

## Autism and Asperger Syndrome and the Church

By Ann Memmott, autism adviser (who is on the autism spectrum)

### What it is

Autism/Asperger syndrome is a brain design difference. The brain is connected up very differently to that of other people. Some things work better as a result. Others don't.



It can affect anyone, of any age, background or intelligence level, from birth onwards.

1 in every 64 people is on the autism spectrum. That's possibly more than there are wheelchair users. Many are church leaders or other church workers already. We're not just people in the pews. We're your fellow workers, too.

Picture of a group of people

### What it isn't

It's not a learning difficulty, though some have a learning difficulty as well. (About 1 in 10, same as the rest of the population)

It's not a behavioural condition, though some show behavioural challenges as well, because of a perfectly logical response to pain, fear, etc.

It is not a mental health condition, though many who are never given support or adapted environments will develop anxiety or depression as a result.

It's not a speech and language condition, though most of us think visually, not in words; we need really clear, really literal language.

It's probably not more common in boys/men. The girls/women are simply 'invisible', because no-one expects us to be autistic, and we're hardly ever sent for diagnosis until adulthood.

Autism and Asperger syndrome are the same thing. Traditionally, the combination of autism and a learning difficulty/speech and language delay was called 'autism'. Autism without those things as well was called 'Asperger syndrome'.

They are intending to call it all “Autism spectrum” soon, because it never made sense to call a mix of different disabilities ‘autism’ and call autism ‘Asperger syndrome’. Many studies show that those with the supposedly milder ‘Asperger syndrome’ are the ones who do worst in life. It’s not mild autism, though some have a mild form of it. I don’t.

It brings great strengths to most of those with this particular design. Generalising, people on the autism spectrum are:

1. Ten times more accurate than others
2. Hugely loyal
3. Great seekers after social justice
4. Honest
5. Diligent
6. Have enormous personal integrity
7. Many have extraordinary specialised abilities, because of the different brain design. Art, music, ability to memorise things or calculate things, etc. Some don’t.

Most are immensely gentle and caring people. These are often the ‘invisible ones’, because everyone’s attention goes to the few whose behaviour is challenging or very different. The myth is that the more challenging the behaviour, the worse the autism. This is untrue. More challenging behaviour means there is a challenging behaviour situation as well.

Every person is an individual with their own particular strengths and challenges in life to overcome. But each of us has the same basic underlying differences:

### **What are the main challenges?**

Autism means there are three main areas of challenge to be overcome. Many on the autism spectrum manage to do so with great skill. It does not mean that they are ‘less autistic’. Autism is almost the opposite of being Blind and Deaf. We hear and see such detail that we can’t make sense of any of it and can’t use the information.

**Firstly, we cannot see body language properly** (eye contact, face expression, gesture). Neither can we hear tone of voice properly. This is a massive disability in a very social world. Most meaning is conveyed using body language, tone of voice, eye contact, etc. Without it, we are socially clumsy.



**Photo of emotions, by Kevin Labianco, under Creative Commons Licence**

We overcome it by learning to ask good questions to find out how someone is feeling. I cannot tell what those expressions in the photos mean. I can guess one or two of them. I'm also faceblind (cannot recognise people from their faces), and it's not uncommon for that to be true for autism.

Eye contact is a nightmare for people with autism. Normally someone can look at someone's eyes, and their brain thinks, "Is this a large predator about to eat me? No? Great! Is it someone I know? Oh it is! Hmm, what do I know about them..." and it runs off to find the right info about that person. It's all automatic, very fast, and means that your face, body and eyes can signal "Hi – I'm so pleased to see you!!" to

their friends. In our brains, the eye contact happens, and our brain gets as far as, “Is this a large predator about to eat me?” and runs out of brain wiring. So it’s stuck thinking, “Arrgh, huge scary predator – run!”. Nothing we can do about it. We just don’t have the brain wiring that does the rest.

That’s why we will avoid eye contact. It doesn’t mean a thing to us, but it scares us silly. It’s why we’ll often sit alongside you, not looking at you, to talk with you. People like me learn to overcome the fear and do it anyway, but it’s still scary.

### **No empathy? Not true!**

There is a myth that people with autism/Asperger syndrome lack empathy. This happened because of that lack of ability to see body language signalling accurately or hear tone of voice properly. If we can’t see it or hear it, we can’t respond to it. Once people realise that the lack of eye contact and strange body language is not meant rudely, many misunderstandings stop. Most of us are empathetic, but we are not good at making our faces and bodies and words match up to how we feel inside.

**Secondly, we need to plan our lives carefully.** Most can cope with the unexpected, but it means that the brain wiring overheats after a while and we need to recover somewhere quiet.

It literally does overheat. Because autism is a brain wiring difference, we’re always using brain wiring that isn’t designed for the job. Put too much sensory and social-contact electricity through it, and it fuses. Then it needs to cool down again before it can work. In children or some adults, that may become a ‘meltdown’ – a sudden display of wild behaviour and wild words that resembles an out of control ‘toddler tantrum’. Unlike a real tantrum, it’s not designed to get something from someone else. It’s as ‘in control’ or manipulative as an epileptic seizure would be, and cannot be reasoned with. Don’t try. Let us go somewhere safe to let our brain wiring cool down again. It can help to wrap ourselves in a blanket or coat for a while. It seems to help re-set the brain wiring overload that way. The scientists aren’t sure why yet. It’s embarrassing for us when it happens, and it’s never meant rudely or aggressively. Once we’ve recovered, just carry on normally. And help us work out what caused that brain wiring overheating.

Many of us have ‘shutdowns’ rather than meltdowns. That’s what happens to me. We stop talking, and may fall asleep fairly instantly. It’s not social rudeness. Our brain has stopped working. Again, we need the wiring to cool down before we can continue.

The advantage of a need for predictability is that our forward planning skills can benefit everyone around us: Meetings run on time. Events run smoothly. People are safe and cared for. It’s not always a bad thing.

**Thirdly, 8 out of 10 of us have some sensory processing differences.** We may be very sensitive to bright fluorescent lighting, background noise etc. We cannot always pick out individual voices in a crowd, so learn to move to somewhere quieter for conversations. Again, it's because of brain design difference. There is a specialist bit of the brain that focuses on just one voice in a crowd, and we don't have that bit.

### **Quick Examples of Visual Processing Differences in Autism**

Picture of hallway with fluorescent lighting



Picture of hallway as seen by an exhausted person on the autism spectrum – far less detail, faces can't be recognised.



A picture of a supermarket or busy crowded indoor event



A picture of a supermarket as experienced by someone with autism. Intense brightness, no idea who's who, no idea how to find anything or what to do. Notices are almost invisible.



I cannot put in pictures of such places sound (deafening, confusing), or the avalanche of smells, or the difficulties choosing things from shelves. But it gives an idea of how challenging noisy, busy, bright places are. Watch autistic children panic in supermarkets and at busy church social events. That's why.

There are also other challenges to factor in –

1. Difficulty judging distance and position (We may need to feel our way round the outside of rooms first. We may stand too close to people, accidentally)
2. Sensitivity to heat and cold and draughts.
3. Extreme pain if jostled in a crowded space or touched unexpectedly.
4. Sensitivity to smells from air fresheners/restaurant vents, perfumes, aftershaves, deodorants etc.
5. There is also a need for very clear signage and information.

### **Basics for Adapting Church Buildings:**

- Keep colour schemes neutral rather than over-bright, but with well marked edges to doors and steps.
- Change failing fluorescent bulbs straight away to avoid ‘strobe lighting’ effect for us.
- If possible, offer side lights or natural lighting in spaces rather than overhead fluorescent lighting. Encourage use of sunglasses or hats to help shade overhead lighting, if it helps.
- Use matt paint surfaces to reduce reflection and echoing. Wall hangings can help reduce echoing too.
- Use carpeting rather than echoing floor surfaces where possible. Watch out for squeaky floorboards and rattling floor grills.
- Keep corridors and aisles clear so that people aren’t squeezing past each other. Or allow people on the autism spectrum to leave first or last so that they do not have to squeeze through spaces with others.
- Use darker paint to show changes in level or sharp corners. so they are clearly visible.
- Make notices immensely clear. Our literalism means we are very likely to misread or misunderstand vital instructions, especially in the chaos of a fire drill, etc.



Fire escape notice showing an arrow pointing upwards. Apparently I have to climb the wall to escape.



This door is alarmed, the notice says. Why? Has someone upset it?



Dogs must be carried on the escalator, it says. Supposing you don't have a dog? What do you do then?



“Keep clear – refuge point for wheelchair users” Help! Am I allowed in the refuge point in my wheelchair if it has to be kept clear? (1 in every 64 wheelchair users is also on the autism spectrum).



“Do not drink” notice. A student may not drink all day until told they can drink again. They may not realise it means, ‘Do not drink water from this tap’.

### **What helps in Churches?**

The research shows that if you make a difference for autism, your congregation numbers increase. None of these things has a big financial cost to them.

The two big things are the same for everyone with a disability: A warm welcome, and asking what we might need. Also think about these:

1. Check the lights in each room, especially fluorescent ones – any flickering ones? Please replace them. (This also helps people with epilepsy)
2. Noise levels. Sudden loud noise or whining background noise is as bad for us as it is for those who have a hearing impairment. Try to warn of any loud noises planned during services, please.
3. The building. Do we know what it looks like, and what the layout is like today? Is information on a simple website, perhaps? A blog can be very handy – just



upload a quick photo of any new layout. Tell us where parking is and how to get from parking to where the building is. It's not always obvious to us.

4. The Order of service/agenda – really clear instructions for us e.g. where to sit, when to stand and sit, what to say at each point in services? Either write it down, or get someone to be with us to offer to quietly say what to do, please. (This also helps those new to church). Different colour paper may help some to read service sheets, e.g. light blue paper rather than white. Don't fuss about fonts – there is no one right answer.
5. We are very literal, and our minds may see pictures, not words. If you need to use complicated language, can someone be available to explain it afterwards if we need it, maybe by email? (This helps those who find reading more difficult, too, which is one in every five people in the UK). We are very rule-driven. Don't think we're being rude if we say, "but that's not the rule!". We're not being awkward. We just need to know what rules are. They are hugely important to us.



**(Cartoon showing people standing on an overhead projector, having heard the Vicar say “We will now stand and sign the next song on the overhead projector”).**

6. Physical events e.g. shaking hands? Water being splashed about? We may find this physically painful, as our skins may be hypersensitive. Please warn us what will happen, and avoid physical contact unless we offer first.
7. Rest area – somewhere quiet to go if we need to, please. Or don't worry if we wander outside for a while, if safe to do so.

8. Socialising. Be aware we find it difficult and exhausting as we cannot 'see' or hear you that well. Our body language can be different to yours, and we may not make eye contact. Please don't think we're rude.
9. Be Clear and Accurate. If you say you'll do something, please do it. Those on the autistic spectrum will always find it very distressing if you promise to help and don't, or promise to phone at a certain time and don't, or if you use expressions like "I'll be back in five minutes" when you mean, "I'll be back some time this afternoon". If you need to change arrangements, please just let us know.
10. Support: Find a quiet caring person to be aware of us, someone ready to lend a little assistance if we need it. Brief them well, and please respect our confidentiality and privacy. Some of us count as 'vulnerable adults' and there may be good guidance in your church or charity about safe conduct around us. It's no different to respectful safeness for anyone else, really. Please make sure your teams are aware of this. Please don't let it stop you sharing genuine safe Christian love and friendship with us. There is almost nothing worse than being treated as a 'patient' rather than a friend in a church setting.

### **Did Jesus know anyone autistic?**

Yes, I believe He did. Nicodemus. Nicodemus took things really literally, not understanding the whole 'born again' thing. He approached Jesus quietly in the dark to get away from crowd noise and jostling. He reached for rule books to solve problems. He turned up at the tomb with a socially embarrassing amount of herbs and spices. Did Jesus try to cure him? No. Did He say Nicodemus was too much trouble? No. Was it worth it for Jesus? Yes.

### **Summary:**

We can't see, hear and sense things the way you can. Let us rest if we get exhausted. Don't think we're being deliberately rude. We're not.

Be really clear about what, where, when. Keep us updated using clear language. Maps, plans and photos may help a lot.

Check that meeting space. Watch out for big sensory hazards for us. Let us know. Try to adapt the space to remove sensory difficulties for us if you can.

### **Result:**

Wonderful friends, loving prayer partners, useful contributors to church life and church tasks. Is it worth it? Oh yes!

(Reading Ease Score of this document = 70, which means it can be read by 88% of people with ease.)

<http://www.oxford.anglican.org/social-justice/disability/welcoming-those-with-autism-and-asperger-syndrome-in-our-churches-and-communities.html>

and <http://annmemmott.org.uk>  
for further information