# ‘If we are what we eat, where does that leave us?’ Exploring comfortable eating with autistic people.

## *Introduction*

Many food and eating behaviours carry powerful emotional messages. Food is both a societal and cultural tool, and eating together and sharing a meal is powerful social ‘glue’. Eating carries all sorts of (largely unwritten) rules and taboos, and for parents, there will always be plenty of people ready to judge you if your child eats messily, refuses vegetables, puts the wrong proportions of foods onto their plates or does not ‘sit nicely’ at the table. Failing to get our children to eat politely, widely and well is a common guilt-inducer for all parents, and for parents of autistic children, it can feel like the ultimate challenge. For so many autistic families, eating becomes a source of anxiety and unhappiness and can end up becoming – or at least being perceived as – clinically ‘disordered’.

Yet understanding the elements that lead to eating challenges is seldom approached from the autistic perspective, and this is what this chapter aims to do. Working with parents of autistic children and with autistic adults able to articulate their issues around food, it aims to unpick some of the reasons why issues regarding eating in autism may occur. Greater understanding of the autistic perspective may lead to more nuanced support for our autistic children and young people to develop a more confident relationship with food. Suggestions can be developed for adjustments in nurseries and schools to facilitate more comfortable eating for our young people. Issues around food in social and professional spaces can be considered. Further, as our population of recognised autistic people ages, the need for respectful and inclusive practices around food for autistic people at places such as day centres and care homes becomes an important, if seldom articulated, consideration. The final section of this chapter, therefore, provides a draft ‘toolkit’ that might be used to explore supports for comfortable eating by autistic people in a variety of contexts.

### *Literature*

Research suggests that there is a higher incidence of eating problems associated with autism (Cobbaert et al., 2024; Nimbley et al., 2023; Spek et al., 2020), with many autistic children and young people meeting the criteria for ARFID (avoidant/restrictive food intake disorder) (Bourne et al., 2022). Recognising hunger, planning and waiting for food, recognising 'fullness' and understanding the emotional effects of some foods requires accurate interoception, sophisticated emotional awareness and adept executive functioning, each of which may be an issue for autistic children (Longhurst et al., 2023). Sensory issues and social issues around food and eating may further lead to complications (Cobbaert & Rose, 2023; Cobbaert et al., 2024; Fixsen, 2024). Lee et al. (2024) list a rather depressing range of issues around food that have been observed in autistic children, including fear of trying new foods, eating a limited range of foods, binge eating, food avoidance, chewing and swallowing issues, pica (eating non-food substances), rumination (regurgitating and re-swallowing food), rituals around eating, and behavioural challenges regarding food. They discuss in some depth how best to observe, assess and measure these issues, but do not explain why these may occur from the autistic viewpoint.

Research also suggests that autistic girls (and potentially young people who identify as transgender or non-binary (Brown et al., 2024; Elwyn et al., 2024; Alvå, 2023; Zorc, 2022) may be especially vulnerable to issues with eating and to developing eating disorders such as Anorexia or Bulimia (Schröder et al., 2023). One recent study of 371 autistic women (Brown et al., 2024) found that 28% of participants had experienced an eating disorder in the past. This study also suggests that after formal autism diagnosis, participants had a lower risk of developing an eating disorder, although it recognised conversely that three-quarters of those surveyed had had a considerable lapse (on average, 14 years) between an earlier identification of an eating disorder and a later diagnosis of autism. Research highlights the lack of investigation into autistic viewpoints, stressing the need for autistic understanding sought through participatory research methods to better understand lived experience around issues of autism and food (Schröder et al., 2023).

Recently, research by Baraskewich et al. (2021) has suggested that 'eating problems' and 'feeding problems' in autism are different and should be viewed as such. This research suggests that the term ‘eating problems’ might be used to refer to behaviours where there is a preoccupation with food, eating or body image, whereas ‘feeding problems’ might be used to describe restrictive, selective or avoidant eating. DSM-5 diagnostic criteria currently prevent co-occurring diagnosis of ARFID and other eating disorders. However autistic individuals may experience both sensory-driven feeding problems and an eating disorder (Elwyn, 2023; Elwyn et al., 2024; Sharpe, 2024). Baraskewich et al. (2021) suggest that the majority (91%) of research into autism and food to date relates to what they term feeding problems with only 9% of the research addressing eating problems. However, until and unless the differentiation in terms is adopted more widely, ‘eating problems’ is used in this chapter to reflect current usage in literature and general discussion.

Further, emerging research that foregrounds the voice of autistic people is challenging neuro-normative assumptions that autistic eating should be positioned as a ‘problem’ at all, arguing rather that it may be an authentic way of managing this element of autistic life. This research posits that having preferred or safe foods, following sameness and enforcing routines are functional ways for autistic people to navigate the sensory and social challenges that eating provides (for example, Stephenson et al., 2024; Schröder et al., 2023; Park-Cardoso & Silva, 2023; Fixsen, 2024; Cobbaert et al., 2024; Cobbaert & Rose, 2023), and should be recognised and accepted as such.

### *Method*

The first author on this chapter initially worked with a range of stakeholders selected purposively and recruited through convenience and snowball sampling to collate autistic experiences with food and eating. These stakeholders ranged in age from 18 to 89, and included family members of autistic people – parents, siblings, a grandmother, an aunt and the child of an autistic mother – together with a range of autistic adults (and all the intersections between these various identities). The criteria for inclusion were that the participant be either a family member of an autistic person, be autistic themselves, or both. No further ethnic or cultural information was gathered as relevant at that time. Ethics committee clearance for the research, including recruitment, analysis, data storage and dissemination of findings, was obtained from Bishop Grosseteste University Ethics

Committee before the commencement of data collection. Pseudonyms for all participants were agreed with them.

The data gathered through the unstructured online interviews was then discussed by the two writers of this chapter, with the primary goal being to explore the meanings, contexts and implications of the participants' comments. The writers worked together to interpret and to draw connections between what had been said by the participants and their own previous understandings. Both writers identify as autistic, one is the parent of two autistic children, and each has lived experience of 'disordered' eating. Their specific expertise was enhanced through the second author's professional role supporting individuals, many of whom are autistic, who are struggling with their relationships with food and eating.

The authors then worked together to use their findings, together with both their professional and lived experiences to create a toolkit of suggestions to support autistic people to access more comfortable eating.

## *Findings*

There was considerable anxiety reported by all participants in this project – from parents and carers and by the autistic people themselves. One participant set the tone: 'as a parent, you panic a bit regarding your child and eating'. For the carers, the anxiety tended to be around supporting their child to access vital nutrients, to eat enough but not too much, and not to be hungry when away from their influence, for example, when at school. These carers had already instigated a variety of food supports and acceptances for their child at home. One carer commented that she 'just accepted a very restricted and repetitive diet for both our children' and another reported that when her child was younger, 'we let her eat on her own if she wanted to, and even … eat in the garden. Eating outside helped greatly'. There was no report in the cohort of forcing food choices or of arguments over food. The carers' primary concern was overwhelmingly to support their child to access nutrition and to 'find ways to make eating manageable'. A father reported that his son 'like[d] very bland food, and only about three things at any one time', but that, as his son's tastes changed over time, he believed that his son was getting sufficient nutrition overall. Another parent indicated that, ‘my advice would be to try not to get too stressed about foods: eating something is better than nothing’.

That said, there remained elements of guilty feelings evident. One parent commented on her child’s lack of communication and shared that ‘if I was busy and forgot to feed her, she wouldn’t remind me’, an experience echoed later by a second parent. Another confessed that her child’s ‘appetite was tiny’ and that her daughter just ‘liked to drink a lot of milk and to eat a lot of cheese’. Parents’ own issues with food were reported. One shared that ‘as the mother of a daughter, I’m very aware of the eating disorder stuff, and calorie counting and so on’. More positively, shared experiences and inter-generational acceptance led to a feeling of closeness regarding eating issues for some. One mother shared:

> With food, [my autistic son] benefited from the fact that I too was an immensely fussy eater as a child ... My Dad really sympathised when I struggled, as he also had had a very sensitive sense of taste when younger and was a cautious eater always. He died when I was pregnant, and being tolerant of my child’s food and eating eccentricities actually made me feel closer to him as a parent.

This inter-generational aspect may, of course, be enhanced as autism has a genetic element, and autistic children are often born into families where autistic experiences are familiar. However, this home acceptance was contrasted sharply with the anxiety regarding eating outside the home. There emerged a shared report of apprehension from participants regarding eating at school. School dinners were remembered with fear, especially where the behaviour policy of the institution included the need to ‘clear the plate’. Participants shared recollections of being kept behind in the dining hall by over-zealous lunchtime supervisors, and this fear of public eating, and of being ‘forced’ to eat, was reported across the age range of the participants. Autistic participants were also able to share the challenges to eating that come from the eating environment:

> I have never particularly liked going out to eat, and I didn’t know why. I just said it was because I didn’t like the length of time it took for the food to come out – but I now recognise that this was because the wait meant that I had to be in the over-stimulating environment for longer. I’ve only recognised that as a sensory issue when my partner (who is also autistic) pointed it out to me. I am an intelligent, 25-year-old who has lived with autism knowingly for 21 of those years … and I only realised that sensory overload was the thing I experienced when another autistic person pointed it out to me!

The autistic participants in this study were very clear about their food preferences and could often articulate very precisely why these preferences or restrictions occurred. One indicated that he has ‘extremely bland tastes regarding food… I can’t manage strong flavours’, and another that they are ‘not great with foods - especially vegetables, and that’s because of both taste and texture’. This sensory element came across clearly. ‘There are lots of mouth-touch textures I actively enjoy, but I find some – particularly stringy wet stuff, or grainy – really horrible.’ Another participant likes ‘food to be separate – not touching’, another indicating that she always eats ‘food one type as a time’, and another remembering with pleasure ‘when I discovered curry, and found that spice completely masks flavours’. One participant shared that they have ‘safe foods’ that they can turn to without the need to make decisions. ‘For example … for a while I couldn’t eat anything except watermelon cubes and oat cake.’

One autistic adult and sibling to an autistic brother shared, ‘I think other people thought our mother was too soft, sort of overindulging us’, but remembered this accepting behaviour with gratitude. Interestingly, this is countered in the comments of another autistic participant who suggests that, although their food preferences were supported, ‘if my parents had accommodated everything for me, I don’t think that would actually have been very helpful’ adding that ‘it is important in the neurotypical world in which we live to learn to be able to make compromises’. Some acceptance of eating challenges by parents may reflect an understanding of anxiety in autism and a corresponding need in the autistic person for autonomy. ‘We learnt early on that one way that May manages anxiety is to micro-manage, and especially around food as it is something she can control – she is in charge of what she swallows.’ This is reflected in May’s own comments that she ‘like[s] to weigh things because that gives me control’. She shared, ‘I like to research things ... [to] think about when to eat, what to eat etc.’, adding ‘[I] don’t want … to get out of control’. A need for accuracy and for parameters is evident. ‘Food was a major issue for Kit. She always wanted a plate filled more than anyone else [which] resulted in childhood weight gain and then in fat-shaming’. Another autistic participant asks for clarity: ‘So, for example, portions sizes: what *is* a “portion”?’

What is reassuring is that for the autistic participants, many of the issues regarding food and eating have been resolved to their satisfaction in maturity, where their autonomy to eat when, what, and how they need has reduced elements of stress. This is reflected in comments by parents and carers of older autistic family members. One indicated, ‘as she has grown up, she has [learnt to] shop, cook simple meals and choose what she eats each day’, with an autistic adult also confirming that she is able to ‘make deals with myself regarding food now that I am an adult’. One parent confirmed this approach of acceptance: ‘my advice would be to try not to get too stressed about foods’, with another adding that ‘you just have to be patient, basically, and hope that it will work itself out’. This parent indicated that she ‘goes along with [food preferences] because otherwise I get upset, then he gets upset… I’d reckon as long as he’s eating, then let that struggle go.’

There is, though, acknowledgement by the adult children in this study that being encouraged by parents to eat ‘not just beige foods, but a wide range’ came from a place of care, and even a touching understanding evident of the issue from their parents’ perspectives. ‘I get that taking lots of time to make a meal, and having your child reject it, can be hurtful’. This participant shared that ‘it would have helped when I was a child … if [my parents] had not taken my eating so personally … [Not eating it] is not a rejection of the person who has provided the food!’

## *Discussion*

Findings from our discussions with autistic people and family members very much supported our own lived experiences of both autism and, more specifically, eating. Autonomy and the ability to manage and regulate type, presentation and combinations of foods came across as important to many of the participants, as did the context in which food is experienced. Lack of ‘comfortable eating’ and anxiety around the subject were powerfully conveyed.

We found the comment made fairly early in this report of a parent who allowed their child to eat outside to be interesting. There is a connectedness with nature suggested here which helps to reposition eating as a natural activity. For many people, nature is a source of calm and regulation, with numerous studies with typically developing children suggesting that access to the natural outdoors may reduce stress, enhance emotional resilience and support cognitive development (for example, Balseviciene et al., 2014; Dadvand et al., 2015; Li & Sullivan, 2016; Li et al, 2018; Li et al., 2019). Research further suggests that supported access to nature can help people who are experiencing disordered eating, with participants in a recent study (Jepsen Trangsrud et al.,2020) suggesting that nature gives a non-judgemental space for self-care, a way to engage with the senses and an environment for calm. We were interested that the child in this chapter's example seemed to have chosen this way of managing eating for herself, highlighting the value of people finding comfortable solutions for themselves.

We recognised that many of the examples given were to do with this sense of control, of having the authority to take charge of the situation or environment. The autistic person may have limited control regarding what food is presented, when and in response to what prompts (time or convenience as opposed to hunger), and so food refusal may become a way of reasserting some authority in an otherwise powerless situation. Feelings of a lack of control over access to food (or at least to preferred foods presented in an accessible way) may prompt experiences more commonly associated with food insecurity caused by socio-economic deprivation. Food insecurity 'has been found to be associated with higher levels of overall eating disorder pathology in cross-sectional studies' (Hazzard et al., 2020 p.73). Perceived food insecurity in childhood may also be associated with the development of disordered eating for a highly anxious autistic child (Elwyn et al., 2024). Element of reclaimed 'control' over food, specifically weighing and routine as discussed in this study, may give structure. However, we acknowledge that there may also be the potential for these elements to lead to more compulsive behaviours; weighing – of both portions and self – could lead to rigidity around routines relating to food and eating for the autistic person.

The concept of 'safe foods' was one that chimed with us, as did the question of why having and turning to these safe foods might be seen as an issue. We wondered if the person is getting everything they need (and the example given of watermelon and oat cakes covers most of the necessary food groups), why this should be a concern. One possibility we discussed from the child's perspective was that it might become a social issue, with some autistic teenagers in particular worrying that their restricted or repetitive eating may be making them visibly different, rather than this being contextualised more generally within autism. Greater maturity and a more confident identity as autistic may lead to more adaptive behaviours and acceptance of own eating differences in adulthood (Kinnaird et al., 2019) and of respect regarding how these behaviours meet needs. A Brazilian study into Insistence on Sameness (IoS) around food choices, food shopping and eating out (Park-Cardoso & Silva, 2023) concluded that behaviours such as eating the same foods, shopping in same spaces and eating out at the same places and at same times were authentic autistic behaviours that protected those individuals. The researchers recognised that these behaviours by their participants may be 'an authentically autistic way to appropriate space through which [to] try to exercise [the] right to equally comfortably exist and live as human beings and as themselves' (Park-Cardoso & Silva, 2023, p. 951). Literature suggests that autistic people, including autistic young people, may be in a constant state of conflict between the need to 'mask' or hide their autistic identity, and the wish to experience authentic autistic experiences (for example, Chapman et al., 2022), with food and eating a part of this dichotomy.

We found the inter-generational report regarding sensitivity to taste across three generations very moving, especially as the child in the example was born after the death of the participant's father. This report runs counter to some research that suggests that generations between autistic young people and their caregivers experience significantly high rates of adverse childhood experiences (Andrzejewski et al., 2023). Instead, the report in this chapter records a positive element of continuity in remembering how it was to be an autistic child, and appreciates that shared experience across the generations, recognising that autism may exist in families for longer than has been formally known.

We contrasted much of the care and acceptance reported by participants in this study regarding autistic children's eating in the home with requirements made at school. There is a considerable age difference between the two writers of this chapter, and it was hoped that the unappetising school dinners of the past, with insistence that everything on the plate be consumed, were a thing of the past. However, although the second author reports a generally rather more positive appraisal of food served at school, autistic issues of fear and anxiety remain. Autistic children face the sensory challenges of the dining hall, the need to queue and make quick decisions, to eat in social spaces and to contend with other people's mess and detritus. Foods may be required to be added on their plate that provide sensory challenges of colour and texture as well as taste, and different foods may touch and overlap in a way that contaminates each element. Autistic adults (for example, Park-Cardoso & da Silva, 2023; Kinnaird et al., 2019) are eloquent in sharing the challenges of eating out in restaurants, and few restaurants are as noisy, busy, brightly lit, policed, prescribed or provide such challenging time constraints as school dining halls.

The solution for many parents to provide food for their child that they hope may actually be eaten is to provide a packed lunch, but these have been demonised in recent years. The Department for Education has issued school food standard guidance through The School Food Plan (Dimbleby & Vincent, 2013; Dimbleby, 2021), setting out actions to tackle unhealthy eating and transform what children eat in school. This strategy indicates that (prescribed) school dinners are their preferred option, and that packed lunches – where available – should conform to certain requirements. Recommendations are that packed lunches should include:

> · at least one portion of fruit and one portion of vegetables every day.
>
> · meat, fish or other source of non-dairy protein (e.g. lentils, kidney beans, chickpeas, hummus, peanut butter and falafel) every day
>
> · oily fish, such as salmon, at least once every three weeks.
>
> · a starchy food such as any type of bread, pasta, rice, couscous, noodles, potatoes or other type of cereals every day.
>
> · dairy food such as milk, cheese, yoghurt, fromage frais or custard every day
>
> · only water, still or sparkling, fruit juice, semi-skimmed or skimmed milk, yoghurt or milk drinks and smoothies.

(https://www.london.gov.uk/what-we-do/health/healthy-schools-london/awards/sites/default/files/sft_packed_lunch_policy_example.pdf)

These recommendations also include that snacks such as crisps should be replaced by nuts, seeds, vegetables and fruit, and that chocolate bars, chocolate-coated biscuits and sweets should be banned. Cakes and biscuits are allowed only as part of a balanced meal and meat products such as sausage rolls, individual pies and chipolatas are permitted only occasionally.

These recommendations may be a laudable attempt to support better nutrition across all children, but they provide a nightmarish challenge for many autistic children and their parents.  Also, they introduce a further element of fear into an already anxious situation.  The recommendations include that packed lunches be regularly reviewed by teaching staff or midday supervisors and that lunch box contents not adhering to the policy should result in penalties:

> Parents and pupils who do not adhere to the Packed Lunch Policy will receive a leaflet in the packed lunch informing them of the Policy. If a child regularly brings a packed lunch that does not conform to the policy, then the school will contact the parents to discuss this.

(https://www.london.gov.uk/what-we-do/health/healthy-schools-london/awards/sites/default/files/sft_packed_lunch_policy_example.pdf)

Although it is noted that pupils with special diets should be given due consideration, this does not acknowledge that in autism parental concerns are often dismissed, with their autistic child merely termed a "picky eater" with no recognition given to the magnitude of the sensory challenges faced (Cobbaert & Rose, 2023; Cobbaert et al., 2024).  In this situation it remains for these parents, or even for the autistic child themselves, to be able to advocate as to why they need their lunch to be different, and to justify this difference repeatedly to supervisors and peers alike, which places a considerable burden on autistic children and their families.  Whilst some advice to headteachers in the School Food Plan (Dimbleby & Vincent, 2013) is helpful for autistic children (for example, that to make menus available in advance to pupils and parents online), other advice provides additional challenges for autistic eaters.  For example, the School Food Plan checklist for headteachers recommends that all children sit together, those with packed lunches and those eating school meals.  This means that an autistic child trying to consume 'safe foods' from their own box will be seated amongst the scents and sight of other foods that they may find repellent.  Indeed, the very notion of a recommendation that eaters 'sit together' runs counter to recommendations for comfortable eating by many autistic people (Park-Cardoso & da Silva, 2023).

### What might be worth a try?

What follows is a ‘toolkit’ of suggestions for autistic people around food, with the priority being to identify strategies that autistic people may request or try, in order to make eating more comfortable. There may be many objections to applying these: practical, economic and social. However, we believe that few needs are as essential to life and wellbeing as food, and that these objections should not be allowed to dominate. None of the suggestions is unreasonable. Most would fit seamlessly into an adult, corporate culture, as we demonstrate with our *Corporate Charter* example at the end of the chapter. If our primary objective is genuinely to support autistic people to access and enjoy eating, and to develop and maintain a healthy, positive relationship with food, then the elements in this toolkit may well be worth considering, at home, at work, in social spaces and in care centres and residential settings and specifically, in the examples we have given, in schools.

The elements of the ‘toolkit’ have been gathered from suggestions from participants in this project, collated from elements that we have seen work in the past, recalled from our own experiences and extracted from published research and literature (with particular thanks to Luke Beardon for his *Autopia Restaurant* ideas (Beardon, 2024)).

# Comfortable eating in autism: a toolkit of ideas to try

### Consideration one: who else is present?

For some autistic people, it is less the food that is the issue than the environment. Many eating spaces are large, noisy, bright and busy, and it can be difficult to manage sensory stimuli of sounds, sights and smells when trying to navigate taste and textures. Further, the act of eating in public, having other people watch you eat or having to watch others, can provide a considerable barrier, and this is heightened if food intake is scrutinised or policed by well-meaning or concerned others. Food eaten in private is very different to food presented in public.

Indeed, being supported to *not* eat around other people may in fact support autistic people’s opportunities to be sociable. One adult participant in this study voiced that she enjoys joining colleagues in the dining hall for lunch, as long as it is accepted that she will not herself be eating at that time. To this end, creation of private, low-sensory eating opportunities that facilitate autistic people to eat comfortably as an alternative to social eating, may support interaction and in fact be a way to ‘reduce unwanted aloneness and social isolation in autistic [people]’ (Park-Cardoso & da Silva, 2023, p. 257).

## Consideration two: timing and time constraints

The ‘when’ of eating can also be as challenging as the ‘what’. Being presented with food in response to timetabled schedules as opposed to being supported to respond to interoceptive signals of hunger can further lead to issues. Some people feel hungry in the mornings and enjoy breakfast; others prefer not to eat until later in the day. The time taken eating can also have impact. Having to eat quickly because the room needs to be cleared can mean that some slow eaters will simply not eat at all. Those fearful of being given food or drink that is too physically hot to consume in a restricted time may opt for cold food, ready packed foods or energy drinks in preference.

## Consideration three: the need for quick decision

In many public eating places, decisions regarding food choices are required very quickly. Having reached the front of the queue (and queueing, we know, may provide additional challenges for autistic people even before they reach the food counter), diners may be faced with a confusing array of choices and have to choose immediately by looks rather than by taste. The diner is required to decide ‘which is better’, and research suggests that many autistic people struggle with real-life decisions that are value-based (van der Plas et al., 2023). It may be extremely challenging for the autistic person to make a choice in this circumstance. Equally, choices may be anyway largely illusionary, leading to further anxiety. The *Checklist for Headteachers* from the School Food Plan (Dimbleby & Vincent, 2013, suggests that lunchtime school supervisors, ‘require children to fill their plates with options from different categories’ or suggests that the supervisors ‘simply put vegetables on their plates’.

## Consideration four: overt, clear and transparent social rules

The social requirements around food and eating are complex, context-dependent, culturally specific and seldom transparent. In some situations, it is acceptable to reach from a shared receptacle (for example, taking from a breadbasket) where in others it is only acceptable to eat what is on your own plate. In some cultures, it is desirable to leave some food on your plate whereas in others this is considered rude. Clarity and consistency of expectation around foods may be needed in order to reduce anxiety.

Similarly, overt requirements regarding social interaction may be helpful, especially reduced or removed requirements to talk whilst eating. Trying to concentrate on tastes and textures whilst navigating the challenges of small talk may be an impossibly difficult hurdle for many autistic people.

## Consideration five: autonomy

Confidence that the food you face is something known and familiar, and is something that you can eat, may greatly reduce anxiety. Many autistic people will choose to eat the same foods again and again and have a limited range of these ‘safe foods’. Having control over which of these safe foods is available may, conversely, facilitate greater flexibility. If three safe foods are all equally available, the autistic person who has true autonomy may choose to voluntarily mix and match.

With this in mind, no food or food group should be positioned as ‘bad’ in a context of comfortable eating. Education about food is important, as is support for access to healthy options, but autistic food choices are unlikely to be made due to nutritional ignorance, and demonisation of certain foods merely increases anxiety. Part of autonomy is knowing that the choice of when to stop eating is also your own. Rules such as not leaving the table until the vegetables have been eaten, or ‘no pudding unless you finish your main course’ position some foods as rewards and treat food punitively. The option to escape from a situation, or to avoid that situation, can make accessing it more manageable. Some autistic people experience PDA (Pervasive Drive for Autonomy/extreme demand avoidance). This is also known as “Pathological Demand Avoidance” – however rather than being pathological, it involves adaptive avoidance of perceived demands due to extreme nervous system responses. It is regarded as a neurocognitive feature within the autism spectrum. Non-demanding framing of requests (such as emphasising choice, asking If someone would like to eat something or not to, rather than making a demand) can support autistic individuals with PDA by reducing stress.

## Consideration six: How to eat

For some people, the mechanics of getting food into the mouth may be an issue. For some the metal touch of a fork to lips or tongue is repellent. For some, the sound and feel of utensils scraping against the plate is actually painful. For some, the smell of the dishwasher detergent that lingers on crockery and cutlery means that food literally tastes of chemicals.

The coordination required to cut up food using a knife and fork may also be difficult, and some people may be embarrassed by poor mastery of this skill. Equally, the act of putting a larger utensil into the mouth may result in feelings of choking or gagging. Yet wanting to eat a main course with a teaspoon may be socially unacceptable.

## Consideration seven: colours and textures

Colours may be experienced differently in autism (for example, Zachi et al., 2017), and specifically, combinations of colours may be distressing. One autistic adult who participated in this study reported how the colour red pulses and vibrates for them, especially against a white background, such as an institutional plate. Another shared that for many years she preferred to eat yellow foods – pasta, cheese, scrambled egg, sweetcorn, mangos, bananas – and that she perceived green or red foods with much the same suspicion as many might feel towards food that is blue.

Textures, and the combination of textures, is also a consideration. Some people may struggle with lumps or ‘bits’ in otherwise smooth purees, others with dry or grainy foods. One participant in this study shared that they enjoy mince, enjoy cheese, enjoy pasta…but cannot eat lasagne as all three textures are interwoven. The need to separate textures and colours, and to avoid contamination between them, has been common feedback. It is also worth noting that the same food may taste or be texturally different dependent on temperature. Hot milk does not taste the same as chilled milk; and cold baked beans, while enjoyed by some, will be an anathema to others. One parent shared that her child would eat only Fridge Raiders at home, but would not eat even these at school because, after a morning in his lunch bag, they were no longer cold. Food temperature may be a further factor beyond the control of the autistic person and may exacerbate feelings of helplessness.

## Consideration eight: biting, chewing and swallowing

Ultimately, eating requires the food that is in the mouth to be taken down into the body. This may sound obvious, but it can itself be a challenge. Food that is in the mouth can still, if required, be spat out. Once it has been swallowed into the throat, there is an inexorability to its being absorbed into the body unless regurgitated. For people with heightened anxiety around germs, poisons and the potential for food to make you ill, swallowing can be a challenging moment. One participant in this project shared that she had a 'a strong fear of getting ill, and fear of eating something that makes me ill'. For her, the act of putting food into her mouth was one stage, but swallowing was a further one.

Gagging and vomiting may be further fears for some autistic people, and for some who have had previous experience of choking or being sick, it can become almost a phobia. One participant reported a 'very strong fear of sickness', and the act of biting into foods and 'taking a mouthful' led them to anxiety about managing to safely chew and swallow.

## Consideration nine: How much is enough?

For an autistic person faced with a new or unfamiliar food, 'too much' may be anything beyond a crumb. For the same person fearful of when the next consumable food may be available, a plateful may be 'too little'. The plaintive question by one of the participants in this project about 'what *is* a portion?' echoes this dilemma. Anxiety about being presented with too much or too little food on a plate compounds existing anxieties about the colour, taste, texture, heat and practicalities of food and eating.

### Consideration ten: what about drink?

Drinking is a further social and cultural minefield. ‘Having a coffee’, ‘going for a beer’, ‘stopping for a cuppa’ are all examples of when consuming a liquid is only part of an adult social contract. Even when this is kept as simple as drinking water, that does not avoid all challenges. One participant in this study described how hearing reports of the Devon water cryptosporidium contamination of the summer of 2024 led to significant health anxiety and to boiling all of their drinking water – despite the fact that they lived 300 miles away. Another reported that her teenage autistic son had become increasingly withdrawn and eventually reported headaches during a holiday in Norway, and she realised that he had not been drinking because the water ‘tasted different’.

## Some suggestions for comfortable eating in institutions

The following suggestions are in no particular order, but collectively address the considerations given above. They are a ‘toolkit’ in that they are designed to be mixed and matched, to be experiments and try-outs, to offer options. None is, we believe, unreasonable, and each returns the potential for comfortable eating to the autistic person. Only that person will be able to tell if any of these suggestions helps – sometimes, occasionally or never, although what does not work one time may be worth keeping in the ‘toolkit’ for another day. What is needed to support comfortable eating when someone is experiencing other stresses may be different from what is needed when stress is low. The context in the toolkit example is education, but the principles are transferable, as will be demonstrated at the end of the chapter. The emphasis is on facilitating access to nutrition for autistic people that is supportive, helpful and above all respectful of needs.

**WHERE**

- Enable autistic people to eat alone if they prefer, or to eat when and where others are not.
- Promote quiet eating spaces, with minimal clatter and talking, and away from cooking smells.
- Create an outdoor eating area or areas.

- Enable flexible arrival and leaving times for eating spaces. Support diners to access/leave when comfortable for them.
- Promote zoned spaces within dining spaces for those who choose to eat packed lunch away from hot dinners (although sitting with dinner-eating peers should also be a choice).
- Consider introduction of 'Please do not disturb' lanyards. Encourage staff to use dining spaces and to model lanyard use to reduce stigma.
- Have a variety of seating options, including at table or in easy chairs/informal spaces if preferred. Consider a 'booking system' to facilitate consistent access to preferred options.
- Welcome parents/carers into schools to join and support children in their eating; support siblings from different year groups to eat together if desired.
- Consider regulations regarding leaving campuses, including the option to go home for lunch if practicable.

**WHAT**

- Enable diners to be secure in choosing 'eatable' familiar foods and to have control over what those foods are. Do not demonise their choices.
- Allow/accept foods to be the same every day as long as overall basic nutritional needs are met, without comment or censure. Offer consistency of choice, so that sameness can be maintained and assured.
- Offer a simple, consistent breakfast option – for example, porridge, toast, fruit – so that access to some food early in the day is supported. Maintain a fixed (subsidised) price for ease of navigation or consider a cash 'honesty box' approach.
- Make the dinner menu for the week available online to facilitate choice in advance and to pre-order. Ensure that this is accurate and that the preordered option remains available at eating time.
- Support a wide choice of portion sizes – 'full', 'side' or 'taster' as a minimum. Support 'tasting' portions to be tried alongside familiar foods when/if the person chooses, without any expectation of full consumption. Enable access to 'seconds' when smaller portion are selected.

- Support those who are not able to eat dinner. Enable these people to be with their peers if preferred, but without eating, or have alternatives to the dining hall available to access if not. *[NB Build, for example, on cultural supports made for Muslim pupils during Ramadan]*.
- Allow nutrition bars/smoothies etc to be consumed at non-dining-hall locations if needed.
- Communicate with parents/carers when non-eating options are chosen so that overall nutrition can be monitored/maintained in openness and transparency.

**HOW**

- Allow diners to eat without interruption or distraction if they require. Encourage use of supports such as headphones if desired.
- Encourage diners to bring/use their own crockery, cutlery and food containers.
- Within sensible constraints, allow flexibility regarding the act of eating – with small spoons, chopsticks, hands. Provide a finger food option.
- Allow 'first sitting'/early access to dining spaces where possible. Limit the need for queueing and interaction with staff.
- Publish and maintain clear and consistent social rule expectations around food; review this regularly with an Autistic Working Group.
- Review payment options. Issues around money can be a source of increased anxiety.

**WHEN**

- Have multiple food-access options during the day to facilitate choice of when to eat. Accept 'little and often' as a valid choice; do not demonise 'snacking' as inherently bad. Support breakfast club access, break time, lunch and after-school nutrition.
- Consider allowing eating in some work environments. Allow access to leisure spaces during break and lunchtimes, including to eat.
- Be aware that in school, some pupils may misbehave in order to try to get a 'lunchtime detention' in order to avoid the dining hall. Understanding this and enabling access to a comfortable space is a more respectful and humane alternative.

**WHY**

- As far as possible, enable people to eat when hungry rather than at prescribed times.
- Support eating as a 'side' activity without pressure; enable lunchtime clubs to include access to food or provide a TV/film room where eating while watching is permitted.
- Support a positive awareness of food as nutrition through education; encourage people to self-monitor their interoception, including whether they are feeling dizzy, have headaches, struggle to remember or 'think clearly', or are overtired. Support understanding that elements such as breathlessness, nails breaking or hair falling out, girls having irregular periods or period loss, etc., may be stronger indicators of malnutrition than weight or what is observed to have been eaten or not eaten.

Much of the above may be heralded as unrealistic, undoable and impractical, and there may well be detractors who suggest that offering these adjustments is not in the best interests of autistic people. Perhaps, though, this needs recontextualising. None of the suggestions above is unreasonable, and many would be deemed acceptable, even expected, by professional adults. Consider the imagined 'Corporate Charter' given under. Why does this sound perfectly viable, where similar suggestions for schools, day centres or care homes do not? One answer, we suggest, may be simple economics – but surely welfare, especially of the vulnerable, should not be compromised by such considerations? It may be time for 'autistic eating requirements [to be] taken just as seriously as other dietary ones' (Beardon, 2024, p. 97).

## An imagined Corporate Food and Eating Charter

*At Corporate Institution, our refectory is open from 7.00am to 6.00pm to enable access at preferred and convenient times. We offer a wide range of foods to meet diverse dietary requirements, including vegan and vegetarian options. Ingredients and allergens are clearly labelled, and all menus are available to view online at least a week in advance.*

*We have introduced a simple online booking system for the refectory to minimise overcrowding and queues. We have a variety of seating options available to meet your* *needs – larger tables, single booths, easy chairs around low tables. All colleagues are encouraged to bring their own reusable mugs and utensils to minimise environmental impact.*

*For staff who prefer their own food, we provide fridges and a variety of heating options if desired, including air fryers and microwaves. Please note, staff are welcome to eat their own food alongside colleagues accessing catering in the refectory, or there are separate dining spaces available. We have a range of outside eating areas and encourage our staff to use these green spaces during breaks in the working day.*

*We encourage colleagues to take their full break allocations, using these to leave the premises if desired. Alternatively, we support flexible working and later start/earlier finish times if preferred. We have a published 'working lunch' protocol, including awareness that some colleagues will need to eat without interruption. We have a visible lanyard system to facilitate lack of disruption for these staff and encourage, for example, use of headphones to facilitate privacy.*

*Pricing of all food at our outlets is reasonable and transparent, with a range of smaller, simpler and less expensive options always available. Our 'plain' sandwich range, for example, is available without addition of mayonnaise, mustard, sauces or salads. We also offer nutrition bar and smoothie options and have recently introduced a 'tasting menu' across our food offer.*

*We encourage our colleagues to look after themselves and to include self-monitoring of wellbeing as part of our healthy conversations.* ***Please note:*** *We respect all colleagues' individual and cultural preferences regarding nutritional choices. At Corporate Institution, it is unacceptable to make intrusive comments about personal food choices, and any that are made will be taken extremely seriously and addressed under our anti-bullying policies.*

# References

Alvå, H. (2023). “The greater dysphoria I’ve had, the greater dysmorphia-they work together”-An interview study on trans and nonbinary experiences of seeking and participating in Swedish eating disorder treatment.

Andrzejewski, T., DeLucia, E. A., Semones, O., Khan, S., & McDonnell, C. G. (2023). Adverse childhood experiences in autistic children and their caregivers: Examining intergenerational continuity. *Journal of Autism and Developmental Disorders*, *53*(7), 2663-2679.

Balseviciene, B., Sinkariova, L., Grazuleviciene, R., Andrusaityte, S., Uzdanaviciute, I., Dedele, A., & Nieuwenhuijsen, M. J. (2014). Impact of residential greenness on preschool children’s emotional and behavioral problems. *International journal of environmental research and public health*, *11*(7), 6757-6770.

Baraskewich, J., von Ranson, K. M., McCrimmon, A., & McMorris, C. A. (2021). Feeding and eating problems in children and adolescents with autism: A scoping review. *Autism*, *25*(6), 1505-1519.

Beardon, L. (2024). *Eating and drinking out* in ‘Reasonable Adjustments for Autistic Children’. Sheldon Press. In press.

Bourne, L., Mandy, W., & Bryant-Waugh, R. (2022). Avoidant/restrictive food intake disorder and severe food selectivity in children and young people with autism: A scoping review. *Developmental Medicine & Child Neurology*, *64*(6), 691-700

Brown, C. M., Hedley, D., Hooley, M., Hayward, S. M., Fuller-Tyszkiewicz, M., Krug, I., & Stokes, M. A. (2024). Hiding in Plain Sight: Eating Disorders, Autism, and Diagnostic Overshadowing in Women. *Autism in Adulthood*.

Brown, T. R., Jansen, M. O., Zhou, A. N., Moog, D., Xie, H., Liebesny, K. V., ... & Deng, W. Y. (2024). Co-occurring autism, ADHD, and gender dysphoria in children, adolescents, and young adults with eating disorders: an examination of pre-vs. post-COVID pandemic outbreak trends with real-time electronic health record data. *Frontiers in Psychiatry*, *15*, 1402312.

Chapman, L., Rose, K., Hull, L., & Mandy, W. (2022). “I want to fit in… but I don’t want to change myself fundamentally”: A qualitative exploration of the relationship between masking and mental health for autistic teenagers. *Research in Autism Spectrum Disorders*, *99*, 102069.Cobbaert, L., & Rose, A. (2023). Eating disorders and neurodivergence: a stepped care approach. *Melbourne: Eating Disorders Neurodiversity Australia*.

Cobbaert, L., Millichamp, A. R., Elwyn, R., Silverstein, S., Schweizer, K., Thomas, E., & Miskovic-Wheatley, J. (2024). Neurodivergence, intersectionality, and eating disorders: a lived experience-led narrative review. *Journal of Eating Disorders*, *12*(1), 187.

Dadvand, P., Nieuwenhuijsen, M. J., Esnaola, M., Forns, J., Basagaña, X., Alvarez-Pedrerol, M., ... & Sunyer, J. (2015). Green spaces and cognitive development in primary schoolchildren. *Proceedings of the National Academy of Sciences*, *112*(26), 7937-7942.

Dimbleby, H. (2021). National Food Strategy: The Plan. https://www.nationalfoodstrategy.org

Dimbleby, H., & Vincent, J. (2013). *The school food plan*. https://assets.publishing.service.gov.uk/media/5fb407d28fa8f54aada6df60/The_School_Food_Plan.pdf

Elwyn, R. (2023). A lived experience response to the proposed diagnosis of terminal anorexia nervosa: learning from iatrogenic harm, ambivalence and enduring hope. *Journal of eating disorders*, *11*(1), 2.

Elwyn, R., Williams, M., Smith, E., & Smith, S. (2024). Two identical twin pairs discordant for longstanding anorexia nervosa and OSFED: lived experience accounts of eating disorder and recovery processes. *Journal of Eating Disorders*, *12*(1), 127.

Fixsen, A. (2024). *The Construction of Eating Disorders*. Palgrave Macmillan Cham.

Hazzard, V. M., Loth, K. A., Hooper, L., & Becker, C. B. (2020). Food insecurity and eating disorders: A review of emerging evidence. *Current psychiatry reports*, *22*, 1-9.

Jepsen Trangsrud, L. K., Borg, M., Bratland-Sanda, S., & Klevan, T. (2020). Embodying experiences with nature in everyday life recovery for persons with eating disorders. *International journal of environmental research and public health*, *17*(8), 2784.

Kinnaird, E., Norton, C., Pimblett, C., Stewart, C., & Tchanturia, K. (2019). Eating as an autistic adult: An exploratory qualitative study. *PLoS One*, *14*(8), e0221937.

Lee, M., Lee, S., Sohn, J. W., Kim, K. W., & Choi, H. J. (2024). Assessment methods for problematic eating behaviors in children and adolescents with autism spectrum disorder. *Journal of the Korean Academy of Child and Adolescent Psychiatry*, *35*(1), 57.

Li, D., & Sullivan, W. C. (2016). Impact of views to school landscapes on recovery from stress and mental fatigue. *Landscape and urban planning*, *148*, 149-158.

Li, D., Deal, B., Zhou, X., Slavenas, M., & Sullivan, W. C. (2018). Moving beyond the neighborhood: Daily exposure to nature and adolescents' mood. *Landscape and urban planning*, *173*, 33-43.

Li, D., Larsen, L., Yang, Y., Wang, L., Zhai, Y., & Sullivan, W. C. (2019). Exposure to nature for children with autism spectrum disorder: Benefits, caveats, and barriers. *Health & Place*, *55*, 71-79.

Longhurst, P., & Burnette, C. B. (2023). Challenges and opportunities for conceptualizing intuitive eating in autistic people. *International Journal of Eating Disorders*, *56*(12), 2189-2199.

Nimbley, E., Maloney, E., & Duffy, F. (2023). A call for autism-led research exploring definitions of recovery in Autistic individuals with an eating disorder. *International Journal of Eating Disorders*, *56*(7), 1335-1340.

Park-Cardoso, J., & Silva, A. P. S. D. (2023). Insistence on sameness for food space appropriation: An exploratory study on Brazilians with autism (self-) diagnosis in adulthood. *Autism*, *27*(4), 938-951.

Schröder, S. S., Danner, U. N., Spek, A. A., & van Elburg, A. A. (2023). Exploring the intersection of autism spectrum disorder and eating disorders: understanding the unique challenges and treatment considerations for autistic women with eating disorders. *Current Opinion in Psychiatry*, *36*(6), 419-426.

Sharpe, S. L. (2024). A living experience proposal for the co-occurring diagnosis of avoidant/restrictive food intake disorder and other eating disorders. *Journal of Eating Disorders*, *12*(1), 110.

Spek, A. A., van Rijnsoever, W., van Laarhoven, L., & Kiep, M. (2020). Eating problems in men and women with an autism spectrum disorder. *Journal of autism and developmental disorders*, *50*(5), 1748-1755.

Stephenson, H., Thom-Jones, S., Lowe, J., & Milne, L. (2024). “I Know It’s Very Spectrum-y”: Autistic Women Reflect on Sensory Aspects of Food and Eating. *Autism in Adulthood*.

van der Plas, E., Mason, D., & Happé, F. (2023). Decision-making in autism: A narrative review. *Autism*, *27*(6), 1532-1546.

Zachi, E. C., Costa, T. L., Barboni, M. T., Costa, M. F., Bonci, D. M., & Ventura, D. F. (2017). Color vision losses in autism spectrum disorders. *Frontiers in psychology*, *8*, 1127.

Zorc, C. L. E. (2022). *Eating disorders among transgender and gender diverse individuals* (Master's thesis, Boston University).