who among us does not recognize the autistic scientist whose clumsiness and lack of instincts have made him a familiar caricature, but who is capable of extraordinary accomplishments in a highly specialized field?” He made a plea to his colleagues to “never give up” on these children ... [urging that] by helping them live up to their full potential, his colleagues would be benefiting society as a whole — a goal even a fervent eugenicist could support.”

“Unfortunately, his strategy of accentuating the positive to his Nazi superiors— shaped by the knowledge that the lives of his young patients were at stake— would contribute to widespread confusion in the coming decades. ... Many clinicians and historians have assumed that he saw only ‘high-functioning’ children in his practice, which ended up obscuring his most important discovery ... [that] autism was “not at all rare”, was found in all age groups, and had a broad range of manifestations ... In other words, it was a spectrum. Once you knew what to look for, you saw it everywhere.”

“Asperger apparently refused to report his young patients to the Reich Committee, which created what he described in a 1974 interview as “a truly dangerous situation” for him.

Twice, the Gestapo showed up at his clinic to arrest him ... At one point, Asperger suggested to his superiors that his little professors would make superior code breakers for the Reich.”

His clinic was eventually destroyed by Allied bombing near the end of World War 2 (Asperger himself surviving, having been sent to serve in the medical corps). By the end of the Second World War “more than two hundred thousand disabled children and adults had been murdered during the official phases of the disability euthanasia programme, as well as “thousands more killed in acts of “wild euthanasia” by doctors and nurses on their own initiative ...[Asperger’s] concept of autism ... was buried with the ashes of his clinic and the unspeakable memories of that dark time.” – not to be ‘rediscovered’ till the 1980s when his work was translated into English for the first time.

Meanwhile, psychiatrist Leo Kanner in the USA was simultaneously defining autism as an extremely rare and uniform condition affecting young children only, and caused by cold-hearted “refrigerator parents” – the latter view further reinforced by the popular 1960s book *The empty fortress* by Bruno Bettelheim (like Kanner, a European émigré who had “come into psychiatry through a back door”), by the prevalence of psychoanalytic approaches, and by active suppression and / or dismissal of Asperger’s [un-translated] work as “unworthy of serious consideration.” Individuals who might have fitted Asperger’s broader criteria were given other diagnoses – usually mental retardation or schizophrenia – but whichever the diagnosis, such children were generally institutionalized and treated brutally with measures “usually reserved for ...intractable adult psychotics.”

A new view began to emerge in 1960s USA through the work of Bernard Rimland, a Navy psychologist with an autistic son, whose book *Infantile Autism* re-established autism as “an inborn condition based in genetics and neurology rather than the complexities of the developing psyche.” To treat this, Rimland promoted biomedical treatments (diet, supplements etc) and “forged an alliance” with psychologist Ole Ivar Lovaas to develop Applied Behavior Analysis (ABA), a form of behaviour modification that included aversive treatment, promoted as “training autistic children to become indistinguishable from their peers”, Lovaas having persuaded his mentor Skinner that [autistic children] were the exception to the rule of not using punishment on human subjects, as they “are not people in the psychological sense”. ... Soon a “rage for ‘behavior mod’ swept the field, hastened by a lack of professional standards and ethics” to guide these.

Besides the direct effects of such approaches on autistic individuals and families, the popularizing of the “refrigerator parent” view attached stigma and shame to autism, while the promise of full recovery through the use of ABA and biomedical treatments, focused the newly formed parents’ movement on an “endless quest for a cure.”

Kanner’s narrow view of autism was finally overturned by Dr Lorna Wing’s team’s re-discovery of the full range of presentations in late 1970s UK, the translation into English of Asperger’s work, inclusion of the broader spectrum in psychiatric manuals, and popularizing through media portrayals. However, the sudden increase in numbers diagnosed that ensued raised fears of an “autism epidemic” (despite evidence that this merely represented the broadened criteria and increased awareness) – once again diverting attention and resources into a search for causes (such as vaccines and environmental toxins) and cures, rather than measures to “improve the understanding, services and resources to help autistic individuals live better lives.”

What might we make of all this from an ANTHROPOSOPHICAL perspective?

When asked “what is the ‘constitutional nature’ of an autistic child?”, I would have to say, from the thousands of autistic people I’ve known, that I have been unable to identify such a thing as a single ‘constitutional picture’ for autism. Nor do I think it a useful pursuit: autism is by nature a complex, individually variable condition, and attempting to ‘rein it in’ into a common ‘constitutional picture’ of autism, seems overly simplistic. I Instead, I would seek out the unique gifts, challenges and meaning for each individual.

However, as anthroposophical doctors, we are also encouraged to ponder the meaning of a condition beyond the individual affected: What could autism mean for society, for mankind? What spiritual challenges might it pose for us all?

Firstly then, let’s consider what benefit autism and other forms of neurodiversity might bring to our world:

Paul Grobstein writes of biological diversity in general:

“The biological process aims to produce variants. This is the only way to be prepared for unknown challenges, times when the environment ... changes in unpredictable ways. It is the variants which provide the basis for dealing with such challenges.” (32)

According to Thomas West, relating this to human culture, neurodiversity may have a “deep survival value” for the human race (33) - we need many kinds of ability, and no individual can have all kinds :

“We should encourage diversity not only to be civil, respectful, humane and just, but also because we have a particular stake in diversity that is rarely, if ever, fully articulated. We want there to be people who have abilities we do not yet know that we need, abilities that we have never tried to measure.” (33, p.276)

Of autism, the author of *Neurotribes* writes:

“In recent years, researchers have determined that most cases of autism are not rooted in rare de novo mutations but in very old genes that are shared widely in the general population while being concentrated more in certain families than others. Whatever autism is, it is not a unique product of modern civilization. It is a strange gift from our deep past, passed down through millions of years of evolution ... Neurodiversity advocates propose that instead of viewing this gift as an error of nature— a puzzle to be solved and eliminated with techniques like prenatal testing and selective abortion— society should regard it as a valuable part of humanity’s genetic legacy, while ameliorating the aspects of autism that can be profoundly disabling without adequate forms of support. They suggest that, instead of investing millions of dollars a year to uncover the causes of autism in the future, we should be helping autistic people and their families live happier, healthier, more productive, and more secure lives in the present.” (24, p470)

This, the author adds, would also help human society to reach its full potential.

West points out (33), as had Steiner (2) and Asperger (24) earlier, how the ‘disability’ of such conditions may be inextricably linked with its ‘gift’ - like the flipside of a coin. Eliminating the alleged cause of the ‘disability’ of such conditions, risks also eliminating its ‘gift.’ This might occur on either a population level (as in programmes to sterilise or euthanise those considered disabled) or an individual level (as in selective abortion, or certain treatments – for example the autistic savant-artist Nadia (34), when subjected to intensive training in verbal and social skills, permanently lost her extraordinary talent at drawing, though her progress socially was still so limited as to confine her to an institution for the rest of her life).

Turning now to how badly autistic people were treated for much of the past 80 years, it is sobering to consider that such shocking large-scale acts of cruelty and arrogance, have a similar basis to everyday acts of bullying, prejudice etc that are still with us today, and call for every one of us to examine our personal conscience. In a world where we seem to be forever blaming someone other than ourselves, it may be reasonable to point the finger at a regime (Nazi Germany) for atrocities against the Jews and the Disabled, but who of us remembered that eugenics originated outside Germany, sanctioned by a majority of scientists? Or to blame the ignorance of an era now past for sanctioning eugenics, “refrigerator parent” theories, or electric shock treatment for children deemed to be “not human in the psychological sense” – yet those were not the only options available. At the self-same times and places that sanctioned and popularised those measures, lived people like Rudolf Steiner, Erwin Lazaar, Hans Asperger and Lorna Wing, working and advocating for very different approaches. Within World War 2 Vienna, hospitals were the site both for the euthanizing of disabled children, and for the *Heilpädagogik Station*.

To quote one *Neurotribe* reviewer:

“Silberman delineates the legacy of our collective acts of humanity and inhumanity toward those who are different ... a narrative that is as much about how we treat each other as it is about autism ... [revealing] not only the multifaceted features of the neurotribe known as autistic people but also the affiliative inclinations of all humans, the way we gather, clamouring, and build exclusive ways of being around shared beliefs — for better and for worse ... when it comes to how society has treated [them], it’s neurotypicals who seem to exhibit the most glaring lack of empathy.” (35)

It’s as though there’s something in the nature of autism that can bring out the very worst or the very best in humanity’s response - by individuals by society. So perhaps autism is a call to each of us – autistic or neurotypical, professional or lay – to examine our own work, our own conscience, our own way of meeting those who come to us with ‘differences’; and also to look at the social fabric of the world we live in. To what extent do we act from our individual conscience? To what extent are we swept up by the lure of ‘miracle cures’ touted in popular or professional literature, or by the personal safety of aligning with a social group? As Asperger pointed out, the difficulty the autistic individual has to ‘fit’ in a social group, may be a social disadvantage for that individual, but an advantage to society.

As parents, teachers, therapists and doctors, we might well examine deeply where we each stand on the questions posed within our own vocation. As a doctor myself, I question the ‘biomedical’ movement: a form of complementary medicine that on the surface looks to fit well with anthroposophical medicine, but some aspects of which I have grave concerns about – such as the absence of ‘insider’ or ‘spiritual’ perspectives in the their practitioner training programmes I attended; and the focus on ‘cure’ - driven philosophically and often economically by groups like CAN (‘Cure Autism Now’) and DAN (‘Defeat Autism Now’) and the profits their associated manufacturing and testing laboratories stand to gain through the promotion of such approaches. I’ve heard practitioners talking flippantly about how easy, fun and lucrative it is to ‘cure’ autistic children - often targeting the very behaviours that ‘insiders’ know to be helpful adaptive strategies, however bizarre they might appear.

My own approach to those autistic clients and their families for whom I consider biomedical interventions such as diet may have a useful role, is to describe such interventions not as a cure but as a way to help fine-tune processing, relieve stress, and

help them function better in a world still not very accommodating of autistic style and needs. Along with that, I encourage them to explore views of autism beyond the 'medical cause-cure' model; to look more deeply at its possible meaning and gifts; and to consider using strategies from the community of autistic adults – like learning how to

“Work with autism, not against it” (37) – so that
“Instead of failing to succeed at what you’re not, you can start learning how to succeed at what you are.” (38)

Near the end of his life Georg Kuhlewind wrote a book about children who set us special tasks and challenges - 'star children' - who have, he says, “been coming to earth in growing numbers ...the most important happening of our age.” (3, p3). This was in fact not the book he set out to write (which was to be on the nature of small children in general), but he had realised, while writing, that (3, p4)

to focus on these 'star children' “would be the most important thing to do, because a great many teachers, psychologists and psychiatrists (anthroposophical ones included) not only do not notice what the problem is when faced with 'difficult' children but sometimes do not even want to notice. ... Writing this book is a first attempt. Research will and must continue.”

Of these 'star children' (children with autism and related conditions) he wrote:

“The main characteristic ... [is to] preserve the faculties and attitudes of the small child longer, sometimes for the whole of life [which means they] will have difficulties adapting to the form of society's thinking, feeling and will, and will have difficulties in school. ... They are very open, not separated from other people, and their defensive reserve is to compensate for this inner make-up ... [but unfortunately] their defensive gestures are mistaken for primary symptoms.” (3, pp.144-146) elaborating elsewhere “For the most part, they have the knowing-feeling perception that we lose once we are no longer small children ... [a] gift through which social difficulties could be solved.” (36, p.210) “Every hidden intention and every secret thought lies open to these children.” (3, p. 74)

“These new children, star children, are coming into the world with the mission to change our lives for the better; but ... can only succeed in this if adults do not hinder them from doing so through the education they grant them. To prevent this happening adults need to muster sufficient insight and courage, and do the necessary inner work If we do our utmost the children will come to meet us with their sensitivity ... This is why thoroughly honest intentions, and a radically understanding attitude, are so important” (3, p.120).

He concludes with the plea (3, p.146)

“The danger is that by not changing firstly our views and then our faculties we are destroying the possibility of the change these children could bring about in humanity, the change to a more human way of life in which the ruling factor would cease to be egotism.” - a change, he says, that we resist by our human tendencies to consider anything different to ourselves as pathological, needing fixing; to look at such children as 'types' instead of individually, and to mistake their 'defensive gestures' for primary symptoms. Concerns close to the hearts of neurodiversity advocates.

So, *on a spiritual level*, could this as Kuhlewind surmises (3, pp.143-145) pertain to both increasing individuality, and a ““steep change in the development of humanity as a whole” - a development towards a more spiritual humanity, but with more “self-awareness” than in former times? He suggests 'star children' may be a source of insight ... and calls on us to radically change our views and develop more conscious faculties to better understand and meet these children – because

“intense spirituality on the one side and the intense practice (not theory) of materialism on the other are clashing with one another. The result is such a rapid and complex increase in the number of 'difficult' children that the 'experts' can hardly keep up with analysing the various typologies and syndromes ... That there are 'difficult' children, and what they can

become should the occasion arise, is largely due to the way star children react if they have lost their mission, the meaning of their existence.” (3, p.75).

A personal view of mine, is that this may be a call for individuals, for society, for humanity, to develop more conscious forms of social connection and empathy. Might autistics be catalysts, guides or even leaders in such a shift?

Reflections on autism and empathy:

Recalling how autistic children like John and Sean (quoted earlier) spent their early life unaware of the relevance of people, human speech etc; and even once aware, were still unable to seamlessly interact with their peers - you might well wonder, how they could possibly develop true empathy?

Let me introduce you to two more friends of mine: MM and Jim. MM writes

“Autism is not being able to close the windows to everything around you...

I have been accused of being self-absorbed and selfish, because I so desperately need quiet and time to myself. My autistic needs do not mix well with what is expected of a woman in the southern USA. But I hate that people think that because I need more quiet that I am a selfish bitch. I'm not. If anything I feel so deeply for others that I ignore my need to protect my senses that overload so easily to be with another person in his / her pain. For I need the quiet not because I have a cold heart but because I can hear every plea from every being in whatever space I stand or sit or lie down in. I need the quiet because I am *too* compassionate. I can only afford a certain amount of time among humans ... [or] my senses will overload, and the rest of the day I will have to put myself in the quiet of my room, and miss out on the trees and rocks and streams that talk to me so much more gently than any human.” (16, p30).

As a child, the human world made little sense to MM, as she describes

“I was raised by our Siamese cat. I could understand her language better than the human language, and so I spoke Siamese way before I spoke English, and I thought the cat was my real mother because I could understand her more than I could understand humans.” (16, p54)

But, surprising as it may seem, MM as an adult became a hospital chaplain, working firstly with dying patients, then with Alzheimer's sufferers, her rapport with whom apparently amazed and surpassed that of her NT colleagues. She writes (16, p49-54):

“Most of humanity is ignorant for not hearing and seeing what's around them. I hear the rocks and trees. Wish me well and tell me I am one of them, one of the silent ones who has now been given a voice, and that I must come out of hiding to protect others without voices: ... persons with Alzheimer's disease. It is my job to explain that [their spirituality] is not lost just because some of their brain cells are scrambled ... My work with persons with Alzheimer's disease is like coming home. They are people who also have a neurological difference. They are blunt and honest, no longer hiding behind cultural norms. ...

Where I have a problem is having to ... explain to NT administrators. It is an uphill climb that frustrates me no end. I get very tired of the dehumanisation of people with dementia. Most people ask them the wrong questions, and treat them like a little child instead of the adult that they are ... I am a good chaplain because cultural norms are dropped during this time. NTs fall apart and don't know what to do. It is an area in which ... I shine.”

In the Introduction to her own book illuminating this work, she writes

“While other professionals were recording cognitive losses, I was discovering a gold mine of spirituality still intact ... This [book] is the record of my sacred time in and with the spirit, wind and breath of my an Alzheimer's unit.” (39)

To me, MM epitomizes two of the *social paradoxes* commonly seen in autism:

Firstly, the paradox of individuals who in early life, seemed unaware of the meaning or relevance of the human world around them, their most meaningful early relationships often with objects or animals, yet who may later show an extra-strong sense of

humanity. NTs (anthroposophists included) commonly fear that attachment to the nonhuman will make autistics more robotic, so try to block or belittle these attachments. But for Dawn and MM, such attachments were vital bridges to the human world; perhaps their best or only means to lay foundations for later empathy with fellow human beings. *Secondly*, the paradox of people who lack that unconscious instinctive ability to 'seamlessly fit' with a social group, yet can consciously develop empathy for individuals so different to themselves; who behind their apparent awkwardness in a social group, may burn with a deep sense of ethics, caring and community.

'Sympathy' is an ancient word and concept (dating back to Aristotle), and involves a semi-conscious 'sleeping into' the other person. Whereas 'empathy' is a more modern word and concept (originating in the past two centuries); empathy for another individual, calling upon fully conscious faculties very different to those for 'seamlessly fitting' into a social group. So maybe empathy is something at which autistic people might potentially excel? Despite misleading stereotypes to the contrary. Some professionals now acknowledge this - as Dr. Glenys Jones writes

[We] "frequently read that those with autism ... lack social empathy. ... Perhaps because individuals with autism have to work out consciously and scientifically what is appropriate, they develop more insight than the NTs who do not have to consciously pay such attention to this." (40, p9)

Returning to the idea (familiar within both anthroposophical and neurodiversity circles) of gifts being 'inextricably linked with so-called defects': Just as the flipside of the autistic difficulty with seeing the whole picture, may be a gift for detail; or of coming up with the 'common' solution (having little idea of social commonality) may be the ability to find a rarely considered but important solution; so perhaps the flipside of the autistic lack of unconscious social instinct, could be the ability to consciously grasp 'what is true and real for this person, in this instance', despite, or maybe because of, having little instinct for what might be 'generally' true for people (which might give rise to wrong assumptions about 'this person, in this instance.')

As Jim outlines in his article "Thoughts about empathy" (41):

"When I am interacting with someone, that person's perspective is as foreign to me as mine is to the other person. But while I am aware of this difference and can make deliberate efforts to figure out how someone else is experiencing a situation, I generally find that other people [NTs] do not notice the difference in perspectives and simply *assume* that they understand my experience. ... If I know that I do not understand people and I devote all this energy and effort to figuring them out, do I have more or less empathy than people who not only do not understand me, but who do not even notice that they do not understand me?"

No idle words those. Jim (whose autism meant he didn't learn to use speech to communicate till he was 12), now works as a counselor, and has been one of the leading pioneers of autistic community. He and MM are just two of many autistic people working in fields where empathy is considered essential (42) – often considered by their clients as 'extra-good' at empathizing, even though their autism is still troublesome in their lives in other ways (so clearly not 'cured.'). Their skill at empathy comes in spite of – or could it be because of? – their autism.

Studies (43) have confirmed, as MM suggested, that autistic people may feel and care even more strongly than NTs once they're aware that someone 's hurt - but how they become aware, and how they show compassion or empathy, may differ, as these autistic adults working in caring professions explain:

"I'm an intensely sensitive person. I'm just not always able to call up the appropriate emotion *in the moment* without the opportunity to process it." (44, p.141)

“It is difficult to analyse social encounters in a busy environment. Meeting people is more confusing than ever, because I am less able to attach any meaning or to interpret what is going on correctly. Busyness makes me feel very unsure, and my generally poor level of coping drops even more.” (45, pp.32-33)

So when the autistic child you live or work with appears to lack empathy, ask yourself whether they're maybe so strongly focused on something else they haven't even noticed someone's hurt? or are struggling to process the situation, to interpret nonverbal or other social cues? or aware something's wrong but unsure what to do? confused or anxious having been being blamed or criticised for seeming inappropriate in the past?

Returning to possible 'meanings' of autism and its increasing recognition in our times, maybe genetic, environmental and social factors are just the *biosocial vehicle* that enable new spiritual processes to unfold:

On the *material* level, autism may well be carried by our genes (Silberman's 'strange gift from our deep past'), perhaps in interaction with environmental factors.

On the *social* level, becoming prominent in recent times because of changes in concepts and attitudes within social sciences and society, regarding 'normality', and what is or isn't socially valued? (such as the increased emphasis in workplaces on teamwork rather than individual skills)

On the *spiritual* level, a wake-up call? A challenge to all of us, whether NT or ASD, to search our own conscience; to stand individually, if needs be going against the popular tide (as Hans Asperger did); to develop those faculties of *conscious* empathy to understand and truly *meet* the diverse individuals who share our world?

Fitting tasks for this 'age of the consciousness soul'?

Maybe having to understand and navigate the social world without radar, by conscious effort, observation and analysis, as autistic people must, is a positive and necessary shift?

I hope this smorgasbord of quotes and ideas, particularly those from my autistic friends, includes something to feed each of you in your work with autistic children, and that by discovering how to make real connections with them, you can help nurture their unique gifts that some day the wider world may value and celebrate!

My closing words are from Jim, on connecting with the ASD child in your life (46):

“It takes more work to communicate with someone whose native language isn't the same as yours. And autism goes deeper than language and culture; autistic people are “foreigners” in any society. You're going to have to give up your assumptions about shared meanings. You're going to have to learn to back up to levels more basic than you've probably thought about before, to translate, and to check to make sure your translations are understood. You're going to have to give up the certainty of being on your own familiar territory, of knowing you're in charge, and let your child teach you a little of her language, guide you a little way into his world. ...

Yes, that takes more work than relating to a non-autistic person. But it can be done – unless non-autistic people are more limited than we are in their capacity to relate. We spend our entire lives doing it. Each of us who ... manages to function in your society ... to reach out and make a connection with you, is operating in alien territory ... We spend our entire lives doing this

Your autistic child is not completely beyond your reach. The ways we relate are different ... Approach respectfully, without preconceptions, and with openness to learning new things, and you'll find a world you could never have imagined If that prospect excites you, then come join us in strength and determination, in hope and in joy. The adventure of a lifetime is ahead of you.”

=====

References

1. Sainsbury, Clare (2000). *Martian in the playground: Understanding the schoolchild with Asperger's syndrome*.
2. Steiner, Rudolf (1924 lecture: 1972 English edition). *Curative Education – First lecture* 25.06.1924)
3. Kuhlewind, Georg (2004 English translation of 2001 German edition). *Star children: Understanding children who set us special tasks and challenges*.
4. Peeters & Gilberg (1999). *Autism: Medical and Educational Aspects*.
5. Robison, John Elder (2011). *Be different: Adventures of a Free-Range Aspergian with Practical Advice for Aspergians, Misfits, Families and Teachers*.
6. Barron, Judy & Sean (2002). *There's a boy in there*.
7. Williams, Donna (1996). *Autism -- An Inside-Out Approach: An Innovative Look at the Mechanics of 'Autism' and its Developmental 'Cousins'*.
- 8a & 8b. Spicer, Dave (1998). *Two lectures: a. Self-Awareness in Living with Asperger Syndrome; and b. Autistic and undiagnosed: My cautionary tale*.
www.bellsouthpwp.net/d/s/dspicer
9. George, Frank. *Where I am Going*. In *Collection of prose writings*.
<http://members.aol.com/autismfg/vrfng.html>
10. Roth, Ilona (2010). *The autism spectrum in the 21st century: exploring psychology, biology and practice*.
11. Prince-Hughes, Dawn (2004). *Songs of the Gorilla Nation: My journey through autism*.
12. Krumins, Daina (2003). *Coming alive in a world of texture*. In J. Kearns Miller (ed), *Women from another planet?: Our lives in the universe of autism*.
13. Golubock, Susan (2003). *Cartwheels and silent tantrums*. In J. Kearns Miller (ed) *Women from another planet?: Our lives in the universe of autism*.
14. Golubock, Susan (2002). Personal communication.
15. Robison, John Elder (2007). *Look me in the eye: My life with Asperger's*.
16. Baker, A (2003). *Differences*. In J. Kearns Miller (ed), *Women from another planet?: Our lives in the universe of autism*. .
17. Meyerding, Jane (2003). *Growing up genderless*. In J. Kearns Miller (ed), *Women from another planet?: Our lives in the universe of autism*. .
18. Lipsky, Deborah (2011). *From anxiety to meltdown: how individuals on the AS deal with anxiety, experience meltdowns, manifest tantrums, & how you can intervene effectively*.
20. Baker, A. R. (2004 update of 2002 paper presented to Inaugural World Autism Congress). *Invisible at the end of the spectrum*. See www.aavaruthbaker.com
21. Gerland, Gunilla. (2013). *Secrets to Success for Professionals in the Autism Field: An Insider's Guide to Understanding the Spectrum, the Environment and Your Role*
22. Shelly, Sola & Gil, Ronen (2008). *Community and Culture: The Israeli Case*. Paper presented at Autreat 2008: Living Life the Autly Way www.autreat.com
23. Sinclair, Jim (2005). *Autism Network International: The Development Of A Community And Its Culture*; http://www.autreat.com/History_of_ANI.html
24. Silberman, Steve (2015). *Neurotribes: The legacy of autism and how to think smarter about people who think differently*.
25. Ne'eman, Ari (2007). *Neurodiversity and the Autistic Community*. Paper presented at Autreat 2007. www.autreat.com

- 26 Carley, Michael John (2008). *Asperger's from the Inside Out: A supportive and practical guide for anyone with Asperger's Syndrome*. (Carley, 2008 - p40)
27. Attwood, Tony (2008). *The complete guide to Asperger's syndrome*
28. Miller, J (2003). Introduction. In J. Kearns Miller (ed), *Women from another planet?: Our lives in the universe of autism*.
29. Gray, C. and Attwood, T. (1998). *The discovery of "Aspie" criteria by Attwood and Gray*; *The Morning News* 11. Also see www.tonyattwood.com
30. Institute for Study of Neurotypicals – see www.isnt.autistics.org (quotation used in article comes from version accessed in 2008).
31. Frith, Uta (1991). Asperger and his syndrome. In U. Frith (ed). *Autism and Asperger Syndrome*, pp. 1-36.
32. Grobstein, Paul (1989). *Diversity and deviance: A biological perspective*; *Bryn Mawr Alumnae Bulletin*.
33. West, Thomas (1997). *In the Mind's Eye: Visual People with Dyslexia and other Learning Difficulties, Computer Images and the Ironies of Creativity*.
34. Treffert, Darold A. (2013). *Savant Syndrome 2013— Myths and Realities*. <https://www.wisconsinmedicalsociety.org/professional/savant-syndrome/resources/articles/savant-syndrome-2013-myths-and-realities/>
35. Willingham, Emily (2015). *Neurotribes - A review and an interview the author Steve Silberman*. <http://www.forbes.com/sites/emilywillingham/2015/08/28/neurotribes-review-and-an-interview-with-author-steve-silberman/>
36. Kuhlewind, Georg (2007). Afterword. In Melanie Bos: *A star mired in earth*.
37. Sinclair, J (1992). What does being different mean? In *Our Voice: The newsletter of Autism Network International*, Issue 1, 1992.
38. Meyerding, Jane (1998). *Thoughts on finding myself differently brained*. <http://www.inlv.demon.nl/> (Articles)
39. Yearwood, Mary Margaret Britton (2002). *In their hearts: Inspirational Alzheimer's stories*.
40. Jones, G (2005). Foreword. In W. Lawson: *Sex, sexuality & the autism spectrum*.
41. Sinclair, J. Thoughts about empathy; *the Maap*, 1988. Also on website <http://members.xoom.com/JimSinclair/index.html>
42. Baker, A.R. (2006). *Autism and careers requiring empathy: Are they compatible?* Paper presented at World Autism Congress, Cape Town, August 2006 – also see www.aavaruthbaker.com
43. Rogers, K; Dziobek I et al (2007). *Who cares? Revisiting empathy in Asperger Syndrome*. *J Autism Dev Disord*; 37(4):709-15
44. Stillman, W (2003). *Demystifying the autistic experience: A humanistic introduction for parents, caregivers and educators*. Jessica Kingsley Publishers London & Philadelphia.
45. Dumortier, D (2006). *From another planet: Autism from within*; Jessica Kingsley Publishers: London & Philadelphia.
46. Sinclair, J.(1993). *Don't mourn for us*. Republished 2012 in *Loud hands: Autistic people, speaking*. Also see <http://members.xoom.com/JimSinclair/index.html>