prospects
across Scotland

Jesus is Central Everyone matters

The Autism Drop-In Conversations

Notes from a monthly Zoom about Autism, Learning Disabilities and Faith

2023

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Introduction:

Prospects Across Scotland is a small Christian charity with a big dream: t*o encourage, inspire and resource churches to welcome people with learning disabilities and autism and tell them about Jesus.*

We offer training and support to churches of any denomination anywhere in Scotland. Our desire is that churches would not only welcome people with learning disabilities, but also recognise them as members of the body of Christ, with God-given gifts. We want to see people being able to belong, participate, grow in faith, and to serve regardless of cognitive ability. 1 Corinthians 12:21-22 (NIV) tells us that:

> 'The eye cannot say to the hand, "I don't need you!" And the head cannot say to the feet, "I don't need you!" On the contrary, those parts of the body that seem to be weaker are **indispensable**.'

Across Scotland, we partner with twenty churches that run Christian fellowship groups especially for adults with learning disabilities. We also offer online groups for those living far from physical groups, as well as an annual holiday weekend.

Our groups are run by volunteers who come from all walks of life; some may have family members who have a learning disability, others are carers or have professional backgrounds. Between leaders and helpers, and our learning-disabled group members, we have a wealth of experiences which we wish to share more widely, to support and encourage others.

There is at present, much interest in autism and neurodivergence in society, including the church. Every church seems to know of someone, usually a child, that they are unsure of how to include. For us in Prospects, we know that many of our group members, in addition to having an intellectual disability, are also autistic. 1 in 3 autistic people have a learning disability, and 3 in 10 people with learning disabilities are autistic. [1] This is supported by NHS England statistics:

> 'The percentage of patients with a learning disability who have also been diagnosed with autism increased steadily from 19.8% in 2016-17 to 28.6% in 2020-21' [2]

For some of our group members, especially those that are older, there will not have been a formal diagnosis of autism, but it seems likely that they are autistic.

For all the interest, there is a gap in focus and understanding when it comes to those who are both autistic and have a learning disability. Two years ago, PAS decided that it was important that we educate ourselves and volunteers. An Autism Work Group was formed consisting of Robin Daldry, Hilary Lacroix, Sheila Macleod, Rachel Newman, Barbara Ann Orr, and Tom Wilson. Robin is autistic, Hilary, Rachel and Tom have autistic family members. Between us we have experience as carers, in education, occupational therapy, church and beyond.

We began a monthly online 'Autism Drop-In' with the intention of hearing from a wide range of voices in an informal setting. Our focus was always on understanding autism, particularly in the context of learning disabilities and faith. The format was broadly similar each month: A one hour Zoom call with an invited guest. They spoke or were informally interviewed for about 15-20 minutes. The rest of the time was used for attendees to comment, ask questions or share responses. Initially I just made notes each month, both general and some verbatim quotes – these are *"italicised in quote marks".*

Later in the year I began to record and transcribe the Drop-Ins as we were hearing some significant conversations and reflections. It felt important to have these kept in detail.

This booklet contains those notes and transcriptions. At the end of each conversation, you will find a brief summary like this:

✓ Key points:

Prospects Across Scotland is so thankful to those who gave their time to prepare and speak as our guests. We are also so glad that such a diverse group of people came along to listen and take part in our conversations – including autistic people, people with learning disabilities, parents, friends, family members, church leaders, and more. We usually numbered around 9-12 people for each Drop-In but what a wealth of understanding and perspective we gained.

We're especially thankful for the members of the Autism Working Group, and all they have given to develop this and our training session: 'Autism in the Church Family' which has been delivered from Stornoway to Edinburgh, online and in-person.

We hope that this may be of service to those wishing to understand, befriend and welcome those who are often on the margins of society, but are deeply beloved of God.

- Hilary Lacroix

https://www.prospectsacrossscotland.org.uk/

Notes:

1 – https://www.autistica.org.uk/what-is-autism/learning-disability-and-autism

2 - https://digital.nhs.uk/data-and-information/publications/statistical/health-and-care-of-people-with-learning-disabilities/experimental-statistics-2020-to-2021/autism

1. 16/1/23 Barbara Ann Orr, retired NHS Occupational Therapist speaking on 'Sensory Processing'

Sensory processing enables us to function in everyday life – vision, smell, hearing, touch, taste, body awareness (proprioception) and movement (vestibular)

We are all different, we all have sensory preferences e.g. Fairground rides, travel sickness, big hugs, being quiet or noisy, loud music. This can be normal or more extreme.

Sensory processing happens in the central nervous system – it makes sense of information from outside or within us e.g. If we don't like loud music, we may behave by putting our hands on our ears but if we enjoy loud music, we may behave by dancing.

People with learning disabilities and/or autism often process sensory information in different ways because of damage to the central nervous system – they are unable to process sensory information in the same way, which can be very hard, leading to behaviours such as running away, shouting, banging head.

Sensory processing is how we *function.*

To sit and listen we need good sensory processing i.e. not too sleepy or not too highly aroused.

We might see *modulation difficulty* – imagine a set of scales nicely balanced – this is a *'just right'* level of arousal – calm, alert, relaxed, able to listen

Too highly aroused: usually when person doesn't like something – not comfortable, system can't cope, can be very sensitive, unable to filter e.g. Sounds, lights, smells. It is very uncomfortable and can be extreme.

Hypo-sensitivity: person **seeking**, needing and wanting sensory input e.g. Deep pressure, hugs – to satisfy vestibular and touch senses. A person needing this might need to be held a lot, sitting on floor, seeking deep pressure. May be harmful – banging head on wall, slapping self, grinding teeth. May include humming, rocking, running, pacing, clapping hands. Swimming can be great.

Proprioception: Think about the first experience of a baby – in water in the womb, lots of pressure. New-borns like to be swaddled, hugged, rocked – these are all calming. So dancing, bouncing, marching etc can be good to help someone feel calm.

Hyper-sensitivity: person **avoiding,** sensory input e.g. Touch, such as labels in clothes can really irritate - not mildly. Very obvious with sound and light, may cover ears or eyes to diminish. It can be very frightening and confusing. If overwhelming leads to behaviours.

Can be complicated – a person who doesn't like noise makes loud noises themselves – humming, shouting and teeth-grinding – these are not in the sound system, but in proprioception (body awareness) causing vibrations, physical sensations.

Some things are not obvious or even localised for average person – e.g. Machinery with a low hum, distant car, person in next room tapping a pen.

✓ Key points:

1. Our bodies are always seeking to balance (all of us) so people with learning disabilities/autism will seek to dampen or get input – seeking balance.
2. If you see a behaviour, think sensory – be a detective – what has/is happening in environment?

What can we do to help?

- Look at sensory environment; tends to be chatty, noisy, music – we can't eliminate but be aware of via training and information. Our understanding of WHY is really important.
- Offer of a side room or quieter space to go to
- Our world is a sensory world, we all have places we don't like and avoid
- Size of room, less echo? Smaller group?
- Important to help whole congregation to understand
- Vital to get to know the person
- It is lifelong, person may cope well, but if we see behaviour, we know there is an issue. Look to have strategies and adapt environment
- Continual learning for us
- Acceptance and understanding leads to compassion, vital for Christians
- Good to allow person to bounce while singing, walk during preach, hum during prayers – anything to help calm themselves
- Temple Grandin – is able to say how it feels – unusual to hear an explanation. https://www.templegrandin.com/

2. 23/2/23 Robin Daldry – autistic man, member of Deeside Christian Fellowship, in conversation with Tom Wilson, both member of PAS Autism Working Group

On Neurological difference – “*a nice way to put it, not because it’s politically correct*”

On being part of the Celebrations Group “*Part of the group, part of the congregation. That’s what Christianity is all about, accepting people, a welcoming community*”

On serving the church with car park duty “*I asked if there was anything I could do to serve, they said this is what I could do.” “Going through boundaries*”

On being part of a home group (which is pastoral and social), Robin wanted to be more interested in people’s views on Christianity, be more part of the church, make friends – not acquaintances, Know Jesus more, challenged in a good way, to know more.

Robin did membership class by meeting up for coffee and cake with a paster 1:1 to have a general discussion to understand and have time to think. Why did he join the church? “*Mum inspired me and encouraged me, but I never had a doubt about it.”*

Church – what’s difficult? “*Making sure that I am not interrupting people”* Conversation and social side and potentially difficult, but that’s like everyday life. People making an effort to connect and bond.

Baptism in November “*It wasn’t about me; it was about Jesus. I didn’t want to be at the centre*” he had two chats over coffee 1:1 about baptism with pastor. At the service the language was ‘user-friendly’ so that both Robin and the congregation could understand.

Robin’s advice to churches about autism: Research it, understand, have awareness. “*Look at me as a person first”*

Key Points: What ideas might make church easier or more inviting for people with additional support needs?

- Makaton
- How to accept people
- How to help and encourage one another
- Helping out, having responsibility
- Having a peer group (who don’t have ASN) to be included in church activities, and have two-way relationships (Tom)
- Clarity of instruction, advance warning of change, knowing what to expect (Tom)

3. 13/3/23 Katrona Templeton – Mission Pioneer leads the Presbytery of Irvine and Kilmarnock's Reachout Together disability inclusion project. Katrona is autistic.

Katrona's work includes:

Reach Out in God: disability education for churches, information days and an audit of the CoS presbytery. The audit showed that most churches have ramps, they all have hearing loops – but not work, most think that they don't have people with disabilities and very few have any groups running, although some do support people with dementia.
Reach Out Everyone: An inclusive craft group.
Katrona has also worked with Parks School (ASN) leading to a youth group for school leavers to know one another outside school, as well as a lunchtime SU group
Made in God's Image: which is a bit like messy Church but is for everyone. The first 15 minutes are together, then there are different spaces for quiet (with activities such as sand for drawing, sensory activities, finger labyrinths, pipe cleaners to make figures and then pray for people), loud (music and space to move and run) , prayer and Bible chat (a place to be able to ask questions – this is a real need)

Question: How did you go about doing the audit?

Asked all churches in Kilmarnock through their Facebook pages and I was very persistent. Speaking to people on buses and on the high street, had church and individual questionnaire's and was determined, Approached local disability charities and asked what was missing in general public.

Question: How are people supportive of your work?

Church of Scotland Disability Working group, the core team.

For more information: https://www.facebook.com/CoSReachout/

✓ Key points:

- Katrona had a diagnosis of autism as an adult. She says: *"I can't be like everyone else, and it's easy to get angry at an unfair world*."
- **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. Invite me, without the pressure to say 'yes', don't expect me to be 'normal', let me be me, don't ask me to leave, include me while I'm different.
- **An autism friendly church**: accepts you for who you are, moving, 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. Finding out what people are good at – tech, music, reading etc.

4. 17/4/23 Hilary Lacroix - The Joys of Autism

Hilary is Mission Development Coordinator of PAS and Theo is her 18-year-old autistic son.

"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 and friend of a number of autistic people, 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 for today, focus on what can be amazing.

My husband and I both spent a number of years as part of the L'Arche community in Inverness. The philosophy of L'Arche is all about mutual relationship with people with learning disabilities, so the relationship often became more important than the disability or diagnosis. We learned to see the gift in everyone, their unique personality. So, we became very disability-positive, and when we were expecting our children, obviously we wondered and prayed about who God would send us. I remember saying to God, we are open to whatever child you send us, even if they are disabled. Oh, but maybe not autistic. We didn't really understand autism very well then. And we all know that God has a sense of humour.

Our first son was a delightful baby, very settled, cheerful and a decent sleeper. We thought…this is easy, let's have another one! So, Theo arrived – and I have his permission to share about him – and immediately we realised that babies can be very different. He didn't like being a baby…let's just say that the first couple of years were a challenge, it was like having a small dragon.

But around the time most children are having their terrible twos, our dragon started to be able to move around, explore his world, move away from things he didn't like, and hold a crayon. He began to draw and express himself. He started building things, like his beloved wooden train tracks, and he found nature. We realised how important it was to him – and how little sense of traffic he had, and moved house, from the centre of town to a small village. He absolutely loved being out in his pyjamas and wellies.

By the time he was three, we wondered if nursery was going to work for him. He was having a great time living on planet Theo. It seemed like a wonderful place, full of creativity. Our home would be filled with drawings, with train tracks and was even wrapped in wool, wound from one piece of furniture to another. It was like stepping through a spider's web! He was a dinosaur, a mouse, a dragon. He loved to dress up and would wear the same costume for days. He would tell me what he wanted as a costume and give me very precise instructions for the look he wanted – a long tail, spikes on his back, a mask with yellow eyes. I knew we would never lose him at an airport!

We didn't know he was autistic, but the signs were all there, and began to be flagged up at nursery and then at school. He would return home exhausted and wrap himself in a thick blanket on the couch.

But out of school, Planet Theo continued to be his favourite place. And for us as parents, it was thrilling when he invited us into it. He became utterly obsessed with frogs, and he spent all winter drawing ponds and happy frogs until we dug a pond for him in the garden. He was engrossed in the world of amphibians, and we had tadpoles in jars, frogs in buckets, wellies…and we too began to appreciate the magic of these creatures in their cycle of transformation, and the joyfulness of one hopping across the grass! At the *age of almost 18, he has retained his love of frogs and newts, and visits a pond most weeks. It's been an unexpected awakening into another world of detail, of noticing change, appreciating seasons and the wonder that is around us.*

I remember climbing with him in the hills near our home when he was about six. We stopped on a rock to admire the view and I felt that we were sharing a holy moment, all he could say was 'wow'.

While Theo was about 8, around the time he received his diagnosis, we went as a family with L'Arche on a retreat to Belgium. We stayed in a large old monastery. As usual, Theo wasn't particularly interested in the children's activities. However, there was a huge fishpond, filled with clear water and over thirty large koi carp. He spent hours and hours observing them, enjoying them, learning about them. By the end of the week, he had a name for each of them, based on their characteristics. He also spotted some rare bats that none of the rest of us had even noticed on the old stone walls. I was still feeling the weight and the questions about his diagnosis, but his close observation of the world, his ability to differentiate and name these creatures made me mindful of God's particular care and knowledge of each of us…surely then Theo would be ok too?

Primary school was hard for Theo, despite some fantastic teachers, the large classes and complexities of relationships were exhausting and demoralising for him. So, we decided to take him out one day a week and work with him at home. I quickly discovered that it wasn't going to work if I tried to give him lessons like he had at school! But if we followed his interests, we could actually do an immense amount of learning. With him, I learned about zoology, fungi, plants, art hill walking and cooking. He was undiagnosed as dyslexic and had trouble reading by phonics, but he loved good stories. We read through Lord of the Rings when he was 10, his finger following and learning the shape of words.

Of course, Theo isn't a perfect child, and we did have some challenges in daily life, but he's always been very caring, polite and extremely funny. Like many autistic people he's very direct and honest – I know better than to ask his opinion about anything I'm wearing! His teachers have always expressed fondness for him, as he always asks them how they are, and he is sometimes known as 'Dad' in his friendship group (mainly of others who are also a little on the margins) because of his caring nature and philosophical wisdom.

Q: What about Theo regarding church?

When Theo was younger, we went to a church in our village for a while – it subsequently closed, but he talks about what he enjoyed: it was small, he knew everyone, he had juice and biscuits before the service and a meal together afterwards. He liked that he could play outside, and he could cycle there. I think it was easier, on a sensory basis. We then went to a larger church that is further away. What helped is that the church is pretty laidback and accommodating, plus he already knew some of the people from the village church. So, when Theo used to seek small spaces – a common occurrence as a child – he would often lie on the floor under our chairs, no-one would bat an eyelid. The children and youth helpers were kind and relational, which helped. He even managed to go to Soul Survivor with a group. He sometimes finds the music and lighting too much, and there are a lot more people. He has persevered in church and is open to helping out with things like coffee serving. He occasionally attends a young adult life group. There are things he struggles to understand, but he continues to ask some amazing questions and shows that he still has capacity for wonder and insight."

✓ Key Point: Rejoice in the unique gifts and perspectives of autistic people

5. 15/5/23 Craig and Tom Wilson in conversation – 'Finding a new Church'

Tom is a member of PAS Autism Working Group, with a background in education and autism. Craig is his autistic adult son. Craig grew up in Deeside Christian Fellowship which continues to have the 'Celebration Group' each Sunday morning for adults with learning disabilities to explore the Bible, worship and pray together.

At Deeside Christian Fellowship Craig learned about the Bible and "*I was baptised in the church – that was good – my friends supported me*". He also became a member and was on welcome duty once a month. He was part of the church youth group with his peers. He needed to change church because it was too far from where he was living, and he had to go on the bus.

Donside Christian Fellowship is nearby. "*When Dad is on holiday, I can go by myself. I can easily get the bus stop right outside the door."*
The church is familiar – it came from Deeside, so there were some of the same folks attending.

Craig likes that there is '*a shorter sermon, so I can sit through it more easily'* as there is no group for him to go out to, like he did with the Celebration group. His membership was transferred so he didn't have to go through the process again.

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

The building is in a campus used by different groups, so we have to pack up and set up. The church has bought the old library from the Council, and it is being renovated.

Question: How does Craig contribute to church life now?

Packing up chairs, the platform, wires etc. Helping with the Mission Weekend in Arbroath where they had a pastor for football speaking, something for children, a curry night, BBQ, face painting. *"I helped at Family Night and Youth Night."*

Craig also helps with tea duty and goes to Homegroup on Thursdays.

Question: When you first went to the new church, how did you feel?

Wasn't sure what to expect, but it helped that I knew people.

Tom: Not having the Celebration group was daunting but the new church was more relaxed. There are children and so more movement.

Craig: *"People know me, and I help out"*

Question: Do you get involved because you are asked or because you see a need?

Craig: *"As I see a need. I'm always, mostly, if they need something, they know where to find me."*

Tom: at Deeside they looked at skills and talents. Craig is friendly and talkative so he was a good fit for the welcome team. As people have got to know Craig, they have encouraged him to help out.

Informality is helpful – he doesn't feel awkward or that people are critical. They are relaxed and laid back eg. When the commentary on the phone went off, no-one minded. Children are also sometimes noisy so it's good for them.

At Homegroup: We have a book so we know what the topic will be. Craig and Tom can discuss it in advance. Tom: "*People value his contributions and he's very much part of the group. It's informal, in a house and we have a cup of tea and so on*" It's about learning to listen to others as well and having an opportunity to ask questions.

Tom: *"It has to be a partnership where we learn from each other – between Craig and the church, asking 'How can we make this work in this situation? Welcome is so important to feel a part."*

Comment from a participant B, who is a wheelchair user and Reader in her church: To be a proper member of the church, we must be active and use our talents. Also, that Zoom/hybrid church is still very helpful, as disabled members can still take part with readings and prayer and a breakout time for fellowship. It works really well.

Comment from participant IM: This is a lesson for all – everyone must use their gifts. Can feel left out if you know you have a gift but it's not being used.

✓ Key points:

- Being involved in church from a young age and having a group that considers learning needs helps nurture Christian faith and belonging
- Having skills and talents recognised and used in the church
- People like to be active and feel that they are fully members of a church
- Relationships with non-disabled peers is valuable – just being part of the group
- Informality allows people to be themselves
- A shorter sermon is helpful where no specific teaching group is available
- Knowing topics in advance help
- Partnership with a church – a two-way relationship is helpful in making things work well

6. 12/6/23 Donna-May Clauson of Catalyst Vineyard, Peterhead – a mother, worship and church leader with a daily family life that includes deafness, neurodiversity and disability.

Donna-May is mother of two girls with physical disabilities, needing communication support and the whole family is either diagnosed or highly likely to be neurodiverse – autistic or ADHD. She is a worship leader and in a small church plant has also worked with the children's ministry. She greeted the Zoom group with Makaton, and told us about her family and church

✓ Key points: Donna-May's tips for welcoming and supporting anyone with additional support needs:

- Welcome beforehand: info on church websites, please ask X person about ASN
- 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 – just saying hello
- Physical access includes small details such as having level thresholds for wheelchairs or those who have mobility challenges.
- 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.
- It's a lonely journey for parents/families – invite us for lunch, coffee, playdates etc
- Use of app to make social stories, with pictures of own church
- Daughter also uses AC on iPad with TouchChat HD Word Power – this allows her to speak when unable to. An excellent but pricey app at £299. She made the point that sometimes her daughter can become very tired from the effort needed to communicate, so these technical supports are incredibly helpful.
- Air pods can be used as hearing aids – an inexpensive and cool-looking solution. Audiologists can input prescription to iPhone.
- We are all the one sheep that Jesus leaves the ninety-nine for. God comes after each of us.

These notes are very brief but Donna inspired us enormously with her passion, experiences – including the frustrating ones - and her evident love of God.

7. The Impact of Autism for a Church Leader and Father

This transcription been anonymised to respect the privacy of the families talked about. The Drop-In took the form of a one hour Zoom call between RC, a church leader based in Scotland, Hilary Lacroix of PAS, two members of the PAS Autism working group, and six others – a diverse group of church leaders, autistic people and others connected to the work of PAS. They provided the questions and comments during this conversation. This took place in 2023.

HL:

Welcome RC. All I know about you is that you are a minister, and that you're very faithful friend and enthusiastic supporter of Prospects and you have a child who's autistic. We're really happy to hear everything that you have to say to us this evening, and from your perspective of being a church leader.

RC:

I suppose it's hard to know what to say about autism and church leadership. Church leadership is a peculiar beast. I sit with about five jobs essentially at the moment! …You're dealing with so many things and you never really have the opportunity, I suppose, to learn this stuff you would like to learn and to do the things you would like to be doing. Ministry is largely reacting; it is largely firefighting. Yeah, you're dealing with things as they explode in your face, so it makes it very difficult to be prepared for things that are coming along. Over the years I've tried to use study leave to do things. I did a counselling course, I did a post grad in healthcare chaplaincy. Things that would perhaps, improve my ability to listen to people and be with people, because I think that's an important part of ministry. In terms of autism, I never really knew anybody with autism. It's never really been an issue at the fore of ministry for me. It did become an issue in the family with my youngest daughter. I suppose part of the problem there, is probably to do with me, as much as anything. My background is - I was a soldier for many years. I worked in a place where everything just happened. The army is very rigid and organised. When my two older daughters were growing up, life was like that. Everybody knew what was happening, and when it was gonna happen, and how it happened, so life was quite…And then my youngest, A came along, and we began very early on to have difficulties with A. We never really knew what the difficulties were. I found it very difficult to deal with the situation that was emerging, and I could get quite angry with her. I sometimes felt the situations that would emerge in the family were emerging because A was just being difficult. And in actual fact, A still feels that can be the case. A no longer lives with me, she lives somewhere else now. I found dealing with A very difficult and I have had to learn. A was diagnosed when she was about 15 and she's 18 now. We couldn't get A to go to school. I mean, I'll be honest, life became very, very, difficult. I tried to manage things, I tried to manage every aspect of life, that was the way things were going to be sorted. Things were going to be laid bare. I tried to the manage the whole situation and that never worked. A left school at 16. School was a big part of the problem. Things have calmed down now. You know what, that was the first time I ever had to deal with somebody, then it's my own child with autism, in the house. It was absolutely full-on, and we didn't know how to deal with it. I now realise that A views the world very differently from me and doesn't see things the way I see things. For me there's big grey areas in the world and with A, there's no grey areas *(laughs)* things are black or they're white. A can't deal with anything in-between easily. We had to adjust as a family, we've had to make big adjustments. And sometimes A will be behaving in a way I would never have tolerated from her two older sisters *(laughs)* but it is just the way A is. We need to live with it and life has had to change.

There're all sorts of changes. In fact, last week I was supposed to be going somewhere, first night out with pals in months and A had been in Edinburgh for day and had a meltdown. We had to go and get A from Edinburgh. You can't be disappointed, you can't be disheartened, you can't blame anybody. Life becomes very different, I think, when you're having to deal with somebody. A does still live with it. A big worry for us has been trying to help A. That's the path of life. And my wife and I have been terrified of the situation. At one point they said A could never ever live on their own. That's a worry. My wife is 60 this month and I'm 60 in January and we've got 18-year-old who are getting told can never live on their own! Maybe if you are thirty, that doesn't seem as imminent, as it does when you are sixty. You kind of think, I've got pals that I grew up with, went to school with, that are already dead. It sounds horrible but at my age, with a child like A, it comes with a whole set of worries for my wife and I, and for A as well.

A is finding the path now and is studying with the Open University. A big step has been that A has started volunteering in a community café in Edinburgh on day a week. That's a big thing. A couldn't pay for a bus ticket, couldn't get on a bus and say 'A half fare to the city centre'. At one point that was beyond her. Now A can take a bus into Edinburgh, work in a café all day and come back. Things are changing, in the family situation and in A's side.

As far as me and ministry is concerned, I think it's made me *[pauses]* because of what I said before: you are always firefighting, you're always dealing with situations that are emerging. Your hope is that you have the skills to deal with them. I think A's situation, and my wife and I having to deal with that over the last few years, has probably improved my toolbelt for dealing with people a wee bit. I'm able to listen better. I'm now, through dealing with A, I find it easier to step back from a situation, before, having to deal with A I would have dived in and just tried to fix things, that's kind of my way in life. I like to manage these things; I like to fix things. But having been in a situation with a child where you have to step back, I find it easier to step back. When a situation begins to emerge, and I'm not sure what's going on, I find it easier now to stop and listen. And try and take stock of the situation, try and work out what's going on. I wasn't good at that. I wasn't good at that before I had to deal with A and the autism. That's been…that's been the change in ministry.

In ministry you are dealing with all sorts of people, and all sorts of situations. No two things are ever the same. You meet one person, and they are telling you great news, someone is getting married and there's going to be a great big family wedding. And then you go to somebody else, and they tell you their granny's got cancer, and they've got six weeks to live. You're never …it's never two situations or two people the same. In ministry, every situation is a unique situation. So, I wouldn't put myself in a place where I would say 'Autism…my child is autistic, I've got a particular set of skills'. I would still treat every situation as a unique situation, and just try to learn and discern, and hear and be there for somebody. You're listening to somebody and they're telling me their story…sometimes people just aren't heard. I find that a big problem in life. Sometimes people are trying to tell a story, but somebody else already knows the narrative better than them *[laughs]* that makes sense! And then you don't seem to be listened to. That's me in ministry and autism. It isn't a remarkable story. That's what it is. I don't know if anybody has anything they want to ask?

Question: It sounds as though it's been more challenging since diagnosis, but I would have thought that it was worse over the years when you didn't really know why A was behaving that way?

RC:

I think we just put it down to bad behaviour. A has two older siblings and to be honest, one of them is a nightmare! *[Laughs]* That was just B! B is still absolutely wild! *[laughs]* Having gone through that..it went on with A . We began to realise it wasn't quite the same thing and I suppose the diagnosis was a shock. A was seeing CAMHS (Child and Adolescent Mental Health Services) and then they made the diagnosis, when A was late 14 or early 15. I don't think it was something we expected to be honest. But…we have a way ahead now. In fact, I was just getting my wife her Christmas book, it's a book about autism *[chuckles]* - that was the book she wanted for Christmas! So, I'm still adjusting. My wife was an RMN, a Registered Mental Nurse, so she's a lot more sensitive to A than I was initially.

I do think that in church there needs to be space for everybody. We need to work to make space for everybody.

Question:

That's what I wanted to pick up on. Obviously, you have been at other churches before. Did A ever go to any of the services at your other churches? Maybe it also makes difference at what age people are? Some things are different when they are children or when they are younger. Things maybe become more difficult the older people get…more of a contrast between them and other adults. Just asking about A being at church.

R.C.

Aye. Well, obviously I'm a minister and I done my best to bring my three children up in the church. Uh..they all went. They no longer go, none of them go to church now. A was always less comfortable with church than B and C. They always seemed able to enter into what was going on. A has always stood on the periphery of things. That was difficult as well. A was involved with *(a uniformed children's group)* when younger. A would go..and was kind of stood at the edge of the group all the time. I used to feel so sad about the way A was, and I didn't know what it was. I didn't know how to deal with it. The same with the church and with Sunday school. What struck me as…when A was really small, about 5 or 6, she was quite wild. We were always getting called into school, about A's behaviour and things like that. A always seemed to be at the centre of any mischief. When A was in Nursery 4 or 5, and we went through this transition as a young child, where A always seemed to be at the heart of things, to the time A was leaving school and wasn't speaking to anybody at all. A rarely spoke to me, to be honest, the time A was 15, 16, she rarely spoke to me. She spoke to my wife but wouldn't speak to her grandparents. I remember a big set-to, she wanted pakora, and I went to get the pakora. I had ordered it on the phone and paid for it on the phone, and I drove down, and I said, listen, you go and get that..'No, I'm not gonnae get that'..and 'It's your pakora, go and get your pakora' 'I'm not going' and this was a right set-to and it happened in the car and I said' Right!' and I drove home *[laughs]* and she never got her pakora! And then I jumped in the car and took her down again, but there were adjustments going on in those days. I found it hard to deal with her behaviour…uh..can't remember where I was going with that, I've lost my thread…

Aye, so we went from a place where A didn't engage with anything – church, school, youth organisations, she just became very withdrawn from everything. That was scary, that was scary as a parent. I don't think she has a faith now, but she doesn't talk to me about it anymore. Sometimes I'll be having conversations and she'll be looking at me out of the corner of her eyes *[smiles]*…I don't know. She's always found…I don't know that she would fit in well with..she has gone to X church a few times and it was largely older people who were kind of…with a young person, as they will do I suppose, and she just didn't like that. They didn't make her feel comfortable and so she just didn't go back.

Question:

It's interesting what you were saying, there's so many parallels, if you like, with for myself and C who is my son. He has autism and would happily tell people that, and yet when he was growing up, we had difficulties when he wasn't diagnosed until almost secondary school. Part of the problem was that we didn't understand what was going on and at that stage, I'm not sure anyone else did either. I think there's a feeling sometimes, that once you get to know about autism then life gets easier – it doesn't! It's more to do with how things develop and how they grow. Particularly at the teenage stage where there's so much going on for teenagers, for youngsters with autism who find it difficult with socialising, the whole language side of things, it becomes incredibly difficult. I want to ask: We're working not just with the person with autism, but the family too – how much support are you getting from you church with regards to A? And the impact on the family – knowing that a minister's life isn't straightforward, 9-5. So, what kind of support are you getting? How important do you think support is for families?

RC:

I think *[his denomination]* as an institution has all sorts of support for ministers. The trouble is that you need to ask for it. I don't think it's easy to go to your employer and say 'I'm struggling here, can I have help with it?' In my case, my employer's a church, I suppose if you work for British Gas, you wouldn't be phoning up the office to say 'I'm struggling here, what help is available?'. We do have support there, if we need it. There are people, in our offices, who offer a programme we can tap into for support. I use spiritual direction, and pastoral supervision as a means of support in the job I do. I'm very fortunate in my situation. I'm not on my own, I work with another minister. I'm in a group of parishes that will ultimately come together into one parish with a team of two ministers. Both of us are already in post…so I do have a colleague, which is unusual in ministry. I do have a colleague that I work with all the time, who I can talk to about things. I think one of the difficulties of a job like ministry is that you can get so wrapped up in the moment that you don't easily see the big picture. That can very easily lead to a situation where you can become totally immersed in the situation that you're in, that you don't see things round about you are starting to go wrong. I don't know anybody in ministry who hasn't been in a situation where they've had to say 'Hold on a minute, what am I doing here?' That's easier with a colleague that you can share things with, and that's what I have here. If I need emergency things, *[pause]* my oldest daughter, when we lived in Paisley, coming home from university, someone tried to murder her outside the house. She was attacked and they tried to kill her. When that happened, the full weight of the church's support descended upon me. But that was really as bad as a situation gets, when someone tries to murder a minister's child. I don't feel the need to ask the church for support with the A situation, because I think things are improving. [The denomination] does try to support us. There're chaplains, there's mentors, there's all sorts of arrangements available to us. They do try to support us, but the difficulty is – you need to ask for it, and it's not easy to ask. Nobody's watching to see if you're OK. You've got to say, 'It's not OK, can I have help?'

Comment:

That's difficult to do, when you're the one who is meant to be the pastoral support for folks from round about. The reason I was asking…I'm very grateful for the church I have been in with my son, because we have had support, usually from friendship groups within the church who were able or willing to understand a bit more about autism. They got to know my son, and this has helped him greatly. The other question is about your age and looking forward. I think when people think about autism, they think about the immediate moment, whereas for many families in our age group, they are looking forward, and throughout their lives they have always been looking forward and asking, 'What's the next step?' Whereas people outside families are thinking – what do we need to do now?

Question:

As we think about training for churches, church ministers have so many different aspects that they have to deal with – autism, people coming in with sight loss, dementia etc. You've got many people coming to you just now, saying ‘You’ve got to do this, you’ve got to that, you’ve got to support our group’. As a minister, how do you respond to that? You may have a specialist saying ‘you’ve got to do this’, but you have to be aware of the wider picture. How do you deal with that?

RC:

Just today, today’s Monday, it’s the beginning of the week, and I’ve got three wonderful training opportunities! During the course of a week, any week, I will be presented with eight or nine wonderful trainings *[laughs]* that I can go on! To train for this or that..I do always look at these things when they come in and I think, ‘Yeah, that’d be a great thing to do.’ Then you realise that it’s over four weeks or four mornings and do you have two days to give to that? In the meantime, I have two parishes, people keep dying in those two parishes, so there is always funerals to deal with. In our area, I have shared responsibility for seven schools that are all looking for attention. And then there’s the statutory training that the church expects you to do, stuff you can’t avoid, like safeguarding training. So, I suppose when you take the time to train, to go on a course, to pick up a set of skills, what you’re trying to see; is something with the most value in? I did the counselling course, only because I thought that learning to listen better, that’s a worthwhile thing. I could justify the time. I did a training day about post-natal depression once, and I did my post-grad in health care chaplaincy. At that point I was spending half a day a week in the hospital. When opportunities and requests come along, you would love to do them all. I would love to pick up lots and lots of new skills, but situations come so thick and fast that you don’t always have the time to train for them. So, a lot of the time you are dealing with situations absolutely cold. Your training is maybe your hour on Google, trying to learn something! Is that an answer?

Comment:

Yes, that’s exactly what I would expect. It’s easy for us to come in a say ‘Oh, you need to do this and that’ whereas you have a whole range of things and a whole set of people coming in saying ‘What we need is the most important thing for your church and we’ll revolutionize your church’, and that has an impact on other people. I assume that what you’re saying also applies to people in the congregation, that they will also be busy people with work and family commitments. Having them attend training means having to give up part of their time. They maybe have to prioritise their time as well.

RC:

Another issue with congregations is the demographic and age of them all.

Question:

When A went to the café, was that a café with specialist training that could help her?

RC:

The café seems to deal with all sorts of groups. A applied to be involved with the café. My wife is actually an advocate for it, so she phoned the people at the café up saying ‘Look, this is A’s situation’. They were quite happy to take her on and she enjoys it. She enjoys the work, and she likes being with the people. Sadly, she became very friendly with a Chinese student who used to volunteer, and she just went back to China. That’s why it’s sad, she had just made this friend and the girl is back in China and they don’t even know if, because of the political situation, if they’ll be able to keep in touch going forward. It’s not like somebody living in France.

The cafe has been a good thing for her, she enjoys it, she goes in, she works hard. She doesn’t take a lunch break, which is maybe a worrying thing. She just works through, because taking a lunch break, I suppose, would mean stopping, sitting down with a sandwich, juice, a cup of tea, it means being with people. She's quite happy to keep going full pelt, just doing the work. But the café, is a big step forward. She's dealing with people in a way that she couldn't deal with them before. I can see her confidence change. She is getting better. When she left school at 16, that was a real worry for us. We didn't know what she was going to do. I had an idea that I ran by A. I asked her if she would study at the Open University, and she said she would. She's been studying a history degree for two years now and she's going into her final year. She'll still only be 18 when she finishes *[laughs]* but she's actually talking about a Masters and where she could do a Masters. So she's gone from a place where everything was just too difficult, to a place where she's starting to make plans. She's gone from 'Can I do a Masters with OU and sit in my bedroom away from people, and study?' to talking about doing a history Masters at Edinburgh. That would be her ideal situation. But from two years ago, when she was leaving school and that was it, there was nothing we could do about it, times have moved on. But I think things have only moved on, partly because we've been able to get more in tune with the situation, but A has become more confident about herself.

Question:

I'm a candidate in training for ministry right now, and my daughter is waiting to get an autism diagnosis, and I'm autistic, so I was just wondering if you had any words of wisdom?

RC:

I don't think..living in a manse can be quite invasive at times, You need to be able to take control of that situation. People will come up to your door for all kinds of things if you let that be ok. I'm not saying that you should be unapproachable. It's one thing people coming up to your door because something bad has happened, but folks can come up to you for all sorts of nonsense. I once had the doorbell ring at half past eleven at night, when the girls were all in bed for school, and someone had forgot to arrange keys to get in the church hall the next morning! So, the whole house was woken up! And they thought that was…*[laughs]* Living in a manse can be quite invasive. People can invade your space quite often, but if you can, take control of the situation. You can be quite firm with people and let them know that it's not OK, and why it's not OK. For example, I discourage folk from phoning me after 9 o'clock at night. If somebody phones me after 9 o'clock at night, I tell them that it's nonsense, they shouldn't be bothering me at this time for this..we can wait until the morning to sort out a key. If it's an emergency, I've got up at half past eleven at night, pulled my jeans on and gone up to the hospital because somebody was dying. Sometimes the invasion into your family, living in a manse, is appropriate and sometimes it isn't. But that's for you as an individual, to set boundaries. If you are living with a family member that has difficulties, I don't know if they're the same difficulties as we had living with A, but I do know that if I had a constant trail of people coming in and out the house with all sorts of *[laughs]* nonsense, that would have affected A. I think it's Ok when you're living in a church house, very few of them are close to churches anyway now, I think it's absolutely OK to take control of the situation and feel empowered enough to say to people 'This is my family, you cannae be coming here at 11 o'clock at night.' But that would be for you to…now you'll be thinking I'm a horrible person, *[laughs]* that I've got a big stick behind the door!

Comment:

I was just thinking of getting some geese for the garden! Better than dogs!

RC:

Most folk are sensible. There's the odd one that'll intrude on your family space, but most folk lean toward leaving the minister in peace. But some folk will bother you, but you can deal with that. Some people will take offence when you're firm with them *[sighs]* there's only been a couple of people over the years. I wasn’t nasty, or bad, or cruel, but quite simply, because they never got their own way. You’re trying to create boundaries for the wellbeing of your family, especially if your family situation is a wee bit…more difficult than two and half dogs, well ok. It’s right and appropriate to put those boundaries in place.

Comment:

We had a woman in our congregation, now in Inverness, who wrote a book about her image of God, and our minister went to the launch and said it was fantastic. Her name is Dr Ruth Dunster, and the book is ‘The Autism of Gxd,’ and she explains in the book why she sees God that way. I just thought it would be of interest to you.

HL:

I know Ruth Dunster, and I have been reading her book. I recommend it, but you might need to sit there with a dictionary! She’s very intelligent, a theologian and a poet. A most interesting person. A very interesting and thought-provoking book.

RN shows the book ‘The Autism of GxD ‘on camera

RC:

Ah, there it is, ‘The Autism of GxD.’ My experience is that everyone relates to God…

Comment:

In discernment they asked me who I thought God was, so I gave them a 2 page equation, mathematically explaining what God was *[shrugs and smiles]*

RC:

Whether you have autism or not, whatever difficulties you have, or problems or crises, or experiences you have had in life, they all accumulate and that’s how you relate to God. It’s the sum total of all these experiences. So, I would think everyone is different. I have always been suspicious of folk who told me the ‘right way’ to *[laughs]* believe in this or that, because we all believe in very different ways, we all do. I’ll look that book up, maybe for Christmas *[laughs]*.

Comment:

Thank you very much for being so honest, there’s no pretence there. It’s been very enlightening. I do appreciate that. I’m married to a minister, and I’m a part-time minister myself, but not in the same way as you are and not in the same situation as you are. I appreciate… yes, thanks very much.

Comment:

After this, we’ll all be able to offer help to any family with autism, I think. That’s obviously been your experience, that there hasn’t been much help available, so the more we can listen and think and understand, the better able we’re going to be able to give some help.

RC:

Aye. In my experience, what we’ve needed with A is patience. That’s been the key thing, of having patience. You’re trying to find patience in the middle of a very tumultuous time of your life. Everything is going crazy around about you and the solution doesn’t seem to fit into the middle of all that. As you move on, you become more patient. The thing for us is *time* and getting the space to be patient and more reflective about the situation, instead of just reacting all the time.

Comment:

Our daughter is a social worker. She's not dealt with so many children that are autistic, but some present with very challenging behaviour. I suppose it's a parallel. When people put themselves forward for adoption or fostering, if they are taking on a person who has challenging behaviour and who's disruptive in different way and difficult to work with, the advice is: Don't have another job, because this is a full-time job! I feel for you and your wife because you were already in a system of ministry to other people and suddenly you've got a huge challenge. Ministry itself is a huge challenge. Children that go into supported living have people there 24/7 who are with them, and they don't have another job. Yet, you are trying to do your job and it sounds really busy. I think you should be patting yourself on the back, because you can't suddenly give up jobs when you have a child diagnosed with autism.

RC:

Perhaps the blessing in this is my wife – she's a retired nurse and she had her NHS pension so she…I said before that I was worried about our age, but perhaps this is where it becomes a blessing. My wife is able to be there for A. They are about to go down to London for a week in October and leave me here with the dog *[laughs].* That's the blessing in our situation! My wife is able to give complete attention to A.

Comment:

That's really good. Enjoy your week with the dog.

RC:

I will.

Comment:

I just wanted to say a quick thank you for sharing your story with us, and just to pick up a bit on what T said, having that shared family experience, those worries and anxieties that are always running in the background, whether it be about the future or whether it be about things that are happening now or the way someone is behaving. It's just nice knowing that there's someone who's got a wee bit of insight into that, because that's always reassuring. It's something that can be quite isolating for families, so thanks again for sharing.

HL:

Yes, I have to say that I'm very appreciative of your real honesty there, of your situation, of your vulnerability really, being very open and honest about yourself. And about what the relationship has been with A, and the impact that has had on you, and on church ministry. There's the positives, what you have learnt from the experience, what she has, unwittingly perhaps, taught you and the person she has shaped you into as well. But also, the reality that this has, and continues to be a very challenging journey for you. I think we are all really grateful to you for your time, and for sharing so openly and such a real way, which is incredibly helpful. I think it's always important for us to keep it real, keep things grounded, with the churches and folks we're meeting.

The conversation ended with prayer.

✓ Key points:

- Autism was not part of RC’s training for ministry but would have given him an insight.
- He has almost too many opportunities for learning now but not enough time. Good for churches to know that learning about a situation may have been one hour on Google!
- An autistic child has taught RC valuable skills for ministry, such as listening, reflecting instead of reacting, offering space rather than a ‘fix’, patience
- The school years can be difficult and affect the entire family.
- Ministers can find it hard to ask for support – even if it is available
- Manse life can be intrusive. 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

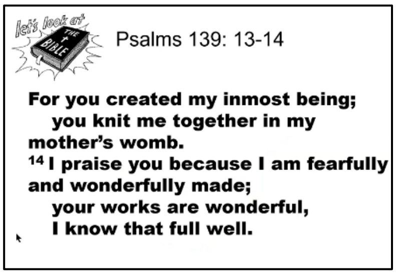
8. 9/10/2023 - Augmentative and Alternative Communication with Barbara Ann Orr, Rachel and Rebekah Newman

Barbara Ann Orr is a retire NHS Occupational Health Therapist, Rachel and Rebekah Newman are sisters. Rebekah is autistic, has Down's Syndrome and learning disabilities. Rachel is her main carer and has wider experience of care. To understand communication with Rebekah watch Rachel in a short video here: https://www.youtube.com/watch?v=NaD6UZku31s

Barbara, Rachel and Rebekah are all part of one of our PAS-supported groups 'Friends of Jesus' at Breich Valley Church. Here is the transcription of the Drop-In:

WELCOME

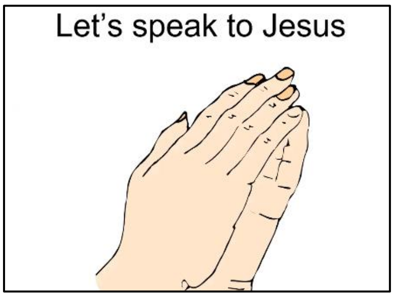
BIGMack: [Recorded spoken message, operated by Rebekah, plus the slide] "Welcome to our Autism Drop-In this evening



Psalms 139: 13-14

For you created my inmost being;
you knit me together in my mother's womb.
[14] I praise you because I am fearfully and wonderfully made;
your works are wonderful,
I know that full well.

BIGMack: [Recorded spoken message, operated by Rebekah, plus the slide] For you created my inmost being; you knit me together in my mother's womb. I praise you because I am fearfully and wonderfully made; your works are wonderful, I know that full well.



Let's speak to Jesus

Rachel: And we're just going to have very short prayer now. Let's pray.

BIGMack: [Recorded spoken message, operated by Rebekah, plus the slide] Thank you Lord God for your words, which show me the right way to live. Thank you that Your way is always the best way. Help me to trust you completely. Amen.

Rachel:

So that was just a brief introduction from me and Rebekah I will hand over to Barbara to talk you through some of the more technical and professional aspects. Thank you.

Barbara:

Just on my phone I'm afraid, so I'm having to go without any visual at all. Thank you, Rachel and Rebekah for that. As part of this drop-in, I'm going to talk a bit about what's known formally as augmentative and alternative communication methods. I'm just going to explain a bit about what that means, and then explain what we thought about it for our own particular Prospects group, what we tried to do and the way forward. Then I'll hand back to Rachel and Rebekah. So , the term AAC refers to methods that either support or replace verbal communication. Since about 25% of people with learning disability and autism have limited, or sometimes, no verbal communication, and we will find this often in our Prospects groups and in other groups that we're part of and in church groups. We started to sort of think about, what did that mean when we were trying to put a group together?

So, if we if we think about the first bit of the AAC that's **augmentative** that means to say that it **adds to** somebody's speech, so they may have some speech. That's what the augmentative bit means, that it adds to somebody. It may add to their level of ability, shall we say. It may be in terms of signs and symbols, gestures, quite a lot of you this evening might be familiar with Makaton. That would come under an augmentative communication method. It adds to what the person's already got.

BIGmack

If we think of something very specific, we've already had an example of with Rebekah and Rachel. BIGMack Is an augmented communication method. *[See picture, left]* Maybe haven't seen one before or you maybe could see Rebekah using hers. They are like a big switch and they commonly been used in the past to switch something on. You may have come across people with a learning disability, that have used the BIGMack to switch the music on, or to switch their lights on, or to switch the television on, something like that. They've also been used for decades as a communication method, to convey a message. You'll find out a bit later that we're using them in our group. So, BIGMack's come under augmentative, meaning 'to add to'. The message is usually recorded by somebody else, but not always, and the message can generally be up to two minutes in length. You can have several messages on the same BIGMack.

Alternative is the second part of AAC. Alternative methods of communication aids are used **instead of speech.** Today's technology, it's led to a lot of what we will probably see, very high-tech computer programmes. You might have heard of voice output computer aids, where you'll see people using these aids. It's a bit like a big screen or like a big notebook or something like, that but it's still digital and that's an alternative method.

Mostly what we're going to be talking about is augmentative, meaning 'add to' so I've said. About BIGMacks; they've been they've been around for quite a long time. You might have come across BIGMacks, maybe as a communication method, between people who are going between home and school, or home and college, or home and the workplace or training place. They're very useful for school, for instance, to communicate to the home environment, what kind of day the person's had. The person who's supporting the individual will record a message, saying, for instance, Rebekah has done this today, Rebekah has done this in the day centre and so on. BIGMacks have been really useful for that type of thing.

Other forms of AAC are really important, and we've tried to do this in our group to establish what we would call, and you will have heard called, a **person-centred environment**. This means, it sounds very jargony, but what it means, is that we are actually doing something that's about the person. We're not doing things around the person; we're not making choices and decisions and activities around the person. We're trying to involve the person. We're wanting the person to be central, the person to be key; their choices, their decisions, their input so whether it's in church or a Prospects group, whether it's in an education environment, or training environment. That's why these forms of AAC are really, really important.

Another example of this, you might have come across, is something called **Talking Mats.** Now this has really come on in leaps and bounds. Not that long ago, Talking Mats literally consisted of a mat with laminated pictures of two or three things, which the person could easy use gesture or by pointing to. To try to make some informed choice - so it might be - what do you want to eat today? There might be a picture of a sandwich, and a picture of a curry, or something like that. Or, what do you want to wear? There might be a picture of a sweater, or a blouse, or a dress. What do you want to do today? There might be a picture of swimming, going to the cinema, going out to lunch - that's the general idea. That was Talking Mats. It also formed part of AC but they have come on in leaps and bounds as well because of the improvement and the great extent that we can now use computers and digital technology. They've gone from being a mat and laminated pictures, to being digital high level computer systems. They're just examples to try to give you an example of what it is we're talking about.

If we think for ourselves personally, in the Prospects group that Rebecca and Rachel and myself are part of. We started to talk about communication, because as I said earlier, an estimated 25% of people with learning disabilities, or thereabouts probably have limited verbal communication and some of those will have no verbal communication. This means that communication is difficult. We started to think about how we can support our members to have increased autonomy and input to the monthly meetings. We wanted it to be for the individuals, the term formally is 'person-centred' making it *about* the person. We're not making decisions *for* the person and that we're not just paying lip service to the person being a group member, that sort of idea. We were thinking in our group about how we could enable people, facilitate people, in our group? It mainly consists of group members who have very limited and some nonverbal communication, so if that's the case, how can we make it for our group members? Bible readings, and news time which is something we do every month. How those things can be really genuinely involving each person who's a member of our Prospects group and has a learning disability? It appeared to be quite a problem. We talked about, prayed about it, Anne and tried to look at ways of resolving. My background is as an occupational therapist, working with adults who have learning disability and autism. Most of the people that I worked with were profoundly disabled and very often had limited or no verbal communication. I often worked jointly with colleagues from speech and language therapy. We often do pieces of work together, like the Talking Mats, like the use of BIGMacks, like the use of signs and symbols and gestures and all of those things. So, in this instance, with Prospects, I collaborated with somebody called Sarah Wadsworth, who is a speech and language therapist. We decided how we could move forward in our Prospects group, because we felt that we'd identified something within our group that we didn't want to ignore. We felt that we've identified something that was significant, and it needed addressing and we wanted to address it. That's just giving you a bit of a background of how we came to be where we feel what we've looked at, what we've considered and how we've got to the point now. We have managed to facilitate, I think more participation and experience for our group members and have improved to some extent, communication methods. We've still got a long way to go. I still have got a lot to learn, and to share further, and maybe in another couple of years, we have more to share with you.

I'm going to hand back to Rachel and Rebekah now because I think that they're going to be able to demonstrate further to you how we've introduced some augmentative communication methods into our Prospects group.

Rachel:

Thank you, Barbara. At the start with the slides, I got Rebekah to press this switch here *[shows BIGMack]* and she's very familiar with using this type of device. Not this size, because this is a very large button, but for many years now, Rebekah has had a smaller version of this switch to activate her CD player that she has downstairs in the living room. You can sort of set them for different functions, so that's the stop/start. She would press it once to start the CD, and if she didn't like it, she would press again to stop, which did happen one time with a Take That CD! The one she has upstairs, that's on a timer. The switch is connected to a timer, then the timing box is connected to a radio. So, when Rebekah goes upstairs to sit on her bed, she can press the switch, and her radio comes on and then when it times out if goes off. It can be anything, I think, for just a few minutes up to an hour, so I have to manually go in and change the timer. But once it's set, it's set. It's not like I have to do that every time. When it switches off Rebekah would just press it again. This particular BIGMack though, it's got quite a lot of recording options. This is called a Step by Step, with levels. So what I did there, for the start of this drop-in is, I'd recorded one message on level one, and then I had to mess about and move the side switch up to level 2, and there was another message recorded on level two. There's also has Level 3. Within each level you can sort of record consecutive messages. I'm sure some of you are familiar with maybe using an echo prayer as part of worship, where the leader will just say a very short phrase or a very short part of the prayer, and the other people will repeat. You could do that step by step and within one level. Just to explain some of the technical things.

Barbara uses this a lot in our worship, for prayers and for readings as well, and for people sharing their news, because most of the people in our group, don't have a verbal communication so this is a good way for them to feel that they are contributing to and participating in the group.

Another positive of this for Rebecca and the other people in the group, who use a BIGMack, is this just requires a light touch. You don't have to have the strength in your hands to operate it. As Barbara referred to as well, a switch system has got many many possibilities. In my working life, I supported a gentleman years ago, who had a spinal injury, and he had a single switch setup to a system to open his door, do his lights, his computer, TV, do his telephone and it was just a light touch because he had lost all the dexterity in his hands due to spinal injury. That's just to let you know how far reaching it can be.

The other thing that we used in our group as well are these **Talking Tiles** [shows Talking Tiles, like the picture, left] so any of you going to the Tulliallan holiday weekend Prospects have, if you went to the prayer room we had this year. Sarah Wadsworth *[a Speech and Language Therapist and NHS chaplain]*, she put that together and a lot of Talking Tiles were used in that. Our youngest nephew is autistic, and when he was at nursery, he would have a Talking Tile. Practically though, these are not… the volume on them isn't as good, and also, it's harder to press. I'd recorded a short message on one for the very start of this evening, but Rebekah was trying to press it and she didn't quite have…maybe if I'd got on this table, it would have been better. The volume isn't as great. I recorded something about going to the shopping centre, can't remember, but I'm just going to demonstrate and you may or may not be able to hear it, but it's just so you know the practicalities of it. *[plays a message on the Talking Tile]* Could anyone hear that? Could you pick that up at all? Alright I've got some gentle nods there, there so practically what I would say is these don’t seem to be as user-friendly for using as a whole group. Even when we're using the BIGMack as part of our worship we do often need to use the microphone against the speaker of the BIGMack to amplify the sound enough, so that everybody in the group can hear. But like I say, these Talking Tiles have been really effective when Sarah’s set them up in the prayer room in for Tulliallan. [*Example shown above]*

The other thing that we have used as part of our group, again to aid people's communication; this is a talking photo book [shows it on video] . There's 20 pockets here, so it's basically like a mini poly pocket and on each one there's a little play button, so again you can record a message for each photo. Another thing we bought is an instant Polaroid camera. This is another thing that is not super practical for sharing in a big group, but after our worship, we sit down and have a cup of tea and refreshments together, so this is maybe more practical to pass round the group. So what we have done was we've given this away to a different person, each month, for them to record their news. They may or may not have taken photos with a Polaroid camera. Again, I've just recorded a very brief message and this again is maybe not so user-friendly, because it requires somebody to use a pinching motion 'cause there's a tiny little button at the bottom, but I will play it now and just see how it picks up on the microphone. [Plays message from photo book] I don't know if you can pick that up I just recorded a short message saying; ‘Here’s Rebekah sitting on the sofa listing to music’ and that was just to go alongside the photo of her actually doing that. So, that's just an example of another way that in that people can share news and as Barbara said, it's all about people feeling more included in the group and being able to contribute in whatever way that they can.

The slides that we had that we showed at the start as well, that was just another example of how we use different visual things as well, to help people focus. We do include videos as well as part of the worship as well, but yeah, it's just about trying to include people a bit more in a way that they can participate in.

I think if people have any comments or questions, and we'll do our best to offer something to you so I'll pass over to all of you.

Question:

I have been visiting a gentleman in a care home, I’m a chaplain and that's part of what I do. He had a mat just as Barbara was describing, very basic, laminated, but it was actually quite laborious for him. He had to spell out all the words! He was trying to tell me a really complicated story which I was able to get, but he had to spell each word, even A-N-D for and. It was exhausting for him and a lot of concentration for me. I just thought a Talking Tile or Mat, that sounds so much better. Are they like a tablet form?

Barbara:

It's a great question. Talking Tiles which you've just seen demonstrated by Rachel and Rebekah, they are quite a different idea to Talking Mats. Talking Tiles would have set up there in a way that would be like the same sort of concept as a BIGMack in that they've got either a word or a phrase recorded on each tile, and so then the way that we use that maybe for a scripture reading so one tile so would have the first line, the next tile the next line, etc.

What you're talking about with the gentleman that you're supporting, the Talking Mat, that's quite a different sort of thing really, to Talking Tiles, because that's to give the gentleman a question. It's a tool to give them an opportunity to make a choice. I haven't seen Talking Mats used where somebody is having to look at each letter, that's using letter by letter. Usually, it's to enable the person to make a choice. Did I misunderstand that?

Rachel:

Just to jump in, I am little bit familiar with what you're talking about and my understanding was that you could get options where there would be words, rather than having to spell out. It might be that it's set up so there's so many well used words or common words. There would be an option for that. I'm not exactly sure what they are called, the equipment. You can certainly get versions more with individual words, like ‘a’ and ‘go’ and ‘the’.

Response:

He had had a stroke, and it wasn't that long ago, but it looked quite well worn, his talking mat and I just thought there must be something a bit for him to use.

Rachel:

Barbara, looking to you, technology has moved on. I’m not sure how many people use physical Talking Mats anymore, it's probably all on an iPad. Quite a few years ago I tried to to get Rebekah’s switch repaired for her CD player, and the first guy I was talking to, he said now what it is, is that people have an iPad and on the screen, there's a representation of buttons. So, you’ve not got a physical button, it’s like a picture or an image of a button on the iPad screen.

Response:

Care homes are not always up to speed on a lot of stuff but people like us, sometimes are resistant to new things and if you're familiar with your special talking mat, and somebody says you could make life easier by using technology… people get kind of horrified whatever stage that you ‘re at.

Barbara:

I think that there's a place for what would be considered now, quite basic forms of communication methods, s and the much more advanced digital communication method and I think that it's really a matter of just working with the individual, or those in your group, or whatever it is. Whatever is right for them, and I suspect that there will still be people with learning disabilities, that will really like the basic original Talking Mat method as was used, and probably is still used. It, won't be right for everybody to go for a digital type of thing because people's level of ability within the LD community is going to be so wide and it's not everybody with a learning disability and autism, that's going to be able to use a digital method. Quite often it requires a level of cognitive ability that they might not have. I don't think we need to throw out basic things like the basic Talking Mats I used years ago with speech language therapists and I'm sure that they are still used. It's just matter of trial and error. If something's an old method that somebody's comfortable with, but that works for them, then I that that's quite right to keep it.

However, the gentleman you referring to, putting letter by letter, finding that quite arduous and quite wearying, so I'm sure that there would be something better for him. But if it is something that works, stick with it.

Question:

Where do you buy the BIGMacks and mats from?

Barbara:

if you want to look at anything like this from the most basic to the most advanced, I'm afraid that does really involve technology or I guess you probably can get catalogues, I don't really know. if you're able to use a computer or able to get somebody to put into a computer ‘alternative communication methods’ or any of the companies like Able World. There's lots of different companies doing different types of equipment, that includes communication method equipment. There's loads, in fact there's so much that Rachel and I have really struggled because we're looking at buying new BIGMacks, and we've really struggled to decide which ones, because so many varying in price but it's really difficult to decide. You either contact a company, of which there are many, and they probably will send the catalogue or look on the computer. There's pages and pages whether it's Talking Mats, whether it's books with signs in, whether it's BIGMacks, anything really. There's so much, and there's so much to choose from. Some things like the Talking Tiles are not a lot of money and I don't think the photo book was a lot of money. I don't think it was a great deal of money.

Rachel;
All I remember now is the BIGMack was about £139 and that was from Amazon, I think.

Barbara:

You can get BIGMacks cheaper than that, but they vary greatly. I know that you can get them well below £100, and then as Rachel says, ours was dearer than that, but really there's so much out there. Once you find a site or the company that deals in this sort of thing, you would either get to catalogue or if you are able to view on your computer, you'll get pages and pages of equipment. There is so much out there.

if any of you had a speech and language therapy contact, I'm sure if you had a contact person they would also point you in the right direction of which company is good to go to, go onto this website. Communication methods, particularly for speech and language therapy, that's their bread and butter and they would point you in the right direction, but there's a lot out there.

It's just difficult to a) obviously get the funding for the equipment and b) to make a choice because there's such a lot and to know that it's going to be the correct choice and it's going to be what you want and what you're going to use. That's difficult sometimes. It may be borrowing something might be an idea. Borrow something before you invest.

Rachel:

A couple of people in our group were already familiar with using BIGMacks. I think someone had one for years and another person, a young person, they used to use theirs for going to and from school. People might have their own equipment, things that they use, that they could incorporate. I know some Prospects groups I've been to, also use this sort of Makaton and also Boardmaker. Some of them are used in the prayer room Tulliallan. Our youngest sister, she helps a group at Kirkintilloch and, to show the order of the service, they have a row of these Boardmaker symbols, so they have the sequence. They have a room where they meet, there's like a whiteboard, so they're just stuck along the bottom of the whiteboard. When their time is finished one of the groups will go and take down the little prayer symbol so the group knows that’s past and it's on to the next part of the plan.

I know that when the Highland groups were leading the worship at Tulliallan, Hilary had those symbols along the bottom of the PowerPoint slides, so you know there’s lots of different forms of communication and different ways you can use them as well.

Barbara:

I think the Board Maker is really useful, if we're thinking about how to make our churches more friendly towards people with learning disability and autism. I think that a really good thing and relatively inexpensive thing, because usually they're laminated. Maybe the pictures have been made and laminated, I think, haven't they Rachel? yeah, and maybe got like velcro on the back or something. So, you just need something to stick them to. They need to be fairly large and I think that’s probably a really basic, fairly inexpensive way of making something visual. People can follow the order of service.

Response:

There's a guy in the church with Down’s Sydrome, he’s speaking more, and I am understanding him more than at first. I’m trying to get the others to speak to him as well at the end of the service. I did not know he had one of these or not at all

Barbara:

it's always worth asking those who support him or his family, does he use anything like this? If he goes to something else, if he goes to college, or goes to a work placement, or anything like that, the chances are he might have something that he's using within that context. You might not have seen him using it but he might use it in another context, like some of our group members.

Response:

He lives in a group home, some of the carers come in sometimes, some don't like to come right in the church in case they get caught! *[laughter]*

Barbara:

That’s classic! It would be worth asking, because we found out in our group, people were using BIGMacks for communication between one place and another, and they weren't an issue using them in our group. We had to find that out and then it was a matter of introducing them into a regular part of our group.

Response:

We'll try to get him on the zoom but hasn't happened yet for some of the Prospects things, but let me keep working on it.

Rachel:

Do you have an in-person Prospects group locally?

Response:

No. We’re trying to start running one in the church. Sometimes we’ll sing a Prospects song from the front.

Rachel:

That’s a good way of spreading a message about different ways of worshipping, different ways of communicating, if we can bring some of our Prospect’s worship into a main church service.

Barbara:

Absolutely. I've seen that Prospects *(now Livability* in England) represented at the Keswick convention in the Lake District, and they've used Makaton gestures, some singing and some dancing and they’ve. communicated to us in that way. It's been lovely, it's probably important that people consider the use of signs and Makaton and gestures and things like that as. I think that’s something that some of our group members are very comfortable with. It won't work for everybody, but

Makaton can be very effective with some people, and it may be something that somebody knows a little of and can be helped to use a bit more. It might not be right for everybody but it’s an important alternative or augmentative communication methods, where you're supporting the person to communicate. We've used Makaton a bit, haven’t we Rachel?

Rachel:

Yeah, we have, yeah and and someone who used to help at our group was also learning British sign language as well, but really for our group Makaton is more appropriate. There’re great resources, there’s someone on YouTube, Becky George, she has uploaded so many worship songs and the video of her doing the signs as well. There's a lot of resources out there, whether you can play the videos as part of your worship, or learn the signs, and then doing yourself in a group… Any more questions?

Rachel:

OK, well just to thank you all for being part of the AAC drop-in. It's been really positive for us, for me and Rebekah, to and share the experience, the different forms of communication that we've used. I'm trying to think how many years we've had these things now, at least four years actually.

Barbara:

I think so, because it was way before the pandemic and we mark everything by that, so I would say for five years, Rachel.

Rachel:

Yeah and it's just been a really positive thing, for people to participate in different ways in our group and even in someone in our group who can talk, they sometimes like to use an a BIGMack or see if you know I've maybe recorded something on the BIGMack, for someone else to contribute to the worship and that person hasn't made it that month, then you know someone else is quite happy to to press the BIGMack. They still feel that they contributed which I think is really… I might have assumed that at first because they can talk, they didn't want to use a BIGMack, but they were happy and to use it to contribute in that way.

Barbara:

Absolutely.

Hilary:

Thank you very much to Rebeckah, Rachel and Barbara and although we couldn’t see you Barbara, we could hear you very well and that was all incredibly interesting. It's fantastic to hear about all the different things that work well in terms of communication and different ways for us to explore and idea that you're trying. I should say, if anyone can it comes across any good ideas, it's always good to share those ideas and share good practise and what's working in your group, so we’d just love to hear more about that from you. “

The Drop-In ended with prayer.

Key points:

- Around 25% of autistic/learning disabled adults don't use speech. In those cases, other methods of communication need to be established.
- AAC stands for Augmentative (add to) Alternative (instead of) Communication
- It supports autonomy, choice, contribution and participation and makes a really positive difference to people without a typical voice
- It takes many forms: technological, digital or physical with sound or visuals. Makaton signing is often more appropriate than BSL for people with learning disabilities.
- In our PAS groups, AAC can be used to support contribution to prayer, readings, sharing news, worship and more
- AAC should be person-centred i.e. they are key, involved and central in the communication
- It is helpful to find out what people might be using in other settings such as care, college, work etc to offer continuity
- Might need to borrow equipment and experiment to find out what works.

Resources talked about:

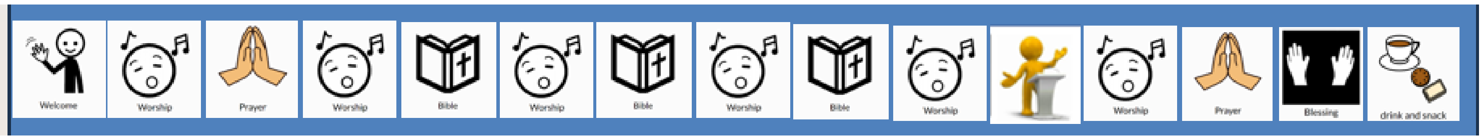
For BigMacks and other AAC technology: https://www.inclusive.com/uk/bigmack.html

Talking Mats: Here’s a video which explains what they are (this is using a literal mat, so quite basic) https://www.youtube.com/watch?v=Fmyt1fE-_U8

Talking Mats website: https://www.talkingmats.com/

Widgit symbols, as used by Sarah Wadsworth. You can try with a free trial, then monthly subscription. Used widely in education seetings in the UK: https://widgitonline.com/en/home

For visual timetables in services Hilary uses Global Symbols, less sophisticated but free: ttps://globalsymbols.com



9. 13/11/23 Graeme McDonald 'Autism and Music' Transcription

"I work in Edinburgh, and I am a church musician at Richmond Craigmillar Church and so I play every Sunday for the congregational worship. In addition, I run four music sessions in the church hall throughout the week and they're not worship song sessions, they are secular song sessions, so pop and rock music and some folk as well. In addition to that I'm out and about a great deal going to the various day centres and folk's houses to play music to them. So yeah, it's a mixture of popular secular music and worship songs I do, and I also run the Prospects Choir as well. Quite often if Roof Breakers are having a celebration day in Edinburgh or somewhere else, I'll pop up and be playing at that. So yeah, musical times. The format is I chose questions and answers - I am more comfortable just playing songs however, you know I don't have a speech ready for you that's for sure! But yeah, I'm very happy to answer any questions that you have.

Question:

Do you feel that there's any difference in your music the way that you perform your music for autistic people and people with learning disabilities, to anything that you maybe perform for other groups?

GM:

Really not. For me it's more enjoyable playing with folk, that you know, we label as having a learning disability. I find the folk that I work with such as R, she's still clapping. That's a born musician. I guess I love playing music **with** people and when folk join in, that's very good. I guess most musicians feel that way especially if they're doing kind of pop and rock stuff and or worship songs. I watch worship leaders in America and if I'm doing research on contemporary Christian music, it's inevitably filmed in what appears to be a fairly significant concert arena and everyone's singing and clapping, so folk are engaging in the music. I guess that's the difference. I find some mainstream audiences that I play to can be very apparently unengaged and you know for a musician, or because music is very much a communication, we want to have some feedback. I guess that's another lovely thing that I find where we're working with local people with learning disabilities - and their staff as well because when I'm running the sessions or I'm doing congregational worship songs - the staff are always involved. There it's a communication with fellow musicians, as opposed to, you know, folk that are just wanting entertainment. That's OK as well but I guess a musician likes to get that feedback. It is communication. There was me saying I didn't have any speeches!

Question:

Would you say that you've observed that music can be a communication for people who maybe don't have other forms of communication? I mean we've got R joining in with us in a very communicative way.

GM:

Yeah. I don't often see the folk outside the music setting. I'm usually working with quite a lot of folk all at the same time, so it's quite easy just to kind of assume that you know the person playing a tambourine and you know outwith the music session ,they're not the not communicating in other ways and I dare say they are but yeah you know undoubtably the folks I work with are just naturally natural musicians. I feel that everyone is, but most folk have gotten inhibition and or more inhibited than the client group I work with. I make the effort to try and learn as much of folk's language in their communication as possible. When I do some work in a one to one or smaller group, I get the opportunity with the staff to find out about what the client responds to. There's one lady that I do a session for, and I’ve got quite a few sounds that she makes and there's no doubt that she responds to me making the sound and she makes the sound back. So, you know, she looks at the clock if we ask what time it is, she's got a lot of understanding as do a lot of the folks that that I work with. I'm really quite surprised sometimes at the level of folks understanding. Unfortunately, too often I see them in a large group, and I miss quite a lot. There’s no doubt that a lot of the folk – I’ll just say ‘the folk’ - have a very good sense of timing you know. R she's clapping, it's just nice and loose and just right on whatever beat. When I'm doing a session the folk they are very much in time. I very, very infrequently find someone that isn't in time and timing is really crucial for a music maker. I'm not sure how much they are actually communicating with me, but I can in a small way, communicate with them. I'll do something that appears to be something daft, like a you know *[makes a toot toot sound with harmonica]* - see the harmonica? Well, that will silence a room. *[toot toot*] if I need anyone's attention, it doesn't matter what's going on, you know it seems a bit kinda daft, but it raises a smile and everyone's quiet. Then we can connect, play out a few ideas.

Question:

I go to a care home; it is for people with learning difficulties but does specialise in autism and all sorts of other things and it's quite big. I go in to lead a service and there's one young man who has autism, 'cause he doesn't really like loud music, and there may be elderly people with dementia and maybe somebody has got a psychotic illness as well. Some love the percussion, but other people don't really like the noise. How can you cater for a diverse group? Maybe it's more a statement than a question, but I wondered how you do that?

GM:

Yeah, goodness, aye.

How to read the room? I find it can be very misleading. You know you can have a learning disability, and I'm no expert, but I think you can have multiple things, including autism. I get folk that'll sit with their fingers in the ears and that's because they want to hear. They are actually kind of blocking out the - you know it's the classic folk singer with a finger in the ear - so that they this they can focus on one sound. Presumably it’s my sounds. Maybe it’s not. You might not be surprised but a couple of folk do this *[hands over ears]* and I asked the carers 'cause these folks have been coming for years, years and years, so obviously over a period of time, I have checked this out with a carer, and they said ‘No, no, they're wanting to listen.’ In fact, I go to the front door and see who's coming down the street, and I see the person coming down the street with a finger in their ears, so you know. Again, I can read the room and I look around the room and I see things like this, and I think Oh my goodness it's me, but no. I guess it is very difficult with some folk even for the care staff or the managers or the family to even know really what is going on. I do also work in ceilidh bands, and we do ceilidhs for organisations, care organisations, and I was playing at one and there was a young lad who I saw sat crossed legged in front of one of the speakers and he's like this and he's just leaning into the speaker. I had to check that out with the care staff, and they said ‘Oh no, he just he just likes the vibration’ again, he wants to drown out the hullabaloo or at least that’s the care worker’s take on it and then I go along with it as well. I guess quite a lot of the guys can become quite kind of overwhelmed by the external. However, it might be, and you know if they're on a stream, it’s maybe the traffic going by. Certainly, this is what I've been told, this is like they are focusing in on one thing. When I'm doing the sessions, I can incorporate all sorts of sensory input. I've got kind of coloured silk scarves that I will be juggling, and then everyone will have a silk scarf and everyone's waving them. And then I've got coloured lights, I’ve never actually had anyone... It's all very soft, nothing’s terribly overpowering but genuinely I can feel that folk like quite a stimulating environment as opposed to you know what we might stereotypically kind of like imagine that folk just want everything is very kinda monochrome but actually you know. I mean the folk seemed to be certainly very happy and come back, so...Trial and error, that's very …as I say I create a fairly high level of sensory environment.

Question:

You started to answer a wee bit there when you were talking about the multi-sensory stuff that you do. I don't know if there's anything more you want to say about that. That would be expand on it - just tell us more about that.

GM:
Yeah, aye. Thank you. Someone asked me if I if this had been part of my training? No, not at all! If you want training, I wouldn't recommend necessarily doing a music degree, it's a great opportunity to learn but, I don't know if you get taught a great deal. One thing that RN was talking about was a session that I ran at the Scottish Churches Disability Group. We had an AGM and I presented five or six different ways of worship using different sensory accessories if you like. One example I could share with you was - this was almost off the top of my head. I got a lady to recite her favourite verse in the Bible three times and we did a background sound scape or mood music if you like behind the recitation. And the first time, it was different to the second time and then the third time it was different again. The lady who is the mother of one of the people with learning disabilities. She really kinda paced the reading from the Bible in a very good way. She would say a couple of sentences and then a pause and we would just be playing instruments, you know it could be shaking the maracas or we've got these nice ocean drums, or the bells and I guess you could sing, or you could hum… The idea behind this, the reading from the Bible, which could at sometimes just be quite a dry delivery from beginning. You start at Isaiah chapter 15, and you read through to 16 or something, whereas she just did a verse once and twice and three times. We had this nice sensory sea of sound going behind her, so for what it's worth, I think was worth trying and I'm certainly wanting to try it with my own congregation. What else did we do on that that day? We used the silk scarves, and you could just choose a song. I think we were waving them. Take yourself a silk scarf and just create some waves and then so we were singing 'With Jesus in the Boat' and 'There is a Flag Flying High' just wafting the flag. The scarves went down well at Motherwell. I can't remember what other ones we did but yeah, that kind of gives you a flavour.

These things that we do in from Sunday-to-Sunday worship. We can change them. As I say, the reading doesn't have to be done just once. Sometimes we'll get a reader in my church and if it's someone new they just go through the verse very quickly because they're quite nervous. If they are nervous, maybe second time they might do their reading more… the reading was a bit more I think, **measured**, is the description for the way that the lady delivered it at Motherwell. It was very kind of der-dum, der-dum, der-dum, it was, Shakespearean, if you like. It was a nice way she did it.

Hi L, have you got anything to ask?

L:

No, nothing. I'm just listening.

GM:

Aye, well. Well done L - yeah, that was another thing that we did at Motherwell, which was just simply listening. I sang a song and folk just listened to it and in terms of worship with members of the congregation with autism, we don't know how much that they're taking in from the song. They might not be singing along but yeah; I value listening very, very highly.

I was mentioning about contemporary Christian music so let's do one and if you don't know this one you can just sing to 'la' or you just listen and R will clap her hands which is just a great way of engaging as well. I will give you the chorus *(Sings Bless the Lord O My Soul)*. Does anyone know that song? Quite a few folks. So, we'll just sing the first verse and then the chorus and then we'll do the first verse and the chorus again. *(Sings song with group)*

Another thing that we did at Motherwell was just speak our way through a verse and well so I'm bringing this back to folks with autism, and maybe they wouldn't find that easy, but there's some people that I work with – and I don't ask the care staff, 'what's this person got?' but there's some people that have almost an encyclopaedic memory of song lyrics and other facts. I don't really check out the facts, but they convince me! There's one guy that I'll when I'm doing pop and rock sessions he will come out and do a song and he'll do Rod Stewart or Queen songs or whatever and he genuinely knows the words all the way through. It'll be onto another song, and he'll have all the words and he's not reading, not sure if he can read or and I'm not sure if he has autism or but that's not entirely uncommon. Probably…you know JK well, her daughter came to one of my sessions and I'm not sure what she has but she certainly has an amazing aptitude for keyboard, unbelievable really. It's …. I find it very very mysterious and very inspiring, and you know I'm just really genuinely wondered by the folk really you know. Huge respect for them as well you know. I'm very happy doing the work with the guys. Another thing that I notice with some of the guys and again, I don't know if they've got autism or what it is, but they will calm down with music …again it's maybe this idea of the fingers in the ears, that the music just gives them a focus and it's almost as if they come from a very almost kind of like scrambled state and into a more unified state. I have noticed this with several folk and I rather suspect it is because of the music or the environment or something. It gives them something to focus on and they very much settle down. They seem happier. I do a session with a lad in his 20s and his mother and you can tell the mother is a little bit… going to having a bit of a difficult time with him at the beginning because he's all over the place, but after a few songs he's just absolutely glued on the music. The only thing he wants to know about is you know what's the next song which is very nice. I notice that the folk can very much settle down and it would appear to me certainly it's because of the music.

Question:

I'm just interested in all that you know of the of the all the sensory stuff that goes on when you're performing - you know like you said about the vibration. That's a big thing either about somebody leaning into speakers and I remember a person in our group who really like to go over to the piano. I think that's a lot to do with the vibration with him as well? When we've got that environment it's doing so much in the environment, so almost like surrounding you. It's lovely because it's about so much, isn't it?

GM:

Yeah J yeah. Absolutely. Most certainly.... You know whether I'm doing my own sessions at in the church hall…I create an environment that is very similar to if we were going to a musical or pop concert or on contemporary Christian music concerts I watch on YouTube. You know there are lights and sounds and it's creating a world for anyone that's in there. I mean for me; it is exclusively adults with learning disabilities and the staff but it's so much better than sitting in a day centre with strip lights are on and there's no atmosphere. I really feel that the sound and lighting is very, very important. If I'm going to someone's house or someone else's centre, then again, when I arrive, I get the lights set up, I get the sound system setup, and we create an environment for the people. We create a world for them, and they engage with that very much more so than if it was in a stark bare environment. I'm just feel that is very important and I just keep my mind open as possible for other ideas. Provided I can pack them on to my bicycle or my motorbike then these ideas will be coming with me. I pack a lot of ideas when I go to a session, but it is really just to connect, to create a multi-sensory experience for the guys. I mentioned the silk scarves, I can juggle, that at this time of the year they can be autumn leaves - you know ‘All the Leaves are Brown and the Sky is Grey’ or if you're doing ‘Under the Sea’ comes from a Disney musical. Equally we could have something from the worship repertoire. I think there's something like two loaves and five fishes and the scarves are now there no longer leaves, but they’re fish so everyone can swish a fish. It is all very simple and almost kind of like obvious. The amount you can do with a scarf!

Question:

I wonder sometimes if within our worship in a Sunday morning whether we need to be looking more at some of those creative arts and including that in our service? Not necessarily every week but at times, so that we can involve people with a disability and allow them to worship God in a way which is important to them, in a way which they can understand. It takes away from this oral presentation all the time. Is this something that you have explored or something that you've done when you've been doing in church worship as opposed to worship with people that disability? I would be interested in your thoughts.

GM:

Yes…We do have a couple of folk with learning disabilities come to Richmond church and and they also come to my music groups. There is a distinction when they come to the music group - this is their environment. I can create a world for them and this is their place and if we get a mainstream gatecrasher come in I just say sorry, you know, you need to leave…so yeah .

Unfortunately, I suppose when we're doing our more mainstream congregational services they are more, as you say, oral delivery and they are quite..traditional, I guess. That's not because of our minister, we have a fantastic minister, and she would be very open to do more creative approaches. I respect her, she knows what I do and she knows what I could offer and I just kind of respect the fact that she's the minister and she'll tell me what to do *(laughs)* I don't know if any of you are ministers as well, maybe that's what you want to hear, that the musician will do what you want. I'd be very kind of cautious…I need to get to back to you on this one….

Question/Response:

I was going to say I realised that that's not an easy thing to do for two reasons. One is that you have no control over the service that belongs to the minister basically, and also there's the whole tradition within churches where we worship. But I'm thinking that we live now in a much more visual world for example and could incorporate simple things like what you were saying about the reading. Maybe a dramatic reading with music and that kind of thing and maybe a starting point so you're not revolutionising the whole service. We're taking one part over that can be utilised, maybe be an introduction to a different way of worship or looking at different parts of the service that a creative side could come into play. I think not necessarily at this stage be changing everything because clearly for some people traditional worship is important. Maybe it's a few small steps that leads to the bigger beginning to change.

GM:

The honest answer is no. …I don't push push things and we don't have a huge congregation, but we have one person who comes along consistently, and they've got learning a learning disability and then we've got another person that comes along occasionally. But in saying that..In the context of Roof Breakers the church has done a huge amount in terms of inclusion in term of making the building more accessible for folk who are wheelchair users certainly and the minister is very supportive of the work that I do midweek - my Monday to Friday offerings which are all done in a very oblique Christian worship. I mean I the closest I get to anything would be ‘When the Saints go

Marching in' or something like that. Our services do tend to be more traditional to answer your question so… maybe I just don't push hard enough.

Response:

I don't think it's that. When I think of churches which are big churches which have that more contemporary worship, I still feel that it's..very much..there's a traditional element to it that doesn't involve something more creative as we were talking about yeah so I don't think it's just your own church and situation, for me it is a wider issue, the wider issue around awareness.

GM:

Aye. Coming back to the ideas that were presented at the Scottish Churches Disability Group meeting, the idea that, just again to repeat myself, of reading a verse from the Bible three times and pretty slowly in a measured way so not just folks with learning disabilities get time to digest it but you know mainstream folk do as well, and accompanying it with some music, so that folk are really engaging. Because I noticed at Motherwell, that the first time the lady read the passage, I was more focused on what I was doing, and then the second time I was actually you know I was beginning to kind of pick up on the fact that she was putting in gaps and it was quite measured. There was a kind of metre to the reading and then the third time I really felt that the whole room was really engaged in the Bible verse. Equally the idea of just reading the words of a song and making that a reading. I feel and I have mentioned this a few times you know, but as I say, I don't tend to kind of push things. I mean I have mentioned them at my church but you know I don't kind of push it and but I really feel that also just reading the words of song nice and slowly so that everyone gets the time to digest them because there that there's a huge amount of wisdom in these songs you know. Coming back to that 'Bless the Lord o my Soul', I mean that first verse you know 'the sun comes up, it's a new day dawning, it's time to sing your song again' well - what a wonderful way to start the day, but by 10:00 in the morning, we've maybe forgotten totally about the idea. That was our intention at the beginning! I genuinely try and use the song lyrics to remind myself of worship practise throughout the day and I think it says 'let me be singing when the evening comes' so you know it's not just we make this you know …it's almost like using the song words like an affirmation. 'Be Thou my vision, be my best thought from day or tonight' …I forgot it but you know I find the words in the songs are very worthwhile and…being slowed down and really kind of digested."

(GM leads us in the Caribbean Lord's Prayer to close)

Key points:

- Music can be engaging and enjoyable for many people with learning disabilities and autism. It can help mood and wellbeing – although it may take some experimenting to see what works 'reading the room'
- People often have a good sense of timing and musicality, and are less inhibited to join in
- Some people have excellent musical abilities which are a gift for the church
- Music can be a form of communication
- Music can provide enjoyable sensory input, for example, through vibrations
- Gentle sensory input such as silk scarves and coloured lights may enhance the experience.
- Many ways to join in – not just with words, but also with humming, clapping, moving etc.
- Many ideas for worship, e.g. combining a percussion 'soundscape' with short, repeated readings of Scripture. Creativity.
- The value of listening

10. Notes from December 11th 2023 Autism Drop-In - An Autistic Christmas

with Tom Wilson, Rachel Newman and Hilary Lacroix sharing their experiences, before the chat was opened up. The internet connection was poor so not everything is recorded here verbatim.

Tom Wilson *came holding a classic Christmas jumper and talked about it. He then went on to say:*

"But one of the problems about that jumper is it's very busy, isn't it? You can spend forever looking at it and finding something different. And to some extent it still leaves me the question is, is this really for I'm looking for? I mean, I think for people with autism, which is really our focus tonight. We're thinking about how busy and how different that Christmas can be.

From that point of view, it can be quite a strange time, can't it? We're doing lots of different things, singing different songs in the church. We're eating different types of food. We're rushing around buying present for people. In amongst lots of people. We're going to pantos and it can all be so different. I think about people with autism, often what they want is something which is the same. And so, when we come to something like Christmas which is so busy. It can be a bit of a difficult time for them. And I think often what happens, two things happens.

1) Is they're like my son, Craig, who embraces it, and of which Christmas has to be the same, absolutely all the time. And if it's not quite the same, it's a bit of a problem for him.
2) Or is something that other people want to maybe withdraw from? And sometimes that creates a problem when everybody else wants to be happy and they just want to be.

And there we are. *[Tom shows us a Christmas jumper with a nativity on it, it's very plain compared to the other one]*

My Christmas jumper. And a very straightforward, simple, Christmas jumper. It tells us the story of Christmas. Of Mary and Joseph in the manger, the wise men and the shepherds and the angels. And what it does, it ..brings it right down to why we celebrate Christmas. Which is the birth of the Son of God. Of Jesus Christ coming into the world. And …really points towards the stable of Bethlehem.

But so often we get caught up in the busyness. That we forget about the stable and the actual story and the reason why we celebrate Christmas.

So, all I wanted to say tonight was to bring together my two jumpers. To help us with the story. And see how do we help people with autism, cope with the busyness and the enjoyment and making it clear?

There is nothing wrong with it. It is enjoyable. But what we have to do is remember the reason why we celebrate Christmas, and the reason is the birth of Jesus. And the hope and the joy and the love that comes through him coming to Christmas. In churches, I think sometimes we can also get caught up with the busyness of Christmas.

…One of these challenges for me over the years, working with Craig, has been trying to help him, not just Craig, but with others, try and help him to enjoy Christmas, going to the pantos and the meals and the presents and all those things, but helping them to see that these are the representation of something that is a celebration. And that celebration is the coming of Christ into the world… I mean, give thanks to God. He sent his son out of his love for his world that we might know that love.

The peace and joy that comes from Him. So my two Christmas jumpers - you can decide which one really is a Christmas jumper and which one is our Christmas festival.

And I'm sure all of us will enjoy Christmas and the fun that comes with it. But it's clearly important and one of the things within the church is that we don't lose sight of why we celebrate."

Hilary: Thank you, Tom. That was wonderful. I love both your Christmas jumpers, but really like the second one. That really got to the heart of things…

I'm going pass the parcel onto Rachel. And we'll see what she has got to say about Christmas and her family.

Rachel: Okay, and well…sharing a different perspective.

For Rebekah, a lot of the things I suppose are associated with Christmas are actually things that are more, I don't know, commercial…those are things that Rebekah enjoys, so the music. She's very familiar with all the songs that you get on the radio and that sort of thing. They've been playing Christmas songs on the radio I think for a good few weeks now, so she has been enjoying that and I've been putting on her Christmas CDs. If we're out and about, you know, the shops and they've got all that sort of music playing. She's absolutely loving that.

She loves the noise of that. And she also quite likes light as well, so all year round has I think or 2 or 3 different sets of lights up in her room for when she goes to bed. So again, that's something that she enjoys. So, at the shopping centre here where we are, they've had their lights up. So again, when we've been going down, you know, taking the time to sort of point out the lights, she enjoys that, and they've got a big Christmas tree.

And then yesterday we went to a local village farm and they had Christmas lights on. It can drop to be a bit darker later on in the afternoon… and looking at the lights, it was fairly quiet, though I would say there wasn't the hustle and bustle that you would get at the shops. And like I say, the light she enjoyed and then they had a fire pit for toasting marshmallows. She seemed quite taken with the fire pit, it was a nice glow. Maybe the warmth of it as well because it wasn't all that warm yesterday. Maybe that's what was attracting her, as well as the marshmallows that were being toasted as well. She was quite interested.

And then, so yeah, so she does seem, you know, she recognizes things like when we've got the tree up. Also, of course, she's very familiar with all the music that we have at church and all the carols as well.

And she would quite often like when we were younger, we would have, you know, the tin of Quality Street and the tin of Roses and she would seem to get quite excited if someone was opening the tub. She would have things with a soft centre, like an orange cream or a strawberry cream, so she always seemed quite excited when somebody was opening the top. It's not something she has as much nowadays but certainly for Rebecca it doesn't seem to be an overwhelming thing for her.

If things are very, busy, that can overwhelm her or if there's a lot of loud noise, so from what I can observe. It doesn't seem to be a specific Christmas thing, and that she struggles with because, it doesn't signal a change in her routine necessarily, or too much of a change in her sort of physical surroundings because lights and music are things that she enjoys anyway.

It's part of her day-to-day life and you know, and she's fine with wearing a Christmas jumper, you know, it's not something that the texture of anything that she would find… because I know some people struggle with that. I did actually buy a new Christmas jumper this year and the neckline was a wee bit higher than usual. It wasn't until I was hanging up here at home and I thought, oh that neckline, but she was actually okay with it. She can sometimes pull at her clothes. If it's not, you know, quite sitting on right or she doesn't like short sleeve things, she'll try and pull them down. If something is too close at her neck she won't, but she was okay with that.

In general, the sort of sensory things that some people might struggle with, Rebecca really seems to enjoy. So, that's just something that I'm really fortunate and really grateful that she does take a lot of enjoyment from all these sorts of more commercial aspects that can be a bit over the top for all of us at the best of times. So very fortunate that we have quite a positive experience of Christmas and a lot of the things that come along with it.

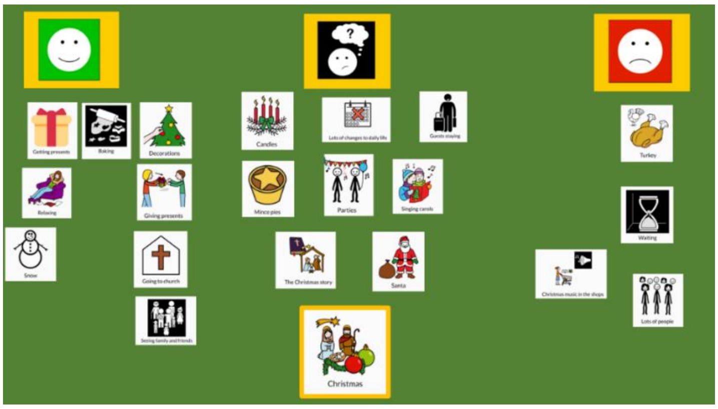
So, I'll hand back to you, Hilary.

Hilary : So I, yeah, just love this [*Christmas mug -shows to camera*] mug that Theo made at primary school around about Christmas. In fact, this morning we've been to a little art group in the village and it's just been a very happy couple of hours drawing, so that's been a really nice thing.

I sat down with him and had a little conversation about what he enjoys and doesn't enjoy about Christmas, and I ended up making a little talking mat with him, so I thought I'd just share that with you because it was quite interesting.

On the left are that things that he enjoys about Christmas. On the right, things that he doesn't enjoy about Christmas and in the middle things that he's not quite sure about.

We had a conversation about Christmas. Now Theo is pretty sort of polite about things. So, he actually didn't really put anything under here *[Not enjoy]* but I noticed that he was very deliberate about where he put things. And so, I've tried to reflect that in some of the pictures as they come up, kind of how he put things up and what was most important to him.



So, his number one, top favourite thing that he loves about this time of the year is snow. He is absolutely delighted when we get snow, and he loves being outdoors and going for a walk in the snow and or being indoors and watching it come down and he absolutely loves it. So that's a big favourite this time of the year. He also likes relaxing. If you can relax, that's a great thing.

Obviously getting presents, that's nice.

He surprised me by saying baking! He does quite like cooking. And decorating, and maybe a bit like Rebekah, he loves having lots of lights up in his room.

Candles? Okay, can be alright. Can have them or leave them. Santa, not really convinced I don't think! Certainly not anymore. He says, ‘I'm too old for Santa now’. Definitely talking about changes to daily life - that can be a bit tricky. But some of those changes could be good, some of the nice things we do at Christmas.

He’s quite ho hum about parties. I think he doesn't mind having one or 2 but he certainly doesn't have good memories of big Christmas parties at school and that kind of thing, he used to find them too much.

The Christmas story, this was an interesting one. He was… I don't think he particularly likes seeing nativity plays or maybe has sort of bad memories of them. So, I'm not sure it's the story itself. I think he's still, you know, we talk quite a lot about what Christmas means, what it's all about, but I think he still struggles to wrap his head around what it means, but he does still enjoy coming to church, so that is good. So, I have to trust God in that, even if he doesn't understand everything.

This was definitely where we started to get into the things that he doesn't particularly like.

Although it's nice to see family and friends at Christmas, having guests to stay in the house. Well, it depends who they are, and how long they stay, but maybe we all feel a bit like that about our guests. Now we're coming on to his top dislikes about Christmas.

Christmas music. In the shops.

And lots of people. Definitely, that's where it starts to get bumpy.

He hates Christmas turkey. And again, I think it's a texture thing, really doesn't like that.

And then the number one thing that he said he really finds tricky, that he says it It's sort of, gets on his nerves is waiting. The waiting for Christmas, the waiting on Christmas morning…

I think, like Tom, we try to focus very much on what is the most important and keep things very simple.

We don't have Turkey for Christmas dinner. We'll be having Theo's request, Haggis on Christmas Day because he really likes haggis and sausages. So not a typical Christmas dinner, but he'll enjoy that. And that'll be great. We'll just keep all the rest of it very, very simple.

Maybe we can all come back in. Have a little conversation. Open it up to everyone else.

A: It's interesting, isn't it? I've heard if you know one person who’s autistic you know one person who’s autistic. Like Rachel said Rebekah doesn't have seems to have any of sensory issues that people quite often do have.

Rachel: I forgot one thing that Rebecca isn't very keen on, snow actually. And she sees it lying on the ground, she's quite apprehensive about, you know, even walking a short distance just from the house to the car.

B: I was thinking about Santa Claus as well because my daughter sent me a video of her son who's 2 and three-quarters and probably this is the first time, he's taking notice of Santa so much. He went to the local Bookbug and Santa was there. He didn't run off screaming, but gave him a very funny, look. I mean, Santa does look really quite weird to think if you've never seen it.

C: Quite a lot with Christmas, you know, it's a minefield for quite a lot of people really.

Hilary: I think that's right. I mean, we all struggle with Christmas. Let's be honest, you know, the time we get to Boxing Day, I think we're all dreaming of spending most of the day sleeping somewhere.

Tom: And you know it's the intensity of it I think… Craig loves Christmas, and you can see one of the things we had to deal with over the years is maybe had to change things a little bit. You will like go to 4 pantomimes and not 5. And you…help them to work through that. Because we did it one year, it doesn't mean, that's what we have to do the next year and that's something we've had to work a little bit on and he's getting much better.

Now, the food side of things, we have turkey, but there's been years, for example, and it's just us and I were having a meal and having far too much so from a practical point of view…And so we talked it through and we would end up having something like maybe a couple of turkey breasts. That's what I do for both of us and which he enjoyed, and he could understand why we had made that change.

D: I know that for some autistic people it can be an issue I think around the Christmas story. It may also be something fairly straightforward like why have I got a tea towel on my head and pretend to be a shepherd, when quite clearly I am not a shepherd and I hate having tea towels on my head! It can be something as simple as that. And it's time to work out where it is and trying to help them to work through.

A: Yeah, I think that's actually a really interesting point now, because our faith in Jesus as God's son and that's the essential part for us, but there does, even in the Nativity plays there seems to be these little bits added on, doesn't there? So, from, what you're seeing and I can understand why, you know, children or somebody autistic might think, well, am I meant to believe that part or what's this other part? Who's that other character who's come in? It seems such a mixture of things, doesn't it? Rather than just the essential story of Christmas that's central to our faith, there does seem to be a lot of various innkeepers, sheep, whatever it might be. That's added often into the Christmas story.

Tom: Yeah, I think that's true, right?

A: I think then it becomes very tricky to figure out it what's different from a pantomime, I think it's very complex.

C: That's useful for me because I'm a chaplain, and I've got several care home services this week and two of them are in homes for people with learning disabilities and autism. We're doing a kind of pass the parcel thing and unwrapping Christmas that way. After each scene we were going to sing. Separates it from pantomime and so hopefully, that does differentiate it.

We did one last year as well. Actually, a bit based last year on the one that I saw at the Prospects carol concert the year before.

Rachel: I didn't manage last year's carol concert with Prospects. But I did go this year's one and every time there was mention of the baby, you had to sing, "it's a baby, yes, a baby boy." …And that was great because it was positive, and it emphasized... fun…being able to join in.

Tom: There's the one story from the Bible that most people will know. And that's because we have the nativity plays at Christmas. Because people don't go to church as much, children don't go to church as much and so they don't have that overall knowledge. The nativity story just gives us our opportunity to remind people that this is something which we see as being real.

C: But it's not just the story. I'm trying to do that, particularly people with a learning disability. I mean, it's just trying to continue to remind them of the details of the story…something which is real for them. Certainly, wouldn't be going into anything about the Trinity or anything like that.

It is important that we went over the basics of the story and very simply. Reminded them that it is about God love sending his son into the world to show he loves us.

Tom: And a basic level that really is what it's all about. You know, and it's helping them to see that and maybe see a slightly different perspective to Christmas.

C: Yeah. I think that's right, Tom. It's the actual emphasis because I'm kind of going to start off on that you know the whole reason is that you know we are loved by God and God sent the Son. I'm going to try and emphasize that because it can get lost. I have to check myself that I don't just major too much on the practicalities of the presentation.

D: How do you include someone who's autistic into that kind of.. and they do have a problem with, for example, putting a tea towel on their head? We still have a situation where we always feel that it has to be perfect.

Tom: Yeah, That's the thing. I think sometimes it's quite helpful just to have them as, you know, part of the crowd who and they don't have to wear anything, they can be part of the crowd that don't wear things or rather the tea towel on the head. Maybe have a cuddly toy sheep and put that beside them, or if they want to, hold it …whatever. They'll just hold the sheep and or sit by them, so they don't have to participate if they don't want to, that might be helpful.

Hilary: Have you seen there's a Lego Christmas story video?

D: Oh yes,

E: Good.. I think I've seen a couple of Lego stories but I'm not sure if I have seen the in the Christmas one. But yeah, different resources are very helpful, aren't they?

There then followed a lively and wide-ranging conversation about what everyone would be eating for Christmas dinner, favourite treats, the difficulties of finding advent calendars with the Christmas story and what services we would likely be attending.

Key points:

- Autistic people (like neurotypical people) have varied reactions to Christmas: from embracing the traditions, decorations, parties and pantomimes to enjoying simpler, quieter Christmases.
- Familiar Christmas music may be a blessing or irritation!
- It may be difficult that not every Christmas will be the same as family situations change. The intensity and rhythm of Christmas may be too much for some families to manage. So, communicating change gradually is important.
- Having time to relax or step away from the intensity is important

- Some sensory experiences are pleasurable for some individuals, such as lights, decorations, music, food treats.
- Some sensory experiences might be stressful, such as music in shops, crowds of people, the texture of turkey, the feel of a Christmas jumper…everyone is different
- Time in nature can bring wonder in winter: snow, fire pits, Christmas trees and lights out-doors
- Feeling obliged to join in with events such as parties and nativity plays can be challenging. How can we help people to feel included but not overwhelmed? Some creative thinking is required.
- Nativity plays can be helpful and an opportunity to share the Christmas story. They should be distinct from a pantomime to reduce confusion between Scriptural narrative and fiction.
- Recognising that we have two Christmases: The Christmas Festival which tends to be more commercial, and the spiritual Christmas which focuses on the gift of Jesus and the love of God.