



Welcoming & including autistic people in our churches & communities

“I passionately believe that these kinds of conversations - and especially this kind of deep listening to those with lived experience of disability - is absolutely vital if we are to be a church where everyone is valued and everyone belongs.”

*Archbishop of Canterbury
Church of England national disability conference 2018*



DIOCESE OF TRURO
DISCOVERING GOD'S KINGDOM
GROWING THE CHURCH

FOREWORD

Every church I know says it welcomes everybody, but things don't always turn out that way. Over 1,000,000 people in Britain place somewhere on an autistic spectrum. Church can be a radically unwelcoming, even dangerous, place for them in ways nobody intends.

I'm really grateful to Ann and others for drawing up these guidelines and to the Diocese of Oxford for allowing it for use in our diocese. Many of their suggested adaptations are simple and effective and explain clearly and practically what worship and other church activities feel like for autistic people. Also, we know, churches that offer a genuine welcome genuinely grow!

It takes a whole world to know Christ, and awareness of every strand of what it means to be human enriches us all within the body of Christ.

I commend these guidelines for our use in the diocese.

A handwritten signature in black ink that reads "Philip Mounstephen". The signature is written in a cursive style with a large, sweeping initial 'P'.

The Rt Revd Philip Mounstephen
Bishop of Truro

If you need these details in a different accessible format, please let us know:

01872 360037 or comms@truro.anglican.org

AUTISM - THE BASICS

Were you surprised by the photos on the front page? Any of those people could be autistic. Many people believed autism was something to do with young boys with baffling behaviour. There are many myths and misunderstandings about this wonderful and diverse group of people, all much loved by God.

We're people of all ages, all backgrounds, all personalities, all intelligence levels, and in all sorts of vocations and careers.

We're also as likely to be Christians as anyone else, and as keen to go to church and contribute to church life.

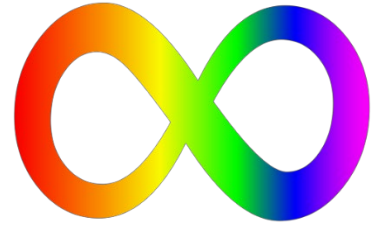
As author of this document, I have the honour of sharing life with many thousands of fantastic autistic people of all sorts. As an autistic person, and parent of a fantastic autistic son, I've had the privilege of sharing his journey to adulthood and watching him thrive. I've also had the challenges of encountering how society can make life exceptionally hard for autistic people and their families, through lack of information, training, funding and support for any that might need it.

Every autistic person is a person of value. Arguably, an autistic person was at the side of Jesus during his ministry and after his death, ever a friend.

Ann Memmott
Author
Diocese of Oxford Autism Adviser

WHAT IS AUTISM?

Autism is a brain wiring design difference. It is present at birth and remains different for life. It is a part of human diversity, sometimes called 'neurodiversity', although some need significant support with some things. An increasing number of autistic people regard themselves as part of a natural minority group. The symbol of autistic neurodiversity is often this one, a rainbow coloured infinity loop. Some use the colour gold, or red.



Autistic people have a different set of social communication skills to non-autistic people. These include a different use of eye contact, different body movements and different use of face expressions. Usually we have a different cultural understanding, and we tend to use spoken and written language differently. There are parallels with the Deaf community who use sign language, and take great joy in fellowship, that rich and different communication system, and in Deaf culture.

But isn't it a tragedy?

It's certainly a tragedy that society has become so autism-unfriendly in recent years. So many autistic people live in fear of bullying, violence, and worse.

Autistic people have brains designed to take in a vast amount of detail. For endless centuries, that wasn't a problem. Small villages were easier places to live, and where the vast majority of people lived. In a busy, noisy, intensely social world of huge towns and cities, the sheer amount of incoming sensory information can result in brain overload. Likewise in busy, noisy modern schools. If overloaded, autistic people cannot 'see' non-autistic people very well, so may miss body language and eye contact meanings. It is easier to meet us somewhere quiet and out of blinding light.

We prefer known situations and known routines, as we can work out how much brain load there will be. There is then less chance of a painful and exhausting brain event.

Most autistic people experience 'shutdown' brain events if exhausted beyond our limits. This means that, when too overloaded with incoming information, our brains may stop us talking and maybe moving. It is very unspectacular to look at.

This photo (right) of a child sitting quietly on a staircase is someone in shutdown, for example.

Some will have brain events called 'meltdowns', which look like a temper tantrum, but are more like an electrical storm happening in the social-decision bit of the brain.



Either shutdown or meltdown is a brain event, not a choice of behaviour, and need quiet and calm for a while to enable recovery - often an hour and a half, or so. After meltdown or shutdown, we may be very exhausted. This is similar to someone who is diabetic who has a low sugar 'hypo event' and needs time to recover afterwards. Better to avoid such things, so our choices of what we do and when reflect that aim of avoiding pain and debilitation.

Sudden changes of plan can therefore be very concerning, for good reason: Can we work out how to stay in safe brain-operating limits during those changes? Some of us are expert at managing such brain loads, and do highly responsible jobs throughout society for decades, including some doing excellent work as clergy of all ranks and types. I am a leader of several very responsible organisations, and I'm autistic. Others may need support to detect the 'triggers' for brain overload, and need help to stay within safe operating limits. For example, when young, or if there is also a learning disability.

Each autistic person will have their own 'profile' of sensory differences. For example often over/under-sensitive to sound, light, texture, smell or touch. They will also have their own 'profile' of how much social interaction they can handle with non-autistic people, (using non-autistic communication protocols), before needing time out to let their brain process it. Some can manage happily for hours in the right setting. Others, minutes.

We'll use noise cancelling headphones or earplugs to reduce noise levels. Perhaps we will use sunglasses to reduce light glare, and take short breaks to pace ourselves, with use of a quiet room to recover for a while.

Some may have extraordinary and very useful abilities, for example being able to detect tiny changes that forewarn of approaching danger. Research shows that autistic people are more likely to 'play fairly' with others and be more honest. Most are very dedicated, and passionate about specialist topics. Many are able to do vast workloads in specialist areas of work. Recent research shows that autistic people tend to give more to charities, and be more involved with social justice.

Autistic people are no more likely to be deliberately dangerous or disruptive than anyone else, although some can show distress behaviour at times when afraid or in pain, or enter a meltdown. Unfortunately, this was misinterpreted as deliberate

nastiness on our part. It wasn't understood that it was a largely avoidable brain event.

Autism is not a mental health condition, although many end up with anxiety or depression because of poor behaviour towards them. Autistic people endure a lifetime of being unfairly feared, ostracised and punished for being autistic. 80% have been victims of bullying. Over 60% have considered taking their own lives. The suicide rate from all the pressure to conform to impossibly different standards is more than 7 times higher than for non-autistic people. This is a vulnerable minority population of people, much in need of safe friendship and supportive environments.

There are estimated to be more than a million autistic people in England. It could be as many as 1 in 30 of the population, on some research. There are likely to be about 80 autistic people in the average parish. It is more common than wheelchair use. You may have autistic people already in your churches, in any number of roles. They may never have told you that they are autistic. Perhaps they fear the responses, because of the myths. Or, they may not even yet realise that they are on the autistic spectrum; many are discovered later in life. Whilst it can be diagnosed by specialist professionals, some autistic people discover that they're autistic and are quite happy not having a formal piece of paper to say so.

Is autism a good thing for our churches?

Yes.

Arguably, our churches exist in part because of autistic design, craftwork, dedication, knowledge, prayer and musicality. We know that most churches that welcome autistic people have congregations that grow faster, and flourish. Why? Many factors, but generally things that help autistic individuals are the things that help nearly everyone else too. Easy instructions. Environments where you can think, and pray, and enjoy, rather than being overwhelmed. Friendly, welcoming leaders who want to make things work, rather than find excuses not to. A church where autistic people are recognised and enabled as disciples, leaders, prayer partners, and in many other roles. A church that is a safe and respectful place for all.

Did Jesus know about autism?

What did Jesus make of autism? Arguably, Jesus had an autistic friend, Nicodemus. In the Gospel of John, we find Nicodemus is a specialist in laws for the Jewish community (a Jewish religious leader), who would have had an encyclopaedic knowledge of the religious texts. He approaches Jesus in the quiet and dark, away from the deafening crowd. A typically autistic way to interact. He misunderstands metaphor, and Jesus re-explains it to him. Another typical autistic feature, misunderstanding non-literal language. Later, Nicodemus grabs a rule book to try to save Jesus, and, at the tomb, there's Nicodemus staggering up the hill with a simply extraordinary amount of herbs and spices. Normally people would bring a small quantity. All of this reads as entirely normal autistic behaviour, and there he is at the tomb, as autistic as ever, and very much part of Jesus's life, as a friend and as someone who was supportive.

For those of us who are autistic, it is a comfort indeed to see such a recognisable figure at Jesus' side.

Two minutes to spare? Read this:

Quick Low Cost Things to Make a Difference for Autistic People

Always ask us what may help. Our brains take in too much detail. Our brain 'wiring' can literally overheat as it tries to handle too much input at once. We try very hard to avoid an overload of sensory or social situations. It's not us being awkward; it's a physical brain difference.

1. **Check the lights in each room.** Avoid fluorescent or compact-fluorescent bulbs, if you can as they appear to flicker like a strobe light, to autistic eyesight. Also, try to avoid bright spotlights.
2. **Noise levels.** If an event is going to have a lot of background noise and chatting, is there a quieter space to get to, if it is too much? Conversation can be impossible to hear in crowds. What about loud hand drier machines in the loos? Any alternatives like hand towels?
3. **The building.** Do we know what it looks like, and what the **layout** is like? Is there information on a simple website, perhaps? Photos?
4. **The order of service** - really **clear instructions** for us e.g. where to sit, when to stand and sit, what to say at each point? Either write it down, or get someone to be with us to quietly say what to do, please. (This also helps those new to church).
5. We are very **literal**, and our minds may see pictures, not words. Please try to say what you mean.
6. **Physical events** e.g. **shaking hands?** Water being splashed about? We may find this physically painful, as many are hypersensitive. Please warn us what will happen, and avoid physical contact unless we offer first.
7. **Rest area** - somewhere quiet to go if we need to, please. Or, don't worry if we wander outside for a while, where safe to do so.
8. **Socialising.** Be aware we find it difficult and exhausting as we cannot 'see' or hear you that well, especially in a crowd. Our **body language** can be different to yours, and we may not make **eye contact**. Please don't think we're rude. Sitting next to us to chat, somewhere more quiet, is easier than facing us. Telling us to 'try harder' to make friends is not helpful; research shows that it's non-autistic people who tend to refuse our offer of friendship, because of misunderstandings and myths.
9. **Be clear and accurate.** If you say you'll do something, please do it. Those on the autistic spectrum will be anxious if you promise to help but don't do so, or promise to phone at a certain time and don't. Or if you use expressions like, "I'll

be back in five minutes” when you mean, “I’ll be back some time in the next half an hour”. If you need to change arrangements, please just let us know. It’s about trying to maintain brain temperature and function, not about being controlling.

10. **Support:** Find a calm and sensible person to be aware of us, someone ready to lend a little assistance if we need it.

ABOUT USE OF LANGUAGE, AND ABOUT VALUE

You'll have noticed that in this guide, we refer to 'autistic people', which is the choice of most autistic people for groups. We respect that some autistic individuals prefer the term, 'people with autism'. Ask what an individual prefers. For groups, use 'autistic people' as the term.

We don't use functioning-labels in this guide ('high functioning/low functioning/severe/mild') because these are inaccurate and misleading. Every person is an individual with their own strengths and challenges, like everyone else. Some need more support with some things, sometimes. Some have a combination of different conditions and brain types which makes it really challenging to get through life, e.g. those who also have a learning disability, dyspraxia, hearing loss, sight loss or a physical mobility difficulty. But those are not 'severe autism'. Those are a combination of things with autism as well.

It's important to also challenge the idea that everyone needs to live independently to be a worthwhile and valued person. We're all interdependent, whether autistic or not. Unless someone is living alone on a desert island and making their own clothing and catching their own food, of course. Everyone relies on everyone else for some things. Whether we rely on people to bring electricity and water to our homes, or the bus driver to take us to work, or people in church to help with the services, we all are interconnected.

The work of the late Jean Vanier and the L'Arche community is well worth looking at for this. The photo below is from the community's website:
www.larche.org.uk/what-wedo

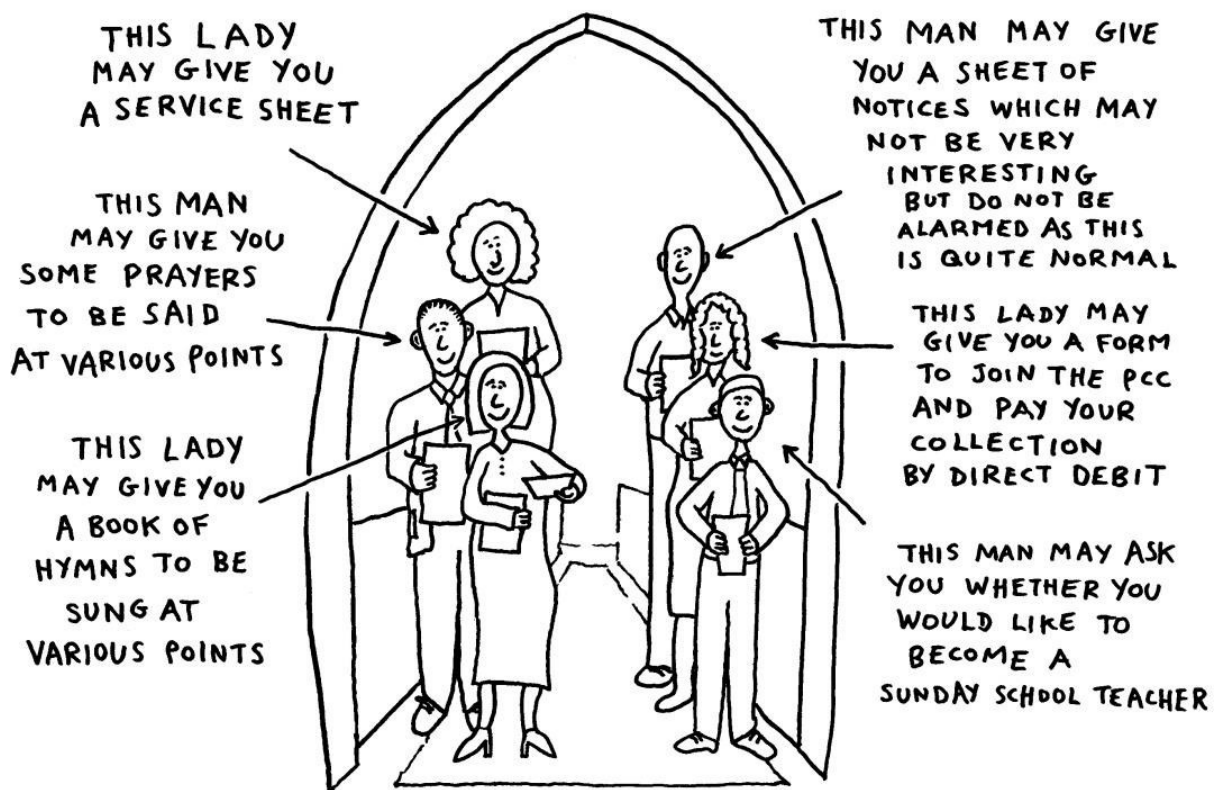
His work may be helpful as a starting point, looking at shared learning, shared growth, from spending time in friendship and fellowship with different people. Every single autistic person is a person in God's image, part of the One Body of Christ, and a loved and valued member of our church groups.



SITUATIONS IN CHURCH

How can we be affirming of autistic people? Even stepping through a church doorway can be an epic effort. Dave Walker explains this well in one of his cartoons, below:

THINGS YOU COULD BE GIVEN



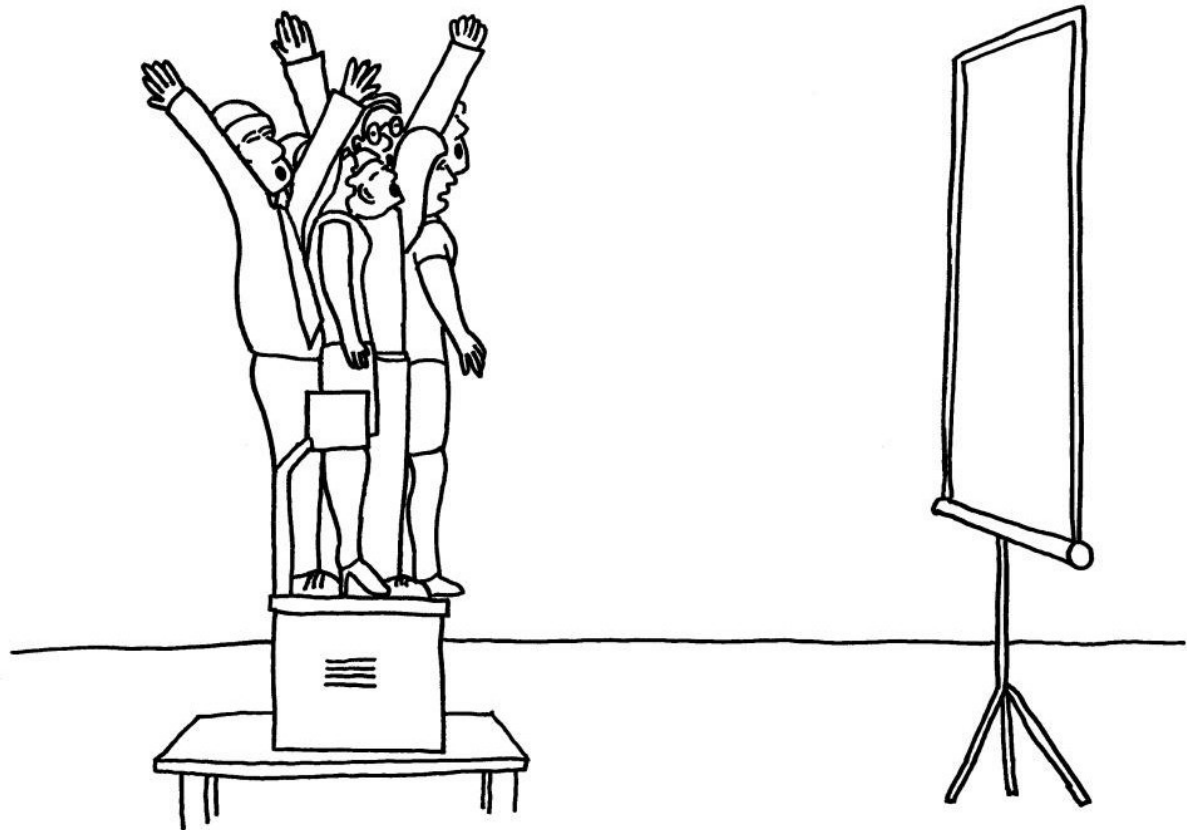
The next problem is where to sit. As we know, in some churches, some people have sat in a particular pew every Sunday for decades, and may be hostile to others sitting there. Can someone help with finding a good place for new people?

Identifying who's who can be tricky for most autistic people. Many are 'faceblind', so may see a group of people like the photo shown on the next page. It's very hard to build good friendships if you cannot recognise people. Others do not have this difficulty.



Faceblindness is not so difficult the first time we're in a church. Trickier the next time, when new possible friends may assume we didn't like them, as we are not acknowledging them. It helps to say who you are, each time.

Quite often, non-autistic people say things they do not mean. For example if the vicar asks that we sing one of the hymns on the projector....

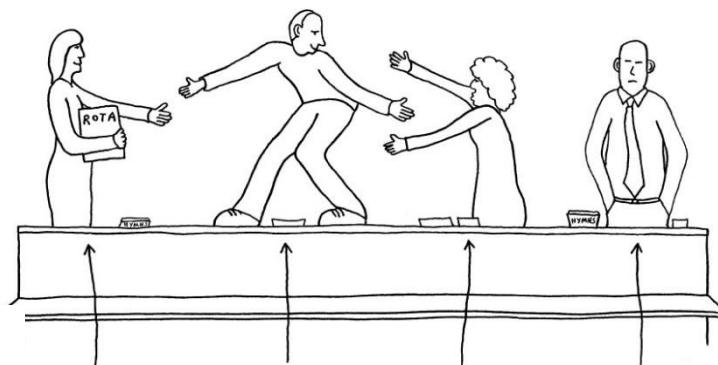


“WE WILL NOW STAND AND SING THE NEXT SONG ON THE OVERHEAD PROJECTOR”

Sharing the Peace can be a surprise to any new churchgoer, but a particular problem for new autistic people. Some may have severe pain when their hand is shaken, or when someone hugs us. It's not a question of being anti-social and not wanting to join in. Sharing fellowship via a wave, or just sitting down in quiet prayer during the Peace should be allowed, without people mistaking it for rudeness.

THE PEACE

THIS IS A TIME DURING THE SERVICE WHICH IS SET ASIDE FOR PEOPLE TO BE NICE TO ONE ANOTHER. DIFFERENT PEOPLE SHARE THE PEACE IN DIFFERENT WAYS:



THE CHURCH
BUSINESS
CONDUCTOR.
WILL BLESS
YOU WITH
MANY MINISTRY
OPPORTUNITIES

THE OLYMPIC
PEACEGIVER.
AIMING TO
GREET ENTIRE
CONGREGATION.
EYES ALREADY
ON NEXT VICTIM

THE PERSONAL
SPACE INVADER.
PURVEYOR OF
UNWANTED HUGS
AND KISSES

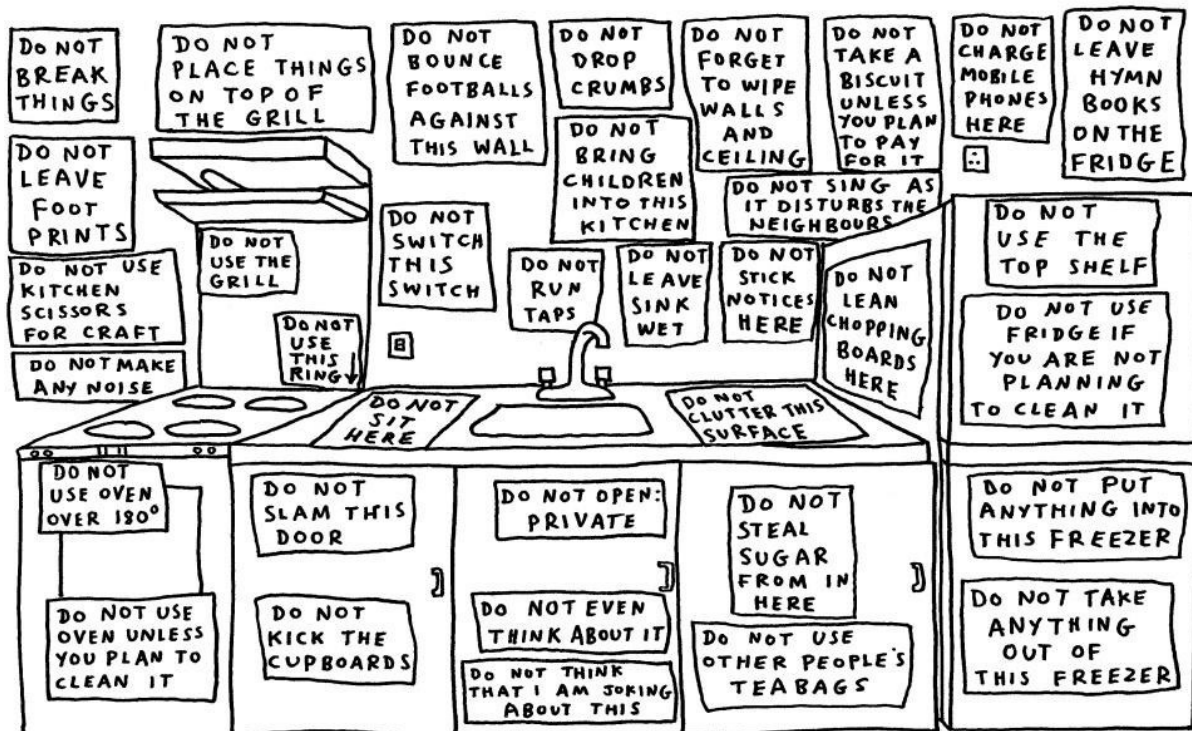
THE PERSON
WITH AN ASD.
WOULD RATHER
BE AT THE
DENTIST AT
THIS POINT

Next, we may be given a plate/bag with money on it. Do we take some, put some in? How much? This is a social dilemma that people expect us to 'just know'. Such rituals are far from clear for any newcomers to church. It helps if there is an explanation on a sheet or website of what to do, and who to hand the plate/bag to next.

Communion, if offered, needs to be explained. Can there perhaps be a simple sheet that tells people/shows them in pictures or photos? Something on the website? Each church has its own way of deciding who goes to the front first. How to signal if they want the bread/wafer and/or wine/juice. Whether to stand or kneel. How to get back to the seat without going the wrong way round a 'one way system' that everyone else knows, and the new people don't.

Often, assisting autistic people makes it easier for everyone else.

THE CHURCH KITCHEN



Every situation has unspoken rules...and we may not know what they are unless you say.

Stan Walden, a wonderful autistic man, explains about autistic people having the same quest to find meaning in church, in faith, in fellowship and friendship.

"...The autistic person can go through life without ever finding the deep uncritical love and affection for which they are so hungry.... Autism is love waiting to find love, but so misunderstood that this objective mostly fails.

"But God is love, so where better should an autistic person go to find love than to the church, the body of Christ? But therein is the challenge for the body of Christ because most ... do not understand autism. And even on the rare occasion when somebody does understand, the usual processes of the church are quite reasonably organised around familiarity and comradeship-type activities that suit most of those who attend, most of which are anathema to an autistic person."

It can help to encounter us through shared tasks, rather than at chatty social events. Something with some structure and predictability for us.

Knowing why we do things is important. Let's look at some examples.

Some autistic people will use their body movements as a way to work out where their body is. Our body 'maps' aren't always very good. Rocking or flapping, or similar, is therefore often very much needed, and not something to be stopped. Some use repetitive movement to calm down. This is sometimes called 'stimming'.

Some autistic people cannot discern tone of voice, or understand whether something was said sarcastically or as a joke. Expressions may not be understood. For example, "Have you changed your mind", I am likely to think

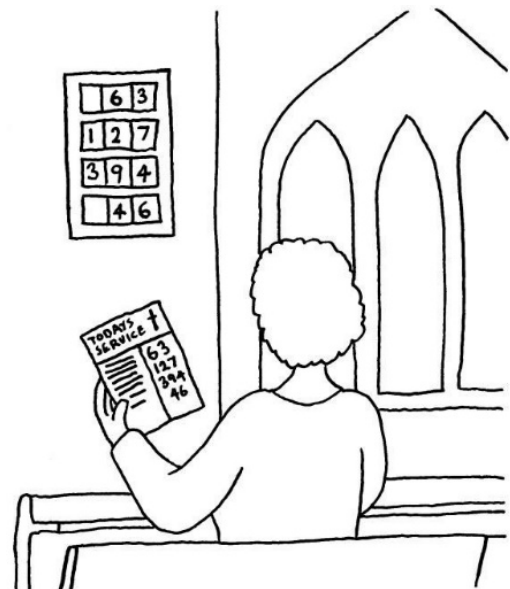
"No, I still have the same mind, thank you", without understanding that you meant to say, *"Have you changed your opinion?"*

If you say *"Thanks VERY much"* in a sarcastic way, some autistic people may not hear the tone change, and may think you are saying this as a compliment.

Great misunderstandings can happen very quickly.

PS - Churches often assume that new people will know what the numbers at the front are for. Do they?

If you are including someone who is autistic and who has a helper, carer or parent with them, please make sure you talk to everyone and support everyone involved. The carers and family want to be able to enjoy church too. Often they are expected to entertain their autistic companion in a side room, in which case they might as well all be at home.



SHE COULD HARDLY BELIEVE SHE HAD WON ON HER FIRST VISIT TO CHURCH

AUTISTIC CHILDREN & YOUNG PEOPLE

Ask the child or young person what helps. Even if they do not use spoken language, they may use technology, or picture clues, or signing, or gesture, to guide you. Take time to listen, and learn. A parent or carer may help interpret.

Parents of autistic children explain what helps them, and what doesn't:

"We had a family of four (now in church leadership), turn round and glare at us for a whole service... Then a really lovely man from my church noticed, came and sat with us and physically shielded us from their glares. I cannot tell you how grateful I was for him and that simple loving act which stopped me from bursting into tears.."

"...someone from the leadership came to me as the worship finished and the sermon began, and asked us to leave because we would certainly become a distraction to the preacher...We didn't go back."

"A really big help is to carry on supporting and visiting carers and the people they're caring for if they're unable to go to church."

"I had to try five churches before I found one that offered me a welcome. The rest either ignored the phone calls or emails, or told me they were too busy to respond right now, week after week. Non-disabled friends had no such trouble. The unspoken message was, "We don't want you here so we'll ignore you until you go away". I wondered if they'd read what Jesus said in Matthew 25: "I was a stranger and you did not invite me in... you did not look after me... I tell you the truth, whatever you did not do for one of the least of these, you did not do for me." It really knocked my faith and my confidence in myself."

"Many children with disabilities are raised by one parent.... We go on holiday to a regional Church camp and this is one of the warmest experiences of my Church year: people remember us, welcome us, speak positively to us etc. My son has never joined the children's groups there and I don't push that, but he listens to the sermons and was fascinated by one that mentioned hats, taking his out and putting it on each time this was said!"

An autistic young person explained their own experiences:

"I went to Junior Church to learn about God and about becoming a Christian, but for me it was all 'colour this in', and singing. If I wanted to colour stuff in, I could do that in my house."

That's a valuable reminder that many autistic children and young people really do want to listen and learn about faith, not attend a crèche and do fun activities. Make sure they are as able to learn about God as everyone else. Assume competence. Even if an autistic child doesn't speak, they can probably understand your every word, and indeed hear what you're saying from an extraordinary distance. If you say negative things about them anywhere in the same building as them, it's likely they'll have heard it. This is well documented. Be aware. And of course, if you're leading children and saying negative things about any of them, it may be time to take a break from leading and a take refresher on Jesus's words about letting children come to him. There was nothing saying, "...apart from the autistic ones, because they don't matter..." They matter.

Expert advice and training is available from autistic specialists and their allies. Inclusive Church has access to some, for example. Through the Roof and Churches for All have others. Look for people who are autism-positive, working with autistic allies, showcasing autistic work and ideas. Avoid people who are describing us as a tragedy that need fixing or hiding or altering to make us just like the rest of the children. That's how autistic children end up with mental health difficulties, from being forced to normalise at huge cost to themselves.

WHAT ABOUT THE ROOM?

A room that looks normal to you may look very different to an autistic person. You can see the others in the room. Can they? See the picture below. The photo on the right shows how a room might look to an autistic person with visual processing difficulties, under fluorescent lighting. Blinding.

Autism: Different sensory system



Exhausting. I need to rest after a while. Difficult to see who's who.

WORKING WELL WITH AUTISTIC CHILDREN & YOUNG PEOPLE

Watch for clues from behaviour; if a child is putting their hands over their ears, they are maybe trying to filter out too much background noise. Chatting, scraping of chairs, background traffic noise, music from a nearby service? Many can hear intense detail, and cannot block it out. Many autistic people see fluorescent lights as strobe lights, with intense flickering. Is it possible to use natural daylight or different bulbs? What about sunglasses, or noise-cancelling headphones, or a pop-up tent as an escape space? A blanket to wrap round themselves can be a comfort for some, as can comfortable clothes rather than scratchy tight ‘Sunday best’.



Make instructions totally clear. “*Do that work on the table*”, may be interpreted as, “*Get onto the table and do the work*”. Well, it could mean that. So rather than assume naughtiness, assume that you’ve not been clear.

Watch out for difficulties with touch. Many are hypersensitive to being jostled in a crowd or on a mat in a circle, because it causes intense pain. It may look like an over-reaction, but this is a different sensory system. If a child is reluctant to go near others, that could be why. Allow a bit of extra space. Some are also very anxious if their possessions are moved, because they are being blinded by the environment, and can’t re-find them. Again, it can look like an over-reaction, but it isn’t. Some are under-sensitive to touch and don’t realise that others aren’t expecting a huge hug from them, for example. Again, assume that it’s a difference in their sensory system. Likewise with standing too close to others; assume that

they simply cannot see how close they are. Think about a simple rule for them to follow, and repeat it as often as necessary. If appropriate, perhaps encourage others in the group to use a simple “No, stop”, signal. Perhaps with a hand held up in a STOP position, rather than using long sentences to ask a child to stop doing something. That visual signal is often more effective.

Keep instructions simple and short, and tell autistic young people what to do, rather than what not to do, e.g. say ‘walk’ (rather than ‘don’t run’). Use pictures as well as words, where you can.

Autistic children and young people will usually not make eye contact and will often seem to slump rather than sit attentively. Those are not efforts to be rude. They are because of sensory differences in the body. It can be because of other conditions such as Ehlers Danlos Syndrome or Dyspraxia. Eye contact is often experienced as painful, and often stops the young person listening at the same time, so do not insist on it. You wouldn’t need to insist on eye contact for a child who was blind, and this is similar in principle.

Because social conversation is so tricky for autistic children, many will only talk about their specialist subject, or won’t talk at all, or may use the same phrase repeatedly. This is polite in autistic culture. Be clear about when they should stop talking about a subject. They will not understand that “*Thank you, Sam*” means “*Stop talking now, Sam*”. Likewise, long hard stares or silences probably won’t mean a thing. Use a clear agreed signal to ask for quiet, or say ‘*it’s someone else’s turn to speak now*’. Allow them time to process and respond to requests.

Use a specialist subject to get them to explore other things. If it’s horses, you can explore whether there were horses in the Bible story, whether the horses were friends with the donkey, what the horse would think if X happened...Use your imagination and allow them to learn in their own best way.



If autistic children and young people seem to lose skills or lose focus, don’t assume that it’s deliberate laziness. A day with too much socialising, or too much sensory pain, can mean little ‘brain room’ to remember or hear instructions. Be patient and prepared to wait, repeat, and encourage gently. Or give time out with a quiet hobby if it’s really too much for them. Then you’ll build their trust, and their confidence in you respecting their brain differences and their need to avoid brain events.

Give them responsibilities that they can handle, and watch them thrive and grow in the group.

AUTISM CULTURE & COMMUNICATION

In the same way as other minority groups have their own culture and communication methods, autistic people do, too. One of the most important things is to learn the word **neurodiversity**. Brains that are different, rather than 'broken', though some needing support of course.

Autistic people tend to thrive with friends and family who are also autistic, and there are many good and supportive groups across the country. The Autistic Pride network is a recent example, where the pride is about boosting low self-esteem and learning to be confident. It doesn't mean being boastful or thinking we are superior.

Autistic communication is designed to minimise brain overload from social and sensory situations. For example, minimising eye contact.

Autistic people are likely to be very straightforward in how they communicate. It's about minimising brain 'heat', by keeping social chat as short as possible. Whilst non-autistic people often thrive on ten minutes of social chatting before approaching the real topic of conversation, an autistic person may go straight to the topic. It's not rude, for us. It's culturally and practically different. We may also suddenly stop talking about the topic and leave, or we may talk about the topic in intense detail. Again, these are cultural or practical differences, not attempts at rudeness. Some of us become non-verbal after a while, so simply cannot speak more, at that point. That's not deliberate rudeness either.

Because autistic people are having to guess the emotions of non-autistic people, they may not guess correctly. Likewise, the non-autistic people are not good at guessing the emotions of autistic people. A noted colleague Dr Damian Milton describes this as a 'double empathy' situation, where both people need to be aware that the other person communicates differently and has different needs. And where both people need to learn to adapt and respond.

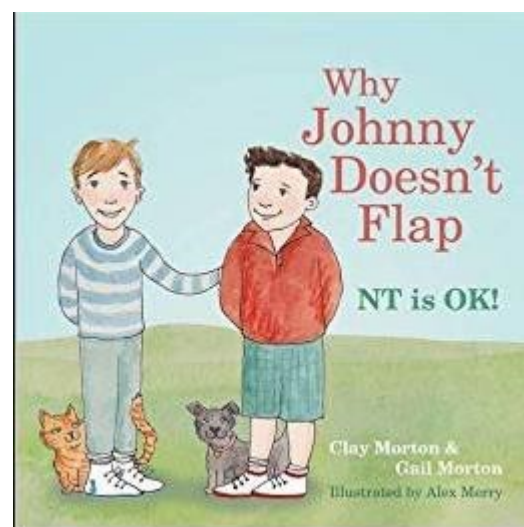
In a room of autistic people, it can look like they are ignoring each other, but an autistic interpreter would identify a wealth of communication happening. Just in ways that are different to non-autistic groups.

So, it is acceptable in autistic culture to be straightforward. To get straight to the point. To use literal language. To avoid eye contact. To sit next to someone, not facing them. And, to email accurate information in great detail, until a point is understood. None of it is manipulative or controlling behaviour, and none of it is meant to be rude. If contact is unwanted, just say so, really clearly. That's a politeness, in autistic groups.

Some autistic people do not speak using words at all, and many others are not always able to use spoken language. Assistive technology such as smartphones and tablets are often used as a way to communicate during such times. Many of us use that superbly and at a very high level. Asking autistic people to leave their phones behind, with assistive software on them, may be the equivalent of asking a blind child to leave their guide dog behind, or asking a deaf child using sign language not to sign. Other autistic people are fully and eloquently verbal and have a superb command of language, so it is vital not to make assumptions about ability and IQ. Some of my autistic friends have PhDs in English Literature and in Theology, for example. We have some autistic people at the highest levels in our churches. Whatever the ability to communicate using standard language, do expect autistic people will understand you.

Learning about a different minority culture can be a wonderful experience, and likewise, finding ways to explain non-autistic culture to us may be helpful for us.

There are books appearing by autistic people and allies, to explain the seemingly strange behaviour of non-autistic people. An example is shown below. The autistic ‘shorthand’ for a non-autistic person is a NeuroTypical (NT). As gentle humour, they can be very useful for introducing cultural and communication differences, and examining some of the strange behaviour that autistic people observe. Of course, non-autistic people consider their own quirks to be normal, because they use that behaviour all the time. Saying they will arrive at 10am and actually arriving at 10.20am, for example. Or saying someone looks nice in a dress when they actually look like a proverbial sack of potatoes. In autistic culture, it would be rude to leave someone looking dreadful. In non-autistic culture, it’s usually important to be complimentary, even it is not true. Simply different.



One important difference between the cultures and brain designs is the handling of errors. Autistic brains are designed to keep society safe. They have been doing that job for arguably thousands of years, being specialist engineers, specialists in detecting smoke or hearing approaching predators, etc. It is vital that society has people who are designed to be accurate, and to keep testing and testing things until they work (whether in art, music, engineering, healthcare or otherwise). With autistic culture, it is always appropriate to state when there is an error, and to keep stating it and trying to fix it until the error is fixed. That is polite, respectful

and appropriate amongst autistic people. It would be shockingly rude in our culture not to do so.

Unfortunately, non-autistic culture often decrees that it's polite to not mention errors. Especially if it's someone of a more senior rank. Seniority of rank doesn't really exist in autistic culture; it tends to have a fairly 'flat' structure. We can see how misunderstandings can happen fast.

Always assume good intent, if an autistic person is raising a query about something that is wrong. Often, they are absolutely right, and sometimes it really does save lives. In the case of autistic reporting of abuse, it is immensely rare for an autistic person to lie about a situation. Always take it seriously and investigate it properly, in line with the safeguarding advice you have. Too many predators rely on churches disbelieving autistic people.

WORKING AT THE THEOLOGY

“Welcoming those with Autism” is an example of the growing confidence of the disabled community in taking up its voice and asking the church some punchy questions:

- Do you really want to be more welcoming to people with disabilities? If you do, then what is likely to prevent you?
- Some would say that scripture passages have often been used in a way which disempowers people with disabilities. Is this so?
- What is your understanding of disability? What should it be?
- Does your understanding of the disabled person need to be challenged?

The work of looking at how Christian theology has developed and how it can lead to marginalising people with disabilities has been spear-headed by the blind theologian John Hull. This work is now being taken up more generally and urgently.

Disability and neurodiversity (“disabilities”) have become linked with many untruths, and unhelpful ill-thought out things are said about it.

Some examples:

- Children with disabilities have parents who have done something wrong.
- People with disabilities wallow in self-pity.
- People with disabilities are a nuisance.
- Disabilities are like an illness and we must do all we can to cure people who have them.
- People with disabilities are in some way defective.
- Disabilities are tragedies and people with disabilities are to be pitied.
- We really wish that these people, “they”, weren’t there.

Some equivalents in traditional Christian spirituality and theology might be:

- Disabilities are lessons used by God to teach us to empathise with others less fortunate.
- Humankind is fallen, but the disabled are more fallen than others.
- Didn’t Jesus set out to cure/heal those with infirmities and aren’t we striving to imitate him by doing the same?

- Heaven is a place where all imperfection has been removed, therefore disability has no place in the heart of God.

Jean Vanier, the founder of L'Arche, a world network of communities for people with intellectual disabilities, lays out the groundwork simply and profoundly:

People with disabilities are like everybody else. Each person is unique and important,

Whatever their culture, religion, abilities or disabilities. Each one has been created by God and for God.

Each has a vulnerable heart

And yearns to love and be loved and valued. Each one has a mission.

Each of us is born so that God's work may be accomplished in us.

The idea of God may not make a lot of sense to some people of any kind, but loving care, reverence, and respect from others can be known. It can be experienced. To someone with a disability, God shows his love through welcome and relationships. He shows it most especially through friendship.

The disability human rights movement is making us aware of the extent to which discrimination and exclusion are experienced by those with disabilities. This poses a challenge to the church. The church has to be faithful to its calling to build a community which includes everyone.

In Acts Chapter 2 verses 4-11 there is a vivid picture of difference and variety as the church began its life. All are included - "the spirit fell upon each of them" Acts 2v3. The story points us to the many languages spoken in the Spirit. Even through "strange tongues" the Holy Spirit includes everyone and "difference" is celebrated.

The church's task today, as it was at its birth, is to build a community of welcome. It is to offer "friendship in Christ". This friendship truly celebrates diversity and accepts people just as they are.

In Luke 14 verses 15-24 there is another picture of the church's welcome to everybody. This parable of the great dinner has been referred to as the "Come as you are" party! The 'poor, the crippled, the blind and the lame' in the story stand for the stranger, the marginalised, and the excluded. From the viewpoint of disability, this story shows Jesus hosting a celebratory meal, where the disabled are invited guests, just as those without disabilities are.

A Welcome is built through making both our buildings accessible and ourselves accessible. These guidelines suggest practical ways of making church accessible to the disability community....sending out the invitation, as it were, to the great dinner. But a true welcome means not only making practical arrangements easier but it also means a welcome from the heart. We have to be open to be changed in

our deepest centre to be truly welcoming. It is not people with disabilities who need healing, but people without disabilities who need to be changed.

The German poet Rilke has written about this:

“We must not refuse to become aware of all that we find distressing or painful or fearful within. If we do, we shall merely project onto others our own inner darkness. Are you white and afraid of your blackness? Are you male and afraid of the feminine within? Are you heterosexual and afraid of your homosexual feelings? Are you rich and afraid of your poverty? Are you young and afraid of being old? Are you healthy and afraid of your mortality? Are you able, and afraid of disability? Are you busily involved and afraid of being useless? Nothing is to be expelled as foreign. All is to be befriended and transformed. Be patient towards all that is unsolved in your heart. Try to love the questions themselves. Do not now seek the answers, which cannot be given because you would not be able to live them..... Live the questions now. Perhaps you will then gradually, without noticing it, live along some distant day into the answers....”

(Rainer Maria Rilke - adapted).

In the end the good news of salvation is that we belong. That we all belong.

This article gratefully acknowledges its debt to the work of, among others, Jennie Block, John Hull and Amos Yong.

References:

Jennie Weiss Block, 2002 *Copious Hosting: A Theology of Access for people with Disabilities* (Continuum).

John Hull’s website, www.johnmhull.biz gives access to a range of short articles and a bibliography of his main works.

Amos Yong, 2007 *Theology and Down Syndrome: Re-imagining Disability in Late Modernity* Baylor University Press, Texas

Other References:

Also see <https://annsautism.blogspot.com/2017/08/inclusion-core-christian-value-guest.html?m=0> by the Rt Revd. John Pritchard, former Bishop of Oxford, writing for the author’s blog on inclusion.

MODELS OF DISABILITY

Be aware of the ‘models of disability thinking’ around churches and autism.

Social Model

In simple terms, the most current and appropriate is the Social Model. In other words, the view that society makes it difficult for autistic people to access buildings and events: Deafening and blinding buildings, events set up for non-autistic communication. Working together, supporting one another, means a good result for everyone. It is a respectful model that honours the strengths of autistic people, whilst acknowledging that some need support, and that a minority may wish not to be autistic. Jesus used it in how he enabled Nicodemus to give of his best as an autistic friend. **This is the model your church should be using.**

Other less appropriate models you may still find include:

Charity Model

The church does things to autistic people, for example praying for inappropriate cures that they may not want, or treating them as tragedies, with suffering parents. Often, non-autistic people are given awards for being nice to us, which is quite humiliating for the autistic people.

Medical Model

The notion that autistic people are broken, and a doctor needs to fix them. This is incorrect.

Some may think that a behaviour specialist needs to give autistic people intensive ‘therapy’ such as Applied Behaviour Analysis, to stop them appearing to be autistic. This is now believed to lead to very bad mental health outcomes for some, including suicide.

BioPsychoSocial Model

The belief that being autistic is a choice, and people should refuse to support us until we decide not to be autistic any more. Similar in principle to assuming that Deaf people simply have a poor attitude to hearing things and need to put proper effort into it. We see very bad outcomes from this viewpoint, for everyone.

Cruel God Model

The belief that autistic people have dreadful times in life because God hates them for the sinfulness (whatever that might be...don't ask me...) and wants them to suffer... so we should let them do just that.

It's fair to say that this viewpoint is a long way from the model Jesus showed us.

Angel Model

The view that autistic people are sent to suffer so that they will be welcomed as angels in heaven. That we really shouldn't get in the way of them suffering, or we might stop their entry to heaven.

I've found a few people with this view too. Not pleasant, or accurate.

The Exorcism Model

The mistaken view that autistic people are possessed by the devil, and need Exorcising. I've met some people with this view. Some children have died from the results. I don't think I need to say more about this.

I would very much like us to put good and proper thought into our thinking about disability and church, and about autism and church. The work of Inclusive Church is very helpful for this. <https://www.inclusive-church.org/blog/something-worth-sharing-7th-annual-conference-disability-and-church>

When you consider autism, work out which of those models your church currently uses to guide its thinking around autism. It can be very instructive.

RELATIONSHIPS & PARENTHOOD

Autistic people in our congregations and parishes are as likely to want loving, permanent relationships as everyone else. Many are happily married, with children of their own.

Research is also showing that some 30% of autistic people are part of the LGBT+ communities. A church needs to be able to enable each person to get the right relationship advice, in a caring and cheerful, informed way. If your church isn't sure how to encounter LGBT+ (lesbian, gay, bisexual, transgender etc) people with love and respect, it might be a good idea to talk with Inclusive Church about useful materials.

If one partner is not on the autistic spectrum, there can be considerable communication differences between them. Their non-autistic partner might not realise why they need to be very specific with instructions. Or they may feel sad that their partner cannot tell if they are upset simply by looking at them. The autistic partner may feel anxious that they are expected to be able to cope with big family occasions for hours, and may fret about how to spot when their partner is upset. Both need to learn to communicate well with one another, without blaming one another for having different neurology.

The book, "Love, Sex and Long Term Relationships" by Sarah Hendrickx is a reasonable and well balanced guide, and may be worth recommending. It talks in clear language about the positive and negative aspects of relationships between autistic people and non-autistic, for example. Many autism charities offer links to relationship support and counselling, so this is also worth them exploring if their relationship has difficulties.

Avoid negative accounts that attempt to put all blame on autistic people. Some claimed that it was deliberate nastiness by autistic individuals, for example, but we are no more likely to be deliberately nasty than anyone else.

Many autistic people make excellent parents, especially if they have autistic children. Honesty, dedication, a determination to learn and get things right, and an amazing set of different abilities are all benefits that may bring a lot to the lives of children in the family, whether autistic or not. If you have autistic children in your church, be mindful that many have one or more autistic parents or other family members. Quite a few autistic parents only discover they are autistic after their child gets an autism diagnosis, for example.

FUNERALS, BAPTISMS, CONFIRMATIONS

The need for clear rules and clear understanding of what will happen is the same for any ceremony or life event in which the church is involved. In each case, and as you would always expect, there is a need to find out if they understand what is being asked of them.

When planning any such event, the more information you can give to the autistic person, the better. Photographs of what will happen may be of much more value than words, in many cases. It may help to suggest they visit any new buildings beforehand to understand the layout and think about the service and what it will mean.

Those with skin sensitivity issues may have problems with cold water or physical contact in Baptism or Confirmation services, so that is something else that needs to be considered in advance rather than let it be a shock at the time. The same is true for the Asperges (a marvellous coincidence of name), since those in the congregation may not be expecting to be splashed with cold water whilst in their seats.

Funerals will almost undoubtedly bring unexpected reactions. The autistic person may underreact, or overreact, or have an extended period of mourning compared to what you expect, especially if it is someone very close to them. They may need extra support, so again the autistic led charities or charities led by autistic allies are the right place to refer them to for specialist counselling if required.

AUTISTIC LEADERSHIP

We have excellent autistic people in all sorts of roles in our churches. We have autistic clergy doing a fantastic job. Often within teams. Sometimes as Priest in Charge. Sometimes as higher ranks of Clergy, too. It's easy to imagine that autistic people are receivers of pity, charity and prayer - but quite often they're the ones offering a welcome, prayer and support to others. Being pitied for being different to other people isn't appropriate.

Individuals on the autistic spectrum are often extremely competent in their specialist areas. A fair number already have well paid jobs, and may have invaluable specialist skills to offer. Indeed almost any individual on the autism spectrum may have skills or abilities to offer the church, and the desire to do so.

"The Chair of Committee has been brilliant in realising how I work best, and as a result of them spending a minute or two thinking about my needs, I am able to make a significant contribution. Whatever they've asked has been done on time and to very high standards, and the Chair has commented that he regards me as a person of the highest integrity".

If you have someone who would like to take on a role within the church, the normal processes of consideration need to take place. Rather than say no, think and plan. Talk with them or email them to ask what would help.

You may well find a surprising number of autistic individuals already in roles in your church - perhaps in the orchestra, the choir, on the committees? Again, you probably just did not know that they were. Worth thinking about how comfortable it feels to disclose autism, in your groups. Do people understand that it's a difference, not a 'problem'?

"Very few people know about the autism, and I'm not sure what to do about that. I feel I should put the congregation's sensibilities above my own personal discomfort at disclosing, yet perhaps part of me is terrified at the response I might get, in that people's perception of me might be damaged, that I would be considered "not fit for ministry".

A Reader explains what happened to her:

"I was asked "to put the altar cloth on the altar in the Lady chapel". So I put the altar cloth where I was told to put it. I reasoned that if our vicar had wanted me to lay the altar cloth on the altar, or prepare the altar, he'd have said that....The preaching module provided other challenges... The feedback I received was extremely positive, in terms of content and message, and ability to relate to the biblical text... I tried to make hand movements to express myself, but what happened was I gradually stopped

using my hands, so that they hung limply by my side.. Some people picked up on this and criticised it...Anyway, for my next sermon, I was determined to put this right.... personally I felt really uncomfortable and as if I were one of the Thunderbirds puppets - it felt really jerky and unnatural. I felt far less relaxed than I'd ever done, and I ended up with a splitting headache afterwards - that afternoon I needed a sleep to recover! ...I think, for me, there is a need to strike a balance between not distracting the congregation from the message of the sermon, and not making myself ill trying to be something I'm not."

You must give each person with a really fair chance to demonstrate how they would do a good job for you, and consider reasonable adaptations to make that possible. You must not pre-judge them, or allow others to disadvantage, humiliate or bully them because of their differences. A little thought and adaptation will usually yield marvellous results. It's well worth exploring.

FURTHER INFORMATION & CONTACTS

Inclusive Church

An educational charity, offering advice, information and training on disability and other topics. In partnership with St Martin in the Fields, Trafalgar Square, running annual disability conferences by, for and with autistic and other neurodiverse or disabled Christians.

W www.inclusive-church.org/disability

W www.stmartin-in-the-fields.org/contact/

National Autistic Society

Although primarily by and for parents, not autistic people, it has a good range of books and information.

W www.autism.org.uk

T 0845 070 4004

Through the Roof

Information, training and publications on church access for autism.

W www.throughtheroof.org/

Looking for a church that supports autistic people? Try the A Church Near You website, and search for autism on it for your postcode. May need to try a few different places to get a result. <https://www.achurchnearyou.com/>

Who to contact



Ann Memmott, Diocese of Oxford autism adviser

E ann.memmott@oxford.anglican.org

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www.churchofengland.org/media/39672/gs1725.pdf

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WELCOMING & INCLUDING AUTISTIC PEOPLE

This guide is written in sections and available as a web document on the Truro diocesan website so that your church can access and/or print just the section that you need, or the whole guide.

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