

# Welcoming Autistic People in our Churches and Communities

**Updated version 2015** 

# Welcoming Autistic People in our Churches and Communities

Guidelines by Ann Memmott, who is autistic

# Foreword The Rt Revd Dr Alan Wilson Bishop of Buckingham



Every church I know says it welcomes everybody, but things don't always turn out that way. Over 700,000 people in Britain, more than one in every hundred, places 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 a new edition of these guidelines for use in our diocese. They know what they're talking about, and explain clearly and practically what worship and other church activities feel like for autistic people. Many of their suggested adaptations are simple and effective. 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 dioces	se
+Alan	

If you need these details in a different accessible format, please let us know 01865 208213 or alison.webster@oxford.anglican.org

#### **Welcoming those on the Autism Spectrum**

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The Guide is written in sections and available as a web document on the Oxford 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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We have used a variety of terms such as autism, autistic, person with autism. Different national and international communities respect and honour different words. All are wonderful, God-created people. We acknowledge and respect autism and its uniqueness.

#### The Autism Spectrum and Church

Autism, which is sometimes called Asperger syndrome, is a brain wiring difference. It is present at birth and remains different for life. It is not a mental health condition.

Autistic people will not look any different to anyone else. They are often excellent at specialised work, but have difficulty understanding social situations. They cannot 'see' people very well, so will miss body language and eye contact meanings. They will have difficulty coping with sudden changes of plan or breaks in their routine. They are often over/undersensitive to sound, light, texture, smell or touch. Individuals may have IQs ranging from very low to very high, the same as any other group of people. Some may have extraordinary and very useful abilities, for example being ten times more accurate than average. Research shows that autistic people are more likely to 'play fairly' with others and be more honest. Autistic people are no more likely to be disruptive than anyone else. It is not a mental health condition, although many end up with anxiety or depression because of poor behaviour towards them. 80% have been victims of bullying. So, despite autistic people being usually very logical and reliable, honest and careful, it is a disability that is often misunderstood. There can be unnecessary negative reactions and fears.

There are estimated to be nearly a million people with a form of autism in the UK. It could be as many as 1 in 30 on some research estimates. There are likely to be about 80 autistic people in the average Parish, and the latest research suggests there are as many women and girls as there are men and boys. It is more common than wheelchair use. It is almost free to include autistic people. There are probably some autistic people already in your church, perhaps already doing a useful job. They may never have told you that they have this diagnosis, or they may not even yet realise that they are on the autistic spectrum.

We know that most churches that welcome autistic people are the ones whose congregations grow and flourish. Things that help autistic individuals are the things that help nearly everyone else too.

Tony Attwood, the International expert in autism and Asperger syndrome<sup>1</sup>:

"...The person usually has a strong desire to seek knowledge, truth and perfection with a different set of priorities than would be expected with other people. ...The person with Asperger's syndrome may perceive errors that are not apparent to others, giving considerable attention to detail, rather than

noticing the "big picture". The person is usually renowned for being direct, speaking their mind and being honest and determined and having a strong sense of social justice. The person may actively seek and enjoy solitude, be a loyal friend and have a distinct sense of humour."

Anyone in any group <u>could</u> be someone on the autistic spectrum



# Two Minutes to Spare? Just 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 difficulty.

- 1. Check the **lights in each room**, especially fluorescent ones any flickering ones? Please replace them with new ones or LED ones with a diffuser panel and no dimmer switch.
- 2. **Noise** levels. Is there anything unexpected in today's service/meeting? Can it be changed easily? If not, can you warn us?
- 3. The **building**. Do we know what it looks like, and what the **layout** is like? Is there information on a simple website, perhaps?
- 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. If you need to use complicated language, can someone be available to explain it afterwards if we need it, maybe by email? (This helps those who find reading more difficult, too, which is one in every five people in the UK)
- 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.
- 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 quieter, is easier than facing us.
- 9. Be Clear and Accurate. If you say you'll do something, please do it. Those on the autistic spectrum will always find it very distressing if you promise to help and don't, or promise to phone at a certain time and don't. Or if you use expressions like, "I'll be back in five minutes" when you mean, "I'll be back some time in the next hour". If you need to change arrangements, please just let us know.
- 10. **Support**: Find a quiet caring person to be aware of us, someone ready to lend a little assistance if we need it. Brief them well, and please respect our confidentiality and privacy.

#### What's going on in the brain?

For a long time, people thought autistic individuals were just being rude, and lacked empathy. Those were myths. People also thought that 'real autistic people' always had profound learning disabilities as well, or couldn't talk. Those are myths too.

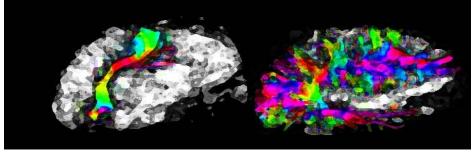
Autism is a different brain wiring design. In ages past, autism may have often been an advantage. Our brains can sense far more detail than most other brains. The tiniest scent of a forest fire. The smallest sound of an approaching predator. The slightest taste of poison in a foodstuff. Our sense of ethics and fairness made us more than a match for occasional 'sociopaths' who would use their excellent social skills to persuade villagers to part with their life savings for no good reason, too. Excellent memories made us useful for recalling exact information. As with everything in this guide, exceptions will apply. But in quiet natural spaces, autism can be an advantage. Not so in busy, noisy places lit with fluorescent lighting, though.

Our brains are wired up differently. As a result, they have a huge amount of connections for data, and not enough for 'people-decoding'. .

If we are placed in a busy, noisy crowd under fluorescent lighting, our brain wiring literally cannot cool down fast enough. It heats up to a point where it is painful/causes great anxiety. We need to be able to escape the noise and any flickering overhead lighting until it cools down. If we do not, for most of us, our brain will switch itself off. This is a 'shutdown'. We cannot communicate during it, and just go quiet and want to get away from others. For some, our brains go into what looks like a toddler tantrum, but it isn't. This is a "meltdown". It's an electrical 'shock' going on in the brain. We may sound angry during it, but the anger isn't to control anyone or get anything. We've no idea what we're saying during one, so there's no point taking it personally.

Below, brain scans. On the left, a normal brain handling a conversation during a stressful moment. On the right, what happens in our brain (as an example). No wonder it overheats.

Trying to counsel us, comfort us using words, or reason with us, during a shutdown or meltdown, isn't going to work. Only time to cool off, somewhere quiet, works properly. An hour and a half, if very overloaded, is common. Most of us are experts in managing our brain's temperature and you will never see this effect. Some worry about trusting us with responsible jobs if this can happen, but it's no different to working with someone with diabetes, who may behave erratically if their blood sugar level changes too much. It's embarrassing for us. It helps if you treat it as a minor problem, not a big catastrophe.



# Ten Minutes to Spare? Read These Pages.

### What can be done to welcome those on the autism spectrum into church?

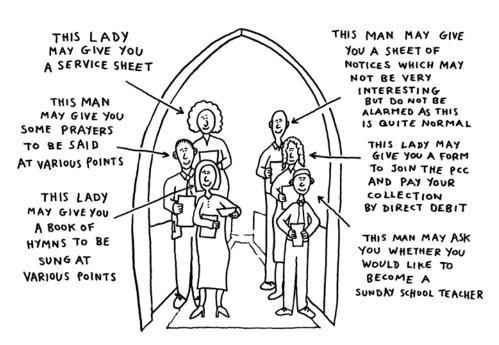
In this guide, we usually refer to all those on the autism spectrum as, "autistic people". We respect that some prefer the term, "people with autism". It is an individual choice, with good arguments either way. We don't use functioning-labels ("high functioning/low functioning") because these are inaccurate and misleading. Every person is an individual with their own strengths and challenges.

First read these two accounts:

#### **Coping with Church Without Enough Detail**

"I know that my brain will overheat and 'cut out' when faced with too much sensory or social information at once. So in any new place or big crowd, I have to be sure how much I can handle before having to retreat. I've now been to this church as a visitor. I am given two hymn books, a service sheet and a selection of other random sheets of paper. It's such a huge amount of information all at once.

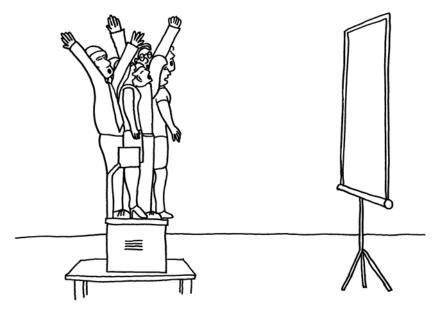
#### THINGS YOU COULD BE GIVEN



The next problem is where to sit. So many chairs to choose from, and I have no way to decide which is correct. Who might get cross if I sit in a particular one? I cannot always work out how to respond, then they may get even more cross.

In front of me, people who apparently know me. Quite a few of us on the autism spectrum struggle to identify people from just their faces. We often have to work it out from hair, shape, walking style...or by the person introducing themselves again. Often people think I'm being rude if I don't greet them warmly. I'm not. I don't know who they are.

I start to read the service book, hoping that it has been well written and has plenty of detail on what I must do. No such luck. The Vicar enters the church, and everyone stands up. It doesn't say to do this. How do they know? Throughout the service, without warning, I am confronted by the many unspoken rules and practices of church. People know what to say, when to say it, when to stand, when to sit, which book to read from, which lines to say two or three times. I need instructions, or routine. The Vicar asks that we sing one of the hymns, "on the OHP". I'm not sure we'd all fit on the OHP. Should I try? I do wish people would say what they mean. He's also using very complex language about social relationships, which I find really hard to understand. I don't know who to ask afterwards to help me.



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

Now the vicar asks us to 'Share the Peace'. I may have problems shaking hands or touching people who aren't close family. It causes my brain to "cut out" for a couple of seconds. I now have to brace myself to shake hands with every person round me. It is difficult to maintain eye contact, remember the words, ensure I appear to be suitably genuine (which means I have to remember how to convey my enthusiasm and caring, which is body language that I don't know how to do automatically). I also have to remember who's who, and who I have already shaken hands with. It's all VERY difficult for me and very tiring. I love being with people and care deeply about them, but my brain doesn't have the automatic people-decoding 'software' that it should have.

Next, I am suddenly given a plate with money on it. Do I take some, put some in? How much? This is a social dilemma that people expect us to 'just know

about'. I don't. I end up dropping coins all over the floor and hoping that I haven't given too much or too little.

I am now exhausted. I wish I could concentrate on prayer, on hearing God, on listening to the Vicar, but frankly the Vicar could be talking about home repairs and I wouldn't know. I do pray - in the short form of, "Oh God, please help!" I'm not sure if I can stay in the room – I want to leave.

Just when my ability to cope is at its lowest ebb, I have to try to understand what I do for Communion. People know when to stand up, when to move forwards (apparently they know to do this just by looking at where someone is standing and noticing the slightest nod of the head. I don't notice this.). I have to work out which bit of kneeling-cushion to aim for, or where to stand, how long to wait before going up there. What to do with my hands when I get the bread and wine and what to say and when. The rest of the people know when to stand up again, when to go back, when to say something like AMEN when you're up there. I try to follow what the others are doing, but it's not easy when you can't concentrate on a lot of things at once, and I can't. have to cope with the flickering candles round me, the taste of the bread, the taste and smell of the wine. The rustling of papers from 50 people in the pews, the sound of traffic outside, watches ticking, people breathing, coughing. It is all very difficult when you have senses that are hypersensitive. It's also not easy trying to remember where you were sitting, unless there's something really obvious. All the faces look much the same, so I could return to the wrong seat.

At the end of the service, I am as exhausted as if I had run a marathon. They ask people to stay to be social, but I cannot. I do not know what to say when just standing next to people. I still love God, but I don't know how to be welcomed and respected in a church that relies on good social skills."

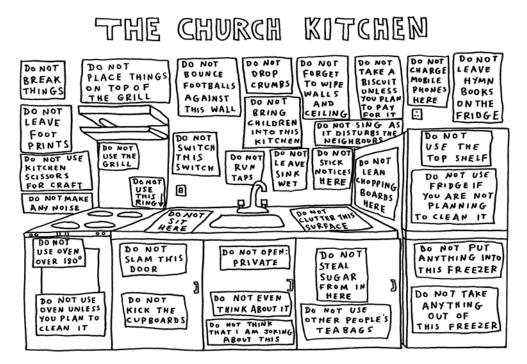
#### **Church the Easy Way**

"The Vicar had already met with me to show me the church, and it has a good website 'blog' with pictures and service updates on it so that I know what will happen. They have already told me what I need to know about the service I will attend. I know they keep the lighting fixed so it doesn't flicker. The people in the congregation are really friendly and they know to introduce themselves each time if I don't greet them by name, so I don't have to try to guess who they are. There's someone who is a quiet friend to me in the congregation, who can explain changes or explain anything I don't know or don't understand from the service. In The Peace, people know that I'm not being rude if I miss eye contact or want to stop shaking hands for a while. No-one is offended.

The service sheet has 'stand up' and 'sit down' written in the right places so it's so easy to follow. At the end, I'm able to find a quiet space to relax in for a while, then I'm able to help with the teas and coffees so that I don't have to concentrate on eye contact or social conversation but can still do something useful. I'm asked to help with the fundraising by keeping the records, and to help set out the church ready for services, which I'm happy to do as it allows me to use my strengths. I can lead worship sessions in home group. I'm happy to ask others to come to the church too."

Cost to the church: Nothing other than a bit of time and thought.

**Benefit**: Enjoyable, accessible church, extra people attending, good reputation, possibly extra pairs of hands to help in the church.



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

Stan Walden explains how supporters in the congregation need to expect a different sort of friendship with an autistic person (Autism is sometimes called an "ASD" (An old term was "Autism Spectrum Disorder")

"The person with an ASD, though profoundly affected by personal feelings for somebody they have learnt to trust, finds it very difficult or almost impossible to forge casual relationships. Standing close, eye contact and touching, the signs of relationship, are not there...The person with an ASD 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 a person with an ASD 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 ASDs. 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 AS person. ...But there is a solution....It is based on a sensitive and understanding person being allocated to securing the confidence and trust of that person....".

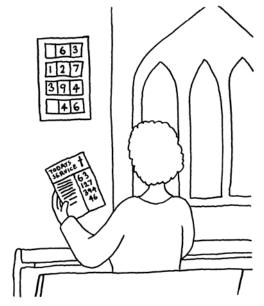
Many autistic people think in pictures, not in words. Some others think mostly in numbers and patterns. Some will not use spoken language, or can only speak sometimes. Each is an individual with their own set of needs, but the basics of autism will always be there.

Most autistic people cannot "hear" 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, I will probably misunderstand and think you are saying this as a compliment. Great misunderstandings can happen very quickly.

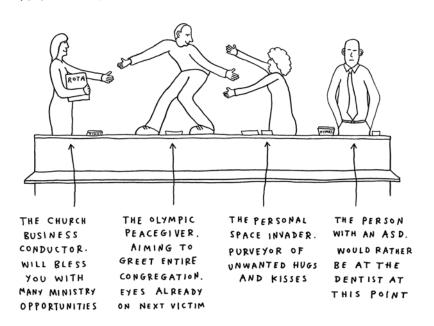
Churches often assume that everyone will just know what the numbers at the front are for. Do they?



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

#### THE PEACE

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



"I cannot always work out when it's my turn to speak. People use voice tone and body language to decide on turn-taking in conversation. As I cannot see or hear those signals, I make mistakes on timing of speech. Discussions can be hard for me to take part in, because I <u>may</u> take longer to process what other people have said. A bit of extra time really helps.

Social communication is all about knowing what to say, which means knowing how the other person is feeling, and what they will think about what you have said. I don't have that skill automatically. I do try to get things right. But without being able to see your face expression clearly, I'm making a lot of guesses. Please don't assume that I meant to be rude.

If you promise to do something, please do it or say why not. It's so scary when people don't, or when they just ignore us.

If you are helping 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."

#### **Further Useful Tips:**

Don't imagine that we want a cure. There isn't one, and many of us are happy being us. Autism is not a tragedy for us. It is how we are made. Don't pray for a cure for us without asking us if that is what we want, please. Don't use words like 'retarded'.

Assume that your non-verbal autistic child or friend can hear and understand every word you say. Don't say rude or negative things about us in hearing range.

#### **Autistic Children and Young People**

Parents of autistic children explain what helps, 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."

"It would be good if churches had a group of befrienders who could look after people with disabilities (especially those new to the church) on a one to one basis. (Probably many people new to a church would appreciate such a service regardless of disabilities!) Someone to sit alongside a new person and explaining the service structure, where the toilets are, what people do at the end of the service (such as stay for tea and coffee) and just generally being a friendly presence would be

appreciated by many. If a church could have a mixed group of people to do this, it would be much appreciated."

"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 wonder 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!"

If you are working with autistic children and young people in your church, take time to learn about autism, and about that particular young person's needs.

Do a general training session with the group about autism and its differences, so that the rest of the group know how to respond to any autistic young person in their midst. You don't have to make an example of a particular child. Expert advice and training is available.

A room that looks normal to you may look very different to an autistic child with visual differences, for example. You can see the others in the room. Can the child? Do not assume that they can. See the picture below.

Watch for clues from behaviour; if a child is putting their hands over their ears, they are 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. If they have their eyes closed, or are hiding somewhere dark, are they struggling with the flickering lighting overhead? 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. Can the young person hear you in that room? You may think they can. But maybe they cannot. Many halls are echoey, which reduces voices to just random sounds for some of us. Try using carpets, mats, banners on the walls,

anything to reduce the echoing. See if it helps. No need for big expense; many people can donate materials.



Yes, the picture on the right is how a room looks to someone like me, in a crowd, under fluorescent lighting. Just one example of a possible sensory difference. Natural lighting or LED bulbs often really help.

Be aware that autistic individuals are often very defensive of their personal possessions. It makes them an easy target for bullying, because bullies soon discover that moving or hiding their things causes intense distress. Then the autistic child gets into trouble from the leaders. Make sure that personal possessions are respected by others. Broken personal possessions may result in an emotional reaction as strong as if the family pet had died. It's not an overreaction, for a child whose world is so often utterly terrifying for them to experience. Those things give them comfort and security, familiarity and routine.

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 overreaction, 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 undersensitive to touch and don't realise that others aren't expecting a huge hug from them. It's not meant in a nasty way. 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 for a child to stop doing something. That visual signal is often more effective.

Keep instructions simple and short. Use pictures as well as words, where you can.

Autistic 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. 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 for a child who was blind, and this is similar in principle.

Autistic young people may rock, flap or make repetitive noises, etc. Those are part of autism, and called "stims". They are how individuals regulate their bodies in crowded social situations. Don't try to stop the actions unless they are causing danger. Get expert advice before attempting to do so. Local autism charities can advise.

Because social conversation is so tricky for autistic children, many will only talk about their specialist subject, or won't talk at all. 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 probably won't mean a thing. 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.

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

This is a very basic summary. Do get good training.

#### 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 has 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, 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

#### Marriage, Sex, Relationships & Ceremonies

Autistic people in our congregations and parishes are as likely to want intimate and long term relationships as everyone else. Be aware that research is also showing that some 30% of autistic people do not identify as heterosexual. A church ideally needs to be able to enable each person to get the right relationship advice. Each deserves the chance to go into a faithful, loving marriage or Civil Partnership with appropriate spiritual thought and in the knowledge of all that may happen. This is something that may also need support from a service such as a local autism adviser. The National Autistic Society can direct to these <a href="https://www.autism.org.uk">www.autism.org.uk</a>

Marriage, sex and relationships for partners where one or both is autistic can present a number of challenges. It may work extremely well and lead to a long and loving relationship, but equally it may not if there is a lack of compatibility and understanding. One might, of course, say the same of any new relationship.

If one partner is not on the autistic spectrum, there can be considerable communication differences between them. Their 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. Even if both are autistic, there can be differences in communication style and habits that lead to particular problems. 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, taking autism into account.

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 those who are autistic and those who are not, for example. The more understanding that a non-autistic partner has about their husband, wife or partner, the better the chance of avoiding relationship breakdown. Many autism charities offer links to relationship support and counselling, so this is also worth them exploring if their relationship has difficulties.

In terms of the marriage ceremony, you may find that this presents very little trouble, as such things tend be to well rehearsed and much easier to cope with than a standard church service. Unexpected events in the church may of course present particular challenges, but there will usually be family and friends there to lend assistance to anyone who needs it.

Many autistic people make excellent parents, especially if they have autistic children. Again, support is often available through local autism charities, as well as online in good social media groups.

#### Funerals, Baptism, Confirmation

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/plans of what will happen may be of much more value than spoken words, in many cases. It may help to ask if they would like to 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 issues of unusual 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. Emotional delay is very normal in autism. They may need extra or more specialised support, so again the autism charities may be the right place to refer them to for specialist counselling if required.

# Working with an Autistic Colleague and Training Issues for Ministry or Leadership

The Equality Act 2010 is very clear that people on the autism spectrum must be given a fair chance to use their skills in a safe and respectful way, and not be judged on their autism unfairly. There are employment settlement sums of more than £1 million for places that unfairly discriminate against people without properly considering their useful abilities. It is very important to realise how many strengths autistic people have within our churches, whether paid or voluntary. There is a myth that autistic individuals are all maths experts or computer programmers. Not so.

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 of 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".

We have autistic clergy doing a fantastic job. Often within teams. Sometimes as Priest in Charge. Sometimes as higher ranks of Clergy, too.

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 to the charities, and in particular contact the National Autistic Society.

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.

"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, 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". ...I just hope and pray, that if there does come a time for me to reveal it, people will see beyond the autism to the person that is me."

It is often assumed that autistic people cannot empathise, and therefore cannot possibly train for ministry, prayer support, pastoral support etc. This is not so. Instant empathy is certainly more difficult if you cannot see faces very well. Autistic people need others to explain how they feel. But by adulthood many have found ways to use good questions and use their own past experiences. This builds a very reliable pattern of what to do or not do in particular circumstances. They are often valued members of a team because of their ability to think calmly about really emotional issues, and bring order to chaotic situations. Encyclopaedic memories are not unknown, which is very handy for recalling the exact right parts of the Bible to comfort or encourage someone.

When assessing such a person, please bear in mind all of the elements of their disability. It is not helpful to criticise an autistic person for not using enough body language in a sermon. Or for not realising that they were supposed to do something, when you were not very specific with your instructions. Remember their need to know what is expected of them. This applies to timings, too. A meeting timed for two hours will cause much anxiety if it stretches to three hours. As a result many autistic individuals become expert in chairing meetings very effectively indeed.

#### 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...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. If needed, there is often financial help and support available from the government and from charities to make it possible for people with disabilities to work, and to adapt the workplace or provide them with a supporter. Advice is available through the Diocese.

A little thought and adaptation will usually yield marvellous results. It's well worth exploring.

#### **Further Information and Contacts**

**National Autistic Society** books, information, training, employment support, advocacy: <a href="http://www.autism.org.uk">http://www.autism.org.uk</a> or 0845 070 4004

**Through the Roof**: Information,training and publications on church access for all those with disabilities, including those with an AUTISM. Also good information about the disability laws for churches: <a href="http://www.throughtheroof.org">http://www.throughtheroof.org</a>

**Prospects**: Christian services, training and materials to help those with learning disabilities: <a href="http://www.prospects.org.uk/">http://www.prospects.org.uk/</a>

#### **Equality Act 2010 Guidance for Churches/Charities:**

http://www.equalityhumanrights.com/sites/default/files/uploads/documents/Old\_Guidance/PDFS/Service\_User/3\_service\_users\_voluntary\_and\_community\_sector.pdf or go to http://www.equalityhumanrights.com\_and search for guidelines for charities. http://www.equalityhumanrights.com/your-rights/service-users/adjustments-disabled-people/three-requirements-duty\_is also useful.

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

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