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Supporting autistic people with eating difficulties

My favourite food is chocolate crispy cake. I only like them if they're melted. I wouldn't want to try new foods because they might make me sick. I only like crunchy things. At birthdays I have a cake and I make a wish and blow out the candles but I never try it. I once had a tiny crumb of birthday cake but it made me feel sick.

Rachel aged 6

If you have met a young person on the spectrum who has issues with food then Rachel's words will be familiar to you. I first encountered the typical style of eating in autistic people when I was a residential care worker for young autistic people. It was my job most evenings to cook dinner and I soon learnt that some of them had very particular preferences, including rejecting food that was the wrong brand or in different packaging (I also learnt to my cost the consequences of hiding or disguising foods; more of that later).

Much of my career has been with young people who refuse foods, many of whom are on the spectrum, but also with those who do not have a diagnosis. Thus, "the pattern of avoidant and restrictive eating we see in autistic people is also observed in children and adults in the neurotypical population and therefore represents a function of traits that individuals have in common, rather than being specific to a diagnosis"¹.

So what are these traits and how do these connect to a diagnosis of autism? Historically, eating issues in autistic people have been considered to be primarily behavioural, either due to parental management or to the repetitive behaviours seen in the condition. By using clinical and research data from the development of eating and food acceptance in neurotypical children, we can instead consider the involvement of other factors. These are a mixture of inherent and developmental characteristics; the interaction of which both causes and maintains the avoidant and restrictive pattern of eating.

Sensory sensitivity

¹ Dr Gillian Harris, personal communication, November, 2012

The relatively new diagnosis of 'Avoidant and Restrictive Food Intake Disorder'² describes the selection (and rejection) of foods based on their sensory characteristics. It is well documented that autistic people have significantly different sensory experiences than neurotypical individuals which include both hyper and hypo sensitivities. In the context of eating, this means being more or less sensitive to how foods:

- look
- smell
- taste
- feel.

Other sensory systems which are necessary for eating are:

- proprioception (body awareness)
- vestibular (balance)
- interoception (awareness of internal states).

In particular, interoception enables the recognition of hunger and satiety, the awareness of which is often reported to be impaired in autistic people.

Autistic children frequently prefer foods of a similar texture, typically either soft or hard/crunchy foods. For some, the eating issues emerge in infancy at the second stage of weaning (7-9 months) with the introduction of textured and lumpy foods. Here, children born with tactile or touch hyper-sensitivity will gag, spit out and refuse these foods. Such sensory based avoidance can lead to a prolonged reliance on first stage (4-6 months) weaning foods, typically smooth purees, or foods that bite and dissolve easily in the mouth. In turn, this may lead to poorly developed oral-motor skills which further perpetuates a reliance on smoother textures. Children who prefer crunchy foods may display hypo-sensitivities and sensory seeking behaviour. Such responses may also play a part in the development of pica - the eating of non-foods.

Cognitive factors

Differences in the way the brain processes information are also documented in autistic people and can help explain other features of their diet. For example, cognitive rigidity and the 'desire for sameness' may result in an adherence to particular routines or rituals around food, such as having to have the same utensils, with the context being often the first predictor of whether a food is safe. Central Coherence theory³, where information is fragmented, may explain why these children notice the 'local' details of a food, such as a black mark on a crisp, at the expense of the 'global' or overall appearance of the food. This can also explain why foods are rejected if the packaging changes.

² American Psychiatric Association (2013). Diagnostic and Statistical Manual of Mental Disorders. 5th Edition

³ Frith, U. (1989). Autism and "Theory of Mind". In C. Gillberg (Ed), Diagnosis and Treatment of Autism, 33-52. New York: Plenum Press.

The pattern of food refusal is usually present by the age of two, and by school age the typical number of foods eaten frequently reduces to as few as 5-10. These tend to be foods from categories that are perceptually similar, for example, 'beige carbohydrates' such as:

- bread
- pasta
- crisps.

Or foods with manageable textures and similar consistency such as:

- Smooth yoghurts – no 'bits'
- Chocolate buttons.

Frequently whole categories of foods are avoided, typically meat, fruit and/or vegetables. This may be because they contain examples of foods that are visually very different from one another. The child who has difficulties forming categories of objects or generalising within categories (as appears to be the case with autistic children) is then likely to stick to those groups of foods that look very similar. In addition, when a child is anxious, cognitive rigidity will increase, making the expansion of food categories much harder.

Food neophobia

Between the ages of 18-24 months food refusal generally becomes more prominent. Neophobia (fear of the new) is a typical stage in the development of food acceptance whereby children reject foods if they haven't seen others eat them first. This is an adaptive response, protecting children, once they are independently mobile, from eating anything potentially unsafe. Typically, neophobia dissipates with:

- age
- the imitation of others eating
- the development of cognitive categories.

However, the social and cognitive differences in autistic people mean that neophobia persists for much longer with the ongoing rejection of new or perceptually dissimilar foods.

Anxiety, disgust and contamination

Anxiety about what will happen during or after eating, such as, whether the food will be 'ok', being sick or choking and in eating situations outside of home is common in autistic people. Additional disgust and contamination reactions are also common. Imagine I squash a sheep's eye between two slices of bread and offer it to you as a "nice, tasty sandwich". Your disgust response is likely to be triggered and it is doubtful you will be able to place it in your mouth, never mind eat it. Again, this is an adaptive response to foods (or indeed to non-foods) that could be dangerous if eaten. Young autistic people tend to display this response when faced with unfamiliar or disliked foods, even if they are socially and culturally appropriate.

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I learnt the hard way about contamination responses during my time cooking for young autistic people. Thinking that extra calories would be a good idea for one young man in particular, I added butter (an unfamiliar food) to mashed potato (a liked food). Unsurprisingly, he promptly rejected it on sight, even before he tasted it. Unfortunately, contamination only works one-way; you cannot make a new food more acceptable by mixing it with an already liked one.

Interventions

I don't just choose to eat that kind of stuff. It's not because I'm being awkward. Whenever I try any food I always get scared.

Rachel aged 13

I first met Rachel she was 13. She had received a diagnosis of autism at the age of 3 and had a long history of difficulties eating. When I met her she was only eating one brand (and packaging) of chocolate biscuit, one brand of breakfast cereal eaten with melted cooking chocolate and one variety of bite and dissolve crisp. Despite this, she was growing according to her expected pattern, was healthy and functioned well at school.

These are common clinical findings and therefore raise the question as to the rationale for intervening? To answer this, one has only to listen to families. Parents report, almost without exception, restrictions to family life and anxieties about obtaining their child's preferred foods; young people report worrying about being different and fitting in, already difficult when you are autistic. Diagnostic criteria also highlights the possibility of interference in well-being and/or an individual's social life. All of which provides a clear platform for attempting to increase the range of foods eaten and reducing anxiety around foods and eating situations.

Before attempting to increase any child's range the first, and arguably the most important intervention, is to allow them their preferred and safe foods. This will maintain weight and growth. Following this a new food can be introduced, preferably one that has some intrinsic value. For Rachel this was toast, a typical breakfast food and one that she could eat after a sleepover. Imagine again the tasty sheep's eye sandwich and think of what you would have to do in order to eat it. This will give you some idea of the task Rachel faced in overcoming her anxiety and disgust at the thought of eating toast. The use of relaxation strategies to reduce her anxiety immediately before trying a tiny piece of toast was successful and repeated trials (at least 10-14 times) eventually consolidated toast as a regular food in Rachel's diet.

This intervention is clinically effective, particularly with older, more cognitively able children. For autistic people with a different level of functioning, other strategies are needed. These include, the pairing of a new food and context, such as a new class at school (where both the food and the context appear to be stored as one 'whole' experience) or the use of sensory integration and/or desensitisation techniques to minimise the impact of hyper or hypo-sensitivities.

Rachel continued to work on expanding her diet and aged 15 she chose food from a restaurant menu for the first time; an experience she and her parents never thought she would have. Now at university she has a range of foods that she can eat with friends and which don't make her

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stand out. Due to the intrinsic factors that underpin eating in autistic people, Rachel is always likely to have a relatively limited diet; but one that she is now firmly in control of. As Rachel herself puts it:

There were so many things I felt like my diet stopped me from doing... I wanted to do them!

Rachel aged 19

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Further Reading and additional links

Infant and Toddler Forum

Website containing downloadable Factsheets on all aspects of childhood feeding problems from birth-5 years old. Many of which are also appropriate for understanding eating problems in older children.

Birmingham Food Refusal Services

Birmingham Food Refusal Services. Service for families and professionals for children who refuse foods. Contact point for the author for further information and consultation.