Life behind closed doors

The challenges faced by parents of autistic daughters remain largely misunderstood, says **Lucy Chantrey**

My own lived experience as the mother of an autistic son has undoubtedly shaped the trajectory of my professional life, both in my work as a therapist and in my research and writing. At school, his obvious differences marked him out as vulnerable, but the school seemed unwilling to accept his difficulties. I was fortunate that a wonderful paediatrician listened to me and gave me hope – she mentioned autism, and we had something to work with.

How starkly the experiences of the parents of autistic girls with whom I have worked professionally contrast with my own. Professionals involved with my son both recognised and validated my concerns because they were typical and well researched – I was believed. But what if I had been imploring people to recognise my daily struggles, yet had no diagnostic box to neatly fit them into, so they were dismissed?

While there is an increasing awareness that female autism is in fact far more common than has previously been thought, there remains a persistent view among many professionals that it is a predominantly male condition.[1] This view is perpetuated by the historic exclusion of females in autism research, so diagnostic tools are based around male-biased studies, and hence the subtly different presentation of autism in girls is frequently missed, leading to late diagnosis, if at all.

Many research studies highlight the deeply negative impact on parents and carers of parenting an autistic child, documenting increased levels of anxiety, stress, depression and burnout.[2] However, there is also a level of trauma experienced by parents when their child's struggles aren't recognised or believed by society. The term 'Cassandra phenomenon' is sometimes used in couples counselling to describe the feelings of isolation, confusion and not being believed, as described by the non-autistic partner in a relationship with an autistic person.[3] They find themselves let down on all levels by family, friends and professionals, simply due to a lack of awareness of the hidden impact of autism on their relationship. In this respect, a parent-child relationship where autism is undiagnosed or denied is little different to that of an adult couple yet is made more complex still by societal pressures to be a 'good' parent.

Autistic girls are well known to 'mask' their social struggles, and to the untrained eye often appear to have a good sense of humour, make good eye contact, have friends and enjoy socialising, with interests that don't stand out as being unusual; characteristics not usually associated with the more well-known male presentation. Parents talk of 'Jekyll and Hyde', describing a daughter who is perfect in every way at school yet volatile, controlling and sometimes aggressive behind closed doors. The lived experiences of parents are frequently met with utter disbelief when discussed with teachers and other professionals.[4] Parents are subsequently labelled as overanxious or indulgent, or may face legal difficulties if a child regularly refuses to go to school. As therapists, it is vital that we understand and recognise the hidden struggles of these parents, in order that we are better aware and informed to support them.

Case study: Accepting anger

Claire* first attended counselling wanting to rediscover her sense of identity as an individual, not just the mother of an autistic girl. Describing herself reaching rock bottom, her lowest point came when she recently had an operation and later found herself back at home secretly hoping that her stitches might break open so she could be readmitted. In hospital, she was simply 'Claire', and spoke of relishing this being her only identity. Her daughter's needs meant that she had given up a job she loved to care for her. She often experienced episodes of intense violence towards her from her daughter, yet outside their home this was never seen, and therefore not believed. Claire began to explore her sense of worthlessness and invisibility and, through this, slowly a deep anger started to emerge. Initially she found this very disquieting and hard to assimilate with her usual easy-going self. She had always regarded anger as negative and to be avoided.

With a safe space to explore this, Claire recognised that her anger was in fact an entirely healthy and valid emotion. She used her internal acceptance of her anger as a platform from which to start to fight back against the professionals who had dismissed and accused her, and secured a suitable placement for her daughter, with much-needed respite breaks for her. She has used these breaks to take up drawing again, and through this has rediscovered a deep sense of personal identity and fulfilment.

Trauma and fear

Parents of autistic girls sometimes live in persistent fear for their daughter's safety. While it is recognised that autistic adolescents have a significantly greater propensity towards self-harm and suicidal behaviour than their non-autistic peers, more recent research suggests that autistic females are at a much greater risk of self-harm than autistic males.[5] Living with this constant fear alongside the impact of witnessing and managing sometimes very significant self-harm can be deeply traumatic for parents, and an aspect of autism parenting that is very often overlooked.

Parents sometimes talk of feeling such a deep sense of responsibility that their very identity as a good parent hinges on their ability to keep their daughter safe. The trauma of watching her once healthy daughter fall apart was described by one mother as 'truly horrific'. One very important yet little acknowledged impact of this trauma is an increase in suicidality in parents. Pushed to the absolute limit behind closed doors, unseen and unheard, dismissed by those who – were they better informed – could help, and isolated from friends and family, some parents feel unable to carry on, such is the depth of their despair.

'Parents describe a daughter who is perfect in every way at school yet volatile, controlling and sometimes aggressive behind closed doors'

Case study: Retrospective guilt

Most parents of autistic girls start their journey with little if any knowledge about autism, and even less about autism in girls. For many, this brings about a profound sense of retrospective guilt around how they had managed situations such as school refusal. Feelings of guilt expressed by parents of autistic girls are multifaceted. One of the most commonly cited is guilt at how caring for their autistic daughter takes them away from her siblings, meaning that their lives are dictated by her needs and limitations. Another is guilt that they have unwittingly forced their daughter into deeply traumatic environments such as school, with one mother describing this as 'throwing her into a fire pit'. This sense of guilt often leads parents to feel that they have not only failed their daughter but their whole family too.

John* hoped that counselling might help him to make sense of the guilt that he felt in not having recognised that his daughter was in breakdown, coming from a place of no knowledge about autism. He spoke about feeling disempowered and a failure as a parent that he couldn't manage what appeared to most people as spoilt and wilful behaviour that he was letting her 'get away with'. His instinctive parenting style was to 'show her who was boss' and enforce his position as her father. It was only after John undertook his own research that he understood that she really needed a much lower-demand approach.

John said that his own parents had been quite authoritarian in their parenting style and this was all he knew. When he began to understand how unhelpful this approach was, he felt consumed by guilt at having forced his daughter into school when she was clearly very distressed being there. Through the sessions, John began to explore what being a good father meant to him and recognised that this didn't mean that he always had to be right or know all the answers; his daughter could show him the way, and this was OK. This enabled John to reframe his feelings of guilt and recognise that they came from his own upbringing; he hadn't failed as a father at all. Embracing this concept allowed him to be far more accepting of his daughter's needs, and he found himself able to defuse situations before they arose, and in turn, while not perfect, family life became much less fraught.

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Case study: Dealing with violence

Child on parent violence is often hidden within the family and, for the parents of autistic girls, creates an unpredictable environment in the household, described by one father as 'walking on eggshells'.[6] Many parents talk of the impact of violence on siblings, and their need to protect and shield them from potentially lethal situations. This feeds into the guilt that parents feel around the impact of their daughter's autism on her siblings. It was likened by one mother to abuse that she would never have tolerated from a partner but had no choice from her daughter. Yet this mother, along with other parents, spoke of a real struggle in speaking out and accessing support, in part fearing the ramifications of involving police and social services, but on a deeper level expressing a sense of real failure as a parent.

Jenny* first came to counselling as she was struggling with deeply conflicted feelings towards her autistic daughter, who was highly volatile and violent towards her behind closed doors. Jenny spoke of the shame and sadness that she felt as a parent when she saw her friends with their teenage daughters, and how close their relationships were. Yet Jenny's daughter would ▶

often fly into a violent rage for no clear reason, and would speak horribly to her, sometimes telling her that she wished she (Jenny) would just die. In the sessions, she found the space to explore her deep sorrow at the loneliness and shame that she felt. Jenny used the sessions as a truly safe place to give herself permission to explore what felt to her to be the ultimate taboo as a parent - her true feelings towards her daughter.

In the therapy room

Parents of autistic children often seek therapeutic support to help them to cope with and make sense of the exhaustion and challenges of their daily lives. However, for the parents of autistic girls, their therapeutic needs are often subtly different, frequently reflecting a sense of invisibility and isolation around their experiences. Judged and blamed by both family and society, they question their own sanity and wonder whether they are, in fact, making it all up as they've often been led to believe.

The non-judgmental environment of the counselling room can at first seem daunting, unfamiliar and even risky for a parent who has spent many months, often years, trying to be understood and have their concerns validated. Parents of autistic girls often approach counselling with a degree of scepticism, guarding against being let down and judged by yet another professional. Therapeutically this can be challenging to manage, but with a thorough understanding of their lived experience, a trusting and safe relationship can develop where they finally feel listened to and valued.

Parents report really valuing the therapeutic space just to talk and reflect; no longer seeking answers, rather somewhere to offload without judgment or opinion, enabling them to begin to create meaning from their experiences. For the first time they feel heard and believed, imparting a sense of agency and control for the parent, where so often they have felt completely overwhelmed by their situation. Many parents use the sessions to help them to adjust to and come to terms with their daughter's diagnosis, frequently underscored by multifaceted dimensions of grief. They often express a great sense of relief and self-acceptance when working through and understanding the valid and cyclical nature of their grief, and find this helpful in managing the trauma of their often gruelling and lengthy fight for diagnosis.

There is frequently a real sense of overwhelm for parents in managing the day-to-day environment for their autistic daughter, not just her sensory environment but often a steep learning curve in counterintuitively challenging and recognising the need for a low-demand environment. If the therapist has a good background knowledge of the pathological demand avoidant (PDA) profile of autism that is suggested to be slightly more common in autistic females,[7] they can support the parent in prioritising and balancing their own needs (and often those of their other children) with those of their autistic daughter.

The counsellor also needs to consider how parents manage their own and other family relationships. Parents might respond in quite different ways to an autism diagnosis in their daughter. There is a hidden but constant stress placed upon all relationships within the family, the most common being between parents, with their individual coping mechanisms. The therapy room can provide a safe space in which to explore this and help parents, either alone or together, to renegotiate their relationship with each other and maintain their connection.

As is evident, parents of autistic girls often lead the most challenging and arduous lives, yet for most this remains firmly concealed behind closed doors. They find themselves seeking support and answers for a pervasive condition that is far better known for its more familiar male presentation yet appears invisible in its female form to all but their close family. The ensuant struggle for recognition and acknowledgment of their difficulties leaves families in crisis, chaos in daily lives and parents' mental and physical health compromised.[8] Through in-depth insight into their daily lived experiences, as therapists, we can truly value the parent as the expert, an experience that is likely to have been denied them. While the therapist doesn't need to be an expert, a thorough understanding of the hidden struggles of these parents can only enhance the therapeutic relationship. So often judged, dismissed, stigmatised and criticised for an outwardly latent lived experience, parents of autistic girls frequently find the therapeutic space to be a safer place through feeling understood and accepted, with their hidden struggles named and validated; such that their lives are no longer invisible. ■

** Names and identifiable details of all case studies have been changed.*

'There is frequently a real sense of overwhelm for parents in managing the day-to-day environment for their autistic daughter'

REFERENCES

1. Duvekot J et al. Factors influencing the probability of a diagnosis of autism spectrum disorder in girls versus boys. Autism 2017; 9; 21(6): 646–658.
2. Lloyd S, Osborne L, Reed P. Personal experiences disclosed by parents of children with autism spectrum disorder: a YouTube analysis. Research in Autism Spectrum Disorders 2019; 64: 13–22.
3. Aston M. The autism couple's workbook (2nd ed). London: Jessica Kingsley; 2020.
4. Kreiser NL, White SW. ASD in females: are we overstating the gender difference in diagnosis? Clinical Child and Family Psychology Review 2014; 17(1): 67–84.
5. So P et al. Gender differences between adolescents with autism in emergency psychiatry. Autism 2021; 25(8): 2331–2340.
6. Ibabe I, Bentler P. The contribution of family relationships to child-to-parent violence. Journal of Family Violence 2015; 31(2): 259–269.
7. About autism and PDA. [Online.] PDA Society. (Accessed 6 September 2023.) bit.ly/45FCJJc
8. Chantrey L. Falling into an abyss: an interpretative phenomenological analysis of the lived experiences of the parents of autistic daughters in the UK. [Online.] Doctoral thesis, University of Chester 2021. (Accessed 6 September 2023.) bit.ly/45FwfKA

About the author

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