

## “I just like Lego!” Self-Autism Mapping as a non-totalising approach

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### *The nature of the problem*

In the past year we have met a number of children with autism and the experience is always interesting and often enjoyable. We are lucky enough to know some wonderful people who care for and teach children with autism. On one visit to a support centre within a primary school we joined a select class of four 7-year-old boys and being introduced to a real professor from the university they began a conversation about the nature of atoms. One of them remarked that atoms can't touch one another. This led to one of his class mates reflecting on the fact that human beings are made of atoms and consequently are not technically able to touch one another. We then moved on to discuss the game of tag and whether the rules of the game are actually tenable given that it is not actually possible for one person to touch and hence 'tag' another. Our philosophical musings with the children were cut short by the teacher who was endeavouring to teach the boys how to wash their hands. On another occasion, at another 'special' school, Becky shared snack time with three children with autism, two boys and a girl. The little girl didn't look at her, or any of her peers, appeared to be unaware of her presence and didn't speak. She was given a bowl of cereal. Becky remarked that it was a little late for breakfast and one of the little boys informed her that “she only eats that - because of the autism”. Later Becky went to find the little girl to say goodbye and was told that she had gone home because she had an epileptic seizure.

We tell these stories to communicate the confusing array of symptoms associated with autism. Official diagnostic criteria seem to present a pretty straightforward list: children with autism have impaired social communication and social interaction and engage in repetitive, restricted interests. The picture is rather different, however, when you discuss the problems these children face with family members, carers and teachers. Autism almost never occurs without additional diagnoses or secondary symptoms including ADHD, epilepsy, maladaptive behaviour, anxiety, depression, sleep disorder and digestive problems. The complexity of autistic symptoms is compounded by the fact that it is a spectrum disorder, which means that children with a diagnosis can have severe or mild symptoms. They also have an unusually wide range of intellectual ability. Some children have severe intellectual impairment and no language at all. Others are able to take degrees before they reach adolescence.

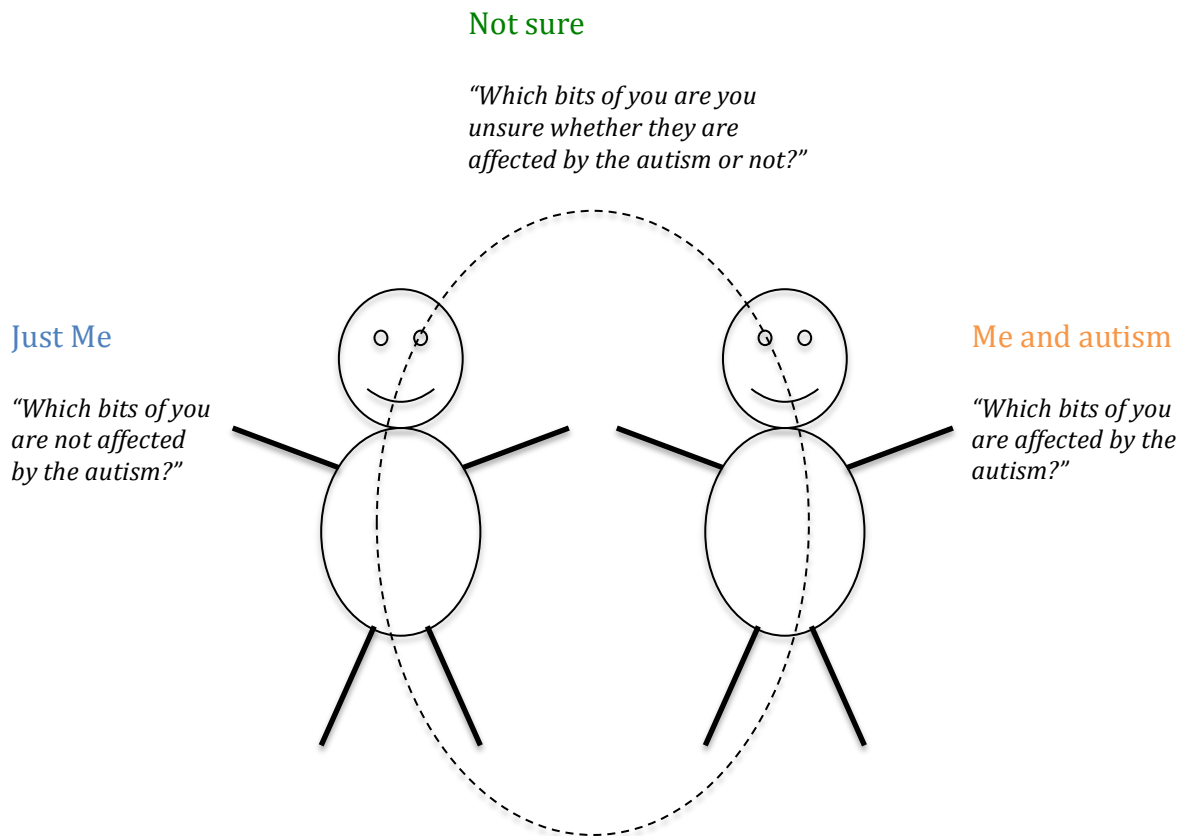
The core and associated symptoms of autism all appear to some degree in the typical population. We all know people who are not comfortable with social situations, who are exceptionally bright or have obsessive interests about which they recall tiny details, which for many of us may seem inconsequential. Given the confusing variation in the severity and presentation of symptoms, the presence of the symptoms (in a less restricting form) within the typical population and the additional problems these children face; it is not surprising that families tend to lack a clear picture about which of their child's behaviours are attributable to autism and which are not. In fact, everything a child with autism does can pretty easily be explained with recourse to something that has been written about the condition and its associated features, hence there is a marked tendency for these children to 'become the diagnosis'. This lack of a clear picture of what the condition consists of is paralleled by the fact that there is also considerable debate amongst professionals, clinicians and researchers working in this area. For example, Asperger Syndrome has been dropped from international diagnostic criteria, largely because it was found to be too unreliable to employ diagnostically. However, many children and their families have become organised around using this diagnostic classification and have claimed it as a positive label that distinguishes them from the emotional, illogical beings they often describe as 'neurotypicals'.

Diagnostic classifications can serve to define a person's sense of identity - he 'is' autistic or he has 'Asperger's' unfortunately such classifications can confer an identity on the person that is totalising (White and Epston, 1990 Anderson and Goolishian, 1986). The person may become seen by

others and see all aspects of themselves, through the lens of the label which focuses on a list of 'impairments' or disabilities from which there is typically no prospect of recovery. Arguably, a totalising view of autism is not necessarily advocated in the diagnostic system, especially as autism is a spectrum condition. People with autism may have mild or severe symptoms and members of the typical population may have autistic traits. We hear something like this in everyday speech when people say he is a 'bit autistic'. Nevertheless, families and children themselves may come to see everything they do as defined by a list of deficits (Anderson and Goolishian, 1986). Reducing this 'problem saturated' framework involves enabling the family to separate what is 'normal' and typical or 'just the child' from the internalised totalising concept of autism. A young adult with autism explained this clearly in discussing his ongoing interest in making things out of Lego. His mother explained his love of Lego as reflecting his diagnosis. His response to this explanation was "No Mum, I just like Lego!" This insightful remark reflects, to some degree, therapeutic approaches focusing on externalising conversations, in that he separated himself from the effects of the condition, thus unravelling what was him from what was *the autism*. We suggest that this kind of separation can help families to recognise how *the autism* can be made less problematic and how and when the family can relate to the child, like any other child.

### ***Self-Autism Mapping (SAM)***

Much of Michael White's (White and Epston, 1990) original work on combating internalised totalising concepts involved conversations with children which contained a sense of fun and enjoyment. In developing Self-Autism Mapping we are inspired by White's narrative approach, and wanted to develop a tool which was appropriate for children with autism who often have limited language and a preference for visual means of communication. SAM is initiated by introducing the child to two figures representing 'Just me' and "Me and autism'. Redrawing these figures can involve the child and the family, encouraging a sense of ownership and enjoyment in creating a representation of themselves and their depiction of autism. Discussion begins with the two figures and what is and is not affected by autism. The child can use different colours to convey their thoughts about what parts are just themselves and what parts are affected by autism. At a later date a dotted circle is added and the children can identify aspects of themselves about which they are unsure. Within the dotted circle, for example, they may place aspects of themselves that sometimes seem affected by autism or appear affected by autism to some degree.



**Figure 1 Self/Autism Mapping (SAM) graphic**

Additional drawings can be created of familiar contexts the child regularly visits (home, school, the park, sports centre etc.) and a timeline of a typical day, in order to facilitate discussions and visual representations around where, why and when *the autism* is more or less troublesome.

We used SAM during a series of family therapy sessions with Nancy, an 8-year-old girl with Asperger Syndrome (High-functioning autism) and her Mum, Marie. Nancy was happy for the therapist to draw her under her instruction and the process caused some discussion and laughter for Nancy, her Mum (Marie) and the therapist (Rudi):

*NANCY - (laughing, looking at the picture Rudi was drawing) I don't look fat!*

*RUDI - (laughing) Sorry Nancy, sorry, sorry. Yeah, we'll put a little tartan... (draws Nancy's skirt laughing)*

*NANCY - (laughing loudly)*

*RUDI - Nancy,...if this is you, I'm sorry, this is a terrible drawing right....*

*NANCY - (Unintelligible sound, laughing) Aghh, I'm fat as a balloon*

*RUDI - And this one is you and Asperger's.*

*NANCY - Asperger's?*

*RUDI - Yeah, Asperger's, that's right. I know that this might be some sort of funny thing to ask, right, but how much is there of a girl that doesn't have Asperger's and how much of you has Asperger's.*

*NANCY - (takes pen and draws) that much has, that much is a...that much is the other girl- My feet haven't got Asperger's!*

*RUDI - (Laughing) No?*

*NANCY - My arms!*

*RUDI - Your arms aren't?*

*NANCY - And my hands.*

*RUDI - Arms aren't, okay.*

*NANCY - My eyes aren't!*

*RUDI - They're not?*

*NANCY - No! My brain is.*

*RUDI - Your brain is? Okay, alright. Well that's interesting.*

*NANCY - My mouth is, yes.....my mouth is Asperger's.*

*RUDI - Okay, well done, that's good!*

Nancy, Marie (Mum) and Rudi continued to talk about the area's of Nancy's brain that were affected by the Asperger's and a discussion developed around the fact that her Asperger's was particularly problematic at school, when talking and interacting with her friends:

*NANCY - Things just come out that I don't mean*

*MARIE - Things come out you don't mean when you speak?*

*NANCY - Yes*

*MARIE - But do you think that's coming from this red bit here? (pointing to the part Nancy had coloured in as being affected by Asperger's)*

*NANCY - Yeah.*

*RUDI - What do you think Marie? I know this might be a weird question but, how do you see it, which bits of her brain are...(Asperger's)?*

*MARIE - I think, um, socialising...*

*RUDI - Yeah*

*MARIE - ...when you're with children, Nancy, sometimes it's a bit difficult, isn't it? Not always! Because you're doing really well with your friendships but...*

*NANCY - Especially Ashleigh!*

*MARIE - Sometimes when you're with children, you think they're being mean to you, don't you?*

*NANCY - Mhm!*

*MARIE - And that, do you think that comes from the red?*

*NANCY - (nods)*

*RUDI - Sometimes you think 'my friends are mean'. Is that right?*

*NANCY (quietly) Yeah. Sometimes my, sometimes I think they are mean and they're not.*

*RUDI - So, what I'm thinking is this, this is the confusing one isn't it? (points to 'sometimes I think they are mean and they are not') the most confusing!*

*MARIE - Hmm, Yeah*

*RUDI - And that's actually; it is hard for all of us to do that isn't it?*

*NANCY - Yeah?*

*MARIE - Sometimes to figure out, right, and I think how, you know, how can we figure out if they, if they mean it or not?*

*NANCY - I don't know!*

*RUDI - Sometimes even when I'm at work Nancy, I think, 'are they really being nice or are they not being nice?' Sometimes it's hard for anyone to figure out what someone means when they say something?*

*NANCY - Once, horrid Henry pretended to be good and nobody knows if he was being good or bad.*

*RUDI - Yeah, so it's quite difficult for anyone to read that sometimes.*

*MARIE - (laughs)*

*NANCY - Sometimes...*

SAM enabled Nancy and Marie to talk about Nancy's behaviour at school and her difficulty interpreting the intentions of her friends. The activity allowed both Marie and the therapist to reassure Nancy that this was problematic for everyone, and was not necessarily to do with her diagnosis. Marie stated that she found SAM particularly helpful and referred back to it spontaneously in subsequent sessions. It allowed her to see the Asperger's as affecting some of her child's behaviour, some of the time and helped her to reframe some of Nancy's behaviour as typical of any 8-year-old child. She and Nancy continued to reflect on when and where Asperger's was most problematic. On one occasion, Marie stated that: "The Asperger's has been hardly there at all this week."

## ***Some final thoughts***

SAM shows promise as an approach, which can support families to escape from a totalising disability model of their child. In some cases, however, families appear to be resistant to the possibility that not all of their child is 'autistic'. This is particularly the case where an exclusively neurological model of autism is very entrenched, or where the parents carry a particularly strong sense of blame for their child's condition (Dallos, 2015). For example, where parents believe that their child's brain is 'wired differently' they may find it hard to see anything the child does as not involving atypical behaviour. For these families starting to consider what, if anything, might be in the 'Not Sure' circle may be a tentative process and they need support to avoid feeling that their understanding is threatened. Here again Michael White's externalising approach can be helpful in exploring, for example, what influences the autistic symptoms, how they vary depending on who they are with, where they are, time of day and so on. This approach may also be less threatening for parents who feel that any erosion of the medical model will result in blame being placed upon them. On the flip side, however, SAM can be helpful for families suffering from a sense of bereavement, post diagnosis, for the typical child they expected to have. Here Sam allows the family to see, in a very tangible way, that their child **is** a typical child 'with autism'.

SAM is designed to help families recognise that their child is sometimes just a child like any other. It is in this way a non-totalising approach. There are overlaps here with White's (White and Epston, 1990) work with children using *externalising conversations*. There are some important differences to be acknowledged, however, in that White generally used externalising conversations to objectify a particular behaviour and separate it from the person. In our case we are responding to a condition, which is recognised by many families to have both negative and positive symptoms (for example, savant skills). Whilst we are informed by White's work, we are not claiming that SAM can eliminate the symptoms of autism. Nor do we wish to undermine families' experience of autism, especially where that experience is perceived to be positive and non-problematic. However, consistent with his approach we do believe that our approach can help to reduce some of the negative aspects of its influence on all aspects of a child's life.

We suggest that SAM draws on is on established narrative family therapy approaches, but is an innovative approach in the context of work with autism. We invite clinicians to consider experimenting with it to develop it is a format for working with families. We also suggest that it deserves further study, in particular, research needs to explore how the visual and non-verbal elements of SAM can be developed for use with children who have intellectual disability alongside autism.

## ***References***

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