

# How should we talk about obesity and weight-related topics with children with autism spectrum disorders and their families?

Project Summary

Centre for Leadership in Child Development

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### WHO ARE WE?

- Amy McPherson, *Scientist*
- Evdokia Anagnostou, *Senior Clinician Scientist*
- Cathy Petta, *Registered Nurse*
- Lorry Chen, *Registered Dietitian*
- Lucia Capano, *Post-Doctoral Fellow*
- Lorena Moltisanti, *Registered Early Childhood Educator*
- Susan Cosgrove, *Family Leader*
- Patrick Jachyra, *PhD Candidate*
- Tara Joy Knibbe, *Research Coordinator*

### WHAT WAS THIS STUDY ABOUT?

Obesity is a global health concern and significantly impacts quality of life for typically developing children, as well as for children with Autism Spectrum disorder (ASD). The purpose of this study therefore was to explore the experiences of children with ASD, families and HCPs specializing in ASD when discussing health promotion and weight-related topics in healthcare consultations.

### OBESITY AND ITS IMPACT ON CHILDREN WITH ASD

Children with ASD appear to be at a higher risk of having obesity than their typically developing peers. One particular risk factor is the use of medications to help control mood and impulsivity, which frequently contribute to higher weights. Although it has been recommended that health care providers (HCPs) speak to families about the potential health risks of unhealthy weight, no work has explored how HCPs communicate with children with ASD and their families about health promotion and weight-related topics.

### WHAT DID WE DO?

We interviewed 8 children with ASD, 8 parents, and 5 HCPs. We asked them about their experiences of discussing and weight-related topics in healthcare settings. We also asked them to tell us about how weight-related discussions could be improved.

### IMPACT FOR CLIENTS, FAMILIES AND CLINICAL PRACTICE

The data we generated provides us with important and valuable insights on how to communicate about weight related issues with families who have a child with ASD.

## WHAT DID WE LEARN?

The information we gathered from children, parents and HCPs grouped into three main categories:

### 1. Managing weight in children with ASD is complex

- Weight and health issues were complicated by a combination of medication side-effects, social dynamics within the home, and quality of life considerations:

*“He’s put on 30 pounds because of the medication, and it’s hard seeing him like that. But if he wasn’t on the meds, he’d be stuck with his behaviour where he gets agitated incredibly easily...It’s not an easy decision but I was desperate to make his life better...I didn’t care how it happened. It was just what’s going to make him happier and make his life better the fastest. He was a suicidal kid” (~Leah, parent)*

### 2. Clinical encounters can be frustrating

- Parents and HCPs were frustrated with weight-related discussions:

*“Sometimes you come to clinic and are told, your kid is overweight. They need to eat better and be more active. But they tell me this as if I don’t already know that...That approach doesn’t work for the majority of people, let alone kids with ASD” (~Natalee, parent)*

*“Because it kind of feels like they’re telling me I’m F-A-T fat. Which isn’t very nice” (~Landon, 13)*

### 3. Wellness not weight is important

- Families, children and HCPs all identified a need to promote overall wellness throughout the life course rather than focusing upon weight:

*“We’re worried about the extent of which [weight]...takes over their life. And then we talk more about healthy habits. Not just losing weight... not obsessing about the number (~ Eugenia, physician).*

## SHARING OUR FINDINGS

We will be sharing our findings with HCPs, children and parents in the coming months through a journal article, conference presentations and at parent meetings

## TO LEARN MORE ABOUT THIS STUDY, PLEASE CONTACT:

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## RECOMMENDATIONS FOR HCPs

- Acknowledge the complexity of the situation
- Engage child in the discussion where possible
- Use clear visuals and examples
- Establish a trusting relationship with the family
- Use a strengths-based approach

## NEXT STEPS

The team:

- is developing a resource to help HCPs have positive conversations with children and families about weight and health
- will be exploring what weight management supports and/or services are desired by children with ASD and their parents

## THANK YOU!

Thank you to the study participants who completed interviews as part of the study. We are also extremely grateful for the support of Centre for Leadership in Child Development and to Sean Peacocke for project management support.

## FUNDING

Centre for Leadership in Child Development