



Jesus is Central Everyone matters

The Autism Conversations

PAS in Conversation with Christians in Scotland about autism, church & faith

- 6 autistic people, including 3 people with learning disabilities
- Some of their family members
- 3 church leaders
- a retired Occupational Therapist

Here is what we heard

The Autism Conversations

This booklet sums up a year's worth of monthly hour-long online conversations with autistic people, family members – some of whom are also church leaders, and volunteer leaders of Prospects Across Scotland. Our main focus in PAS is to encourage, inspire and resource churches to welcome people with learning disabilities – but 20–30% people with learning disabilities are also autistic – see <https://www.england.nhs.uk/wp-content/uploads/2020/01/Learning-disability-and-autism.pdf>

We wanted to have a better understanding of the experience of autistic people (with and without learning disabilities) in local churches in Scotland and so we set out to listen and learn.

This is a brief summary of detailed notes and transcripts from our conversation. Get in touch if you would like to read further. PAS also offers '**Autism in the Church Family**' training online and in-person. Often autistic people come along and share their experiences too – one of those is included here. We continue to learn.

We hope these will be helpful to you and your church. Our thanks to everyone who shared their experiences.

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Robin, a young autistic man, from Aberdeen:

Look at me
as a person
first.

"I am part of the group, part of the congregation. That's what Christianity is all about, accepting people, a welcoming community"

"I asked if there was anything I could do to serve... going through boundaries"

On baptism: *"It wasn't about me, it was about Jesus. I didn't want to be at the centre"*

Robin's advice to churches about autism:

- Research it, understand, have awareness
- Accept people, help and encourage them.
- Having a peer group helps - you don't all have to be autistic or have disabilities - to be included and have friends
- Clear communication - knowing what to expect
- Give advance warning of change

Katrona, autistic Church minister

I can't be like everyone else, and it's easy to get angry at an unfair world.

*Invite me, without the pressure to say 'yes', don't expect me to be 'normal', **let me be me.***

"In discernment they asked me who I thought God was, so I gave them a 2 page equation, mathematically explaining what God was"

You can make a big difference if you talk to me, interact with me, let me join in – or let me sit on the sidelines without joining in.

An autism friendly church:

- accepts you for who you are,
- being on the phone or knitting (it's not rude or disrespectful – it's another way to listen), space to move, headphones being ok,
- don't assume healing is wanted! This is an assumption that life is not as good. People with autism are 'teachers for the church' made in the image of God.
- We need more people in leadership roles. Find out what people are good at – tech, music, reading etc.



RC, minister and father of autistic young adult, Edinburgh

I now realise that she views the world very differently from me and doesn't see things the way I see things.

*"She has gone to X church a few times and **they didn't make her feel comfortable and so she just didn't go back.**"*

"I think she has probably improved my toolbelt for dealing with people a wee bit. I'm able to listen better. I find it easier to step back from a situation. Before, I would have dived in and just tried to fix things... I find it easier now to stop and listen. I wasn't good at that before... that's been the change in ministry."

Autism in a Church leader's family:

- Autism was not part of training for ministry but would have been helpful
- Having an autistic child has taught RC valuable skills for ministry, such as listening, reflecting instead of reacting, offering space rather than a 'fix', patience
- Ministers can find it hard to ask for support
- Church leaders are right to put in boundaries around their family's needs and privacy.
- In church there needs to be room for everyone and for them to feel comfortable

Donna-May, worship leader, mother of two.
Her whole family is autistic/ADHD and have other disabilities.

We are **all** the one sheep that Jesus leaves the ninety-nine for.
God comes after each of us.

HELLO

Just say 'hello'
 to my family,
 invite us for
 a playdate.

How to be a welcoming church:

- Put info on church websites: 'please ask X person about Additional Support Needs'
- Encourage churches not to be nervous, come and say hello, ask questions, be friendly, ask what works/helps and what is difficult – being asked helps you feel included.
- Get to know people – mistakes may be made but relationships are so important
- Getting the right welcome on the door
- Different tools help different groups: Makaton, signage – so it's a wider inclusion
- The importance of routine! In her family routine is absolutely vital to avoid meltdowns. Routine is so helpful in church too.

Rebekah, a non-speaking autistic woman with Down's Syndrome and her sister Rachel:

Rebekah needs to do things in her own time and have space to do them.

"Rebekah has quite a profound learning disabilityif I was to say "Do you want a drink?" she's got no way of indicating to me by speaking or signing or pointing to a picture. So I would have to offer her juice and she would take it off me or push it away, so that's really how a profound her learning disability is."

Finding belonging in a church family:

- Routine is very important
- Rebekah likes to sit in the same seat - perhaps seats could be reserved?
- Stewards can be a real help with finding a good space.
- Rebekah might yawn, vocalise or grind her teeth - it's calming for her. Sometimes it's hard to predict how Rebekah will react in an environment but it's **so helpful to have a church where 'no-one bats an eyelid'**
- Music is a way to take part - Rebekah loves to listen and clap along
- Rebekah can join in using other ways of communication - see below.
- Don't expect eye contact - many autistic people find this uncomfortable.
- Rachel feels blessed to be part of a supportive church family

Communicating and Contributing:

Rebekah and Rachel with Barbara, a retired Occupational Health Therapist

*'We've tried to establish **a person-centred environment...** We're wanting the person to be central, to be key; their choices, their decisions, their input, whether it's in church or a Prospects group. That's why Augmentative Alternative Communication is really important.'*

About **25%** of people with learning disabilities and autism have limited, or sometimes, no verbal communication.



Ways to participate and communicate

- Use a **BigMack** or **Talking Tile** - it's a button with a recorded message. Rebekah can press it to lead a prayer or do a reading
- **Talking Mats** - a way to express choice and opinion
- **Makaton** - simple signing
- **Symbols**, photos and pictures

K, an autistic Christian

I love my church family...
[but] being there on a Sunday
is incredibly difficult for me
and when I get home,
I literally need 'recovery' time.

"The hall where we meet after the service, is **virtually impossible** to be in because, it's far too loud, too many people, crowded, lots of sensory stimuli. It 'hurts' my head when I can hear multiple conversations all at the same time. Trying to filter out and focus on one is so, so hard."

**I found myself
rocking, silent,
unable to
communicate**

What can make church tricky:

- Things I say that are deemed "inappropriate"; I wish there was greater understanding that the "appropriateness" filter in some Autistic people is malfunctioning!
- The noise of cups, drinks being made, smells, the coffee; visually I don't know where to look, and contact...
- I'm not a 'touchy feely' person, I don't want to be hugged (I need to be able to control my own 'touch' barriers) and there's an assumption that I'll be totally okay with it. It's all far too overwhelming
- I have even been told that I **shouldn't** do those 'self-soothing' things [*rocking or fidgeting*] because it makes others feel uncomfortable!

If you see a behaviour:
think sensory – **be a detective** – what has/is
happening in
environment?

Sensory Processing

Autistic people often process sensory information (taste, touch, sound etc) in different ways which can be uncomfortable, distressing and painful. This may lead to upset and even to shut-down or melt-down if the person is unable to get away from the source of stress.

What can churches do to help?

- Look at the sensory environment in your church activities – try to mitigate them.
- Vital to get to know autistic people in church – what bumps them? What do they enjoy?
- Offer a quieter space with natural lighting, soft furnishings and neutral colours.
- Sensory bags/boxes with fidget toys, colouring, pipe cleaners etc. can be calming
- Important to help whole congregation to understand
- It is lifelong – not just affecting children
- Allow people to bounce while singing, walk during preach, hum during prayers – anything to help regulate themselves
- Acceptance and understanding leads to compassion, vital for Christians

Craig and Tom, an autistic man and his father, Aberdeen

"I was baptised
in the church
– that was good –
my friends supported me".

"When Dad is on holiday, I can go by myself. I can easily get the bus stop right outside the door."

"I read the Bible on my phone. Some of the talks are quite interesting. They use photos to illustrate the story."

"People know me, and I help out"

How to feel a valued member of church:

- Having a group that considers learning needs helps nurture Christian faith and belonging
- Having skills and talents recognised.
- A chance to be active and use gifts
- Relationships with non-disabled peers is valuable – just being part of the group
- Informality allows people to be themselves
- A shorter sermon is helpful 'so I can sit through it more easily'
- Meeting 1 to 1 to explore baptism and membership



Hilary, parent of an autistic young adult and leader in Prospects, Inverness

His close observation of the world...
made me **mindful of God's
particular care** and knowledge of
each of us...surely then my son
would be ok too?

It's been an unexpected
awakening into another world of
detail, of noticing change,
appreciating seasons and the
wonder that is around us.

"When you think of autism, you may not automatically think of **joy**. Often autism is thought of in diagnostic, medical terms, or educational issues. Language such as impairment or disorder doesn't really help. We are naturally afraid or wary of what we don't know, the unknown.

But in my personal journey as a mother, I have experienced a lot of joy, and I wanted to focus on that aspect of autism for me. I don't want to diminish the challenges that autism can bring, but I prefer to focus on what can be amazing.



- **Rejoice in the unique gifts and perspectives of autistic people**