

ASPERGERS AND A.S.D. IN OUR ECCLESIAL FAMILY?

This article is offered, from a parent's perspective, as a means of encouraging greater understanding of the growing number among us described as being "on the autistic spectrum". Over 500,000 people have an "autistic spectrum disorder" (A.S.D.) in the UK alone. The rapid increase is believed by some to relate to modern diet; food additives; medical drugs; genetic factors; and so on. Today, signs are often recognized in a school setting and early help is given. However, in the past such children received no help. Instead, they passed into adulthood with a perception of life and a manner of social interaction which, while potentially producing great strengths, also affects their relationships with others, not least their Brothers and Sisters. Yet if they cannot turn to Brothers and Sisters for company and understanding, where can they turn?

This article hopes to achieve three things. First, that Brothers and Sisters are no longer left surprised, confused or offended by the (at times) unexpected, abrupt or in other ways markedly inappropriate words or behaviour of some on the spectrum. Second, that we all become more aware of the vulnerability *and* strengths of children and adults on the spectrum. Third, that those on the spectrum are not left bewildered, in danger or with nowhere to turn for supportive company, understanding and stability.

It must be said that the use of the word 'autistic' can in some cases be somewhat misleading. When we hear the word, many of us immediately think of classic, 'core', 'Kanner' autism – one manifestation of which was shown in the film 'Rainman'; or of those with autism who are almost unable to communicate; or of the spectacular 'savant' skills manifest in a small minority of autistic children. 'He's/she's/I'm not *autistic!*' might be our shocked response. But 'core' autism is at one side of **a broad spectrum**. In fact, the autistic spectrum covers a wide array of differing diagnoses, albeit with three traits in common. A diagnosis can also indicate potential strengths. However, while many on the spectrum are of decidedly higher than average intelligence and can often be creatively or artistically gifted, their different ways of thinking can lead to significant misunderstandings and bewilderment for them and those they mix with. This is as true in an ecclesial setting as anywhere else.

When we look at the word 'autism', "Aut" is related to "self", thus: "*Self*-ism". We are not saying that a person with an A.S.D. is self-*ish*. We are saying that for **developmental** reasons the awareness they have of their own inner world is stronger and clearer than their awareness of the outside world *and particularly the way others view and express that outside world*. Those on the spectrum can go through life with some degree of anxiety and bewilderment as far as relationships and daily interactions are concerned. Some can be vulnerable members of our ecclesial family who need the loving care of Brothers and Sisters who understand their different ways and appreciate their strengths.

The autistic spectrum is believed to be a ‘continuum’ embracing such difficulties as dyslexia, at one end of the spectrum, through dyspraxia, attention deficit disorder (A.D.D.), attention deficit hyperactivity disorder (A.D.H.D.), semantic-pragmatic language disorder, high functioning autism (H.F.A.) and Asperger’s Syndrome - with classic, core (‘Kanner’) autism at the other end of the spectrum. The term Pervasive Development Disorder (P.D.D.) is also used. Each diagnosis varies in degree from mild to severe. There can be mild ‘ghostings’ of symptoms in siblings, parents or extended family. While diagnoses are as individual as the persons themselves, each shares three traits:-

Difficulty using language for communication – leading to over-complex, verbose use; inappropriate use; or under-use of language.

Difficulties with certain elements of imagination – particularly insofar as it affects the skills of empathy and sympathy.

Impaired social interaction and social skills – involving inappropriate speech and behaviour.

These three areas of difficulty tend to lead to: **Repetitive behaviour patterns; Resistance to change in routine and Obsessive/intense interests.**

A.S.D. is notorious as the “invisible disability”. There is nothing outwardly visible to show that an individual has been trying to handle, often from a young age, a mind-set that significantly affects their interaction with others. What is often all too markedly visible to the outsider is their at times inappropriate, awkward or abrupt behaviour as they work to ‘fit in’ with those around them.

In families, public life and the ecclesial setting certain expectations exist regarding one’s own and others’ behaviour. How quickly we judge when some fall outside those expectations! When meeting someone for the first time, we can make all kinds of snap judgements. The criteria we use include facial expression, words spoken, body language, tone of voice. Those on the autistic spectrum not only find it hugely difficult to *read these signals* in others, they also have great difficulties *expressing themselves via* each of these areas. No wonder there is so much scope for misunderstanding! They often find it very hard work to communicate and interact with others in a socially expected way. We all know the feeling of appearing calm externally while in reality “padding furiously underneath”! This can be how they experience most social interaction. **Let’s look at the three areas in more detail, taking care to remember that in each individual the areas of difficulty manifest themselves to differing extents.**

Difficulty using language for communication. Many of us are familiar with those at one end of the autistic spectrum who are clearly withdrawn, with little use of language, some of whom show their needs by gesture alone. It is hoped and prayed that their difficulties are recognized, their needs met and that their

ecclesia gives the support and love which they and their families need. In those further back along the spectrum, their symptoms are at first sight much less visible outwardly. Hence society often expects far more of them, having little if any knowledge or understanding of the challenges they face daily. As far as communication is concerned, those on the spectrum often show a concrete, rigid, over-literal understanding of language. Many experience difficulty with metaphors or sarcasm and have an inability to 'read between the lines', 'get' jokes or infer from a given comment/situation. They find it hard to 'join the dots' as it were. This can result in all kinds of misunderstandings and misinterpretations - some painfully obvious, others completely unbeknown to those around them, festering away, to surface months or even years later.

It may be noticed at a young age that some on the spectrum have impaired auditory memory, finding it hard to sequence words/actions or to listen to multi-part instructions/arguments. Despite (or because of) this they often employ the most convoluted thought patterns and explanations to help themselves make sense of life. This can often be particularly apparent when they put their thoughts to paper. To make sense of a set of circumstances, they may come up with an idea, no matter how unusual, and run with it to the 'nth' degree, to see if it is viable. If one is on the receiving end of that thought process, it can be a long and winding road listening to or reading their words, as they seek to grasp what is right and true. Many express themselves in stark language with minimal use of nuances or shades of meaning, such that some of their writings have been likened to 'being operated on without anaesthetic'.

Many are of considerably higher than average intelligence; many are extremely creative in the writing and artistic fields; some develop excellent numerical or reading skills (hyperlexia) far earlier than their peers. However, when their difficulties in language reception or language expression affect their learning and communication they can build up a great deal of hurt and frustration.

Difficulties with Imagination insofar as it Hampers Empathy and Sympathy. As children, and often well into adulthood, they typically have rigid, inflexible ways of thinking. For much longer than other children, they will not so easily 'by osmosis' of previous experiences absorb the correct thing to do so that they can apply it to the next time. Instead, they tend to memorise rules and try to memorise whether they are in the right situation to apply them, using memory and ultra-strict logic rather than experiencing empathy. You can see that social situations can be pretty exhausting for them. They might appear thankless at times as their impaired sense of empathy means they may remain somewhat unaware of the efforts of others on their behalf. They often demonstrate a highly attuned sense of honesty (in order to keep to the rules by which they make sense of life); are resistant to the telling of any lie; without malice, 'without guile'. Some as children have little fear of real dangers; giggle at inappropriate times and are often over-active. Some have a defiant manner but may develop an extremely low self-image as they can build up enormous frustration at their inability to communicate with others successfully.

Impaired social interaction and social skills. Understandably, they often have difficulty mixing with others, finding it hard to interpret social situations or to adapt their behaviour accordingly. It is hard for them to figure out the social rules of life, words people speak, gestures given, meanings implied.

Many are painfully uncomfortable with ‘small talk’, often lacking in the giving of the usual ‘encouragers’ in conversation: eye contact, facial expressions or the giving of other kinds of acknowledgement that they are understanding or agreeing with what you are saying. They typically give few of the usually expected social responses. As children, rather than absorbing rules of social interaction through natural interplay with others, many need to learn rules of friendship and social interaction almost by rote. They often then apply those rules in a blanket way, regardless of how relevant they may or may not be in a given situation! This rigid, rule-based approach follows through into adulthood and can lie at the root of problems in their interaction with others.

Typically they have difficulties with “theory of mind”, that is, they are poor at reading the likely thoughts/feelings/reactions of others. They find it hard to make hypothetical calculations about the knowledge another person may have, or about how their own words/actions might make another person feel. This explains why some can talk excessively on a subject with no appropriate regard for the listener, or interrupt or launch into a subject without giving sufficient explanation of the background to it. Some have diminished appreciation of social acceptability; giving inappropriate regulation of cuddles or body space (some give physical contact too closely, others reject being touched).

As children, the ‘gateway’ to their sensory nervous system can have difficulty “sifting” through the many sights, sounds and senses coming at them. This can render them indecisive or anxious at times, particularly in busy, lively social situations when there is so much sensory information to sift through. Some shrink from bright lights; are sensitive to loud noise; or have ‘food fads’ due to distorted taste or preference for the routine of certain colours/textures of foods.

They are often highly intelligent. Yet because of their difficulties using language in communication we can never assume that they have understood any given situation or conversation in the way we would expect them to. We need to double-check in straightforward terms that they have understood what is expected of them. When they are relaxed, comfortable and in a familiar situation it can be hard, if not impossible, to tell them apart from anyone else. Yet it takes just a small misinterpretation of a phrase, or an incorrect perception of a situation, for them to become bewildered; angry; or floundering socially. Social (and thereby many ecclesial) situations can be very hard work for them.

Where too many sensory stimuli are coming at them all at once, including in an ecclesial setting, they can inwardly be in a state of near panic. At the same time many demands are being made on them for social interaction, which is already a problem area as they have significant difficulty picking up on social

cues! Anxiety becomes overwhelming, they drop down into a more basic gear, lose the social lessons they have learned and out floods panic, frustration and/or anger. And of course, with lower empathy levels, they are less aware of the effect of their behaviour upon others!

At these times they often initially become very anxious, manifest by becoming agitated. We need to interpret this as a warning signal as soon as it begins and try to remove the over-stimulation, taking them out of the situation if at all possible and assisting them to calm themselves down. It is crucial to *cease* any argument at this point. No amount of attempts at verbal reasoning can help for now; *further input will only escalate their behaviour*. We might as well speak Russian to them. They have dropped down into distressed sensory overload, *past the point where they will be able to take it in rationally*. They tend to mirror the emotions being offered them, needing calm, gentle while firm handling, leading them out of the setting to a peaceful place, to quietly process what has happened and think the situation through in an undistracted way.

Repetitive behaviour patterns. They can encounter significant chaos in their world whenever they experience bewilderment about communication and social understanding. Repetitive behaviour is their way of bringing order and predictability to their unstable world. Familiarity and routine are soothing and reassuring. This explains the distress or anxiety shown when cherished patterns or a previously agreed set of plans are interrupted or broken: stemming from frustration and fear. They tend not to be comfortable with the unexpected. Try to remember to warn them at each arrangement that a change to plans is possible and prepare them with plain, straightforward contingency plans.

Resistance to change in routine. Often rigid in their thinking they find it hard to cope with change. Most demonstrate “perseveration”: it is inordinately difficult for them to stop one activity and move on to another. If change is inevitable, try to introduce it as gradually as possible with good warning, a ‘timing countdown’ (e.g., we’ll be leaving in 15 mins, 10 mins, 5 mins) and with a new plan clearly given. If you give them clear boundaries they usually work very well indeed within them. This means thinking ahead!

Obsessive interests. They can be hard to motivate unless or until they find a special interest, in which case they can become obsessive, utterly engrossed! Often awkward at ‘small talk’, they can, with little regard to the listener’s needs, talk at great length on their pet topics! They are often highly creative, ‘original thinkers’ who labour hard in their areas of interest. If they have a love of study, including Bible study, they can work at it to great depth, research it in great detail and speak/write on it at great length. Indeed, the very fact that their interests are usually followed through so thoroughly, intensely, wholeheartedly and single-mindedly can lead some to find ‘the pearl of great price’ via that very route. Many are also successful in music, art, horticulture, cuisine, writing, mathematics, science or in computer work where, in each case, social contact and social communication need not be the number one requirement.

Those with A.S.D. try to learn, then keep to, “the rules” in life and expect others to try equally hard to do so, under all circumstances! They find it almost unbearably difficult when others do not. It throws their hard-sought-after grasp of the world into painful imbalance. Well into adulthood they may apply a rule rigidly in ‘blanket’ fashion, even when inappropriate. Yet, where human nature is concerned, it is ‘inappropriate’ to expect anyone to behave ‘according to the rules’ at all times. This is where we need to share the principles of failure, forgiveness and grace. The words of 1 John 1:8, 9 are invaluable – *“If we say that we have no sin we deceive ourselves and the truth is not in us. If we confess our sins He is faithful and just to forgive us our sins and to cleanse us from all unrighteousness.”* Needing the security of rules, they also need to learn flexibility and forgiveness. Rom. 7: 24,25 – *“O wretched man that I am, who will deliver me from this body of death? I thank God through Jesus Christ our Lord!”* Rom. 3:19-26 is helpful. Verse 23: *“For all have sinned and come short of the glory of God; being justified freely by his grace through the redemption that is in Christ Jesus...”* Formal lectures, or any ‘academic’ debate are a classic minefield, generating countless opportunities for misunderstanding – see **1 Tim 1:4, & 2 Tim 2:14,23** - ‘doubtful disputations’ indeed! Our communication on spiritual matters needs to be calm, clear, straightforward and heartfelt. Our offers of company and fellowship need to be more of the practical than the academic kind and our manner patient and gentle.

You may have observed the traits we have outlined, in mild or more noticeable forms, in individuals you have met over the years. While children are diagnosed earlier today, such traits present in adults are likely to have remained undiagnosed and unmanaged. You may have blamed their personality, their past or their family. Please take time to scan through the typical traits again. Remember that their journey through life has not been a straightforward one. Try to walk a mile or two in their shoes... One of the hardest things for them ever to be able to do is to imagine what it is like to walk in ours... Thus our empathy for them may not always be reciprocated in ways we might wish.

However, what many “on the autistic spectrum” *can* offer is a unique take on life, an original creativity, a highly attuned sense of honesty and often a rich sense of humour. Try to be patient with one another’s different/unexpected responses in conversation or manner. Albeit that many on the spectrum are often highly intelligent, it still helps to keep things plain, simple and step by step, to minimise misunderstandings on *both* sides. Recognize, rejoice in and encourage their often notably creative talents in the writing, artistic, scientific, culinary, gardening, music, computer or other skills which can in various ways be valued within our ecclesial family. Once we are aware of the classic traits, we can start to anticipate the areas of life in which they are likely to encounter challenges. We can help to ease the way before them, and be more spiritually fruitful in our fellowship. May we grow more aware of each other’s needs so that, as an ecclesial family journeying towards our Father’s Kingdom, we can face these challenges - and benefit from one another’s strengths - together.