



Diocese of Oxford

Welcoming those with Autism and Asperger Syndrome in our Churches and Communities

Welcoming those with Autism and Asperger Syndrome

Guidelines by Ann Memmott

Foreword

The Rt Revd John Pritchard, the Bishop of Oxford

We talk a lot about how to make church welcoming, but we sometimes forget that for the one person in every hundred who has a form of autism, church can be a bewildering or frightening place. That's why I'm so pleased that these guidelines have been produced for use in the Diocese of Oxford. They explain clearly what it can be like to have an Autistic Spectrum Disorder and how we can help to welcome those with an ASD into church. Small changes can make a big difference.



God loves and cares for every one of us. I want churches to show that love and to value our differences. Together, in all our variety, we make up the body of Christ.

I am grateful to those who have produced this booklet and those who have shared their experiences.

I commend these guidelines to you.

Bishop John

**If you need these details in a different accessible format,
please do let us know
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Welcoming those with Autism and Asperger Syndrome

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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Autism and Asperger Syndrome

What is it? Why do I need to do something?

Autism and Asperger syndrome are a type of learning disability, also known as Autistic Spectrum Disorder (ASD). People with this will not look any different to anyone else. Those with an ASD have permanent difficulty understanding social situations, cannot 'see' people very well, and have difficulty coping with sudden changes of plan or breaks in their routine. They are often hypersensitive to sound, light, texture, smell or touch. Individuals may have IQs ranging from very low to very high. Some may have extraordinary and very useful abilities. It is not a 'mental illness'. People with an ASD are often very logical and reliable. Unfortunately it is also a disability that is often misunderstood, leading to unnecessary negative reactions.

"I believed what it said in the Bible, that Christians love people even if they have a disability. When I went to the church, I thought that was what would happen. I didn't expect them to laugh at me and ignore me, or for it to be so confusing and so scary to be in a church service with no idea what they wanted me to do. It was as if I didn't belong there either and God didn't love me at all. I was just so very sad."
(account of a young person with an ASD)

There are estimated to be over half a million people with a form of autism in the UK: One person in every hundred. There are about 40 people with autism in the average Parish. It is almost as common as wheelchair use. There are probably some people with an ASD 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.

Tony Attwood, the International expert in autism and Asperger syndrome¹:

"...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 could be someone on the autistic spectrum
—children or adults, male or female.***

¹ <http://www.tonyattwood.com.au/> accessed on 6 May 2008

Two Minutes to Spare?

Just read this:

Quick Low Cost Things to Make a Difference for People with an ASD and Everyone in your Congregation

1. Check the **lights in each room**, especially fluorescent ones – any flickering ones? Please replace them. (This also helps people with epilepsy)
2. **Noise** levels. Is there anything unexpected in today's service/meeting? Can it be changed easily? If not, can you warn us? (This also helps people with mental health conditions and those who are deaf)
3. The **building**. Do we know what it looks like, and what the **layout** is like today? Is information on a simple website, perhaps? (This also helps people who have visual disabilities or those who are nervous of attending somewhere new)
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). Different colour paper may help some to read service sheets, e.g. light blue paper rather than white.
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)
6. **Physical** events e.g. **shaking hands**? Water being splashed about? We may find this physically painful, as we're hypersensitive. Please warn us what will happen, and avoid physical contact unless we offer first. (This also helps those with arthritis, and those who are nervous of being touched because of memories of violence)
7. **Rest** area – somewhere quiet to go if we need to, please. Or don't worry if we wander outside for a while. (This also helps people who have chronic fatigue illnesses, and mental health conditions for example, as well as those with back problems who may need a quick lie-down on a bench)
8. **Socialising**. Be aware we find it difficult and exhausting as we cannot 'see' or hear you that well. Our **body language** can be different to yours, and we may not make **eye contact**. Please don't think we're rude. (This also helps people who are more introverted).
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 this afternoon". 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.

Ten Minutes to Spare? Read These Pages.

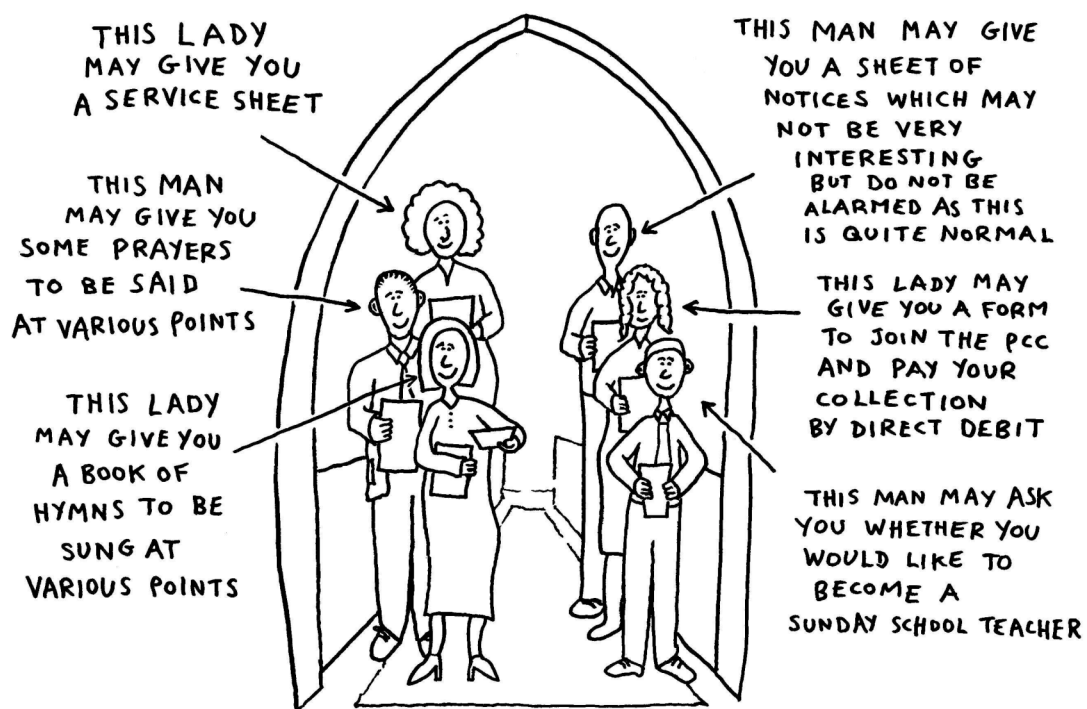
What can be done to welcome those with an ASD into church?

First read this, so you can understand the problem:

An account of a church service by someone who has Asperger's Syndrome:

"I've now been to this church many times, but I cannot recognise who's greeting me at the door – how embarrassing. I am given two hymn books, a service sheet and a selection of other random sheets of paper, I am now worrying about how I will know what each of these is for today. I'm also worrying about dropping them, since I'm not very co-ordinated.

THINGS YOU COULD BE GIVEN

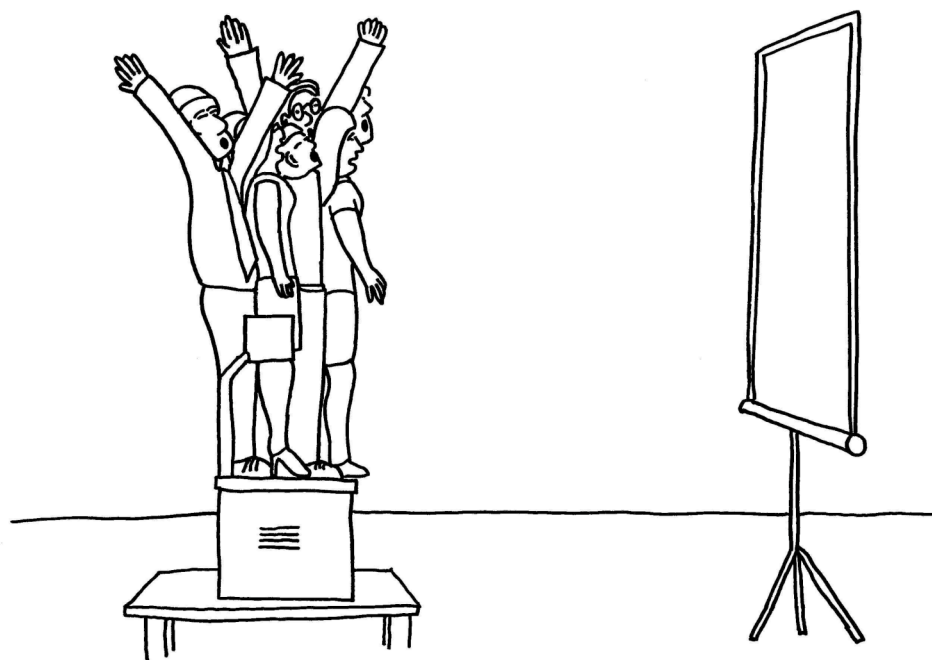


The next problem is where to sit. So many chairs to choose from, and I have no way to decide which is correct. Deciding where to sit is a huge challenge for me. Worse still, the vicar has rearranged the church without warning me, and now all the chairs in a different pattern. I am so surprised that I almost drop the collection of hymn books. I can't cope with unexpected change.

Where to sit...the back? The front? The side? In front of me, people who apparently know me. I recognise one of them, though I'm not sure where from. I wonder what I should say. I feel a bit silly admitting that I don't know

his name or recall detail about him. Others take this sort of social thing for granted, but for me it's a blank.

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. I need instructions, or routine. The Minister 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, and 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 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.

Next, I am suddenly given a plate with money on it. I've forgotten to get my money out, and because I'm not very co-ordinated, I end up dropping coins all over the floor. This is embarrassing too.

I am now exhausted. I wish I could concentrate on prayer, on hearing God, on listening to the Minister, but frankly the Minister 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. I have to cope with the flickering candles round me, the taste of the bread, the taste and smell of the wine. 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 wish I knew how to make new friends, but all the rules for that are too complicated for me to work out. I need someone to let me have a quiet space to think in for a while, then perhaps a simple task to do so that I can feel useful but not have to make "small talk" with people. It's more difficult as the weeks go on, in a way, because other new people have then made good friends, but I am still struggling. It feels lonelier than ever. I wish someone would help me, but they just think I'm rude or antisocial or that it's someone else's job to help, not theirs. So now it's no-one's job to help me, and often I find I have to sit alone. I still love God, but I don't know how to be good enough to be welcomed and respected in a church. Friends ask if I'd recommend a church to them. I'm not sure what to say."

Church the Easy Way **An account by someone with Asperger Syndrome**

"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. She has 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'm happy to ask others to come to the church too."

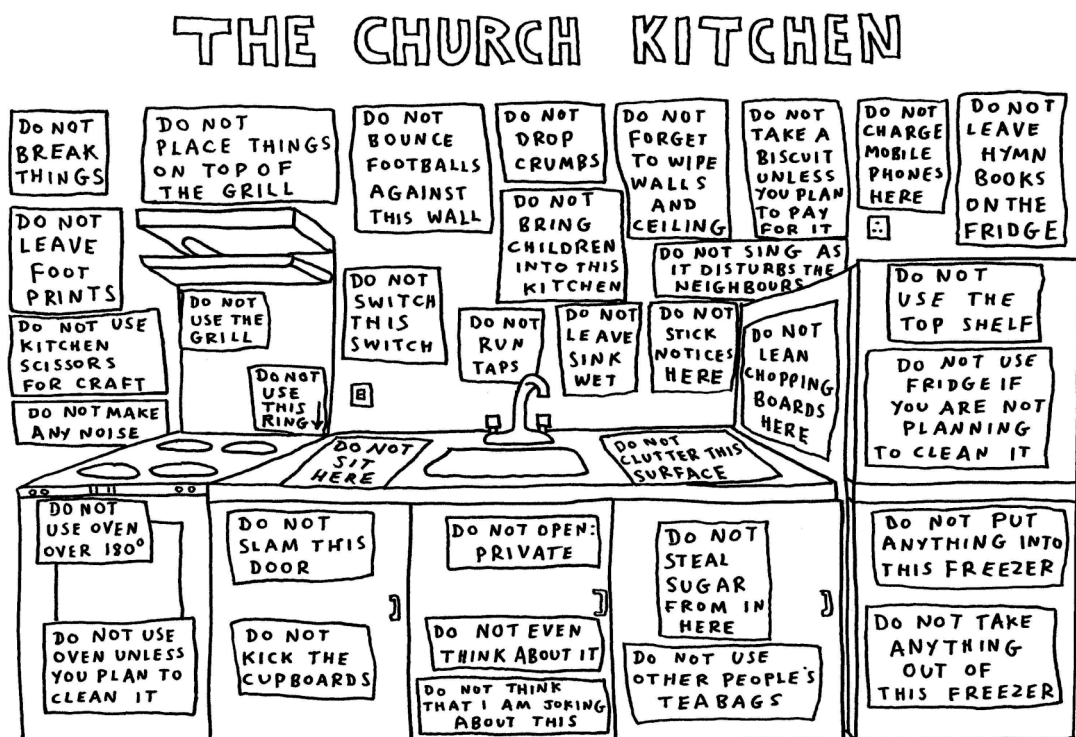
Cost to the church: Nothing other than a bit of time and thought.

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

How to Get It Right

Handy hints from a person with Asperger syndrome:

1. I am an expert in being me. **Please ask me anything you need to know about me** preferably in a confidential quiet setting in a way I can cope with. Give me time to think, please. Ask what I need, what works, what doesn't, maybe by email rather than in a meeting if I'd prefer it?
2. I am a person. **Please treat me with love and caring, even if I am different to you in some ways.**
3. I need to have some idea of where I will be, and what will happen when I'm there. **If things change**, or if I don't know the rules for an event, I find it very difficult to adjust fast, and again will end up exhausted and distracted.



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

4. **Please let me visit your church before a service so that I know what to expect.** Does your website show what the church is like, or have photos of the inside or the key people? It helps, a lot. (A 'blog' can be created in only half an hour by almost anyone to give key information online. See the section later in the document). If the church layout changes, please can you try to warn me? Please can you find a way to let me know what the service will be like, what will happen, where I should sit, and what you expect me to do.
5. Is there someone who can read these guidelines and sit with me to guide me and be a **supporter**? Can I please meet them safely first, somewhere quiet and private, preferably accompanied by someone else I can trust such as the Vicar? Please don't ask me to meet people in noisy hallways or places where personal answers to disability questions can be overheard. I'll find any meeting very stressful and will need all the help I can get to make it a success.

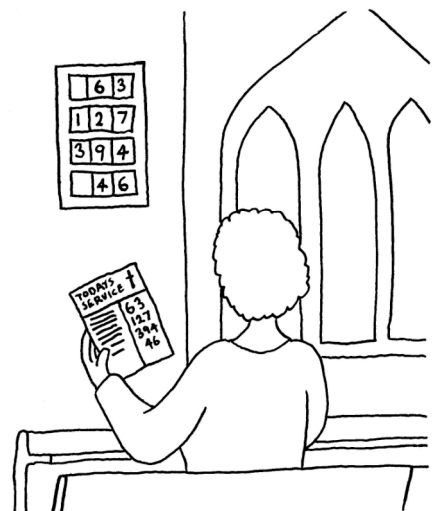
Stan Walden explains how supporters in the congregation need to expect a different sort of friendship with someone with an ASD:

"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....".

6. My brain senses things differently. I may find flickering fluorescent bulbs or high pitched noises as distracting as you would if you found a pneumatic drill in the room or a firework display happening in the corner. I also may find some smells, tastes and textures very difficult to cope with. **Please can you check your room for flickering lights or distracting noises first, and check whether I can cope with a lot of incense if it is used in the service?** Air conditioning may be switched off when I first visit, but switched on during the service, and that's the sort of change that I won't expect.

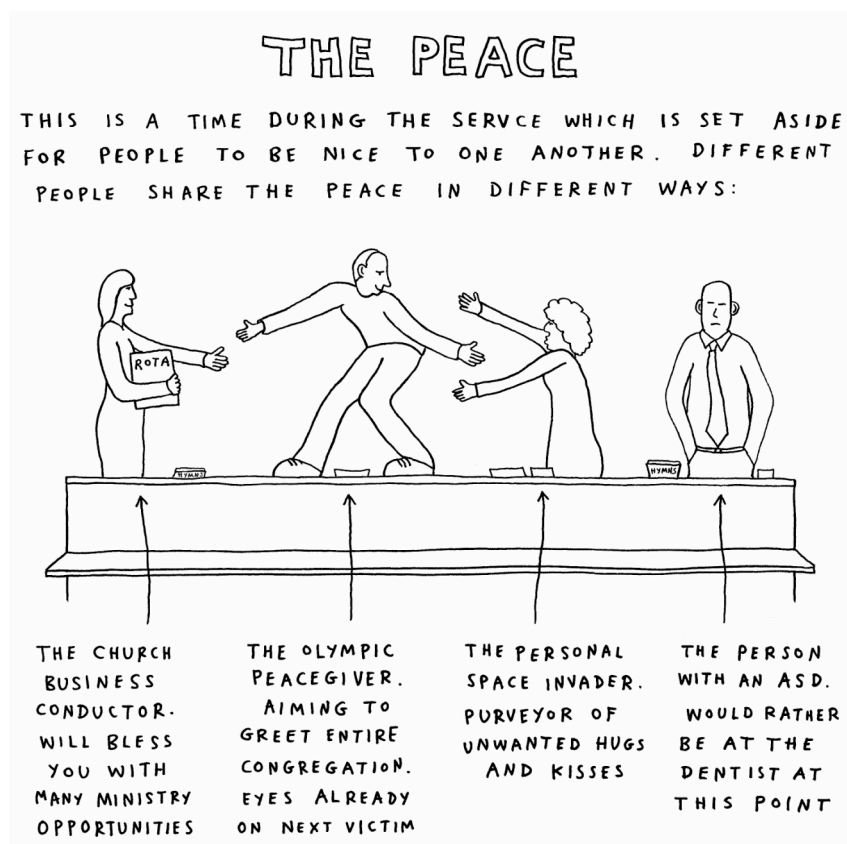
7. My brain probably works more visually than yours, and I may find spoken words or sermons much more difficult to concentrate on or understand, even if I may have a high IQ on other tasks. Some theology may be quite impossible for me to understand. I don't want to stop everyone else getting the sermon they want, but **please can you let me ask questions afterwards if I need to, or perhaps let me have notes, or use clear diagrams to explain things.**
8. I probably cannot "see" your body language or facial expressions very well, or manage body language correctly myself. In fact, I may have huge difficulty in telling who you are, unless you say, or unless you have a label on which says your name. I also find making eye contact really difficult, though many adults do manage anyway. Church services are a big crowd of people, and no way to tell who's who or what they are feeling. **Please do not rely on body language or facial expressions to explain what you mean, and please do tell me who you are if I seem uncertain.** If you use body language or facial expressions, please make it clear and "big". It sometimes helps if you happen to have a very expressive sign language interpreter in the church, especially for those on the autistic spectrum who do not use much language and communicate through signing.
9. I cannot always "hear" tone of voice, or understand whether something was said sarcastically or as a joke. I also think very logically and literally. If you ask me, "*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. **Please can you try to be clear about what you mean? If I misunderstand an instruction, please just tell me what I got wrong, very calmly, rather than being cross. Please don't assume that I don't understand you.**



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

10. I find being touched unexpectedly very, very scary. Saying The Peace and shaking hands with people may be extremely hard work for me, especially if there is no logical order to it or if there is hugging and kissing involved. Working out the rules for it might be more than I can cope with. **Please think about whether those with an ASD are able to cope with The Peace as part of your services, if it is included. We might be able to manage shaking hands with the people around us, but not more than that.**

11. I cannot always work out when it's my turn to speak. Discussions can be hard for me to take part in, because I may take longer to process what other people have said. **Please be patient if I get it wrong, and please try to make sure I genuinely have nothing to say on a point, rather than simply being unable to work out when to say it.** Because my brain is not 'wired up' correctly for social events, I get very, very exhausted at any social gathering. Purely social events such as when people say "*stay and have a cup of tea*" are quite stressful when we can't always know who we're speaking to, or work out what they are 'saying' with their body language, or what they'll find interesting to talk about. **Please don't think I'm being rude if I take some time out, or seem distracted, or leave suddenly at the end of an event. I'd love to be more social, but I don't always know how, and I may simply be too exhausted to say proper goodbyes.**



12. 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. **If I say or write something that seems rude in some way, please just help me to get it right. Complaining that I seem rude or uncooperative doesn't help me. I'm not rude deliberately.**
13. **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.
14. 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.** It can be very hard work and very long

hours when helping someone who is profoundly autistic, and the carers might need all the prayers and support they can get too.

Parents of children with an ASD/those with an ASD 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!"

Further In-Depth Information Understanding Autism in Your Church

Every church needs to know how to welcome those with an autism spectrum disability (who may refer to themselves as having AS, or being Aspie or Autie as “shorthand” for their disability). We can do what Jesus did in welcoming and supporting those with disabilities, and helping them to find spiritual fulfilment. We are also then fulfilling our duties as a “service provider” in the disability laws. Do take time to read the Disability Discrimination Act and see how each church service or official meeting has to ensure that those with a recognised disability of any kind are given a proper chance to participate, and are protected from harassment, bullying or social exclusion because of their disability. You must consider disability awareness training, often available at a good rate or free for churches.

“Our son attended a Sunday evening Youth Group but found it very difficult to access. Here he encountered the ridicule of others and the isolation of being different. They would snigger at his answers, laugh if he spoke to himself and never invite him to their parties or social functions. This problem stemmed from a leader who had not encountered or had any training in dealing with someone with an ASD and who did not give the other members a strong enough lead in caring and acceptance.”

That could perhaps have been easily solved with an autism awareness session.

Why is it called a Spectrum?

Some individuals have low-functioning autism, often unable to communicate with most other people in meaningful ways, seemingly locked in their own world, with behaviour which may be very different from that of other people. They may make random noises or flap their hands, for example, and may be obsessed with rocking backwards and forwards or playing over and over with the same toy or item. They may have a very low IQ.

“It is difficult being the parents of lively ASD children in a church environment; the children look normal (and in the cases of our sons are quite intelligent) but have challenging behaviour. Churches tend to have a great emphasis on family life; along with that comes the expectation of well-behaved obedient children. When your children don't match with to the church social norms, it is a very stressful situation for the parents/carers as they feel they are failing to live as Christians should. Many Christians claim to care about families and children but when asked for practical help and support they can be strangely reluctant (although they are usually happy to pray for the children and families concerned)... we know our children better than anyone else and are quite happy to give advice and tips on how to manage them. Come and ask us! We can tell you if they have particular obsessions, rituals, sensitivities and other difficulties. God

loves and accepts children with AS and their families; please can churches do likewise?" (Mum with two children with an ASD)

There are also at least as many individuals who have Asperger syndrome, or "High Functioning Autism" (HFA), who have normal or high IQs that allow them to gradually learn more and more about the social world around them, and cope in society to a greater extent. Their public behaviour may become so normal that it is difficult to spot the disability. It does not mean that their disability has gone, it only means they have learned to disguise it in order to survive in our world, and found themselves in the rare and fortunate position of being in a well structured environment with low socialisation levels where they can thrive. Those with an ASD and higher IQs may be able to go on to lead relatively normal, if sometimes rather eccentric, lives. Many have families and jobs. Some choose to become university professors, mathematicians, accountants, specialised lawyers, company directors and advisers to the Church. Some are organists, vicars, or members of the choir. A few are "savants" – people with amazing abilities, like Stephen Wiltshire, <http://www.stephenwiltshire.co.uk/index.aspx> who can draw any building or cityscape he sees, perfectly, from memory. People like Einstein and Leonardo da Vinci are believed to have had an ASD. In popular imagination, autism is imagined to be about poorly-functioning boys, but there is a huge diversity. Many experts now believe that there are as many females with an ASD as there are males, but they had not been found because they were looking for the wrong things. The vast majority are believed to be adults who may not even realise they have an ASD, because there was no diagnosis when they were at school.

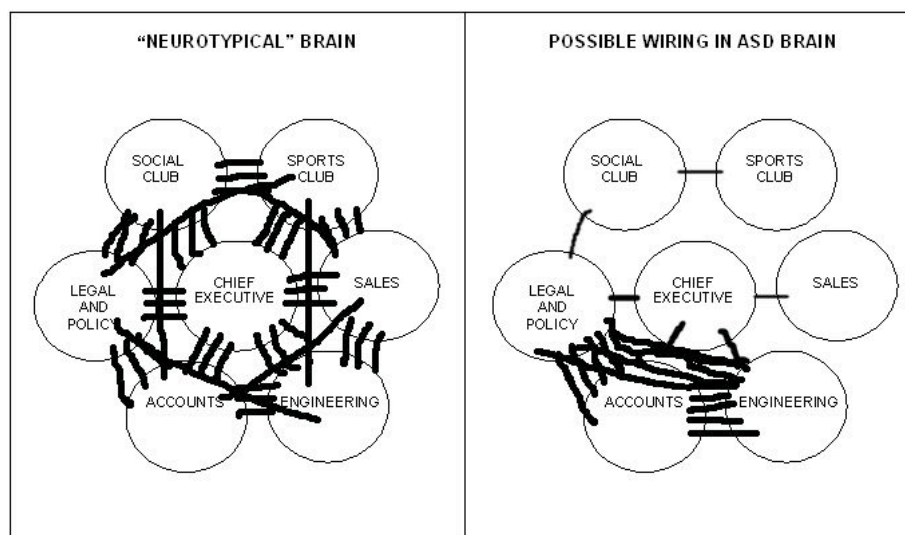
All who have an ASD are individuals who have their own likes and dislikes, their own needs and their own understanding of faith matters. All are loved by God.

All, no matter what their IQ, have problems coping with social events, making new friendships and understanding social rules. Many people with an ASD like routines, have very strong and often unusual interests, and find it really hard to cope with sudden changes of rules or activities, or cope with anything that is wrong, out of place or breaks a rule.

Why does it happen?

People with an ASD are usually born with brains that are wired differently from birth or which become wired differently during their very early years. We don't know why. It stays like it. Their brains don't "see" people properly, or automatically know about social interaction and the rules of friendships and relationships and social structure. In fact, a lot of the wiring in their brains is connected into patterns that are just not the same as other people's. Whereas most people are social, knowing how to read body language, tone of voice, how to recognise people, and how to interpret facial expressions, they simply cannot do this automatically, ever. It has to be learned step by step, painstakingly, and they may never be able to 'see' or hear enough to be really good at it. People with ASDs struggle to interpret things that you take for granted. It is a little like being almost blind, but only affecting how they 'see' people.

The world-famous Dr Temple Grandin², who is autistic, explained that an autistic mind as being like an office building, in which the accounts and engineering department got all the phone lines, and the people in sales and marketing didn't really get any at all. In simple terms, it could be described like this:



Obsessive habits or strange movements or noises can be distracting, but is it any more distracting than other children playing or crying, or people who leap up and yell "hallelujah!", or those who dance in the aisles, or those who sing loudly out of tune? People who are at the lower end of the autistic spectrum may not understand danger, but are no more likely to be deliberately violent than anyone else, although children and those with low-functioning autism may have toddler-style 'tantrums' ("meltdowns") if they are very exhausted and/or very overloaded with new events or scary social situations.

"My son is very fond of his junior church leader and she has done loads of little things to keep him included. Even though some of them don't work, I am really heartened by her willingness to be creative and think of my son and want him to be happy in the group and to be able to contribute. He often is offered a musical instrument and is the person she asks to draw the curtains and switch off the lights. She accepts a certain level of noise from him and encourages me to contribute to the group overall. He often starts his prayers at night with thanking God for her.It is helpful to have people who are willing to learn and understand and treat us both like human beings with feelings. Someone asked me for what they could do to make it easier for him when we went for a picnic together, and that individual approach really helps."

If you are trying to welcome someone who has an ASD, and you have any concerns, speak to them, or if that is not possible, to their carers, the National Autistic Society, your local autism support charities, or to Through the Roof, the national charity that helps churches to include those with disabilities.

² <http://www.templegrandin.com/> accessed 21/05/08

Find a suitable time to talk to them in a confidential setting. Ask what's the worst that happens if they get overloaded, and what the best thing is to do about it. Most of us just get really exhausted and go home.

If you are in the rare situation of finding an individual whose behaviour is really challenging, they should of course be stopped from accidentally hurting themselves or others, and thought given to how to make events and meetings safe for everyone. It is not the job of our church teams to rugby-tackle anyone in the churches, whether autistic or not.

Talk to the parents/carers and the charities. Suggest they bring a big enough team with them to cope with any sudden racing about or other disruptive behaviour, or perhaps suggest they listen from a side room if the individual is too lively. You might wish to think about running a separate service for



them if that doesn't work, perhaps combined with other churches who have anyone with similar needs or challenging behaviour.

People with an ASD will often hear words and phrases literally. If you ask them to "take a seat", they will be wondering where you want it taking to. They will not hear sarcasm in a voice, and it may be difficult for you to tell what they are feeling, too, as their body language and tone of voice may not be what you are expecting to "read". They may also see the world in very visual terms. Temple Grandin, the world-famous engineer who has an ASD, describes her struggle against literalism and finding ways to convert words into pictures in her mind so that she can understand them³:

"The Lord's Prayer was incomprehensible until I broke it down into specific visual images. The power and the glory were represented by a semicircular rainbow and an electrical tower. These childhood visual images are still triggered every time I hear the Lord's Prayer. The words "thy will be done" had no meaning when I was a child, and today the meaning is still vague. 'Will' is a hard concept to visualize. When I think about it, I imagine God throwing a lightning bolt. Another adult with autism wrote that he visualized "Thou art in heaven" as God with an easel above the clouds. "Trespassing" was pictured as black and orange NO TRESPASSING signs. The word "Amen" at the end of the prayer was a mystery: a man at the end made no sense."



It becomes easier to see how written ideas can become very difficult images in people's minds, and why some of those with an ASD can struggle with poetic language in hymns, prayers and parts of the Bible.

Another example, from a Bishop addressing a group of Christians, *"The pressure groups will now be backing their horses, and staking out their ground. My skin feeling is that Synod will coalesce.."* A person on the autistic spectrum would perhaps have an image of something pressing on a group,

^{3 3} <http://www.grandin.com/inc/visual.thinking.html> accessed 22 April 2008

some horses, someone hammering a stake into the earth, and someone's skin. They might not understand a single word of the meaning as a result, no matter what their IQ.

People with an ASD *may* have some balance or **co-ordination** problems, so do check what you're asking them to do and make sure they can do physical tasks you set for them safely. They may also not have very good muscle tone, which means they may not sit as attentively as you would like. It does not mean they are slouching through rudeness. They may also find it very difficult to realise they are ill or injured, so if someone in your church who has an ASD is behaving very 'out of character', it's worth bearing in mind that they may be ill or in pain, but may not even realise they are.

People with an ASD are very **literal**, may read the Bible literally, and expect their church to follow what Jesus said exactly. If we do not do this, they may find it absolutely baffling and lose faith in the church, instead perhaps settling into a direct "prayer and social justice" relationship with God. There is a "theology of autism", which is somewhat different to that of the rest of the population, because of the different way they see the world. They may not be able to forge what we view as excellent relationships, or be able to experience what we would view as a rich prayer life, but they often care deeply about social justice issues, or find fulfilment through donations of time or money to the church. Even the most profoundly affected person with an ASD can find peace and spirituality in the right setting.

People with an ASD are not good at politics or displaying natural **empathy**, although some do learn this by considering things from a social justice point of view. They tend to be very naïve, may not realise when people are being cruel or sarcastic, and many surveys show that they are at extreme risk of bullying at every stage of their lives, sometimes in our churches. We need to be aware of bullying behaviours and be ready to help prevent them. They may also have great difficulty in realising that a rule applies to a slightly different situation, or applies all of the time, so if you say to a younger person "Do not touch this" they may think you meant "only now" and not realise you meant "ever". They may also not comply unless they understand the reason, otherwise it is not a logical request. They need love and respect, and people to care about them in the congregation.

Some people with an ASD may ask questions that seem rude because they do not understand the **social "norms"**, and some of those who are younger/ those at the lower end of the autistic spectrum may have difficulty wearing different 'Sunday' clothes because of the hypersensitivity to texture or the feeling of restriction, and may try to disrobe, which can be a temporary challenge for their carers and any audience.

"...our son was given a loving welcome and quickly became involved as an acolyte and later as a Crucifer, a job which is still of extreme importance to him and contributes towards keeping his self esteem levels up. He has always been sensitively supported in this by the other servers who have shown great patience and given time for practise when needed. He has what I would describe as an "intangible spirituality" there is no doubt that God is very close to him although it is impossible to tell what sort of faith he has or how much he understands. He attended confirmation classes when he was 14 and

six years later is still working through what he was taught, sometimes recognising passages from the Bible which were studied or phrases about Jesus' life.

He loves the repetitive nature of the regular Eucharist service and has taken a while to adjust to the more informal approach once a month and the All Age Worship which is altogether noisier. Babies crying, children running around seriously disturb his enjoyment of worship because he can only deal with one sound input at a time. He loves to pass the Peace as it is not intellectually challenging and he receives feedback from those around him who he would normally find it difficult to make contact with. His favourite form of worship is Evensong at the Cathedral which he attends most weeks. He likes the order and finds the music calming. He also receives a warm welcome here."

A mother of a young man with an ASD.

Those at the higher-functioning end of the autistic spectrum who have learned how to appear to "fit in" to society may not see themselves as disabled, but as differently-abled, and may not thank you for suggesting that you feel sorry for them or that they could be cured. For them, their way of thinking is simply their personality, their way of being.

"Healing is a big thing at my church. Unfortunately those whose prayers are answered in the affirmative are favoured and talked about. The church generally forgets to journey with people like us and there is no comment on the raising of our very personal hopes to then feel disappointment in the Loving God. I will not let people get away with inaccurate hype in my cell group, because everyone doesn't get healed. There must be hundreds of people profoundly affected by this and potentially driven away in churches that believe healing is for today. I have had periods where I stop participating in prayer for healing so I can accept my son as he is and not feel the frustration of the unanswered prayer which is easily directed at him. But I do want to be at a church where the possibility exists. He however, is very happy in his skin and would happily have prayer for achieving his potential but I have had very few indications from him that he wants anything to be different."

There is a strong 'anti-cure' movement in some Asperger syndrome internet groups, for example, which sets out to remind people that not all disability is bad or broken or needs healing. We as a church have much to learn from listening to all those on the autistic spectrum and what they have to say about themselves. Jesus, of course, always asked before offering to heal someone. We may need to take the same view.

"Personally I feel very strongly that it should be the churches' aim to create a positive, loving, welcoming and supportive environment in which those with Autism may engage with God through the power of His Holy Spirit in whatever way they can. "

A mother of a young man with an ASD.

Jesus called us to 'tear down the walls' and make all welcome, a message echoed by Bishop John in his opening Foreword to this document. Each church needs to consider its mission to people with diverse needs and gifts, and needs to have thought about how to take the best action for everyone.

Mr Phelps-Jones, of Causeway Prospects, explains:

"You can't [always] make a sermon suitable for people with a learning disability, because it would be too simplistic for the rest of the congregation....You can summarise the points of the sermon into a couple of sentences at the end of the teaching. You can provide a careful introduction to songs, and choose ones that are memorable and easy to pick up. You can avoid relying on notices being given in the spoken or written word. And you can avoid speaking too quickly." ⁴

The disability laws in the UK say that churches and church groups have to try to include people, and must think carefully about how to make it possible. Churches are not allowed by law to turn people with a disability away without doing a proper assessment, getting expert advice and thinking about all the possibilities for helping them to be as included, as we would do for people in a wheelchair or who are deaf or blind. It is good practice to record your assessment in case of future query. **Ask, get help, get ideas. Keep supporting people in whatever way you reasonably can.**

⁴ <http://www.churchtimes.co.uk/content.asp?id=38422> accessed 28 July 2008

Working at the Theology.

“Welcoming those with Autism and Asperger Syndrome” 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 every body 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 Lk 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

Blogs and Websites

The internet is the natural home of many people on the autistic spectrum. With a lack of body language, tone of voice and eye contact to worry about, it is often much easier for those with an ASD to communicate via email and find information on the internet.

Many churches only have the most basic of information about their church, its people, its services and its beliefs available on the internet. Yet this is often the best way to get information to many of your Parishioners at very little cost, not just those with an ASD. Seven out of ten households have access to the internet. You may be worried about how to get useful information to lots of people at once, since creating a full internet website can be a challenge. There is a quick, simple, cost-free alternative: Create a 'Blog' – a very simple website which can be set up by a novice in a very short time and with no technical skills required.

To see what we mean, see the excellent and entertaining blog of Bishop Alan, the Bishop of Buckingham:

<http://bishopalan.blogspot.com/>

Your blog might include photos of the church and its leaders, service plans, church layout changes, anything that might help those on the autistic spectrum and everyone else in your congregation who might need to know more about what's happening at the moment.

If you need to create something more extensive or with a better 'ownership' for your church, you may need a full website. Perhaps someone in your congregation already has these skills - maybe someone on the autistic spectrum with a good knowledge of computers?

Always give proper thought to who will update it, and know how to keep it legal (Data Protection Act, keep all statements truthful etc). The same applies to any literature your church produces, so this should not be particularly difficult for you. There is advice available through the Diocese, for example on using services like "A Church Near You" website <http://www.achurchnearyou.com/> if you are not already doing so.

Marriage, Sex, Relationships & Ceremonies

People with an ASD in our congregations and parishes often want intimate and long term relationships, and there are certainly those who wish to marry and have children. In these situations, a church needs to be able to enable them to get the right pre-marriage advice and help them to go into a marriage 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)

Marriage, sex and relationships for those with an ASD 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 feel very depressed or stressed, not realise why they need to be very specific with instructions, feel sad that their partner cannot tell if they are upset simply by looking at them, and may need extra support. Even if both have an ASD, there can be differences in communication style and habits that lead to particular problems.

Because of issues of extreme physical sensitivity 'overload', difficulties coping with the unknown or unexpected, the need for rules, possible low self-esteem from bullying, or sexual obsessions, you may find unexpected questions about sexual relationships, so these are worth considering in advance or obtaining advice from autism experts before giving advice to the couple in question. 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 have an ASD and those who do not, for example. The more understanding that a 'neurotypical' (non-ASD) partner has about their husband or wife, 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 to be 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.

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 person with an ASD, 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 issues of unusual reactions. The person with an ASD 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 charities are the right place to refer them to for specialist counselling if required.

Working with a Person with an ASD and Training Issues for Ministry or Leadership

Higher functioning individuals on the autistic spectrum are often extremely competent in their specialist areas, may already have well paid jobs, and may have invaluable specialist skills to offer. Indeed almost any individual with an ASD 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”. (A person with an ASD working as an adviser for the Church of England)

If you have someone with an ASD who would like to take on a role within the church, the normal processes of consideration need to take place. Are they capable of doing the job, either by themselves or with the right support in place? Do they understand exactly what will be involved? Are there elements of that job that could be transferred to someone else in order to make it easier for them to do it? Rather than say no, think and plan, talk to the charities, and in particular contact the National Autistic Society and ask about their job support scheme, Prospects.

You may well find a surprising number of individuals with an ASD 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. A person with an ASD explains why they fear prejudice:

“Very few people know about the Asperger's, 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 ASD to the person that is me.”

It is often assumed that those with an ASD cannot empathise, and therefore cannot possibly train for ministry. This is not so. There are certainly already ordained individuals with an ASD, although they may not have mentioned it to anyone so far. Empathy is certainly more difficult, but by adulthood many higher functioning ASD individuals have found ways to empathise with others by using social responsibility skills, logic, and their own past experiences to build a very reliable ‘database’ of what to do or not do in particular circumstances. They are often valued members of a team because of their ability to think rationally about issues and bring order to chaotic situations.

When assessing such a person, please bear in mind all of the elements of their disability. It is not helpful to criticise someone with an ASD for not using enough body language in a sermon, or for not realising that they were supposed to do something if you were not very specific with your instructions. Remember their need to know what is expected of them.

A Reader in training 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 “

Please remember our duties under the Disability Discrimination Act. No matter what your personal views, you must give each person with a disability 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. There is 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.

Further Information and Contacts

National Autistic Society books, information, training, employment support, advocacy:

<http://www.autism.org.uk/20594> or <http://www.nas.org.uk>
0845 070 4004

For autism training, contact Christopher Barson, National Autistic Society External Training Manager, Castle Heights, 72 Maid Marian Way, Nottingham NG1 6BJ, 0115 911 3363
www.autism.org.uk/training

Through the Roof: Information, training and publications on church access for all those with disabilities, including those with an ASD. Also good information about the disability laws (Disability Discrimination Act 1995) for churches:

<http://www.throughtheroof.org>

Causeway Prospects: Christian services, training and materials to help those with learning disabilities:

http://www.prospects.org.uk/index.php/causeway_prospects/

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