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How some systemic practices might help young women with autism spectrum conditions, and their families

Sarah Helps

This article gives a description of some of my systemic practices when working with young women who have autism spectrum conditions and their families.

Taking a relational perspective

One family member's ideas, strengths and difficulties affect and are affected by the ideas, strengths and challenges of other family members. This applies to families where children (whatever their age) follow an ordinary developmental course, and to families where development takes a different path. Therefore, it is valuable to work systemically with individuals who have autism spectrum conditions. In line with others (e.g. Baron-Cohen *et al.*, 2009) I prefer the less pathologising term autism spectrum condition over the formal diagnostic term of 'disorder'.

Young women and autism spectrum conditions

Although there is no gender-based difference in the diagnostic criteria used, it is increasingly recognised that girls and women with autism spectrum conditions present in slightly different ways from boys and men. Women may be seen to have fewer repetitive, stereotyped behaviours and fewer school-based social difficulties and externalising behavioural difficulties (Mandy *et al.*, 2012; Wing *et al.*, 2011) but the repetitive behaviours that are present might 'look' like intense versions of 'ordinary' female gendered activities. Young women are therefore often harder to diagnose and are often under-identified and under-served by professional services (Lai *et al.*, 2015; Shefcyk 2015).

Theoretical ideas that help me – Shotter and Belenky

One of my hypotheses about the way in which autism spectrum conditions affect people relates to the challenge of reading and responding and a kind of missed relational-responsiveness. I am particularly influenced by John Shotter's ideas about what ordinary communication is and how we 'go on' in conversations (Shotter & Katz, 1999). I am struck by how, in his detailed descriptions and theorisations of what it is to be in ordinary dialogue with another, Shotter seems to be describing the very deficits experienced by many people affected by autism spectrum conditions.

Shotter writes of how "it is in the sensed relations between our outgoing gestures...and the responses coming back to us from them as a result...that we can each begin to get a 'sensed shape', so to speak of each other's inner lives" (1999, p. 3). What strikes me about the conversations I have with people with autism spectrum conditions is that relationships are 'sensed' in a different way. By this I do not mean that my way is the right way and 'their' way is the wrong way, but in acknowledging that there are differences in sense-making and in relational-responsiveness this helps me explore and how we might go on in the conversation.

For young women, it is often the missed embodied, cognised, smooth, connected dialogue and interaction that pose a problem. It is the lack of connection that leads young women to retreat or to act in ways others might regard as unusual, in order to find a place for themselves.

I am also influenced by Belenky's ideas about how women come to know things (Belenky *et al.*, 1986). I particularly like the notion that, instead of acting as a teacher (therapist) who can 'deposit' knowledge, women can find a more relational, connected, showing-rather-than-telling way of imparting and receiving knowledge more helpful. In this way, the teacher or therapist acts more as a midwife, helping the student (patient) give birth to their own knowledge. I find it helpful and hopeful to hypothesise that young women may have 'got stuck' at a point in their learning and knowing about how to be in relation to an other, such that they listen and copy rather than integrating, owning and feeling able to initiatively use the things that they know.

Systemic work in context

I work in a specialist multidisciplinary team where our patients either have already had or come to have a diagnostic assessment of their social communication difficulties. As well as completing diagnostic assessments, we provide therapeutic intervention. Some team members work with children, some with parents, some with whole families. Whomever we work with, and however we theorise what we do, the overarching aim is to promote the ability of the person with an autism spectrum condition to relate in more comfortable ways (Rhode, 2008; Helps & Sheppard 2015).

Generally, my systemic work involves a combination of individual and family conversations. The confidentiality of these conversations, and the possibility of sharing information between them, is discussed. I always emphasise that I cannot not know what I know, and that the questions I ask in each conversation will be informed by all other conversations. Most interventions are relatively lengthy, and families might maintain a connection with the team for a couple of years. This reflects our commissioning structures and the importance of going slowly enough - but quickly enough - to effect change.

As I write, I have in mind some of the difficulties that the young women come to us with. They might be attending college or university, might be working, might be living at home or away, and are sometimes in intimate relationships. They often describe how perturbing the social and sensory world is, how anxiety provoking it is to do the things 'around' specific college or work-related tasks. They talk not of wanting to fit in to the neurotypical world, but of wanting to decode social communication

How some systemic practices might help young women with autism spectrum conditions, and their families

Can we help young women with autism and their families

sufficiently such that they can make more informed, less anxious, more fluid choices in social situations.

Themes of systemic work

The techniques I have developed, of focusing on meanings and understandings, going slowly, using restricted interests and patterns of communication, and the use of self-reflexivity, are key to my current practice. I see these techniques as mapping onto the two domains of autism spectrum disorders as defined in the DSM-V (American Psychiatric Association, 2013): deficits in social communication, and restricted interests and patterns of behaviour.

Meanings and understandings of autism spectrum conditions

In wanting to distance myself from earlier damaging ideas about mothers causing autism, I explicitly state that families do not cause the condition. I do acknowledge that families of all children play a crucial role in facilitating development and that families of young women with autism spectrum conditions can be influential in helping remediate the social-communication deficits experienced (e.g. Green *et al.*, 2015; Gutstein, 2009).

Once reasons for seeking therapeutic help have been established, conversations usually start with stories about the (often traumatic) process of diagnosis. Sometimes, young women have no memory of, and have not heard their parents' stories about, the process of searching for a way of understanding how their daughters are 'different'. I find that these are very important family stories to share, unpick and explore.

Part of the work around meaning-making is related to psychoeducation, taking and sharing a knowledgeable position in relation to autism spectrum conditions. This is akin to taking an opinionated dialogical position (Bertrando, 2007) where I offer my knowledge and expertise developed through working with young women and their families to see if any of my stories of practice resonate with this family at this point in time. I see this as a form of witnessing, acting as a bridge to offer stories told to me in ways others might make use of.

Going slowly

Because of the way that people with autism spectrum conditions use and process language (Jolliffe & Baron-Cohen, 2000), I monitor and match the rhythm and pace, the stops and starts of conversations. Early on in the work, I ask for permission to interrupt lengthy, detailed descriptions that I experience as going off-topic, often in a process-oriented way such as, "How is this relevant to the thing that we are talking about?".

In line with the practice of others (Stoddart, 1999), I frequently ask family members to slow down, repeat what they have said and to unpack their comments, pulling out stated and non-stated ideas and embodied but unexpressed emotions. This may not be so different

to practice with other groups of people seeking family therapy but, given the difficulties that these women have in thinking about the minds of others (Baron-Cohen, 1995), in order for them to 'get' the layers of communication, the pace needs to be altered.

Illustrating to families the complexity of social communication by showing bits of tape of sessions (often just a few seconds) can be particularly rich. This enables the young woman and her family to gain a different perspective on how they communicate with each other and to consider ways of doing something different. This also enables me to explain how I have come to my questions or hypotheses. This isn't so as to 'prove' my hypothesis but to show my working out; to offer a transparency in my thinking that informs my questions.

My contribution to the therapeutic relationship – shifting between different kinds of inner and outer, thinking and feeling conversations

Capturing and sharing inner dialogue, accessing and reflecting on thoughts, feelings and ideas can be a mystery for young women with autism spectrum conditions. This may relate to difficulties in 'theory of mind', or in understanding the mental processes of self and others (Baron-Cohen *et al.*, 2013). So, I demonstrate, model and explain what I am thinking and feeling and how I try to understand these thoughts and feelings in relation to the conversation. The young women are often very skilled at gathering, copying and utilising social skills in this way; so, in explicitly demonstrating my self-reflexive process, I often start to see young women experiment with the use of inner and feeling-related dialogue and then, in future sessions, hear about how these skills have been applied to real-life 'out-there' interactions.

Using restricted and repetitive interests and patterns of social communication

I use special interests and restricted patterns of behaviour to encourage movement from static to more dynamic and interactional ways of being. The special interests reported by young women often more closely fit with the interests of 'neurotypical' young women but vary in their intensity (Gould & Ashton-Smith, 2011) compared with the special interests of boys and men, which are often seen as falling on the edges of or outside 'usual' interests.

Influenced by behavioural experiments, if a young woman has a particular interest in one famous person, we might explore how to broaden the interest into all people who are famous for doing that same thing. If the young woman has a rigid routine, for example, if they only wear a certain kind of eye-shadow or drink a certain kind of coffee from a certain coffee shop every morning, then the challenge might be to buy a different brand or try a macchiato or a drip filter and to then 'catch' and report on

the thoughts, feelings and emotions of what doing something different was like. While these things might seem very simplistic, they enable a person to make steps to introducing variation in life. These steps serve to interrupt well-rehearsed, static patterns of action and open up possibilities of more dynamic ways of being.

If families have particular rigid patterns of being with each other, such as sitting at the dining table in a set way, then the invitation might be to change seats. If it is possible to manage the anxiety that exists in making such small changes within the family setting, it can be more possible to try out making similar small changes in the outside world. These individual and family experiments can then be discussed and explored to find the 'difference that makes a difference' in continuing to live with change.

Final thoughts

The challenge of writing just about young women is that, in choosing this focus, it is easy to place gender in a silo. If the narrative performance of each aspect of identity is constructed in relation to the other (Prins, 2006), in practice, the performance of gender cannot be separated from conversations about all other aspects of identity. But, in privileging gender, I hope to have drawn temporary attention to some of the particular challenges faced by young women with autism spectrum conditions. The ideas I have described might equally fit for young men with autism spectrum conditions. Indeed the concept of gender and the possibility that people with autism spectrum conditions may be less wedded to 'typical' gender roles is increasingly documented (De Vries *et al.*, 2010). I see the overall aim of conversations with young women and their families as not about assimilation into neurotypicality but about recognition of neurodiversity, and the search for more comfortable ways to go on in the world. By using the techniques I have outlined above, I hope my approach respects, embraces (rather than 'others') diversity, and contributes to ways of going on more comfortably.

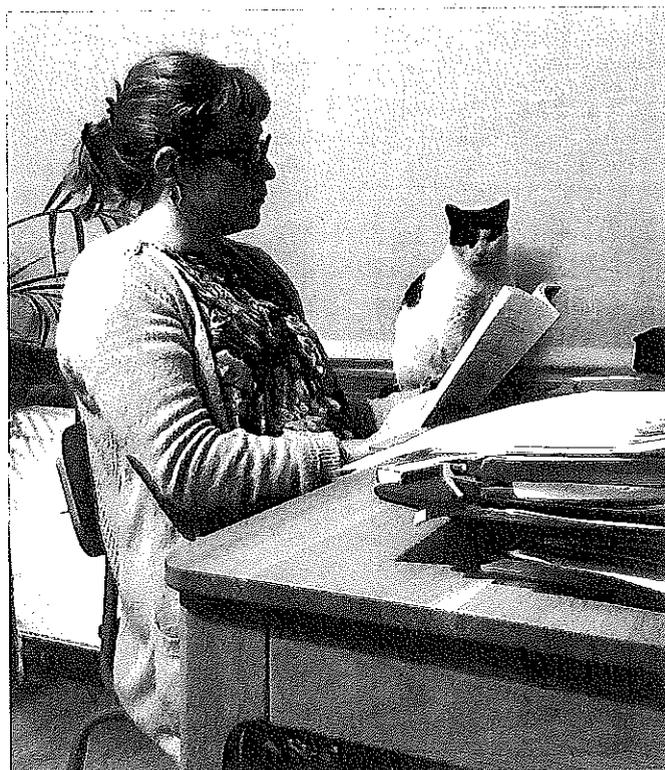
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