Theology in Scotland
30.1 (2023): 14–22
https://doi.org/10.15664/tis.v30i1.2575

One autism story, two autism theories, many autism gifts

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Abstract

This article reflects on how autism interacts with the Christian faith and the Church. From considerations of the lived experience of the author's son, who has autism, tensions are noted between the two main theoretical stances which are commonly applied to autism and how this has a bearing on a 'theology of autism'. Of these two stances, it is suggested that 'Intense World' theory is more useful because it treats autistic people with greater empathy; ironically, an aspect that an 'impaired' Theory of Mind suggests they lack. This has implications for how the Church can learn from and be enriched by neurodiverse people.

In this article, I will consider how autism interacts with the Christian faith and the Church. I am particularly interested in not just how churches might best adapt to be fully inclusive for children with autism spectrum disorders (ASDs), but what it is that we think is going on in autistic children's minds on matters of religion and faith. Within the limited literature available on this topic, since many point out that it is an area requiring additional research,[1] I note a tension between the two main theoretical stances which are commonly applied to autism and how this has a bearing on a 'theology

[1] John Swinton and Christine Trevett, "Religion and Autism: Initiating an Interdisciplinary Conversation", *Journal of Religion, Disability & Health* 13, no. 1 (2009): 3.

of autism'. I also note a 'culture clash' between autistic people and the Church, and how a different attitude within churches might spark fresh thinking benefitting not just those with ASD, but the whole Church. Throughout this reflection, foremost in my mind will be the experience and development of my son Daniel, who has autism.

The decision to tell Daniel's story is not in order to assert that his experience is the only ASD experience. Instead, it is a way of asserting that his experience is important – to him, obviously, and to me – and might illustrate ideas which would otherwise remain abstract. This is one of the tasks of practical theology: the understanding of human experience as it aligns (or doesn't) with God at work in the world and the Church. This can inform our thinking about faith; our experience 'is a "place" where the gospel is grounded, embodied, interpreted and lived out'.[2] There are some frustrations in autism literature that there is not enough quantitative research available; however, qualitative accounts 'are not simply meaningless personal anecdotes; they are important sources of knowledge.'[3] With this in mind, and with the permission of and edits by Daniel himself, here is an account of our own 'family ethnography'.

Daniel's Story

Daniel was born in the late noughties, our first child. He was a healthy and contented baby. As a toddler, he would rhythmically bounce back and forth in his cot, bumping his head against the headboard as a sensory routine for getting to sleep. He still has sleep problems today, but this is now managed through a Melatonin prescription.

When Daniel was 2/3, I told him the Christmas story at Advent. He was totally fascinated by it. He would ask me to repeat the story again and again, remembering when I'd forgotten a particular part. Similarly, he loved the story of his namesake and the lions' den.

When Daniel went to primary school at age 4½, his P1 teacher swiftly noted that Daniel would not join in with story time and seemed very troubled, often trying to escape out of the fire exit, having meltdowns and/or hiding under the tables. We finally pieced together a number of

[2] John Swinton and Harriet Mowat, *Practical Theology and Qualitative Research* (London: SCM Press, 2006), 5.

[3] Swinton and Mowat, 38.

factors which pointed towards autism and embarked on the diagnostic pathway with support from the school.

Daniel was diagnosed with an 'autism spectrum disorder' when he was 6, following interactions with a speech and language therapist, educational psychologist, occupational health nurse, and community paediatrician. The diagnostic report commented that, 'Daniel can become overwhelmed by his environment and the demands of social interaction'. It also noted that Daniel was particularly interested in animals. In fact, when he was having a meltdown, one possible solution would be for me to get down on my hands and knees and pretend to be a cat, nudging his knees with my head and meowing softly. Daniel would be comforted by this and would stroke my hair as if I were a real cat.

Having listened to other parents' stories within an autism support group at the school, we decided to carefully and thoughtfully tell Daniel his diagnosis. Almost overnight, we saw a huge change in him. He seemed more at ease with himself and the world.

When Daniel was 7, we decided to visit the local Baptist Church in which we have now made our home. We had experienced great difficulty getting Daniel to go into Sunday School at our previous church despite their best efforts. In contrast, on our first visit to 'the new church', Daniel stayed in Sunday School throughout the service. He was happy to wear his ear defenders and didn't seem to feel self-conscious. In the car on the way home, I tentatively asked, 'Well, what did you think about that church?' Daniel responded enthusiastically, 'I love it! I love it! Can we go there every week?!'

For Daniel's P4 class assembly, he wanted to take part although he hadn't before. The previous year he had been allowed to sit next to the teacher who was operating the sound desk so he at least had a role. This time, his support teacher was in the wings and I had a reserved front row seat so that I would be clearly visible to Daniel. Daniel got on the stage with the others and with feet shoulder-width apart and the middle and ring finger of his left hand in his mouth (palm upwards), his right hand touching his ear, he rocked slowly from side to side. Our eyes locked and he smiled victoriously at me. It was an enormous moment. Later, I whispered in his ear, 'You were the best.' And I was telling the truth, because there was nobody on that stage making more effort than Daniel.

Daniel asked if he could become a Christian at age 9. Concerned that he didn't cognitively understand enough to make this decision, I

questioned him, to which he responded that he loved God and Jesus and wanted to be a Christian. So we prayed together and then he went back to playing Minecraft!

When I asked Daniel at age 11 whether there was a particular Bible story/passage that he liked, he thought for a moment and said, very slowly and deliberately, 'Blessed are those who mourn, for they will be comforted'. So I said to him, 'Why do you particularly like that part of the Bible?' And he said, 'I just like the idea of being comforted when I'm sad.' 'And do you feel that God comforts you when you're sad?' 'Yes.'

At the time of writing, Daniel is now 14 years old, a budding philosopher and computer scientist, having accessed a place at a specialist autism support unit at secondary school. He still loves the stories of faith he learned as a child. Now, as a teenager, he asks many deeply insightful questions about God, faith, scripture and doctrine, refusing to accept simplistic explanations. He has a great sense of humour and is a joy to be around.

Reflecting on Daniel's story

Daniel has a form of autism which most people would recognise as Asperger's Syndrome (AS). This was a specific designation within DSM-IV (one of the main diagnostic and statistical manuals used in the US and the UK) which was removed for DSM-V in favour of the more generic ASD. It goes without saying that autism covers a huge range of behaviours (a 'spectrum') and that no two individuals present alike, albeit there are commonalities. There are two significant theoretical stances within autism research today. The first of these is that those with autism have an impaired 'Theory of Mind', as theorised by clinical psychologist Simon Baron-Cohen et al. in 1985.[4] In this setup, the person with AS has 'mind-blindness' and is unable to understand the thoughts and feelings of other people, since they have difficulty reading social cues, etc. Baron-Cohen caused consternation among many autistic people for suggesting that they lacked empathy.[5] This seemed to feed into existing stereotypes within

[4] Simon Baron-Cohen, Alan M. Leslie and Uta Frith, "Does the Autistic Child Have a 'Theory of Mind'?", *Cognition* 21, no. 1 (October 1985): 37–46.

[5] Baron-Cohen's thesis isn't all bad, of course, depending on how it is interpreted and by whom; a fascinating, recently-published theology of autism by

popular culture about what autism is and how it manifests itself within the 'Aspie' population, e.g. Dustin Hoffman's character in *Rain Man*, Benedict Cumberbatch as Sherlock Holmes, and Saga Norén in the Scandi-noir drama *The Bridge*. If someone lacks empathy, are they fully human?

The second main idea in autism research is 'Intense World' theory, posited by neuroscientists Henry and Kamila Markram,[6] which instead asserts that autistic people do not lack empathy. In fact, because of their sensory sensitivity, they can easily become hyperstimulated and over-emotional, leading them to shut down and withdraw in order to cope with sensory overload. It is a theory which presents autism not within a 'deficit' model (in which autistic behaviours are pathologized), but says that autistic people are actually very empathetic. Too empathetic: 'Autistic people perceive, feel and remember too much'.[7] This rings true to me since Daniel struggled as he entered a large primary school and all its attendant noise/people, as evidenced in his diagnostic report.

We can see at once that the manner in which autism is categorised determines our attitude to the condition. For example, even whilst noting difficulties with Baron-Cohen's use of the word empathy, Macaskill betrays himself when he points out that some autistic people's behaviour may be 'difficult or even unacceptable'[8] and rejects the idea that the 'Aspie' community is an alternative culture to the church, even as he acknowledges that churches, 'may behave in hellish ways towards the autistic'.[9] Similarly, when autistic behaviours are judged in a certain way from the outside looking in, it can lead to us thinking we know what a child can or cannot do. I include myself in this in terms of the way I

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an autistic author puts Baron-Cohen's 'mindblindness' as one of three elements/facets of 'autistic empathy' which roughly parallels a sense of 'Mindfulness of Separation' which can be experienced by all people as a 'universal autism'. See: Ruth M. Dunster, *The Autism of Gxd: An Atheological Love Story* (Eugene, OR: Pickwick Publications, 2022), 74, 85–86.

[6] Henry Markram, Tania Rinaldi and Kamila Markram, "The Intense World Syndrome – an Alternative Hypothesis for Autism", *Frontiers in Neuroscience* 1, no. 1 (October 2007): 77–96.

[7] Olga Bogdashina, *Autism and Spirituality: Psyche, Self and Spirit in People on the Autism Spectrum* (London: Jessica Kingsley, 2013), 33.

[8] Grant Macaskill, "Autism Spectrum Disorders and the New Testament: Preliminary Reflections", *Journal of Disability & Religion* 22, no. 1 (2018): 20.

[9] Macaskill, 25.

wondered if Daniel would cognitively understand what being a Christian 'meant'. It's as if there's a separate 'autism culture' which seems alien to us 'neurotypicals'. People with ASD report this sense of being in a different culture, too. In this baffling, intense world, interacting with others can feel like a maze of difficult eye contact, sitting still, and trying to interpret what others say in a non-literal way, like speaking another language. No wonder, then, that a popular autism site is called www.wrongplanet.net! The effort that autistic people make to fit in to neurotypical culture shouldn't be underestimated, as seen in Daniel's monumental effort at his class assembly.

How, then, can Christian faith communities, themselves a subculture often removed from popular culture, best respond to the challenges posed by those who struggle with social communication and sensory overload? Although Macaskill's argument tends to be undermined by some attitudes outlined above, he does helpfully work on a theology of inclusion based on a Christological reading of Paul's Corinthian letters. Here, he points out that the body of Christ as set out in 1 Cor 12:12–13 is made up of diverse individuals who are each 'given' by God and therefore these individuals, given to the Church by God as gifts, are to be 'accepted with joy and thanksgiving, with *Eucharist*'.[10]

Brock tells the story of his own son's autism, outlining a New Testament eschatology which is based on readings of two parables. The first sees the reversal of the question asked of Jesus in the story of the Good Samaritan: not 'Who is my neighbour?', but 'To whom have you been a neighbour?' It's not a case of a congregation deciding which people will be worthy of their kindness. Plus, Brock argues, the actions of a faith community in the present are more important than everyone being healed and perfected in heaven after death.[11] In the second case, Brock draws from the parable of the vineyard in Matthew 20, in which those who worked for one hour receive the same reward as those who worked all day; this shows that the Christian community does not work for a reward, but instead the vineyard itself contains, 'the intrinsic value and meaning of their task'.[12]

[10] Macaskill, 24.

[11] Brian Brock, "Autism, Care, and Christian Hope", *Journal of Religion, Disability & Health* 13, no. 1 (2009): 19.

[12] Brock, 22.

So, the Christian Church is supposed to be a radically counter-cultural place. People ignored by the world or deemed as somehow 'lesser' are to be seen as equals and as gifts to the Church. The Church is to embody Christ as the Good Samaritan to all 'neighbours' rather than question who those neighbours should be. So how do we do this?

There are a number of resources available to churches to enable them to be more inclusive towards autistic people. For example, there's a comprehensive table covering areas to consider on the Churches for All website.[13] Additionally, the Church of England has produced some helpful guidelines[14] (cf. the striking picture on p. 5 of a boy with his hood up which resembles Daniel), which includes ideas about the provision of noise-cancelling headphones and a pop-up 'safe space' tent to which autistic children can retreat. That would certainly have made our encounters with churches much easier, especially if such a space had been available within the sanctuary. Although when we went to 'the new church' with Daniel he felt comfortable wearing his ear defenders, for them to be freely available is a more obvious 'permissioning'.

However, in considering these issues of accessibility, there are underlying and significant theological questions about the nature of (especially evangelical) worship, which go beyond concerns about autism. For example, one question might be whether some styles of worship require autistic people to adapt to neurotypical patterns in terms of noise, light, length and format. If worship is too loud for autistic people, do they need to put on ear defenders, or does the church need to consider its use of silence and/or more reflective practices? Is worship a place in which people address God (often noisily) together, or is it a space in which opportunities are taken to hear God quietly as the corporate body of Christ? Could neurotypical adults benefit from steps taken to make worship genuinely more inclusive for neurodiverse children?

Interestingly, two of the more practical articles I discovered in this area were written from a Catholic academic viewpoint, relating to faith communities and the autistic person's involvement with the sacraments,

[13] Churches for All, "Autism Spectrum", https://churchesforall.org.uk/about-disabled-people-and-church/autism-spectrum/.

[14] Ann Memmott, "Welcoming and Including Autistic People in our Churches and Communities", https://trurodiocese.org.uk/wp-content/uploads/2019/06/Autism-Guide-2019.pdf, 19.

taking us back to Macaskill's point regarding the Eucharist. McGee, a Parish Catechetical Leader in Newark, New Jersey, rightly notes that, 'Through including persons with disabilities in the sacramental life of the Church, we become a richer community of faith.'[15] She cites the example of Andrew, an autistic child who was supported to take his First Communion in her church, partly because she made the assumption that he could. Meeting with Andrew and his family regularly, she learned that 'when we warmly accept the child; we warmly accept the entire family.'[16] We certainly felt this with Daniel when we moved church. As a family, we were able to put down roots because of the care shown by the Sunday School team.

Finally, Swanson, an autism consultant working in schools, writes in her moving account of her (often non-verbal) interactions with Justin, an autistic child, that there are a number of ways to know God, and words/verbal cognition are not necessarily required so much as 'experiential religion' which is felt as an embodied self.[17] Justin's embodied experience of the Mass, i.e., sitting, standing, kneeling, gave him knowledge of God in a different way. This begs questions of the 'free churches' about how such an embodiment could be incorporated within non-liturgical worship. Is the lack of embodiment within certain church traditions in fact a theological stance, designed either implicitly or explicitly so that the mind is prioritised? If churches even indirectly implore congregations to 'sit still, face the front, and listen to the sermon', is there a realm of encounter with God being missed?

Putting the child at the centre sounds like something Jesus would do, yet many find it difficult to listen to children in general, perhaps especially autistic children. When I asked Daniel about his favourite part of the Bible, I thought that he wouldn't be able to come up with something that demanded metaphor or abstract concepts, so it surprised me that he was drawn to the idea of God's comfort. Although there are difficulties with

[15] Diane McGee, "Widening the Door of Inclusion for Children with Autism through Faith Communities", *Journal of Religion, Disability & Health* 14, no. 3 (2010): 286.

[16] McGee, 282.

[17] Susan Swanson, "Experiential Religion: A Faith Formation Process for Children with Autism", *Journal of Religion, Disability & Health*, 14, no. 3 (2010): 244. Swanson has since become a Speech and Language Pathologist at the Department of Psychiatry of the University of Massachusetts Medical School.

talking to children about their views on faith and spirituality,[18] it is worth the effort as a faith community from both an ethical and theological point of view and is a two-way process where both parties benefit. Talking to Daniel about his diagnosis was a similar act. We wanted to hear from him about what autism felt like 'from the inside' so that we could help him more. Now that he is older, I have high hopes that his church youth leaders will enthusiastically welcome, encourage and nurture his many questions and insights rather than pushing him towards a simplistic faith which he would inevitably reject.

In this short piece, it would be impossible to cover all the ground I would like to. However, I am suggesting that underlying theories of autism have a bearing on any theology that is applied to autism. Intense World theory is more useful because it treats autistic people with greater empathy – ironically, an aspect that an 'impaired' Theory of Mind suggests they lack. Perhaps, in fact, it is 'neurotypicals' who need more empathy, not in expectation of any reward, but so that they can engage better in the 'vineyard eschatology' outlined by Brock, in which the task of caring for people is its own reward. Before launching into any adjustments the Church as a whole needs to make, the priority must be to engage with autistic people and their families first, in order to establish what their needs, hopes and aspirations might be. We might just discover that if we listen properly, we can learn from children like Daniel, and in so doing, become enriched.

[18] See especially in relation to children's silence: Ann Lewis, "Methodological Issues in Exploring the Ideas of Children with Autism Concerning Self and Spirituality", *Journal of Religion, Disability & Health* 13, no. 1 (2009): 64–76.