

Growing up in an Asperger family

Maxine Aston, counsellor and author specialising in the issues of Asperger's syndrome, talks from her extensive experience about the impact parental Asperger's has on children and young people

Sarah was 17 when she first came to see me; she had been in therapy before and had a history of eating disorders, self harm and anxiety. Sarah was not the first member of her family who had found their way into my counselling room as I had been seeing Sarah's parents for almost six months.

Sarah's mother had initiated counselling for herself and her husband, as she suspected that her husband was on the autistic spectrum but had not realised she was also affected. During our counselling sessions, I recommended that both went for a diagnosis and this resulted in a diagnosis of Asperger's syndrome (AS) for both of them.

During one of my sessions with Sarah's parents I raised the issue of their only daughter and asked if they would describe her to me. They described her as being a 'problem'. Her father felt she did not put enough effort into what she did and could have done better in her GCSEs. He also said that she played her music too loud and made a mess everywhere. He went on to describe how she would walk around eating a piece of toast or cracker bread without using a plate, dropping crumbs on the floor. Sarah's mother joined in to say how hard she had tried to make things better for her daughter and how her daughter just argued with her all the time. Totally confused, she recounted how she had told Sarah that if only she would concentrate on her work and stop spending time with her loud friends, she might be happier.

As I listened to Sarah's parents describe their daughter, I realised they had not told me anything about who she was, only about what she did that they found frustrating. With this in mind, I asked 'How do you think your autism has affected Sarah?' This question was met with total silence. Sarah's mother was the first to reply by asking what I meant. I explained that presuming Sarah was not on the autistic spectrum, how would they know if they had met her needs and really understood who their daughter was?

Sarah's parents struggled to understand this concept and it was becoming clear that they did not truly comprehend their daughter's world or what it consisted of. They asked if I thought it



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would be useful to see their daughter. I said I would be happy to see Sarah but it was important that she was also happy to see me and we agreed that the sessions would be confidential to Sarah unless she gave permission otherwise.

So now, with Sarah in front of me, it was clear that she was aware of her parents' diagnosis but not of what it meant. I explained AS to Sarah and its potential effect on her upbringing. It was not long before Sarah was in a flood of long overdue tears. 'At last,' she cried, 'I finally understand what caused all the problems – I have spent all these years believing it was me. At times, I thought I was going mad. I knew my parents loved me, but could not understand why I never felt it!'

Communication and AS

AS does not create bad parents; bad parents exist irrespective of whether or not they are affected by AS. AS does, however, cause difficulties in communication, social interaction and the ability to comprehend another person's state of mind or perception, in other words, empathy. It is this difficulty with empathy that has the biggest impact on parents' ability to understand their children

and to recognise that their thoughts, needs and perceptions are different from their own. Gillberg sums this up well¹:

The fact that some parents of children with high functioning autism (HFA) and AS themselves have autism-associated features begs the question of parenting skills in such individuals. It would not be unreasonable to assume that poor empathy in the parent might contribute to some behavioural/psychological problem in the child quite apart from any genetic influence. However, one might equally argue that a parent with similar but milder problems would be better able to understand and cope with some of the child's problems because they may be perceived as personality style rather than 'disorder'. Future studies should seek to explore these issues and try sensibly and sensitively to avoid the mistake of the past regarding the scapegoating of parents.

Gillberg points out that poor empathy skills, part of the core effects of having AS, could have a negative effect on the child's mental health and outlook. If the child, too, is on the autistic spectrum, the AS parent may have a better understanding of their child. In some cases, this is undoubtedly true. In her book *Pretending to be Normal*², Liane Holliday Willey talks openly about the struggles of being a parent with AS and confesses that she finds understanding her children with AS far easier than those without it. She says:

I worry a lot about the influence I have on my daughters' self esteem and happiness. I do not want to fill their lives with anxiety or shame. My concern for them pulls me toward the mainstream even if I bruise along the way. I feel bad that I do not encourage them to have many friends over... I regret that small talk with the parents of my daughters' friends is not easy for me. I am shamed when I do not know how to act. I dislike myself very much when I hear myself say 'Be quiet! Stop. Slow down. I can't keep up. Please don't talk to me all at once' when my girls are only happily excited to share their day with me.

Liane has clearly developed an understanding of the positives and negatives that can affect the parenting skills of an adult with AS and she has done much to explore, understand and give her children the best upbringing she could. Liane is a 'good enough' parent, but what happens if the parent is not aware they are on the autistic spectrum? In my research³ I divided my original sample into two groups: the first was women married to, or living with, a partner diagnosed with AS where both partners understood and accepted the effect this can have; the second was women married to, or living with, a partner who did not

accept they were on the autistic spectrum despite the fact their child had been diagnosed and it was quite clear that this highly genetic disorder⁴ had been inherited from the father. When asked if they believed their partner's condition had caused problems with the children, the answer 'yes' increased by 26 per cent in the latter group, indicating that awareness and understanding of AS may play a crucial role in difficulties raising children. However, it needs to be noted that even in the group who were aware, 40 per cent said they were having problems that could be directly attributed to one of the parents having AS.

The effect on the child

What are the issues that are likely to arise in a family when one or, in some cases, both parents have AS? What effect can this have on the child and what is the most valuable support and help that can be offered within the counselling environment?

Some of the main issues that arise are the parents' difficulty understanding their child's individual way of thinking and realising that the child's thoughts and perceptions are different from their own. For example, when I saw Nicky she had just begun university and was finding it a real struggle to cope alone with the demands of living away from home. Nicky described how her father insisted that the whole family had to fit in with his inflexible routines; her upbringing was very controlled and completely dominated by her father. Time and routine seemed to be the centre of their lives – they had to get up at the same time, eat the same food on the same day at the same time, bath at the same time and only watch the TV programmes he watched. He was very religious and religion became a strict and inflexible routine in their lives. There was little time for fun and laughter in the household and, if the routines were broken, Nicky's father would become reactive and highly anxious. They could not have friends round because they would interrupt his routine and he would stare at them, making them feel uncomfortable. He would say impolite things to her friends – one day he gave her friends a lift and he referred to them as 'excess baggage'.

The impact this upbringing had was one that left her with no confidence in her ability to make decisions; she was vulnerable and had very low self-esteem. She tried hard to fit in with others and had developed little awareness of who she was. We worked on increasing her self-esteem and restoring her confidence in herself as an individual. She needed to learn to be autonomous and not feel guilty or fearful of being separate from her family. Helping her understand AS helped her to understand her father's need for control and routine. Just this understanding helped her gain a very different perspective on how she had been so rigidly brought up. This highlights again the importance of understanding what AS is and the effect it can have.

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Valued for achievement rather than self

Another issue frequently experienced by adolescents brought up by an AS parent is one of not feeling valued for who they are, but rather for what they achieve. This was well described by an 18 year old who had just received her A-level results. She had worked hard and done well, obtaining three As and a B. The B was in chemistry in which her father, who had AS, had received a first at Cambridge. He was bitterly disappointed in his daughter's B grade and focused on this entirely, completely ignoring the three As she had achieved. She felt totally devalued and very hurt that none of her hard work had been recognised or acknowledged. Her father had belittled her and left her feeling guilty and despairing.

This client was 18 years old but this situation can occur at any age; it might be a five year old's failure at doing up laces, a 10 year old not winning a gymnastic competition, a 13 year old failing a science project or a 15 year old not winning a cross-country race. The expectations AS parents have of their children can be very high and it can be taken at a very personal level when they do not live up to those expectations. This can leave children feeling undervalued and can push them into having unrealistic expectations of themselves they can never achieve. They may become desperate in their attempts to please their parents and receive the praise they so desperately seek, or they may rebel and refuse to conform to any authority.

When working with children who have had this type of pressure put on them, it is important to acknowledge the value of who they are and not just what they achieve. The counselling should focus on their personal qualities, reinforcing that it is OK and human to be just good enough. Helping them to understand AS and why their parents have such high expectations of them is a crucial part of their recovery.

AS causes difficulty in using theory of mind, which means a difficulty in being able to put oneself in the other person's shoes. Because of this, the AS parent cannot see the pain they are causing their child by having such high expectations and often believes it is in the child's best interest that they achieve more and more. The expectations the parent will have of their child will be based on what they believe their child should achieve and will not always take into account that this might be higher than their child's developmental level or capability allows.

Personality development

A child's personality is developed by what is reflected back at them from their parents. Initially this is non-verbal – babies look into their parents' eyes from a very early age and are sensitive to the way they are handled and cherished. Sometimes a heightened sensory sensitivity can present itself in individuals with AS and this can cause an extreme

reaction to certain smells, touch, taste, sight or sound. For some AS parents, women in particular, there can be an extreme aversion to their child's vomit, soiling, smell, crying or, in some extreme cases, their physical contact. There is little the AS parent can do to combat this since, for them, their reaction is real and, in some cases, almost painful. To the child, it can be emotionally disabling and have a profound effect on how they feel about themselves; some of the adolescents I see describe never being hugged or touched by their AS parent.

Words are also a way in which children receive a real message about themselves and can be valuable in positively reinforcing the child's self esteem and self-awareness. Statements such as 'what a kind girl you are', or 'how considerate that was', is how we learn who we are at a very early age. Eye contact may be difficult for the AS parent as may finding words that emotionally reinforce the positive attributes of the child.

The AS parent will not be able to look intuitively into their child's mind and recognise the invisible qualities their child has, such as kindness, caring, and honesty. They may judge their child by what is visible – tidiness, school achievements and time-keeping, for example. They may treat their children as mini-adults and have the same expectations of them as they have of themselves. The AS parent is often unaware of the damage this can do to the child's self-esteem. Liane Holliday Willey⁵ talks on her video with Tony Attwood about how she bought books on child development so she could better understand her non-AS children. Liane had the incentive, understanding and motivation to take action and do something about the difficulties that having AS were causing in her parenting skills. Unfortunately, due to lack of awareness and understanding, this may not always be the case.

The sibling effect

Another issue that may exaggerate the problems caused for the child is whether there are siblings. Sarah, the client I introduced at the beginning of this article, was an only child. This can be the most problematic upbringing for a child with an AS parent as it precludes having a sibling to play with, confide in and, most importantly, bond with. A young man who had a father on the autistic spectrum told me he remembered that every Christmas and birthday his parents would buy him lots of toys and games; the trouble was that his parents would not allow anyone to come and play with him. This young man was struggling with being able to share and interact with other people and this was causing him difficulty in forming a relationship. Potentially he could also present with some AS ways but, without doubt, this would be severely influenced by the lack of encouragement to interact that he experienced as a child.

Adolescence is often the hardest time for children

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growing up with AS parents as this is when they may begin to challenge parental control, opinions and demands. The AS parent will struggle to understand their adolescent children and the developmental stage they are in and may see their behaviour as unacceptable. The parent may attempt to control their teenage child by undermining them or by making it difficult for them to have friends around, not because they wish to stop their child having friends but because they will not understand the importance of friendships as they themselves may have no need of friends. Some adolescents have given examples of their AS parent being very rude to their friends. One girl described how her father told her overweight friend that she looked like a Sumo wrestler. Her father had simply spoken his thoughts but the result was that her friend never returned.

Sometimes an AS parent can have a favourite child and almost completely exclude the rest of their children. This can cause much sibling rivalry and feelings of jealousy and low self-esteem in the child who is not the favourite. The effect can be even more exaggerated if the AS parent is a step-parent. AS parents struggle to relate to their own biological children and experience even more difficulty if the child is not their own.

The reason for this can be explained by understanding that AS is a developmental disorder; this means that, on an emotional level, the developmental stage stops at pre-puberty or even younger. The effect this has as an adult is that when they become emotional they will revert to child state and therefore often perceive their children, and especially step-children, as competition. The AS father may compete for mum's attention and not understand that mum's responsibility and love for her children is different from her love for him. He can at times be highly competitive and behave in a way that is childlike in order to divert attention onto him. If this does not work, he may distance himself altogether and have little to do with the children at all.

Parental separation

I sometimes see parents who are separating or divorcing and this is often when the mother may have concerns regarding custody. If it is the father who has AS, her concern might be whether he is able to care adequately for the child since an AS parent could become distracted while looking after the children. One woman I saw reported coming home from college to find her husband had left the children unattended because his employer had rung with an issue they needed him to address. It had not occurred to him that a seven year old was too young to be left alone.

Concerns such as these may result in some traumatic custody battles and the children may find themselves in the middle. Children are unlikely to

understand why the non-AS parent is so concerned and may resent her for not letting them spend the time they want with the other parent or, perhaps, they do not want to go with the AS parent and resent being made to do so. It is at this time that all family members, but in particular the older children, may become confused and in need of extra support.

These are all issues that anyone working with children and young people who have parents on the autistic spectrum will need to understand. Being raised with an AS parent will present a particular set of difficulties unique to this group and different from other types of upbringing. Often the AS parent will have the best intention in the world for their children but, unfortunately, it will often only be from their perspective, not the child's. Without support this can result in the child being confused, emotionally insecure and needy, with low self-esteem. A similar effect is also found in the partners of an AS adult, which appears to be caused by the emotional deprivation that can occur in the relationship. I call this Cassandra Affective Disorder. The Cassandra effect was first discussed in Karen Rodman's book *Is anyone listening?*⁶ where partners and adult children discuss the effects of living with a partner or parent with AS.

Websites such as ASpar⁷ for the adult children of an AS parent have been set up to offer support. If a counsellor can show understanding of and insight into their young client's world, this in itself will do much to feed their desperate need to be acknowledged and understood for who they are, not what they do. ■

References

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- 7 ASpar. Information, support, advocacy for people raised by an autistic parent, or a parent with AS. www.aspar.klattu.com.au

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