

Including Young People on the Autism Spectrum in Church Groups

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March 2013

At least 1 in every 100 people of every age in the UK is on the autism spectrum. It is sometimes called 'Asperger syndrome'.

With brains designed for detail, persistence, honesty and error-spotting, autistic young people are as important and useful as everyone else in the room. Often fantastic problem-solvers and sources of information on their specialist interests.

Stuff it's not: It's not true that there is always a learning disability. Most have a normal or high general IQ. It's not true that there are going to be speech difficulties. (But using speech for social stuff is going to be very difficult). It's not true that it's mostly boys/men. It's not true that there is no empathy. That's a total myth. It's not true that you will spot it (mostly it's a hidden disability). It's not true that a diagnosed person can be 'mildly autistic, needing no assistance'; it's always the real thing. 'Mild autism' that has no effect on life doesn't get a diagnosis. But some may refuse adaptations because they have been let down so often. It's not true that it's 'bad behaviour'; Deliberate challenging behaviour (apart from repetitive movements) isn't part of autism at all. Some may have episodes of 'meltdown', but those are no different to a diabetic child having a hypoglycaemic episode and becoming shouting and rude until their blood sugar is right again. It's not deliberate and you can't reason them out of it. It'll be a totally automatic pain/fear overload response. So treating it as a behaviour thing will get youth leaders nowhere. See later.

Everyone will have their own needs, so all of this is generalising.

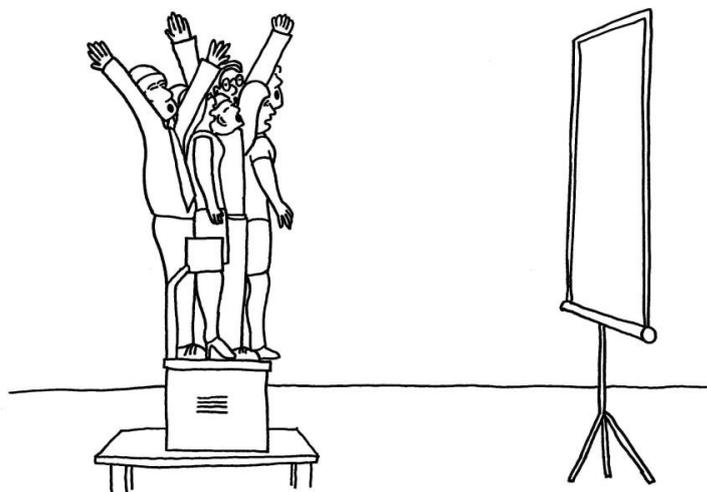
Always ask about specific needs.

Autistic young people nearly always...

1. Have a huge need for routine and need to plan ahead in great detail.
2. Cannot see body language very well or work out what face expressions mean. Can't use body language well.
3. Find eye contact very difficult, painful or puzzling
4. Cannot hear tone of voice very well
5. Cannot understand long complicated sentences easily, but can often speak in them. This can lead to big confusion all round.
6. Tend to think in pictures, not in words.
7. Have sensory processing needs - light levels, sound levels, no flickering overhead lighting, no background strong perfumes or odours, etc.
8. Cannot pick out just one voice from many.



9. Are very literal in understanding instructions.
10. May have difficulty recognising people and recalling the right information about others as fast as other people can.



“WE WILL NOW STAND AND SING THE NEXT SONG ON THE OVERHEAD PROJECTOR”

All of these things are important to think about in advance.

Always try to include autistic young people when planning your meetings as well as when running them.

Have a look at this two minute clip. It will tell you a huge amount about autism's sensory processing differences:

<http://vimeo.com/52193530>

Where Will The Gathering Be?

Think about transport. Be really clear about how they get there, where to find bus stops before and afterwards, where to put a bicycle, etc.

Maps, photos of outside and inside, a clue where to find a loo. Think about the surface of car parks – is it noisy crunchy gravel for hundreds of yards? This can be painful for the feet, and the noise can seem deafening. Is there a need to walk through or next to lots of traffic? If so, how exhausting are the noise and the fumes? Can the young person cross busy roads safely to get to the venue? Not everyone on the autism spectrum can do so alone.



What is the Inside of the Building Like?



Check it out for sensory hazards by asking autistic people with sensory processing differences to visit and test it. Unless you can see, hear and sense those things yourself, you're just guessing.

Watch out for flickering overhead lighting (fluorescent strip lights etc). Can they be

turned off? Flickering projector screen are another hazard.

Listen for background noise: aircraft, traffic, dripping taps, whirring computers and projectors, noise from other groups and rooms. Be aware that the hearing range of autistic young people can be far greater than that of non-autistic people.

Listen for very echoey rooms. Ones with carpet and curtains are often much better.

Are the loos another echoey smelly space with hot air hand dryers that have a terrifying noise and blast of air? Perhaps find a quieter loo somewhere else in the building.

Is there a quiet space to use as a rest area? It really must be quiet, with lower lighting levels possible. Often such spaces get used by other people as a space to have a chat in. Make sure that people are aware that quiet means quiet.



Microphones – check for sudden loud feedback. Keep phones and other devices away from microphone equipment to stop them getting static from those too.

Outlines, Materials, Timing



Get materials to people a few days before the event. The outline of the session is really important. Make sure the timings are clear and realistic. Make sure you follow it. The moment you improvise, you will have panicked the autistic young people in the room.

Are papers in easy-read English? Are there pictures and visuals? Most autistic young people think in pictures, or find visual materials much easier to understand. Are sentences short?

There should be an accessible version available at the same time as the more complicated ones. Autistic young people cannot join in if they cannot read what's there properly.

Have people avoided using metaphors and strange expressions – written and in their speeches and presentation slides?

Familiar Safe Supporter

Autistic young people will take a long time to trust someone, even if they seem friendly. The friendliness can be a learned response to mask inner panic. Will this person know that I'm autistic? Will they respect my needs? Will they suddenly ask me to do stuff I can't do and I'll make a mess of it and my brain will switch off my ability to speak? It's not about confidence and self esteem, it's about balancing how

much pain they can handle in any one session. They have to trust that person. If you are constantly changing helpers and giving them people who place them in difficult situations, they probably won't turn up again. It's not worth risking the pain.

Touch, Friendship, Safety and Safeguarding

It is very rare for autistic people to lie. They are every bit as accurate as others, and often very rule-based and law-abiding. There is normally no hint of trying to get others into trouble.

But they do have a different sensory system. Unexpected touch can hurt like an electric shock. It's no small thing. It may get a huge reaction that seems totally 'over the top', but it isn't. Be aware of this. Always always ask for permission to use safe public touch. And respect the answer. It doesn't mean leave them out of the social



contact the others enjoy - it means others in the group need to do so slowly, with their permission, in ways they can handle. Ask, negotiate what's OK and what isn't.

If they are panicked, a blanket wrapped round them in a quiet room can really help. That feeling of being 'hugged by the blanket' can be very reassuring. If they are having a meltdown (meaningless episode of anger caused by intense brain wiring pain), get them to a quiet safe space and let them just 'be'. Don't talk. Don't make eye contact. Don't reason with them. If they have stopped talking altogether, that's called a shutdown (and is more common - it's what happens to me). Same applies - find a quiet safe space, let them just 'be'.

A few may respond to fear by running away. Check this out with them or their family/carers and check how to avoid that happening. Make sure they know what to do if they feel afraid. Make sure there is a safe quiet space for them to escape to. Do a good risk assessment and be realistic about it. No-one has a duty to put a young person or helpers at physical risk, so you must be sure that things are safe. If they run, something went wrong. Rather than blaming them, think about what it was. Is it sensory overload? Was it something unexpected? Are they afraid of someone in the group (bullying?).

Socially inappropriate behaviour is part of autism. Clumsy use of language, clumsy 'young' physical behaviour are part of it. Don't rush to take offence. Be really clear about what you expect, make sure they know what's really not allowed. But if they make a mistake, it's likely to be just that; a mistake, not a predatory or violent intention. Explain vital rules in pictures as well as words. Explain more than once. Check for understanding.

Make sure your safeguarding teams know about autism as well. They need to be aware of the information, so they know what is likely to be social clumsiness. A lonely fearful young person with autism may be a perfect target for predators in a church setting; many will truly believe someone when they say that they are their friend....that it's OK to do (whatever inappropriate thing it is). They can be very very easily led into difficulties. Be watchful and caring.

Conversations

It is easier to speak with us when sitting side by side somewhere quiet, not facing us.



Introduce yourself. Don't assume that autistic young people immediately remember who you are. People can look very similar to us, because our brains get info on people from their 'filing system' much more slowly. We are unable to see your body language and hear your tone of voice, so use words or pictures please. "I am feeling sad" is good. Looking

sad is often meaningless to us. It's why people think we can't empathise. We can, if we are told what you are feeling like.

Be aware that autistic young people can often speak in complicated sentences – but may still not understand you if you do. Keep conversation to short sentences. Check for understanding.

Do not try to talk with autistic young people in the middle of a busy room filled with noisy people. Autistic brains cannot filter out voices so that they can hear just you. Move away from the crowd.

Do not expect eye contact. Do not expect the autistic young person to look like they are listening to you; listening to you and looking at you are two different things to autistic young people. They cannot do both at once.



Do not try to read their body language. Autistic body language does not work. We may seem rude or bored or tired when we are not, so do not assume any of that. Ask instead.

Be prepared for straight answers. Autistic young people do not do social niceties very well. Conversations may not start with, "How are you? So nice to meet you" and may not finish with, "It was lovely meeting you, have a wonderful day" etc. Autistic individuals get straight to the point and tell you the truth. If you ask how we are, we will tell you the truth (but we may not be very good at knowing the answer....emotional responses take a long long time to put into words for many of us). If you ask our opinion, we will give it. It is not meant to be rude.

'Social age' may be very different to intellectual age, so do not assume that clumsy social communication is a sign of bad motives. Check for understanding first. Some may have hobbies or interests that are very 'young' for their age or very unfashionable. Watch out for anyone in youth groups bullying them because of this.

Repetitive behaviour ("stimming") is common. It could be rocking in a chair, or flapping of hands, or anything else that is done repetitively. It has a purpose for the autistic person - often a way to find out where their body is. Our brain's 'body map' is often not very good, and we can struggle to know which bit is us and which is someone else. Stopping the stimming isn't helpful.

Be aware that autistic young people may stand too close or too far away during conversations. Awareness of physical distance to others is a big challenge for many on the autism spectrum. It is almost never meant in a threatening or rude way. Be clear about needing your personal space, if necessary.

Autistic young people cannot often time when to speak in a group. This is vital to know. They may talk at the same time as others, or be unable to guess when to join in. In group conversations, use a signalling system to give autistic contributors a chance to say 'stop' and 'don't understand' and 'I want to say something'. Watch for people sitting in silence; it usually means the autistic young person is struggling to understand....or struggling to join in.



Stop....ask.....wait....be aware.

Autistic young people may not realise you wish to speak and may continue to talk, unaware that you are waiting to say something. Say so.

Some will use communication devices rather than spoken language; iPads or picture-exchange systems. Get to know them and get to know how it works. It's great stuff.

Regular Breaks are Vital

Remember autistic young people need routine and need to let their brain wiring cool down - from too much social interaction and/or sensory overload.

Build in regular breaks. Once every 45 mins is good. Make it for at least ten minutes.

Watch out for having meetings which don't allow for lunch breaks etc; eating at the 'wrong time' can be frightening for someone with autism and they may not eat at all.



Food and Drink



Ask about food needs and make sure that special diets can be catered for.

Difficulties with physical 'clumsiness', routine needs and sensory needs mean that food and drink can be a big problem.

Use mugs with large handles and flat bottoms, not tricky-to-balance tiny china cups and saucers.

Don't ask people to hold a plate of food, eat, hold a glass, and talk all at the same time. Let people eat in silence somewhere quiet if they need to, sitting down.

'Finger foods' (not made with real fingers...) in busy gatherings are much better than something with a knife and fork needed. Why? Less noise and chaos from clanging cutlery and crockery!

Sharing

Autistic brains are a different physical design. Instead of that superfast "people-interpreting bit", ours has a superfast "data-and-our-stuff" bit. Imagine someone came into a room, grabbed your child or pet and threw them around a bit. You'd be horrified, angry, etc, yes? That's the exact emotional response when someone comes into a room and messes with the stuff of someone on the autism spectrum. It's the same bit of the brain doing the reaction. That is why they may panic or shout.

If exercises involve sharing stuff, explain the rules for this very carefully. Get others in the group to be very respectful of an autistic young person's personal stuff. Be aware that bullying of autistic young people is hugely common (8 out of 10 are badly bullied) and bullies soon learn that moving or slightly damaging their stuff gets a big fear reaction. Be aware of it. Know that it's a very real disability situation, not the young person exaggerating.

Be clear with your questions and language



Oblique questions may have no meaning for many on the autism spectrum. "I wonder what we should do now?" may not be interpreted as a direct question, for example. Be totally clear with people on the autism spectrum. "Do that exercise on the table" may well lead to some getting on the table. Well, you just told them to.

"Take a seat" may lead to some picking the seat up to take it somewhere. You just said to do that.

Watch out for emotional language and spiritual language in materials; brains that think visually can struggle with liturgy and faith-concepts. What does a 'grace' look like? Do we magnify God's holy name with a magnifying glass? ! Autistic young people can get totally baffled by language. Be prepared to explain concepts and use clear language.

Co-ordination Difficulties and Unexpected Exercises

Many on the autism spectrum struggle with co-ordination for new tasks. It can take longer to manage them. Be aware of this in team games, for example.

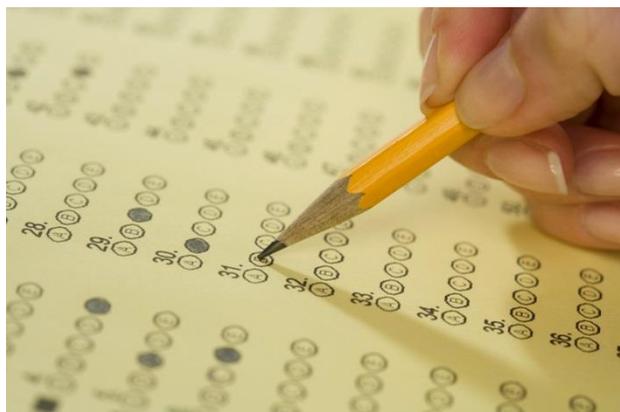
Anything unexpected is a nightmare for those on the autism spectrum. Even nice surprises can be petrifying. Do all you can to pre-warn those with autism about what you are going to do. Don't pick on them unexpectedly for tasks. Ask them first. It doesn't have to spoil the fun of others - it can be done quietly before hand or as a quick question during an exercise.

Away Weekends and Festivals

Everything that applies to standard weekly events applies also to away-events. Plan, prepare, make sure there is a safe helper, really good advance info for the young person, and somewhere very quiet and safe for them to just 'be'.

Questionnaires and Written Work?

Make sure that materials are easy read and have plenty of visual information in them too. Allow plenty of time. Let young autistic people know how to get help for those who may not know what questions mean or what is being asked.



More Info?

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<http://www.autism.org.uk/> website of the National Autistic Society

This information is available in different formats on request from Ann. She can be contacted on 0118 921 0130 during work hours.