Eating difficulties in children and young people with disabilities

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West London Mental Health
NHS Trust
Contents

3. Introduction

5. Understanding eating difficulties in children with learning disabilities

10. Managing eating/feeding difficulties

23. Pica

25. Overeating and obesity

29. Eating disorders

31. Example food diary
Introduction

What are eating/feeding difficulties?

Behavioural difficulties at mealtimes

• Refusing to eat
• Selective eating/food faddiness – eating a limited number of foods or only certain colours/flavours/textures (though this may also be due to sensory difficulties in children with ASD – see below)
• Bad table manners
• Refusing to come to the dinner table
• Tantrums at mealtimes
• Eating too fast or too slow
• Regurgitation, vomiting or spitting out food during eating

Pica

• Eating inedible objects e.g. soil, cigarette ash, hair, stones and faeces

Overeating and obesity

• Eating more than recommended daily amounts either through increased snacking or larger portions and requests for more.
• Eating a high fat diet

Eating disorders

• Anorexia Nervosa
• Bulimia Nervosa
• Binge Eating
How common are eating/feeding difficulties?

In a London study of 3-year olds:

- 16% were judged to have poor appetites
- 12% were considered faddy eaters.

In 5-year olds:

- Over one third of the children were described as having mild or moderate appetite problems or eating problems.
- Two thirds of these were considered to be faddy eaters, while the remainder were thought not to eat enough (Douglas, 1989).

Research studies investigating weight status of adults with learning disabilities (LD) found that there are greater proportions of both overweight and underweight people with LD (Simila & Nisahanen, 1991).
Understanding eating difficulties in children with learning disabilities

There are a number of things that may influence the development of eating/feeding difficulties in children or young people with disabilities:

Medical difficulties in babies/children

Children with disabilities may have medical difficulties that have influenced their early feeding experiences. This can disrupt their ability to learn to eat appropriately according to their developmental stage.

For example, if a child has previously been fed by nasogastric tube, they may have missed out on early opportunities to become familiar with food and eating.

Babies and children who have had difficult early experiences with food (e.g. gastro-oesophageal reflux, choking or gagging) may learn to fear eating as they associate it with pain and discomfort, and so avoid and reject food.

Babies who have difficulty with breathing can find it difficult to learn how to coordinate sucking, swallowing and breathing.

Children with epilepsy or heart conditions commonly have difficulties with eating, and tiredness associated with this may also impact on their ability to eat effectively.
Eating difficulties in children and young people with disabilities

**Illness and medication**

Loss or change in appetite is a common indicator of feeling unwell. If there has been a sudden change in your child’s eating behaviour, consider:

- Is your child unwell? For example, some individuals may have gastrointestinal problems or constipation
- Does your child associate eating with pain or choking? Do they have difficulties with chewing, swallowing or jaw function?
- Has your child recently started medication? For example certain medications can have an effect on appetite.

If you are concerned about your child’s physical health then arrange an appointment with your doctor.

If you are concerned that your child has physical difficulties with chewing or swallowing, then it may be helpful to speak to a speech and language therapist.

If your child has eating difficulties and is losing weight (or is very underweight for their age), then you need to speak to a doctor and possibly a dietician.

**Syndromes and disorders**

Certain syndromes and disorders may affect eating behaviour in people with learning disabilities. For example:

- People with **Prader-Willi Syndrome** have an insatiable appetite and eat excessively even when they are full.
This can lead to chronic obesity and behavioural problems such as aggression when someone is prevented from having food.

- People with **Down’s Syndrome** can have a small oral cavity and delayed development of teeth, which can result in difficulties with chewing.

- People with **cerebral palsy, epilepsy or degenerative disorders** may also have difficulties with eating and swallowing.

- **Hyperphagia** (eating excessively and not feeling full) can be a characteristic of some other syndromes. This can result in food grabbing, eating inedible objects, obesity and behavioural problems.

- Children and young people with an **autistic spectrum disorder (ASD)** commonly show eating difficulties such as food refusal, selective eating, over-eating and behavioural problems at mealtimes. They may have a preference for routine and sameness, and this may mean that meals need to be at the same time everyday, in the same place.

  This may also extend to them wanting to eat the same foods every day. People with ASD often pay close attention to detail and may become upset if the positioning of food on a plate is altered, or food is slightly over/undercooked (even if you may not notice this).

  They may become upset if food packaging is altered. Sensory difficulties experienced by people with ASD mean that a child may be particularly sensitive to texture, taste, smell and noise, which will affect what and where they eat.
Severity of learning disability

The risk and severity of certain eating difficulties such as Pica (eating inedible substances) increases with increasing severity of LD.

In addition, swallowing, vomiting and regurgitation can be a common problem for people with a SLD. It is extremely distressing for family and carers, and often it is difficult to determine the cause because of difficulties with communication.

Some possible causes include hiatus hernia and gastrointestinal disease, poor posture during and after meals, food being eaten too quickly or not chewed properly. Being moved or re-positioned too quickly can also lead to vomiting or regurgitation.
Care-givers responses to eating difficulties

Often a child’s lack of interest in eating can turn into a power struggle, even when the initial underlying cause of the difficulty is medical.

A child refusing to eat can cause great stress for parents and care-givers. Parents worry that their poor eating will lead to illness, malnutrition, weight loss and life-long problems.

In addition, often parents work very hard to prepare a nutritious meal for their child, and understandably feel angry and upset when their child refuses to eat it.

These situations can result in parents pleading, urging, criticising, threatening or punishing children for not eating.

Unfortunately children may then learn that this is a way of controlling or getting a reaction from parents.

When eating becomes a battle of wills, parents cannot win by forcing their children to eat. Force will only aggravate the problem and children may even choose to endanger their health rather than give in.
Managing eating/feeding difficulties

Create a Food Diary

If you are concerned about the diet of your child this will provide you with useful information about their eating pattern, including what they eat, how much and where. You can use the example food diary at the back of this leaflet as a guideline.

- Encourage children to become familiar with food and eating
- Look at books with your child on food and eating to help them understand why we need to eat (ask school about these)
- Encourage your child to handle food. This could include messy play with foods, and helping out with meal preparation (see below)
- Make a food chart. If your child can write, ask them to write or draw a list of the foods that they like and dislike. You could also ask them to think about foods that other family members like and dislike. At the bottom of their list write “This week I will try (name of food)”. Agree with your child which food they will try – you could give them a number of foods to choose from.

If your child has more severe learning disabilities and limited communication, you could use choices of two food choices to help ascertain their food preferences. If you wish to expand the range of food types within their diet you could consider providing a more desirable food type as a reward for eating something else.
Prepare for mealtimes

The period between 4.30pm and 6.30pm in the afternoon can be a difficult time for parents. Parents and children are often tired at the end of the day, and parents have a lot to do during this time e.g. prepare meals, help with homework, keep children occupied.

Common problems at this time include children whining and demanding attention or complaining about being hungry.

Children are often better behaved during this time if there is something they can do to help during meal preparation. Often parents prefer the child to be out of the way so that they can organise the meal without interruptions.

However, being involved in cooking helps children learn new skills. In addition, being involved in meal preparation often encourages the child to eat the meal.
Finally, involving the child in cooking keeps them occupied, thus reducing the likelihood of temper tantrums and complaining.

It is best not to compel young children to help, but to give them the opportunity if they wish. Boys and girls can be invited to help out with kitchen tasks under close supervision. Here are some guidelines:

- **Plan a weekly menu of balanced meals.** Include some of the child’s favourite meals and avoid serving meals that they do not particularly like on consecutive nights.

- **Try to have a regular time for meals each day.** This can be important for some children, but you can allow some flexibility. For example say lunch will be between 12.15pm and 12.30pm.

- **Before each mealtime ask your child if they would like to help.** Let them know that you are about to prepare dinner and suggest something that the child can do safely while you watch e.g. setting the table, handing you items from the fridge, washing vegetables. If your child wants to do something that is too hard or dangerous (e.g. chopping), explain that they cannot help in this way and suggest something else instead. If they do not want to help and would prefer to continue playing quietly then that is fine.

- **Interrupt what your child is doing every so often to praise your child for appropriate behaviour.** This is particularly important for children who have been disruptive and demanding during meal preparation.
• If your child interrupts, demands or whines during meal preparation, describe the problem behaviour. Calmly but firmly tell your child that you don’t want to be interrupted while you are preparing dinner. Offer a choice of either playing quietly or helping prepare the meal.

• Give your child a warning before serving the meal. Ten minutes prior to the meal being served, tell your child to clear away any game or activity and go to the bathroom to wash their hands.

• Invite your child to assist you in serving the meal. There will be times where it is not possible for your child to help out with meal preparation – e.g. if you are in a hurry or have a special dinner occasion. At these times let your child know that they cannot help and suggest an alternative activity.

Handling behaviour problems at mealtimes

The key to overcoming this problem is to make being at the dinner table as positive and rewarding as possible. This goal is best accomplished by setting reasonable, attainable goals and by providing positive attention for proper eating.

Here are some guidelines:

• Try to relax. Take some time to disengage yourself from the power struggle and think about why you are so upset about your children’s eating habits.
Are you worried about nutrition and health? Do you feel that their response is another example of them not appreciating you? Do you worry that the behaviour will continue to escalate and your child will develop an eating disorder?

By understanding your own emotional response, you will be able to control your reactions and deal with the problem more effectively.

- **Consider your child’s hunger level.** Although most adults have been socialised to believe that meals should occur three times a day, that is often not the schedule that best suits young children.

  Most children need four to five smaller meals a day: morning, mid-morning, noon-time, mid-afternoon and evening. If your children have a snack at 3.30, they may not have a big appetite at 6.00. Some mealtime battles can be eliminated by accepting that your child does not have the same appetite as you.

  If they eat nutritious snacks mid-morning and mid-afternoon, you don’t need to be concerned about them having a big dinner.

  However, if you do have concerns about their health, check with your paediatrician to ensure that their weight for height is within normal limits. Remember not to judge adequate nutrition by the quantity of food eaten since there are wide differences in the amount of food individuals need. Set a goal with your child for the amount of food to be eaten e.g. all of the vegetables and half of the stew.
Make sure that you set a goal that your child has a reasonable chance of achieving. Don’t try to make them eat everything on their plate. It is more important that they sample the foods presented.

- **Eliminate constant snacking and junk food.** On the other hand, don’t let your children nibble all day long or they will learn poor eating habits. If they eat constantly, they never have the opportunity to read their body’s hunger cues.

Limit your child’s access to food to no more than five times a day, at regular times. This teaches them that opportunities to eat are limited. The logical consequence of this is that if they skip a meal or snack, they will feel hungry.

Ultimately, you want them to learn to eat when they are hungry and not eat when they aren’t.

Also try to encourage your child to avoid junk foods such as salted crisps, sugary drinks and sweets. These foods spoil mealtime appetites, and their artificial flavourings can become almost addictive, decreasing your child’s interest in more nutritious foods such as fruit and vegetables.

In addition, milk and fruit juices can be filling so avoid giving them to your child for one hour before mealtimes. Instead give them water if they are thirsty.

Some parents are reluctant to be firm over between-meal snacks because they are afraid that it is unfair
or their child will starve. However, if a child can eat whenever he/she likes then there is no incentive for them to learn how to eat normally and eating difficulties can continue over many years. It is important to establish good eating habits as early as possible.

- **Have time limited meals.** Some children drag mealtimes out by eating slowly, complaining at every mouthful and playing with their food. Instead of letting meals drag on and on, determine a reasonable amount of time in which you will expect your children to finish eating, perhaps 20-30 minutes.

Make sure that the meal is ready before calling your child to the table to reduce unnecessary waiting. Explain ahead of time that when the timer goes off, their plates will be removed. Don’t nag or plead if they don’t eat, and resist the urge to countdown the minutes, but do give your child one warning.

When the timer does go off, calmly remove their plates. If they haven’t eaten much, you might say, “well I guess you’re not very hungry today”.

The goal is to make them feel responsible for their own eating. This may involve allowing them to go hungry after several uncompleted meals.

Once they realise that time is limited and experience the logical consequences of not eating, they may become more interested in eating at mealtimes rather than trying to get your attention by not eating.
For more severe eating difficulties, you may need to help your child get started with eating by prompting them and praising them for each mouthful. Once your child is eating ten to twenty mouthfuls, you should start to reduce these prompts.

The time limited approach may be useful if your child finds it difficult to remain seated at the table throughout a meal.

Youngsters do not have much tolerance for the adult concept of meals, where people sit for long periods, eating slowly and chatting. They learn to endure and even enjoy the process, but this comes slowly. Initially, you must accept that they won’t want to stay at the table once they have finished eating.

Decide how long you can reasonably expect them to pay attention to their food and remain seated.
For a child with learning disabilities, this may only be ten minutes. Whatever you decide, set a timer for this interval. When it goes off, your children may leave the table. This should reduce fidgeting and complaining during meals.

- **Offer limited choices.** If your child is picky and refuses to eat most of the usual family food, give them an option. Allow them to eat what the family eats or, instead, one type of nutritious food that they like.

The choice should be made well before each meal, so that you are not forced into last-minute preparations.

Providing such an option diminishes the power struggle that results when you try to force them to eat a particular food.

By giving them an alternative, you give your child a way out of the conflict without them winning by refusing food altogether. It also introduces the idea of compromise, a concept that is useful in resolving all types of conflict.

Offering choices indicates that you’re willing to give them some room to negotiate. Finally, when you offer an alternative you know they like, you don’t have to worry that they will starve.

In time, when your child realises that mealtimes are not battlegrounds for control, it is likely they’ll become more interested in trying new foods.
• **Serve small portions.** Often parents base the size of their portions on what they think their children should eat, rather than their actual needs or appetites. Children may not be hungry and resent having food forced upon them. Allow them to serve their own portions if possible. Having some control over the food that goes on their plates may reduce the struggle over the food that goes into their mouth.

For younger children, offer small portions (less than you think they’ll eat) to lead to a sense of successful eating. Sandwiches can be cut into quarters, drinks filled only halfway, etc. It’s very pleasant to have your child ask for more instead of complaining about having too much.

• **Ignore picky eating and bad table manners.** Shouting, nagging and criticising can often reinforce eating difficulties and escalate power struggles. Children learn that refusing to try foods or playing about with food is a powerful way to gain attention. Try to ignore eating behaviours that are irritating so that you are not giving your child attention for misbehaving.
• **Praise good eating and table manners.** If your child displays behaviour which challenges at the table, find opportunities to praise them or other children when they are behaving appropriately. For example, praise your child for staying seated, using cutlery carefully, trying a new food, talking quietly.

If one child is eating mashed potatoes with their fingers, you could praise their sibling for example by saying “Good using your fork!” When you pay attention to good manners, your child learns that this behaviour receives praise and inappropriate behaviour does not.

• **Reward good eating and behaviours.** You could also make a tangible reward system, such as a reward chart that lists a number of mealtime behaviours like staying seated until the timer rings, talking quietly, and finishing their food before the timer rings (example opposite).

At first, you may find it most effective to reward behaviours other than eating. Removing the focus from eating emphasises that food is not a source of conflict between you and your child. Therefore, what goes into their mouth is their choice.

• **Use natural or logical consequences.** Nagging or threatening your child if they refuse to eat is not effective.

You cannot force your children to eat at mealtimes, but you can have control over what they eat between meals. Hunger is a natural consequence of not eating so use it to your advantage.
Explain to your child, “If you do not eat your lunch by the time the timer rings, I will take the plate away and there won’t be any snacks until dinner.”

If you regularly serve pudding, the logical consequence of not eating the main course is to miss out on pudding. Do not make children sit at the table after other family members have left, as this will lead to negative associations with mealtimes.

- **Gradually increase food variety.** Once your child is eating about fifteen mouthfuls or more each mealtime, you can start to work on increasing the variety of food that they will eat. Add a very small amount of one new food to the meal. Reward your child with a sticker, smiley face or lots of praise for trying the new food (even if they just have a very tiny bit or only lick it). At the next meal try another food.
Once your child has tried new foods, occasionally add them to the regular meals you serve. Gradually increase the amounts and keep adding new foods. If your child has a particularly negative reaction to one food, leave it out for a couple of weeks and try again.

Everybody dislikes some food. The aim is to have your child eating a range of foods from the different food groups in the same way as the rest of the family.

For some children you may need to introduce new foods very gradually over a few weeks, rewarding your child with praise and stickers when they reach each target.

For example:

- Have a new item on the table
- Place a small piece on the plate
- Encourage your child to touch the new food
- Encourage your child to lick the new food
- Encourage your child to hold the food in their mouth
- Encourage your child to chew and swallow a small piece of the food
- Increase the amount of food they will eat
**Pica**

Pica is a feeding disorder characterised by repeatedly eating inedible objects over a period of one month or more. The behaviour must also be inappropriate for the child’s developmental level.

Common examples of pica include eating cigarette ends, paint chips, faeces, paper and dirt. Addiction, nutritional deficiency and mental health problems have all been connected to the development of pica.

Research has suggested that between 4% and 26% of people with learning disabilities show pica, and the likelihood of pica occurring increases the more severe the level of learning disability.

Pica is one of the most dangerous eating difficulties for people with disabilities. Eating inedible objects may lead to physical consequences such as gastrointestinal obstruction, choking, illness and poisoning.

**Managing Pica**

- **Assess and alter the environment**
  Survey your child’s physical environment and think about if it could be arranged in a way to make pica less likely to occur. For example, if pica tends to occur when your child is bored then keep them occupied.

  If it tends to happen when they are alone, then try to supervise your child whenever possible. If your child eats a certain item (e.g. paper) then try to keep that item out of your child’s reach unless they are being closely supervised.
• **Consider the relationship between pica and other difficulties**
  For example, does your child have any nutritional deficiencies? If so, arrange to see your doctor who may suggest supplements or medication.

  Did the pica coincide with other changes in your child’s mood or behaviour? If so the pica could be connected to emotional, behavioural or mental health difficulties. If you are worried that this is the case then arrange for your family to meet with a clinical psychologist.

• **Offer alternative activities, praise and reward to discourage pica**
  For example, encourage your child to engage in activities that they enjoy and that keep their hands busy (so they cannot engage in pica).

  If you are with your child and they try to eat an inedible object, gently remove the object from them and calmly tell them “no” they should not eat that.

  Do not give your child positive or negative attention for the behaviour. Instead, praise your child with words, hugs, smiles and/or sticker charts when they do not show pica.
Overeating and obesity

Obesity is when a person is carrying too much body fat for their height and sex. A person is considered obese if they have a Body Mass Index (BMI) (weight in kilograms divided by their height in metres squared) of 30 or greater.

Obesity can happen when you eat more energy (calories) than you burn off over a period of time. The rate at which you burn off calories from food and drink is known as your metabolic rate.

This is often faster during growth spurts and puberty, but reaches a fairly steady rate by adulthood. People who are very active generally have a higher metabolic rate than those who are inactive because they burn off calories faster through energetic activity.
Most of us have more food than we need, and much of it is higher in calories than the human body was originally designed to cope with. Fast foods, high calorie snacks, and large portions all mean it is easy to take in more energy than we need.

Obesity has now become one of the most serious medical problems of the western world. According to figures from the National Audit Office, being obese can take up to nine years off your lifespan.

It also makes you far more likely to develop a range of health-related problems, including diabetes, heart disease, high blood pressure, gallstones, infertility, osteoarthritis, some types of cancer, and depression.

Obesity is not just a problem that affects adults. The number of obese children has tripled over the last 20 years. At least 10% of six year olds and 17% of 15 year olds are now clinically obese.

Childhood obesity should not be dismissed as ‘puppy fat’ - it is a strong indication that the child will be obese as an adult and is likely to lead to serious health risks in later life.

**Causes of obesity**

- **Eating habits** are an important factor in influencing weight. Eating more calories than you need may be down to poor food choices - for example, eating high sugar, processed, or fast food - rather than filling up on fruit, vegetables and unrefined carbohydrates, such as wholemeal bread and brown rice.
• **Lack of physical activity** is another important factor that is related to obesity. If we are not active enough to use up the energy provided by food, the extra calories are stored as fat instead.

• **Medical reasons.** Scientists have discovered certain genes that make you feel hungrier, or make it take longer for you to feel full, which can lead to obesity. In addition certain disabilities may be associated with hyperphagia – whereby somebody feels constantly hungry.

This can result in overeating, grabbing food at any opportunity, pica and obesity. Certain medications can contribute to weight gain. In very rare cases an under-active thyroid gland may cause weight gain.

**Managing overeating and obesity**

The best way of tackling obesity is to reduce the amount of energy that your child eats and encourage them to be more physically active. Here are some guidelines:

• **Increase your child’s activity levels** by supporting them in physical activity that they enjoy e.g. swimming, going to the park, dancing to music, trampolining. Praise your child for taking part in physical activities.

• **Encourage your child to eat three meals** (breakfast, lunch and dinner) plus two snacks per day (3+2=less!). This will stabilise their blood sugar levels giving them more energy and reducing the need to binge eat.

• **Encourage your child to eat sitting, sociably and slowly.** Eating quickly while standing up can trick us into eating too much as our brain does not know when our stomach is full. Praise your child when they manage to do this.
• **Eat fruit and vegetables.** Encourage your child to fill up on fruit and vegetables. Try to give them at least 5 servings of fruit and vegetables a day. Give your child fruit and vegetables as snacks instead of high energy foods. Praise your child for eating fruit/veg.

• **Base meals on starchy foods** such as bread, potatoes, rice, noodles, pasta, etc – these are low fat foods that will help your child to feel full.

• **Include dairy foods** (cheese, milk, yoghurt) and **protein** (lentils, beans, fish, meat) in your child’s diet.

• **Limit high fat or sugary foods** such as butter, cooking oils, pastry, chocolate, biscuits, crisps and sugary/fizzy drinks.

• **Read food labels** and choose foods that are low in energy and fat, and high in fibre and vitamins/minerals.

• **Model healthy eating and exercise.** Children learn healthy eating habits from their family.

• **Focus on positives.** Try not to criticise your child or give them negative messages (e.g. “you’re lazy”, “you’re greedy”). Criticism is likely to make your child feel negative about themselves and thus make weight even harder for them to manage.

  Instead, focus your attention on times that your child does well – e.g. when they eat fruit and vegetables, or take part in an activity (even very small successes).

*If you are very concerned about your child’s weight or overeating, speak to your doctor.*
Eating disorders

These often become more noticeable in adolescence, and may be connected to a number of psychological issues including:

- Feeling helpless (thus using eating to gain some control)
- High achievers and perfectionism (expecting a lot from self and others and setting impossibly high targets)
- Avoiding growing up (starvation delays menstruation and the physical process of becoming a woman)
- Comfort eating.

The main types of eating disorder are:

**Anorexia nervosa**

Anorexia is where someone restricts their eating to the extent that they maintain a very low weight or lose weight dramatically, compared with the standard weight for their age.

A person with anorexia will believe they are fat, however thin they appear to other people. They may also become preoccupied with exercise or running. Anorexia may cause serious health problems, such as irregular periods; dizziness and fainting; heart, bowel and kidney problems; seizures; brittle bones, and hair loss.

Anorexia is also associated with a number of other psychological difficulties, including disrupted sleep; anxiety; poor concentration and motivation; depression and self-harm.
Binge eating and bulimia nervosa

Binge eating usually involves periods of self-denial or extreme dieting, followed by eating large amounts of high energy foods accompanied by feelings of loss of control, anxiety, guilt or distress.

When this urge is followed by a desire to purge oneself (by vomiting or laxatives), this is known as bulimia nervosa.

The signs of bulimia are less obvious as often a person’s weight may remain within the normal range. However you may notice binge eating, using the toilet to vomit after meals, eating secretly or hiding food.

What can you do?

If you are concerned that a child or young person you know has an eating disorder, the most helpful thing to do is:

• Listen to them
• Encourage the person and their family to get some support by speaking to their GP or other doctor
### Example food diary

**Week starting: ..................................................**

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<th>Times of eating</th>
<th>What was eaten?</th>
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