SENSE AND SENSITIVITY –
FUSSY EATERS OR FUSSY BODIES

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Autism, feeding/eating problems, «picky eaters», idiosyncratic eating behaviours
A brief overview of the most common feeding/eating problems in autism, and a range of possible solution of these problems.

We are what we eat’ – is a widely accepted statement, and most people do try to eat healthy foods to improve their well-being. However, if we deal with autistic individuals there are many problems related to ‘healthy food’, ‘balanced diet’ and eating in general. Some will eat anything and everything, whether it is edible or inedible (pica). Others will refuse to eat 99% of food we offer, and 1% they accept can be the ‘wrong’ food for them – causing allergies, ‘leaky gut syndrome’, leading to challenging behaviours. For some, food can be a source of fear. Others will accept their ‘selected food’ only if it is presented the ‘right’ way, be of the ‘right’ colour, etc. or they reject it immediately and will go without any food for hours if not days. Many will refuse to try any new food and keep eating three or four items from the menu for years. It is important to remember that these are not behavioural problems where children are being deliberately defiant – these children have increased sensitivity to certain types of food (Attwood 2008), and specific autistic perceptual difficulties.

There are several issues to consider: What causes what, or what is the primary problem – sensory perceptual difficulties leading to restricted nutritional input, or biochemical abnormalities creating sensory perceptual difficulties, or both.

We will start with sensory perceptual problems, leading either to very restricted diets or ‘all-goes’ consumption. Before we can be sure that we fulfil the nutritional requirements of growing up children, we have to make sure that our ‘healthy nutritional diet’ (with the correct proportions of proteins, fats, carbohydrates, minerals and vitamins) will get into their mouth.

And this is a big problem for many autistic children. All the many suggestions how to do it (encourage your child to try new food, rewarding with stickers, etc.) are often inapplicable to some children with autism.

While discussing sensory perceptual and nutritional problems experienced by people with autism, it is important to keep in mind that autism is a spectrum disorder, it can be seen as many ‘autisms’ each caused by different problems in different individuals, but leading to the same behaviours ‘on the surface’, and there may be different types of autism in different people and sometimes more than one type of autism present in the same person (Bogdashina 2006). Donna Williams (2010) compares ASDs to ‘fruit salads’, for example, each of the recognized features of autism (impairments in social interaction, communication, rigidity of thoughts and behaviours) can be caused by a few specific problems – different in different individual (Williams 2010). That is why what works for some will be useless (or even
harmful) to others. The manifestations of sensory perceptual problems are very different in different individuals.

Feeding problems can start from birth (when a baby is very difficult at feeding times), or later – at the age of 18-24 months; the eating difficulties seem to peak in the one- to five years of age (Legge 2002). However, some children will start off eating everything they are offered but then regress, usually at about 18 months. Some children limit their total food intake to three or four items (e.g., potatoes, pasta, cereal, milk) and refuse to try anything from ‘outside of their menu’. It is interesting to note that many autistic children with restricted diets seem to have extreme reactions to heat and cold as well (Attwood 2008).

The most obvious ‘feeding problems’ seem to be related to taste/smell hyper-/ hyposensitivities. Some autistic children have olfactory sensitivities comparable to canines (Morris 1999). For them, almost all types of food smell too sharp. Some assume that so-called ‘picky eaters’ can be encouraged to eat if they can watch other children eat. But there are autistic children who cannot stay in the proximity of anyone eating – some may even vomit because of intolerable smell or noise. Their sense of taste is so acute that if they are offered, for example, something they like (but a recipe has slightly changed) they would not accept it. If a tiny amount of new food is added to the food they like, it will be discarded as inedible.

Some will refuse to stay (to say nothing of eating) in a room if there is something with a particular smell there (often the smell goes undetected by ‘normal’ people). The smell of food is very important for many children. Some children would vomit if they encounter the smell they cannot tolerate, which they can detect even from two rooms away.

Children with hypotaste/hyposmell chew and smell everything they can get – grass, flowers, dirt, play dough, toothpaste, etc. They sniff and lick objects, play with faeces. However, not all ‘smelling behaviours’ indicate hypersensitivity, sometimes it is the only reliable channel for the child whose visual perception is distorted so he/she has to smell everything to be sure what is in front of him/her. When visual problems are address, the behaviour disappears.

What complicates the matter is, that the child’s sensitivity can fluctuate (from hyper- to normal/hypo- and vice versa). What has been a favourite food for years, one day can become absolutely unacceptable. In this context, one should mention also idiosyncratic tastes: some will eat ‘incompatible foods’ together, for instance, ice-cream with gherkins.

Apart from senses of taste and smell there are other, equally important sensory perceptual issues, which contribute to the ‘eating problems’. Other sensory channels’ abnormalities can aggravate the situation. For example, some children do not experience hunger (in the case of hypoproprioception) – their body does not tell them when it is time to eat; they can go without any food for very long periods, without being bothered about it. Motor problems are quite common: some children have difficulties swallowing, others have problems with chewing so they swallow everything as a whole. Texture of the food is very important: some children cannot tolerate any (even the tiniest) lumps in their food which should be consistently smooth, others would eat only dry foods with crunchy bits – anything with gravy or sauces is unacceptable. It is not the case of stubbornness, but rather a physical problem of certain textures intolerance, when a child becomes sick is the food of the ‘wrong’ texture gets into his mouth. That is why these children have to feel the food before they eat it; if they do not like the feel of it, they reject it without tasting. Some are very peculiar about the temperature of the food: some will eat only cold foods and drink cold drinks.

Auditory and visual modalities are also involved in the ‘assessment’ of foods on offer. Thus the sound the food produces in the mouth can be unbearable and frightening. Because of literalness and Gestalt perception (Bogdashina 2011) appearence is extremely important: the container (package, cup, bowl, etc.) should be the same – colour, design, etc.– or the child will reject even his favourite food, drink. The food (they accept) should come from the same package (with the same picture in front, of the same colour and the same design).

Manufacturers tend to alter the appearance of the packages from time to time (in the name of ‘improvement’), that is a big blow for many autistic individuals. It does not matter that the contents of the container is something they like, if it looks different it becomes ‘inedible’. And if the taste is slightly dif-
ferent (‘improved recipe’), it is out of the menu for someone with autism who can detect a difference and will not like what is supposed to be of ‘improved’ taste. The look of the food is very important, too. If something they like looks slightly different or ‘imperfect’ (for example, toast is not ‘brown enough’, or there is an eye in a cooked potato) it will be discarded straightaway. Sometimes ‘imperfect’ or ‘wrong’ look of the food makes some children gag or sick.

The colour of the food plays a huge role in acceptance of certain foods. For example, some children would not touch (to say nothing of putting in the mouth) anything red (or yellow, or green). Quite a few children would reject even their favourite food if it is of the ‘wrong shape’. Presentation on the plate (and on the table) create problems as well: some children will refuse to eat if there are different foods on the same plate, or if different foods touch each other as if they become ‘contaminated’. Others will re-arrange the food on their plate to be symmetrical before they put it in the mouth. Still some others will eat and drink only from a particular plate or cup, for example, they insist on the ‘juice cup’ which is different from the ‘water cup’; even their favourite food/drink presented on the ‘wrong’ plate/ the ‘wrong’ cup will not be touched.

There are many other issues that can affect eating behaviours, most common being:

- The ritual is very important for many autistic children: they insist on certain rituals before they eat even their favourite foods, for instance, packages should be open a particular way, certain foods should be sliced a particular way, etc. A child can eat certain foods at home on Sunday, but refuse to eat the very same food on Wednesday or in school (because it is ‘Sunday food’ eaten at home), and vice versa: what is acceptable in school, is out of the question at home.

- The fear of change, of anything new and unfamiliar often leads to a strong aversion to eating or drinking anything new and unfamiliar. Some are fearful of growing up and get very upset about it: they dislike changes in their bodies and reject food in hope that they stay the way they are if they do not eat. (However, some children, if told that this particular food will help them become strong and big, will be motivated to eat it.)

- Favourites: There are some foods (different for different children) that they crave (and usually the favourite items are not on a ‘healthy list of nutritional foods’. Some children dip all the foods they eat into ketchup, or a particular sauce. Others would stick with what they know and like, without any desire to add anything new to their menu, for example: “I had no need for variety in my food. I just liked eating the same things all the time…for long periods I ate nothing but skinless sausages and chocolate pudding” (Gerland 1997, 14).

Understanding reasons for children’s eating intolerances and idiosyncratic ‘eating behaviours’ is vital if we want to help them.

Behavioural techniques to encourage children to eat are based on positive and negative reinforcements. However, these methods ignore real difficulties some children experience (e.g., hypersensitivity) and often will not work with autistic individuals. The more pressure is applied, the stronger resistance emerges. The extreme form – force-feeding – will make the situation even worse. On the other hand, encouragement through shaping and fading while addressing the sensitivity problems and offering rewards with recognition (praise) of the child’s efforts to achieve it is a better option and worth trying. Starting with acceptance of a new food on the child’s plate, to letting the food to touch face, then lips, to very small amount of the food in the mouth, and finally swallowing it.

Desensitisation techniques address the problems directly: if the child is hypersensitive to touch, facial massage may be used, then gradual desensitisation to textures, sounds, tastes, smells, etc.

Creating a stress-free environment with no pressure but introducing ‘eating routines’ and rewarding the efforts to try any new food may help.

- Disguising new food – e.g. under ketchup (if the child likes ketchup).
- Structure and routine: creating new routines (introducing new foods in new places, e.g.)
- Using visual aids, written rules explaining what is expected in certain situations may be successful with some children.

Providing new foods that look similar to those they already like: some may try something if it looks similar to what they like.
Obsessions/interests/fascinations can be offered as rewards for trying new food. Sometimes offering ‘character meals’ (food in shapes of the character, objects, etc. the child is interested in) can encourage the child to eat/to try new food. But the effect can be the opposite for other children – they can refuse to eat their ‘favourite characters’. Favourite characters can be used as role models, e.g., if the child likes rabbits, telling him that his favourite rabbit likes carrots may encourage him to eat it.

Because many autistic children monoprocess (use only one sensory channel at a time), distraction can be used with them, for example, if they are watching TV or reading a book while eating, they may have no idea of what they were eating or what they thought or felt about it. This type of processing is taken advantage of by the parents of some autistic children with very restricted diets who will eat better if they are watching a video, listening to music or talking to someone (Bogdashina 2011).

Making choices: Some faddy eaters can be encouraged to choose the food (e.g., giving them two options) they would like to eat. This will give them some control of the eating process. Yet again, there may be difficulties with this as well: if both options are unacceptable, or a difficulty to make a choice, etc.

Involvement: in some cases children become more ‘adventurous’ if they are involved in the whole process – starting from buying necessary ingredients in the supermarket, opening packets, (if they can tolerate the smell) cooking, serving, and then eating the food.

Peer pressure and desire to please family is relevant for children with Asperger syndrome who want to fit in and/or to make their parents happy, but it is unlikely to work with someone on the more severe end of the autistic spectrum. Some will agree to try a new food but insist on having a glass of water to wash it down in case they do not like it. Some will listen to explanations about different products and their benefits for the organism and will be eager to eat ‘healthy foods’.

Eating in a new environment can bring both problems and opportunities. For example, the chaos in school at lunchtime and pressure from lunchtime staff can put the child off not only from trying something new but also from eating his/her packed lunch. On the other hand, a thorough preparation and introduction of a new ‘eating routine’ (which will include new food in the menu) in a new setting can encourage the child to eat new food (which will be associated with this place and routine).

Mineral and vitamin supplements: Children with very restricted diets are given mineral and vitamin supplements.

No pressure: Keeping the pressure off and the least fuss about trying new foods brings better results – the child is more relaxed and may become more curious about new foods that others eat and would want to try. If the new food is regularly presented on the table, so the child get accustomed to the sight, smell and feel of it without any pressure from the parents. Asking (from time to time) if he wants to try it can result one day in ‘Yes, please.’ Gradual introduction is a slow process but with patience and consistency it works for some children. A tiny amount of new food is presented on the plate, the child encouraged to try it (without any pressure – “If you don’t want it, don’t eat it, just leave it on your plate”, but with lots of praise if the child tries it.)

According to Tony Attwood (2008), most children with Asperger syndrome eventually grow out of their ‘food sensitivity’. Likes and dislikes change with time. With age many children will try new foods, especially those high-functioning youngsters who become more aware of diet and nutrition and will try to follow the advice to improve their eating preferences. However, some will continue to be on a restricted diet throughout their lives.

In some autistic people sensory problems, such as sensory overload or sensory hypersensitivities may be caused by certain vitamin-mineral deficiencies and food and chemical allergies; so it may be possible to address these by exploring underlying biochemical problems, such as hormone imbalances and their effects on enzyme production affecting digestion, the synthesis of vitamins and minerals and their interconnectedness with auto-immune problems such as food and chemical allergies and intolerances (Williams 1996). For example, for Donna Williams candida albicans was one of a major contributors to her sensory perceptual and some other autism-related problems. On the other hand, some of these metabolic and chemical problems can be due to chronic heightened stress caused by sensory perceptual problems. In this sense, the two can become a vicious circle. For example, vitamin B, magnesium and zinc deficiencies can relate to pitch and brightness hypersensitivity, although whether these vitamins and
minerals are consumed in coping with these sensitivities or whether they make a person more vulnerable and susceptible to these hypersensitivities is not clear and only further research can answer that (Williams 1996).

Unfortunately, specialists usually start with addressing ‘diagnostic features’ of the condition, neglecting the causes of these features (that can be different in different children).

Some sensory perceptual difficulties can be caused by correctable problems, which, if addressed, can affect the efficiency of functioning through improving the supply of nutrients and reduction of toxicity (e.g., treatment of the fungal infection, candida albicans; casein/gluten intolerances, vitamin-mineral/ amino acids problems, etc.). Other problems can include metabolic disorders, ‘gut leakages’, viral infections, etc. Reduced delivery of nutrients to the brain through the blood can mean limited ability to process information, delayed processing, sensory hypersensitivity, overload and shutdowns.

In some children and adults with ASD, various diets and supplements that address biochemical, immune system and metabolic problems, bring significant improvement in their processing of information, sensory hypersensitivities, communication and behaviour in general. The alternative to avoidance diets is desensitisation (also called neutralisation) that is used to reduce allergic reaction to food or chemical substances. It involves ascertaining the tolerance threshold for any problem substance and then giving very carefully adjusted amount of the same substance (either as dilutions or in injection). Progressively, as the system adjusts, the person is able to tolerate more concentrated dilutions as he becomes less sensitive to this particular substance, until eventually being able to again tolerate exposure to the allergy-causing substances in the environment or diet. According to Donna Williams, desensitisation is still about treating symptoms, and, if possible, one should look for the underlying causes of food and chemical sensitisation and treat those first before returning to the option of desensitisation if still necessary (Williams 1996).

The special diets research has been criticised for being ‘anecdotal’, lacking ‘scientific evidence’. However, none of the approaches would benefit the average person with autism – the underlying causes (leading to the same clinical manifestation of the condition) are different in different individuals. There is no one-fit-all treatment. Temple Grandin puts forward this argument: if 20 children are involved in the study and four benefit from the therapy (diet), while 16 do not, is it ethical to deem the therapy ineffective? If the quality of life for these four children has improved tremendously? Don’t they (and others like them) count? Surely, we must look at autism research from a different angle, for instance, posing questions like ‘Why does… work for some and for others?’ Is it wise to overlook a large (and growing) body of anecdotal support? (Grandin 2008). Keeping in mind that there are no two autistic individuals with the exactly same sensory-perceptual profile, specialists working with this population should approach each case individually and decide what is best for each particular child. Sometimes mistakes will be made, but by trial and error (with consistency and patience) we can change “what they eat” to make them healthier and happier. The process may be slow and complicated, but let us remember – whatever autism is, it is never boring.

Bibliography