

# ESSS Outline Obesity and weight management in children and young people with autism

Robert Sanders 11 December 2020

# Introduction

This summary provides an overview of evidence relating to obesity and weight management in children and young people with autism.

#### About the evidence presented below

We searched for academic research and grey literature using a wide range of search terms including: obesity, weight, food, food selectivity, eating, teenagers, children, young people, autism, autism spectrum disorder (ASD), aspergers, interventions, support, treatment, and weight management.

There are evaluated weight loss interventions effective for typically developing children and young people, but very few for those with autism. There is little evidence that these general interventions are transferable to those with ASD.

### **Accessing resources**

We have provided links to the materials referenced in the summary. Some materials are paywalled, which means they are published in academic journals and are only available with a subscription. Some of these are available through <u>The Knowledge Network</u> with an NHS Scotland OpenAthens username. The Knowledge Network offers accounts to everyone who helps provide health and social care in Scotland in conjunction with the NHS and Scottish Local Authorities, including many in the third and independent sectors. <u>You can register</u> <u>here</u>. Where resources are identified as 'available through document delivery', these have been provided to the original enquirer and may be requested through NHS Scotland's <u>fetch item service</u> (subject to eligibility).

Where possible we identify where evidence is published open access, which means the author has chosen to publish their work in a way that makes it freely available to the public. Some are identified as author repository copies, manuscripts, or other copies, which means the author has made a version of the otherwise paywalled publication available to the public. Other referenced sources are pdfs and websites that are available publicly.

# Background

Autism Spectrum Disorder (ASD) is a developmental disorder characterised by social and communication impairments and repetitive behaviors. It is estimated to affect around 1 in 160 children around the world (<u>Dhaliwal, 2019</u>).

The prevalence of obesity is seen to be significantly greater among children with ASD, compared to the general population. Overweight and obesity can have a detrimental effect on physical health, social and emotional well-being, self-esteem, and quality of life.

The key significant risk factors reported in the literature that contribute to weight problems and obesity are increased sedentary behaviors, sleeping and feeding problems, and difficulty engaging in physical activity (<u>Nor, 2019</u>).

# Evidence

The available evidence on the prevalence and association of obesity in children and young people with ASD is inconsistent, but there is a small but growing body of research on food, physical activity, screen-time and weight issues in children and young people with ASD.

Body weight is determined by energy balance, which is influenced by environmental (e.g. nutrition), behavioural (e.g. food selectivity), and biological (e.g. metabolic dysfunction) factors. There are significant comorbidities with ASD, making associations difficult to separate and research difficult (Dhaliwal, 2019). Many studies rely on self-report data and measures and are limited by lack of comparators and small sample sizes.

Very few studies have targeted weight loss in children with ASD.

# Reasons for weight issues

Adolescent obesity rates are rising generally, and adolescents with ASD are particularly vulnerable due to hallmark characteristics related to the disorder (<u>Strahan, 2016</u>). Unhealthy weight in children and young people with ASD (and the interventions for managing it) are likely to be multifactorial.

Increased rates of overweight and obesity could potentially be explained by several mechanisms (<u>McCoy, 2019</u>; <u>Balogun, 2016</u>) such as:

- 'food faddiness' (being exceptionally fussy about food)
- sensory difficulties related to diet
- increased calorie intake
- sedentary lifestyle (characterised by preoccupation with armchair entertainment such as games consoles and television)
- lack of physical activity
- medication usage

Corvey (2016) argued that ASD diagnosis and severity were not independently associated with obesity or overweight status or the likelihood of engaging in physical activity after controlling for secondary conditions and medication use. Decision makers, clinicians, and researchers developing interventions for children with ASD should consider how secondary conditions may impact weight and related activities.

#### **Medication**

Most studies and literature tend to focus on food or physical activity but medications such as atypical antipsychotics prescribed to young people with greater ASD severity can be associated with weight gain. One systematic review showed that those taking antipsychotics had a weight gain of 2.7–2.8 kg compared to placebo groups (McCoy, 2019; McCoy, 2016).

# Food and eating

An estimated 46–89% of children with autism spectrum disorder (ASD) have feeding problems, which may include unusual eating patterns, rituals, and food selectivity (<u>Bandini, 2017</u>).

Reasons for feeding difficulties may be related to core autistic features such as insistence on sameness and rigidity, as well as sensory issues (<u>Matheson, 2019</u>). These abnormal feeding behaviors and patterns along with limited dietary intake could influence weight status (<u>Dhaliwal</u>, 2019). But it is not clear from the current literature to what extent feeding behaviour is a contributor to excess weight gain in children and adolescents with ASD.

#### Food selectivity

Children with ASD are frequently associated with picky eating and aversions to specific textures, colours, smells, temperatures, and brand names of foods (<u>Nor, 2019</u>). Many require foods to be presented in certain ways (i.e., on a special plate or with specific utensils) (<u>McCoy, 2016</u>).

The degree of food selectivity appears to be an important indicator of acceptance or rejection of food and may promote unhealthy weight status and obesity (<u>McCoy, 2019</u>; <u>Nor, 2019</u>).

Adolescents with ASD eat a significantly narrower range of foods and prefer more calorically dense foods. They have a significantly different diet composition compared with their typically developing peers (consuming more processed foods, sugary beverages, snack foods, and less fruits and vegetables) (McCoy, 2019).

Limited intake of fruits and vegetables, due to factors such as taste and texture, has been associated with weight change (<u>Dhaliwal, 2019</u>).

Strahan's study (2016) looked at food selectivity in American adolescents with ASD. It showed the adolescents were distinctively

selective in the type of food items they chose. Similar studies show adolescents with ASD preferring energy dense foods such as fries, chips, cakes, hot dogs, and pizza. This preference may contribute to obesity in adolescents with ASD (<u>Strahan, 2016</u>).

Bandini's study (2017) assessed food selectivity and changes, in children with ASD between two six-year time points. Food refusal, including fruit and vegetable, improved overall with age, but with no increase in food repertoire (number of unique foods eaten). Half of the participants with high food selectivity at baseline remained high at the follow-up. These findings support the need for interventions early in childhood to increase variety and promote healthy eating. The study, consistent with others, observed a significant increase in the prevalence of obesity at follow-up.

Food selectivity has been associated with parental stress (<u>Bandini</u>, <u>2017</u>). Another possible risk factor for obesity is the use of food as a reinforcer to calm children down (<u>Nor, 2019</u>). Improved food choices may not be offered in an attempt to maintain mealtime routine and decrease disruptive mealtime behaviour (<u>Strahan, 2016</u>).

Gastrointestinal disturbances are frequently reported among the ASD population and this could potentially affect food intake and food choice (<u>Nor, 2019</u>).

### **Physical activity**

Atypical physical activity among children and adolescents with ASD has been suggested as an explanation for high obesity rates in this population (<u>Balogun, 2016</u>). Adolescents with autism spectrum disorder were found to engage in less physical activity than their typically developing peers. As parent-reported autism spectrum disorder severity increased, the adjusted odds of being overweight and obese significantly increased and physical activity participation decreased (<u>McCoy, 2019</u>).

Reasons for this are generally found to be related to:

• physical limitations such as impaired coordination

• impaired social communication restricting participation in group exercises in and out of school

Access to physical activity sessions and weight management interventions may be restricted due to factors associated with autism. Findings suggest a need for targeted programs to decrease unhealthy weight status and support physical activity opportunities for adolescents with autism, particularly for those at the severe end of the spectrum (McCoy, 2019; Balogun, 2016).

A small study based on the TEACHH program demonstrated that small and inexpensive modifications can improve the involvement of children with ASD in physical activity sessions (<u>Balogun, 2016</u>).

More research is needed to determine if physical activity interventions are effective in increasing regular physical activity and decreasing overweight and obesity in this at-risk population (<u>McCoy, 2016</u>).

# Approaches and interventions

Obesity is multi-faceted and challenging to manage in children with ASD, and the risk of increases with adolescence and a corresponding decline in physical activity.

It is important to identify these risk factors and potential treatments and interventions to support weight loss and management (<u>Matheson, 2019;</u> <u>Nor, 2019</u>).

Despite the need for targeted weight management interventions there is a lack of evidence-based weight-loss and management treatments for young people with autism.

Generally, the standard management for obesity in children and adolescents generally is diet, increasing physical activity, and reducing physical inactivity. These are carried out using behaviour modification techniques for modifying eating habits and improving activity patterns, and the involvement of the family in weight management (<u>Nor, 2019</u>).

Findings suggest the need for clinical settings to monitor weight status of children and youth with autism spectrum disorder in a bid to manage or prevent overweight / obesity (<u>Granich, 2016</u>).

# Typically developing

Weight loss interventions for typically developing children - focusing on nutrition, physical activity, and behavioural management techniques - tend to show positive effects (<u>Dhaliwal, 2019</u>; <u>Healy, 2019</u>).

Whether these weight loss interventions are transferable or generalisable to children with ASD is under-researched but does show weight management to be more challenging. Several factors might affect this.

Participants in Kinnaird's study (2019) commonly viewed the aspects of autism that contributed towards their eating behaviours, such as sensory sensitivity, as intrinsic and unchangeable. These characteristics can conflict with weight loss behaviours.

Children with ASD, can struggle with social and behavioural communication, and changes in routine. A lack of social partners or preference for sedentary behaviour can conflict with attempts to increase physical activity. Restricted dietary habits, such as high calorie foods, may limit efforts to reduce calorie intake. There are further complications from the comorbidities associated with ASD and obesity, such as sleep problems and gastrointestinal disorders (Dhaliwal, 2019; Healy, 2019).

#### Adaptions

Research into weight management programs for children and young people on the autistic spectrum suggest that successful interventions involve individualisation, including tailoring of any dietary or behavioural recommendations to consider aspects such as sensory sensitivity (Kinnaird, 2019).

Adaptations to the weight loss programmes available to the general population could make them more accessible. Evidence from Public Health England (<u>2016</u>) on people with learning disabilities shows that:

- mainstream health promotional resources are likely to require literacy skills and often use abstract images - accessible information and resources are needed
- people with learning disabilities benefit from a multi-disciplinary and multi-component approach that takes an individualised approach
- people need support to understand the risks to their health to aid sustained motivation - training and appropriate information can help people to feel more positive about physical activity
- the involvement of peer partners without disabilities, who provide reciprocal support, has been shown to encourage participation in exercise in community settings

Croot's study (2018) aimed to identify adjustments to the Slimming World weight management programme to improve accessibility and assess acceptability and feasibility for people with intellectual disabilities. People taking part in the study were positive about the adjustments and lost weight, but wider issues limited the acceptability of Slimming World even with these adjustments. It suggests that environmental and organisational level interventions are needed alongside those targeting individual behaviours.

# Food

Physical changes of foods may improve impaired sensory processing of ASD children to promote their fruit and vegetable acceptance. Chung's study (2020) lasted for 4 weeks, with three episodes of fruit and vegetable exposure per week, taking place in schools in a quiet room. Food transformation constituted changing bananas into ice-cream, courgettes and sweet potatoes into chips, apples and kiwis into popsicles, and carrots into juice. ASD children increased their consumption of all fruit and vegetables, but only banana consumption

was statistically significant. For habitual consumption, parents reported increases in all consumption for all fruits and two of three vegetables.

Chawner's systematic review (2019) looked to identify different types of interventions promoting increased acceptance of new foods or dietary variety for those with development disorders and to determine their effectiveness. Multiple component interventions based on operant conditioning, systematic desensitisation and combined environmental and family-based interventions appear effective when applied to the individual. Environmental changes at mealtimes appear to be less effective and less researched in this population, whereas behavioural interventions grounded by learning theory, such as systematic desensitisation, and reinforcement appear to be effective at increasing intake for a variety of novel foods.

Galpin's study (2018) examined the effect of a whole class, Sensory Snack Time intervention, carried out in a special school setting that was integrated into part of the daily school routine. Results indicated that pupils ate a wider variety of foods and displayed significantly reduced food selectivity, distressed mealtime behaviors, and food refusal following the 12-week intervention. Further research is needed around the potential for the intervention to be generalised to main meals and different settings, such as pupils' homes.

### **Physical activity**

McCoy's study (2019) examined the links between physical activity behaviours and BMI classification in children and adolescents with ASD. Findings suggest that as BMI increases, physical activity decreases and interventions targeting physical activity behaviors may potentially impact unhealthy weight status.

Arslan's study (2020) aimed to determine the effects of a circuit exercise program on the physical fitness parameters of children with atypical autism spectrum condition. Significant improvements were observed in running speed and agility, balance, standing long jump, reaction times, handgrip strength, and flexibility. It recommends children with autism

start sports training immediately when diagnosed with autism and participate in structured physical activities with their peers.

Garcia's pilot study (2020) demonstrated preliminary efficacy of an 8week judo program to promote physical activity in young people with ASD. Participants attended most of the judo sessions and 50% of the sample continued participation in judo or a similar martial arts program following the 8-week program, suggesting that a judo program may be well-received by this population. Preliminary results showed favourable increases in physical activity following the 8-week program.

One intervention noted in Healy's review (2019) featured the use of a treadmill walking protocol, individualised in speed and progression rate based on the ability and behaviour of the participant. The simple, individualised, solitary, and highly structured nature of the intervention modality used may be a necessary component for successful exercise-based weight treatment interventions for those with severe ASD.

### **Comprehensive interventions**

Comprehensive interventions most often produce favourable outcomes in weight management for typically developing children and young people, and in the limited research on those with ASD. These usually included nutrition, physical activity, and motivational components. Healy's review (2019) demonstrates the potential of these interventions, particularly individualised, comprehensive, and multidisciplinary teambased interventions, some of which are highlighted below.

#### Family or parent based behavioural treatment

The current gold-standard behavioural intervention for weight loss in children is family-based behavioural treatment (FBT), which is provided to both the parent and child and provides nutrition and physical activity education in addition to parenting skills and behaviour modification strategies. Studies show that parent-based treatments (PBT) are as effective as parent and child treatments in promoting weight loss in the target child (Matheson, 2019).

Matheson's study of a parent-based weight-loss treatment for children with ASD (PBT-ASD) found both children and parents lost weight from pre- to post-treatment. Parent-reported child physical activity and vegetable consumption increased at post-treatment. The TEAM UP program consisted of 16-weekly, hour-long, parent-only sessions. At week 8, both the parent and the child attended the group to promote adherence. Treatment focused on four target areas: dietary recommendations / calorie reduction, physical activity, behaviour change, and parenting strategies. Behavior therapy targets included selfmonitoring, stimulus control, portion control, goal setting, planning for high-risk situations, utilising motivation systems, and relapse prevention.

Ptomey's study (2016) aimed to better understand parents' perspectives on the strategies and barriers for helping children and adolescents with intellectual and developmental disabilities manage their weight. Parents reported a positive attitude toward the program, liked the convenience of the program, and felt that they learned beneficial strategies to encourage healthy habits in the home. Parents found time to be a major barrier to supporting their child with a diet and physical activity intervention.

Parents play a large role in weight management in children and adolescents with intellectual and developmental disabilities, and their views should be taken into consideration when designing a diet and physical activity intervention for weight management. Healy's study (2018) examined how parents of children with ASD perceived mediating a physical activity intervention delivered via a private Facebook group. It suggests parent-mediated, web-based interventions may have the potential for improving the effectiveness of physical activity interventions for children with ASD.

#### Intervention examples

Duhanyan's study (2020) examined a residential health and wellness intervention for students with ASD. The primary methods were (a) diet / nutrition, (b) exercise / physical activity, (c) health informatics monitoring,

and (d) care provider training. The students lost between 9 and 59 lbs. and had corresponding reduction in BMI. Three of the four students classified as obese preceding the intervention achieved non-obese status; one of them also reached non-overweight status by conclusion of the study. The fourth student was classified as overweight but not obese preceding intervention and subsequently achieved non-overweight status. Parents of the students rated the health and wellness intervention positively around procedures and outcomes.

Hinckson (2020) looked at the effectiveness of a program in managing weight, through changes in physical activity and nutrition behaviors in overweight and obese New Zealand children and youth with intellectual disability or autism. Twenty-two children and their families participated in a 10-week school-based program. The program consisted of 18 sessions focusing on physical activity and nutrition. Most quantitative outcomes were either unclear or trivial. There was, however, a substantial reduction in the consumption of confectionery and chocolate at the two measurement points. Parents commented that during the program there were less hospital visits and absences from school related to illness.

Burrell (2020) evaluated a structured multidisciplinary treatment program, the Changing Health in Autism through Nutrition, Getting fit and Expanding (food) variety (CHANGE) program. Ten children (ages 5-12) with ASD who were overweight or obese participated in either CHANGE or parent education program for 16 weeks. CHANGE provided nutrition and behaviour management strategies, while the parent education program provided ASD education.

Pona (2017) investigated the effectiveness of a specialized multidisciplinary weight management program for children with disabilities including ASD, ages 2-18 years and their families. Significant BMI reductions were observed over the course of treatment. Younger children exhibited greater decreases. The Special Needs Weight Management Clinic involved:

- the family in assessment and goal setting
- the use of a multidisciplinary team including a clinical child psychologist, nurse practitioner or paediatrician, dietitian, and occupational therapist
- the individualisation of all aspects of the program depending on the child and family's needs, including the tailoring of the initial interview, assessments, dietary and behavioural recommendations, and the program schedule

Ptomey (2016) studied an enhanced Stop Light Diet (with the addition of fruits and vegetables), combined with lifestyle modification sessions focused on social support, self-monitoring, physical activity, environmental control, and self-efficacy for young people aged 11-18. SLD's benefits include being easy for children to understand, especially with assistance from parents, and the use of portion-controlled meals reducing the burden on parents. The study also used a tablet to track food and beverage consumption, and to facilitate weekly video-chat meetings between the child and parents, and Registered Dietitian Nutritionists.

In Gephart's study (<u>Healy, 2019</u>) caregivers of young people with developmental disabilities, living in community group homes, were provided with weight management education, and a communication tool that provided information on the youth's diet order, weight and / or BMI percentile goal, activity goal, monthly weight, height, BMI percentile, and any new instructions from the health care team. Almost all young people in the healthy weight category met their goal of maintaining their BMI. Results were less favourable for participants who were already overweight or obese.

# Conclusion

Research on weight management among children with ASD is scarce but does show increasing interest and promise. It remains unknown whether weight management treatments that work for typically developing children can be generalised to those with ASD.

Most of the literature agrees there is a need for comprehensive, individualised, tailored lifestyle and physical activity interventions given the characteristics of ASD, and the challenges and barriers faced by those who live with it. These are likely to include physical activity, dietary, and motivational and behavioural components.

As autism is a spectrum disorder, there may be differing opportunities for interventions depending on severity.

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