What Matters to the Kids? Perspectives of Children with ASD on Weight and their Bodies

by

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Abstract

Introduction: Overweight and obesity (OW/OB) affects children with Autism Spectrum Disorder (ASD) at high rates, often compromising their health.

Objective: To advance an understanding of OW/OB in relation to children with disabilities.


Results: Numerous actors beyond the individual child must be considered when supporting children with disabilities and OW/OB. While weight-management programs for this population are scarce, existing programs can be accommodated to include children with disabilities. Children with ASD were mostly unconcerned about their weight, view their bodies positively, and value being physically active.

Discussion: Health care providers must critically examine their assumptions about weight. This work promotes shifting focus from weight and body size to health and growth to promote child-centered care.
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Chapter 1
Introduction

1.1 An exploration of higher weight in children with Autism Spectrum Disorder

This master’s dissertation, broadly, explores higher weight in children with Autism Spectrum Disorder (ASD). The overarching goal of this dissertation is to advance understanding of pediatric overweight and obesity (OW/OB) in relation to children with disabilities. More specifically, this dissertation examines: risk factors for OW/OB in children with disabilities using a socioecological lens; weight-management services and supports designed to meet the needs of children with disabilities; and, the opinions and perspectives of the key stakeholders: the children themselves. By taking different approaches to conceptualizing weight and higher weight, we aim to challenge the normative assumptions in society that higher weight is innately bad, and the negative associations about people with higher weight.

1.2 Terminology

To ensure consistency and clarity, in this section of my thesis I will define the key terms that are used throughout. Throughout this dissertation, I use the words child/children to refer to young people ages 0-18 (1). Disability is defined and interpreted differently depending on the study, population, and model within which it’s being contextualized. This thesis primarily focuses upon disability as a clinically diagnosed condition causing impairment or functional limitations. I recognize that disability can also result from an interaction between those impairments associated with a particular condition, and the attitudinal and/or environmental barriers that obstruct their active participation in society (2). Exploring and problematizing disability further is beyond the scope of this project.

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1 As a Master’s student, I was the lead investigator of all three inquiries. I was supported with each manuscript by one or more committee members to the point that they were co-authors on the submitted manuscripts. However, for this Master’s dissertation, which describes my journey as a research trainee, I have elected to use the first-person pronoun “I” throughout.
Throughout this dissertation I use person first language when referring to individuals with disabilities (3). I believe that using person first language emphasizes the fact that children with disabilities are children first and foremost, with their disability a component of their being but notprefacing their personhood.

In Western society, Body Mass Index (BMI) is the dominant way of categorizing an individual as having OW/OB (4,5). BMI is measured by weight in kilograms divided by height in meters, squared (6). According to the World Health Organization (WHO), a BMI between the 85th and 94.99th percentile categorizes a child as having overweight and a BMI ≥ 95th percentile places a child in the category of having obesity (1,7). While I recognize that BMI alone does not provide an accurate understanding of the health, wellbeing, or quality of life of an individual (4), it currently dominates as the consistent way of determining if someone has OW/ OB. Thus, our conceptualization and definition of overweight and obesity being a chronic condition based on BMI remains consistent with the WHO’s definitions. Moreover, I consistently use person first language, referring to people as having overweight or obesity, rather than being overweight or obese, as advocated by the Canadian Obesity Network (8) and Obesity Action Coalition (9). Person first language avoids labelling someone by their condition and works to eliminate and reduce weight related biases and stigma (8).

Throughout this dissertation I consistently use the personal pronoun “I” to denote my work as a graduate student author. Further, I use personal pronouns to emphasize the importance, within an interpretive paradigm, in valuing the role of the researchers and their subjective experiences, positionalities, and biases.

1.3 Rationale/ Evolution of the Study

According to the World Health Organization the prevalence of childhood and adolescent obesity is rising globally (1), affecting about 33% of children (aged 5-17) in Canada (10). OW/OB is typically referred to as a public health crisis and an epidemic (11). It is important to address these normative notions and understand that OW/OB alone is not a public health crisis or an epidemic and that a person’s weight alone is not an indicator of health (12). Higher weight can, however,
put children at risk for the development of numerous physical health conditions (12) that require action and support. Further, the pervasive weight stigma in North American society can be, arguably, equally detrimental to children and have negative psychological, physical, and social implications (5,13,14). All children are at risk for OW/OB, weight-stigma, and the consequences. Children with disabilities, however, are at an increased risk (15,16). Specifically, it has been suggested that children with ASD may be up to 30% more likely to experience OW/OB (17–19) and more serious consequences resulting from weight and weight related stigma.

While OW/OB alone is not a concern or crisis, the conditions resulting from weight and weight related stigma can be detrimental for children with ASD. To address this, we addressed risk factors for OW/OB, weight-management programs and services for children with disabilities, and the perspectives of children with ASD about weight related topics. The first two manuscripts explore different aspects of OW/OB for a broad range of diagnoses and types of disabilities. The third manuscript specifically explores OW/OB for children with ASD, due to the increased risk for this population and the lack of available literature including their unique perspectives.

1.3.1 Manuscript 1

Customarily, energy intake (i.e. food eaten) versus energy expenditure (i.e. physical activity) are considered the main factors affecting weight (20). While this equation is important, it frames OW/OB as a purely individualistic issue, disregarding the impact of environmental, biological, and social factors (21,22). The common focus on an individual’s diet and amount of exercise needs to be expanded to consider broader influencing factors contributing to higher weight. Thus, the first goal of this study was to explore and conceptualize the factors impacting higher weight in children with disabilities. I aimed to shift from the purely individualistic approach to OW/OB that dominates in North American society (23), towards a more holistic approach that considers factors in the environment that put children with disabilities at risk for OW/OB. Thus, I called upon Bronfenbrenner’s Ecological Systems Framework (24) and Davison and Birch’s (21) Ecological Systems Framework to explore the factors in the child’s environment that may put them at risk for higher weight. Davison and Birch adapted Bronfenbrenner’s Ecological Systems Framework to examine the factors in the environment that contribute to higher weight
for children (21) and I expanded this framework to include factors that can impact children with disabilities specifically. I chose to include a variety of disabilities in the framework, rather than focusing only on ASD, as all children with disabilities are at higher risk than their typically developing peers for OW/Ob (25,26). This Ecological Systems Framework proposes that Health Care Providers (HCPs) shift their thinking from individual behaviours, and consider the holistic environment in which the child lives, so that programs, conversations, and supports can address all of the influencing factors contributing to a child’s higher weight. Further, exploring the multitude of factors in the lives of children with disabilities can aim to reduce weight stigma, as it alleviates the individual onus of OW/Ob.

1.3.2 Manuscript 2

During the creation of the Ecological Systems Framework, one of the factors in the macro level was highlighted as needing further exploration: Access to Services. While weight-management programs have become increasingly common across Canada (27), they are routinely designed for typically developing children and often present challenges for the participation of children with disabilities (28–30). I therefore aimed to identify literature describing any available weight-management programs that were designed for a pediatric disability population. To do this, I conducted a scoping literature review using rapid review methodology. We identified four existing programs, reported in five studies, describing existing weight management programs for children with disabilities. Three themes captured commonalities between programs, including: using interdisciplinary teams, family engagement and utilizing technology to deliver the program. All programs reported promising results and engaged children and families during the duration of the program. While alarmingly few programs exist, this review highlights promising features of weight management programs designed for children with disabilities.

1.3.3 Manuscript 3

While it is crucial that weight-management supports and services are available for children who require them, it is equally important to recognize that higher weight alone does not mean that every child requires or desires supports. Our literature search confirmed limited weight-management programs and services for children with disabilities. Thus, we determined it was
essential that we asked children about the weight-management supports and services that they want. It is important that research exploring weight-management in children with disabilities captures the perspectives of children themselves to ensure that programs and supports can be established to best meet their needs.

Given that children with ASD have been identified as a high-risk population, I focused my research on this population. Our study intended to explore the experiences and perspectives of children with ASD with regards to weight-management services and supports. However, during the interviews I noticed that the participants did not seem interested in talking specifically about weight, nor did they appear to be concerned about their weight. The notion of weight-management did not seem to be a priority to them. This called me to examine my assumptions underlying this research. Examining my assumptions and reflecting on them, I recognized that I had internalized the normative notion in North American society that weight needs “fixing” through programs and services (22). These assumptions reinforced the stigmatizing perspective that weight is innately bad and is a problem that requires solutions. I realized that programs and services to address overweight did not seem to matter to my participants. Therefore, this third manuscript explores what does matter to children with ASD with regards to weight and their bodies.

1.4 Purpose and objectives

My overarching goal was to advance the understanding of pediatric OW/OB in relation to children with disabilities.

Objectives:

1. To apply a socioecological perspective to examine the risk factors impacting the development of OW/OB in populations of children with disabilities.

2. To identify weight-management services designed for children with disabilities described in peer-reviewed literature and examine their characteristics and outcomes.

3. To explore what matters to children with ASD with regards to weight and their bodies.
1.5 Research paradigm

This research was conducted within an interpretive paradigm: going beyond purely describing the themes in our data, rather, interpreting and searching for deeper meaning (31). My ontological, epistemological, and methodological assumptions reflect my positionality working within an interpretivist paradigm. The ontological position of this paradigm assumes a subjective interpretation of the world and reality (32,33). Epistemologically, an interpretive paradigm assumes that knowledge is both subjective and co-created (32,33). My epistemological position reflects my understanding of human experiences as being subjective to the individual, and therefore each child will differ in both their experiences living with a larger body and their experiences with weight related matters and conversations (32). Further, within an interpretive epistemological approach it is important that the researcher’s personal experiences and biases are not excluded from consideration, but rather that the researcher explicitly acknowledges these while engaging in critical self-reflection (32). I believe that knowledge is co-constructed between the researcher and the participant (33) and I value the subjective experiences of the researcher as an important contributor to the knowledge I am generating. Lastly, my methodology is that of a phenomenological approach. Phenomenology is a methodological approach that focuses on the essence of human experiences (31). Further, my methodological position reflects an inductive reasoning approach. Rather than generating and testing a hypothesis, I allowed the findings and results to come directly from the data (32).

1.6 Reflections on positionality of the researcher

In qualitative research, specifically within an interpretivist paradigm, value is placed on the experiences, perspectives and knowledge that the researchers bring to the study (34,35). Being reflexive allows readers to understand how the researcher’s own assumptions, experiences and biases influence the ways in which they approach and interpret the research (34).

The ways in which I view the world, and disability and obesity specifically, impacted the ways in which I co-constructed this research with participants. Within an interpretivist paradigm, my experiences and perspectives are seen as a strength in the research, so long as I engage in crucial self-scrutiny throughout the process and am explicit about my assumptions, biases, and
experiences (35). The lens through which I view the world has been shaped by my personal and educational backgrounds and experiences, as well as my own embodied experiences of ability/disability and weight/obesity.

I am a young, Caucasian female, in a graduate program studying rehabilitation sciences. I do not experience any physical or cognitive disabilities. I have an average BMI and have never experienced higher weight. I value, and frequently engage in, physical activity and face no barriers when trying to participate in physical activity.

My educational background is in in Child and Youth Studies: the disciplines of sociology, psychology and anthropology through a child and youth lens. I obtained this honours bachelor degree from Brock University.

Whilst I do not have a clinical background or any clinical training, I have been working with young people with varied disabilities for the past fourteen years. When I was ten years old, I began to care for a four-year-old girl, Olivia, who is blind. While babysitting Olivia, I quickly noticed how independent she was (be that physically able to do things by herself, or to advocate for support). This challenged my early assumptions of disability as limiting and restricting. Rather, what I saw as the biggest barrier restricting her full participation in her school and community was the stigma and social exclusion she faced. I became fascinated about working with her to raise awareness about vision loss, while promoting a culture of genuine inclusion and acceptance in our elementary school.

During my high school and university years, I worked at Merrywood Easter Seals camp, an overnight camp for children with physical disabilities. I met numerous individuals at camp who shared their stories and experiences with me, which further reinforced my assumption that some of the biggest barriers faced by people with disabilities are the social stigma, attitudinal barriers and social exclusion. I became passionate about raising awareness about disability to increase acceptance and inclusion among people who are considered to be able-bodied. My underlying assumption is that if we can reduce attitudinal barriers and stigmas, we can create a society that is accessible for people of all abilities.
Researching weight and obesity was new to me. After much research and personal reflection, I was drawn to further explore the notion of weight stigma and how it can cause social isolation, impact psychological wellbeing and decrease overall quality of life in a similar way to disability stigma. I drew parallels between what I knew about disability stigma and my new understanding of weight stigma. I strongly believe that the social construction of higher weight as innately negative has created numerous assumptions about people with higher weight. These assumptions are manifested through people’s prejudiced actions and thoughts, leading to a culture of weight stigma which can have detrimental outcomes for people with higher weight.

Before I arrived at my interest and passion for exploring weight stigma, I had not previously engaged in any weight related research, conversation or reflexivity. Thus, I had not been called to examine my own assumptions about weight or weight related stigma. At first, I noticed that my subconscious thoughts aligned closely with the normative notion in obesity research that diet and exercise are the two main influencers of weight and that higher weight equated to ill health. I had never reflected on these assumptions, or questioned my own beliefs. Part of my rationale for believing this is due to the culture in which I grew up. I grew up surrounded by media and advertisements that reinforce this belief that body size is a direct result of diet and exercise. Further, as a young woman I found myself surrounded by messages from peers, media, and society that emphasize the need to maintain a small body size, focus on diet, and engage in frequent exercise. Soon after recognizing these beliefs, I realized that I needed to question them.

Through working on the different manuscripts that make up my dissertation, I realized that the way I conceptualize weight and my assumptions about weight have shifted dramatically. Coming from unexamined beliefs that weight was rooted in a person’s choices with regards to food and exercise, I now view higher weight as something that can be caused by numerous internal and external factors, and it is crucial that we have supports that consider all factors that could be contributing to higher weight and resultant conditions. I realize that weight alone does not equate to health, and that ill health may be impacted by higher weight but also many other interacting and intersecting factors. Furthermore, I recognize the critical role weight stigma plays in the way our society views and treats people with obesity. I recognize the detrimental consequences of
weight related stigma, and the importance of examining personal assumptions that influence the ways we understand OW/OB.

Beyond my own position as a graduate student, I acknowledge and appreciate the lenses that my supervisor and committee members brought to this research. My primary supervisor, ACM, has a background in health psychology and works primarily within an interpretivist paradigm. She conducts mostly qualitative research, and focuses her work on understanding and promoting health and wellbeing for youth with disabilities. One of my committee members (SN) has a clinical background, working as a physiotherapist. SN works within a critical qualitative paradigm, and most of her work focuses on HIV and disability in both Canada and Southern Africa. My other committee member (JH) has a background in both qualitative and quantitative research, with a focus on preventing weight related disorders in young people. All three of my supervisors approached the research topic with unique views and ideas rooted in their traditions and expertise as scientists working in health and rehabilitation research. ACM and JH have previously worked on obesity and weight related research and provided insights as to how they conceptualize weight and weight related matters. They both provided me with literature in the field of obesity, weight stigma and weight-management programs and services. SN contributed a critical qualitative view, and was instrumental in helping me learn how to conduct interviews with participants on such a potentially sensitive matter. Further, she was influential in helping me recognize the importance of being reflexive throughout the process and determining my own assumptions and how such assumptions have shifted with the evolution of this project. I appreciate the ways in which ACM, JH and SN modelled reflexivity through ongoing examination of their own assumptions and beliefs about weight, obesity and disability.

1.7 Interviewing children with ASD: challenges and successes

The study detailed in manuscript three involved conducting qualitative interviews with children with ASD. Doing this kind of qualitative exploration was an important part of my research journey; however, my experience is not fully captured and explored in the third manuscript. Thus, I outline below the challenges and successes of conducting qualitative interviews with children with ASD.
ASD is a spectrum of neurodevelopmental disorders that affects approximately one in 66 Canadian children (36). While gender differences are currently being explored and re-evaluated, there is thought to be a 4:1 ratio of males to females diagnosed with ASD (37). ASD has the potential to influence the development of language, social skills, and communication. Further, children with ASD often experience both sensory and behavioural challenges (18,38). ASD ranges in severity and the way it affects people is very individualized, which made interviewing children with ASD a unique experience.

Having the opportunity to conduct qualitative interviews with children with ASD was an insightful experience with both challenges and successes. Because the voices of children with disabilities are so scarcely included in research (39), I did not have many resources to use as precedents to inform the creation of my interview guide or interviewing techniques. I have 14+ years of working in numerous educational and recreational settings with children with a variety of physical and cognitive disabilities, including with young people with ASD. These experiences greatly assisted me in the way I planned, organized and executed my interviews.

1.7.1 Creation of my interview schedule

To account for potential shorter attention spans, my interview guide was brief. On average, interviews ran for between 15 and 25 minutes. Many children with ASD struggle to understand hidden meanings and infer deeper meaning from questions. To account for this, I was clear and direct with each question, minimizing abstract questions. While qualitative interview questions are typically open-ended, I had to balance this with my knowledge that many children with ASD have limited verbal abilities. To address these potentially limited verbal abilities, I decided to use art to support my interviews. I provided all children with a large piece of paper and markers. Initially, I was going to ask the children to draw what they were saying. However, after two pilot interviews I found that this was not a natural way of conducting interviews and made the process feel disjointed. Therefore, I altered it so that the children had the option of drawing/doodling while they spoke to me but it was not a formal part of the interview process. Further, I provided all children with pictures that could help them answer my questions. Included in the pictures were images of: mothers, fathers, teachers, doctors, nurses, a hospital, a doctor’s office, a school,
and a home. These pictures were a valuable tool in helping the children who were less verbally fluent think of an answer, as well as communicate their thoughts with me.

Many children with ASD struggle with emotional recognition (40). To address this, I included pictures of different emotion faces. I used “emoji” faces consisting of: happy, sad, nervous, angry and embarrassed. I chose to use emoji faces as many children between the ages of 10-18 (our target age group) use technology as a common mode of communication and I determined this would be a relatable and recognizable method of expressing and pin-pointing emotions for this population.

1.7.2 Conducting interviews

As previously mentioned, my decade of experience working with children with disabilities equipped me with some of the skills I required for interviewing this population. My ability to read and recognize the emotions of the participants aided me in choosing both what questions I would ask, and how I would ask them. I needed to be prepared to alter my interview guide depending on the mood, temperament and verbal abilities of participants.

As part of a larger study, we were also interviewing parents when we visited the homes. To allow the participants time to become comfortable with me, I often sat and spoke with the participant informally, while the research coordinator interviewed their parents. When we would sit down for our interview, the participants seemed more comfortable as I was more familiar to them. To account for shorter attention spans, I offered participants breaks when I felt they were becoming bored, uninterested or needed to move around. In addition to providing participants with art materials, I also set out numerous fidget toys. All participants chose to either doodle and/or play with a fidget toy during the interviews. There were two advantages associated with the inclusion of these things. First, many young people with ASD struggle to make and maintain eye contact. Providing toys and drawing materials alleviated children from this stress, and allowed them to simply focus on talking and looking at whatever they were playing with. Second, the inclusion of toys and art materials seemed to relieve participants of the pressure that
can be associated with one-to-one interviews. Participants seemed more comfortable and natural talking while playing and fidgeting with toys and art materials.

With the permission of the child, parents frequently remained in the room during the interview. At points, parents would contribute and re-word a question I was asking to make it easier for the child to understand. Additionally, parents would provide an example for the child of whatever I was asking, to make it more applicable to them and therefore easier to relate to and answer.

1.7.3 Challenges associated with interviewing children with ASD

One of my greatest successes of this thesis was my ability to conduct qualitative interviews with a population whose voices are so frequently excluded from research. However, while this process was rewarding and mostly successful, there were some challenges that I faced. First, many of my participants were limited in their verbal abilities. My pictures helped with this, in addition to re-phrasing questions if I felt that the way I had it written made it difficult for the participant to formulate an answer. I had one participant who was fully non-verbal. While she was not able to verbally communicate, I spent some time with her before the interview to learn how I could best conduct this interview to ensure she felt comfortable while able to freely share her experiences and perspectives. To do this, I used a white board where I would verbally ask a question and she would write her reply. I asked her at the start of the interview if I could complete her sentence for her if I thought I knew what it was going to be. This is an important question I have learned to ask any child who uses alternative communication devices. It is essential that I do not assume that any child wants me to finish their sentence, even if I am relatively confident that I know what they are trying to communicate. Many children, in my experience, appreciate this. This participant did want me to complete her sentence if I thought I knew what she was trying to say. Our interview needed only slight accommodations to account for the fact that she was writing all her answers. She also used the pictures to indicate her answers to many questions.

Another challenge I faced was the temperaments of two of the boys whom I interviewed. They seemed extremely agitated during the interview. I was unsure if their temperaments were angry generally or whether the content of the interview had led to these emotions and behaviours. I
assume it to be the former, given the nature in which they greeted me and acted with other people in the home prior to, and after, the interview. However, I ensured I was exceptionally gentle in the way I approached the interview. While I always tried my best to ensure I was being gentle, I made an extra effort with these two boys. They got frustrated frequently and tried to brush off my questions. When I thought appropriate, I would probe for more, however if I could tell they were getting angry or annoyed, I simply moved on.

Moreover, I faced challenges regarding how suggestable some participants were. This can be a characteristic associated with ASD. One participant, in particular, agreed with whatever I had last said. For example, if I said: does your mom, dad, doctor or teacher talk to you about weight? She would say teacher because I had said that last. When I re-ordered my examples, she would always answer with my last option. To avoid this, I would just show the sheet of photos and avoid reading them out as much as possible. Further, I would try to re-frame questions numerous times to see if her answers were consistent.

Despite facing challenges in conducting and facilitating interviews, I empowered this population to share their stories so that they have a say in the work and care directly impacting them.

1.8 Thesis organization

This introductory chapter, Chapter 1, has introduced the research topic, positioned the work within an interpretive paradigm, reflected and explicitly stated the assumptions of the graduate student researcher and supervising scientists, highlighted challenges and successes of interviewing children with ASD and clarified terminology. The remaining dissertation is organized in a manuscript format. Chapter 2 is titled: Beyond “eat less move more”: Applying a disability lens to Bronfenbrenner’s Ecological Systems Framework to examine risk factors for pediatric overweight and obesity and explores risk factors in the lives of children with disabilities for developing higher weight. Chapter 3 is titled: Weight-management services for an underserved population: A rapid review of the literature. This chapter explores what services and supports currently exist for weight-management treatment for youth with disabilities. Chapter 4 is titled I work out, who cares if I’m bigger: What matters to children with ASD
regarding weight and their bodies? and explores what matters to children with ASD regarding weight and their bodies. Lastly, Chapter 5 discusses the importance of this work, the limitations and strengths of this dissertation, and future directions for research related to weight and disability.
Chapter 2
Beyond “eat less move more”: Applying a disability lens to Bronfenbrenner’s Ecological Systems Framework to examine risk factors for pediatric overweight and obesity

2.1 Chapter Introduction

This chapter includes a manuscript that applies a socioecological lens to explore the risk factors in the lives of children with disabilities that put them at risk for higher weight. I present a framework I created based on Bronfenbrenner’s Ecological Systems Theory and Davison and Birch’s adapted Ecological Systems Framework.

2.2 Abstract

Overweight and obesity (OW/OB) levels are high among Canadian children, with rates surpassing the adult population. With such high pediatric OW/OB rates, it is imperative that risk factors are identified and explored. Thus, Davison and Birch developed an adapted framework, based on Bronfenbrenner’s Ecological Systems Theory, which identifies and categorizes the factors in a child's life that put them at risk for OW/OB. While a socioecological perspective has been a useful tool examining risk factors in typically developing pediatric populations, this holistic approach has not yet been applied to populations of children with disabilities, who are at an even higher risk of OW/OB than their typically developing peers. This commentary, therefore, explores Bronfenbrenner’s Ecological Framework as applied to OW/OB by Davison and Birch, and critically examines its application to children with disabilities.

2.3 Introduction

OW/OB rates are high among Canadian children, with rates recently surpassing the Canadian adult population (22). A sub-group of children at high risk of OW/OB are children with disabilities, who experience OW/OB at 2-3 times the rate of typically developing children.
Although a socioecological perspective has been a useful tool to examine the environmental risk factors putting pediatric populations at risk for OW/OB (21,43), this holistic approach has not yet been applied to populations of children with disabilities. Identifying the complex set of factors that contribute to OW/OB among children with disabilities will inform appropriate intervention approaches among this high-risk group.

As childhood OW/OB rates rise, there is an increased risk of secondary health conditions (44,45) that affect both the immediate, and future, physical and psychosocial wellbeing of children (46,25). Physical complications include: increased pain, fatigue, high blood pressure, insulin resistance, hyperlipidemia (25), type 2 diabetes, cardiovascular disease, hypertension, non-alcoholic fatty liver disease, metabolic syndrome (47–49), asthma, and sleep apnea (47). Furthermore, the prevalence of weight stigma can expose a child to negative psychosocial experiences (50), resulting in poor mental health, pervasive negative emotions, an altered sense of self-identity, and further weight gain (51–53).

The secondary physical and psychosocial consequences that can result from OW/OB and weight related stigma are detrimental for any child. However, they can be compounded when a child has a pre-existing disability, further hindering independence, mobility, and social participation (41), posing a threat to their overall health and well-being (4).

With such high pediatric OW/OB rates, it is vital that the risk factors for excess weight gain among this population are identified and explored. Typically, the main influencing factors are considered to be energy intake versus energy expenditure (20). However, this approach oversimplifies OW/OB and positions it as exclusively an individualistic issue, rather than the result of numerous intersecting environmental, biological, and social factors (21,22). To understand these complexities, Davison and Birch (21) developed an adapted framework, based on Bronfenbrenner’s Ecological Systems Theory (54). Bronfenbrenner’s Ecological Systems Theory examines the numerous levels in the environment that interact and affect a developing child (24). It is divided into four levels that interact with, and influence one another, ultimately determining the development of a young person (54,55). Davison and Birch (21) collapsed these four levels into three levels, with the individual child in the middle. While each level is distinct
and has its own unique characteristics and risk factors, each level is dependent upon, and influenced by, one another. Risk factors in the microsystem, for example, will impact different factors in both the mesosystem and macrosystem.

Davison and Birch’s adapted Framework provides a useful tool for identifying and categorizing the factors in a child’s life that put them at risk for OW/OB (21,22). However, their accommodated framework fails to include the specific factors that affect a child with a disability. We address each level in turn, and apply a disability lens, with examples from different disabilities dispersed throughout the levels.

In order to properly address the unique risk factors that contribute to OW/OB and the associated secondary conditions in children with disabilities these children must be examined within the context of their environment.

Figure 1: ‘The contextual model of childhood obesity’ (21) on which the current analysis is based.
Figure 2: Bronfenbrenner’s Ecological Systems Theory applied to OW/OB in children with disabilities.

2.4 Ecological Systems Theory: A Disability Lens

2.4.1 Microsystem

The first layer is the microsystem, which encompasses the child and her/his direct environment (21,22,54). The microsystem includes the socio-demographic characteristics of the child (21,22), in addition to settings such as the school, family home, and extra-curricular activities (54,55). For all children, this includes their gender, biological susceptibility to weight gain, a child’s diet, the age of a child, and how active a child is (21,22). For a child with a disability this includes additional factors that pose a threat to their overall health.

- **Disability characteristics**

  The specific cognitive and physical involvements of a disability are central to the factors in the microsystem that can put a child at risk for developing OW/OB. For example, ASD is associated with a spectrum of cognitive involvement, which may make children with ASD less aware of the health and medical risks associated with higher body weight, as well as the potential physical, social, and psychological consequences (56,57). Further, many children with ASD take psychotropic medication (e.g. atypical anti-psychotics), some of which has been associated with...
considerable weight gain as one of the side effects (58,59). Another example is Chiari malformation, a common brain malformation in children with spina bifida that can cause feeding and swallowing difficulties. This can lead to an alteration in food preferences towards foods with low nutritional value (60,61). Metabolic irregularities and lower resting energy expenditure also put children with spina bifida at an increased risk for OW/OB (60–62). In addition, children with spina bifida can have less lean body mass and lessened height velocity. Together, these factors pose a risk for developing OW/OB (61,63).

The way children with disabilities view ‘health’ may also differ from typically developing children (41), in turn impacting how they perceive healthy lifestyles and make healthy and nutritional choices. It is important to note that for many children with disabilities, there is a large functional spectrum on which they can fall. Thus, the way their impairments affect them will vary; however, a child’s functional capacity should be considered when determining risk factors for OW/OB.

- **Sedentary Activity & Physical Ability**

Children with a range of diagnoses may be limited in their physical ability to participate in activities because of the functional limitations of their disability (25,29). As a result, children with cognitive, sensory, and physical impairments are more likely to participate in sedentary activities (16,25,26). Frequently, existing functional impairments can make it difficult to physically interact with the environment, making sedentary activities appear more feasible. Children with ASD, for example, commonly have reduced motor abilities, balance difficulties, and poor coordination, making physical activity a challenge (17,64) and increasing sedentary activities (38,65,66).

- **Food Selectivity**

There are numerous nutritional challenges that arise for children with disabilities (25,28,39). Many children with disabilities are susceptible to altered feeding and eating behaviours. Some children with ASD, for example, are prone to altered food selectivity, especially sensitivity to food textures (25,65,66) frequently leading to the development of atypical eating behaviours with preferences for a limited range of energy dense food (25,65,66). Further, children with genetic
conditions, such as Down Syndrome, also have a tendency to overeat due to damage to the hypothalamus (which is responsible for weight regulation) (67).

2.4.2 Mesosystem

The mesosystem encompasses the interactions and relationships between major settings within which the child is immersed (54,55). These include family dynamics, parental employment, and the parent-teacher relationship. Davison and Birch highlight the mesosystem’s key characteristics with regards to weight gain and OW/OB as parenting styles and family characteristics (21,22). For children with disabilities, parenting styles and family characteristics can be even more complex, posing further risk to the development of OW/OB.

• **Familial Income**

The costs of caring for a child with a disability are far greater than that of a typically developing child (68). Children with disabilities have unique needs and frequently require ongoing therapies and specialty care (68,69). Furthermore, often the needs of the child require one or both parents to either lessen their workload or stop working, in turn affecting the family income (68,70). A lower family income can act as a risk factor for OW/OB (71). In addition to not being able to afford nutrient-rich foods, parents may not be able to afford exercise and sport classes for their children, especially where adaptive equipment and additional support may be required for a child with a disability to successfully participate in activities.

• **Participation in School/Community activity**

Within the community and school settings, specialized instruction and accommodations to make physical activities accessible may not be readily available. Many instructors and staff lack appropriate knowledge and training about how to best accommodate children with disabilities, limiting their capacity for participation (25,28). Within the classroom, nutritional education is frequently not accommodated to meet the unique learning needs of students with intellectual disabilities, putting these students at a disadvantage for understanding healthy choices (25).

Despite requirements in the Individuals with Disabilities Education Act (IDEA) mandating the inclusion of all young people in physical education, the majority of young people with
disabilities do not receive comparable physical activities to their typically-developing peers (25). While this may be partially attributed to the lack of trained staff available to accommodate activities, the physical environment also hinders participation. Environmental barriers take the form of inaccessible physical environments, lack of adapted equipment, and transportation difficulties (61,72).

- **Food as a Reinforcer**
  Davison and Birch suggest that parental and family dietary patterns largely affect the child’s feeding behaviours (21,22). The type and amount of food a parent provides greatly shapes how the child eats (21). For children with disabilities, an additional nutritional challenge can be the frequent use of food as a reinforcer or comforter. Parents of children with disabilities are more likely to use food as a reinforcer and a comforter when their children experience unpleasant feelings and situations (25,39). Using foods to reinforce behaviours or comfort children may both encourage excessive consumption of nutrient-poor foods and encourage an altered view of food, which can accompany them into adulthood.

- **Social Isolation and Exclusion**
  Children with disabilities experience bullying, isolation and social exclusion at far higher rates than typically developing children (73,74). Social isolation can reduce a child’s participation in group activities, and increase their engagement in sedentary activities (42,65). In addition, children with OW/OB are twice as likely as children of lower weights to experience bullying and exclusion (53). This combination of having a disability and OW/OB puts children at a huge risk for experiencing bullying, loneliness, stigmatization, and isolation (53), all risks for further weight gain (53,73).

- **Relationship with Health Care Professionals (HCPs)**
  HCPs represent a critical support for promoting the health of children with disabilities. However, it has been documented that, similar to the general population, HCPs can experience stigmatized thinking and actions towards those with higher weight (5,13,75). As an individual’s BMI increases, HCPs negative attitudes, beliefs and actions simultaneously increase (76). The stigmatization of people with OW/OB not only exacerbates negative physical and psychological
consequences caused by higher weight, but can further interfere and hinder effective weight-management behaviours and treatments (13,76). Counter to this, sometimes HCPs fail to raise the topic of weight-management at all (60). Children with disabilities usually see their HCPs more often than typically developing children, so frequently have established relationships with them. Even so, the topic of weight is rarely raised (77). There are often time constraints and competing priorities during medical appointments, resulting in an infrequent discussion of weight-management (63,77).

2.4.3 Macrosystem
The macrosystem relates to the overarching culture in which the child lives (54,55). This includes attitudes, rules, laws, legislation and mass media. The macrosystem encompasses all major systems and institutions that govern and shape society.

- **Weight Bias in Society**
The prevalence of weight bias in North American society impacts physical health and function (5). The experience of weight stigma can produce a cycle in which the internalization of stigma can increase cortisol and metabolic abnormalities, contributing to even higher weight, further increasing stigmatization (5,53). The experience of weight stigma causes physiological (cortisol level increase and metabolic abnormalities), cognitive (altered executive functioning) and behavioural (eating) changes that increase body weight, and weight related stigma (8). The pervasiveness of weight stigma in North American society makes this cycle difficult to break, and is another serious risk factor for the development, or increase in, OW/OB. For a child with a disability and OW/OB, the discrimination that they are facing may be more intense as they may be experiencing both weight related and disability related stigma.

- **Access to Services**
Numerous pediatric weight-management programs have been created across Canada over the past ten years (22,48). Such programs play a key role in addressing secondary medical and psychological health conditions, while supporting both children and families in making positive lifestyle behavioural changes (48). While these programs are becoming increasingly common, they have been largely designed with children without disabilities in mind, and children with
disabilities and OW/OB often experience challenges and barriers accessing them (28–30). Many families face barriers including familial stress, transportation, and financial strain that restricts their ability to access these programs (78). In addition, families of children with disabilities often have frequent medical appointments competing for the time they could spend at a weight-management clinic (39).

2.5 Conclusion

Pediatric OW/OB is complex and requires a variety of approaches to address a range of risk factors at multiple levels (22). The framework presented here builds on Davison and Birch’s adaptation of Bronfenbrenner’s ecological model of childhood obesity (21) by applying a disability lens to identify key factors of relevance for children with disabilities. This conceptualization of OW/OB for a child with a disability moves beyond an individualistic approach and examines multiple layers of influencing factors to focus on the ways the environment, personal characteristics, and societal factors interact to put a child at risk for OW/OB. With high rates of childhood OW/OB, especially for children with disabilities (25), and the serious negative implications that can result, examining risk factors that pose a threat to the health and wellbeing of a child with a disability is timely and imperative. This framework will allow clinicians, dieticians, and researchers to consider a child with a disability and OW/OB in the context of their environment to ensure their unique and complex needs are being met.
Chapter 3
Weight-management services for an underserved population: A rapid review of the literature

3.1 Chapter Introduction

This chapter includes a manuscript of a rapid scoping review conducted to explore existing weight-management programs that are designed to meet the needs of children with disabilities.

3.2 Abstract

Introduction: Overweight and obesity (OW/OB) rates are high among Canadian children, with rates currently affecting one third of five to seventeen-year olds. OW/OB is associated with numerous physical and psychosocial consequences, which are compounded when a child has a pre-existing disability. This is concerning as children with disabilities experience OW/OB at two to three times the rate of their typically-developing peers. While weight-management programs have been increasing, they are generally designed to meet the needs of typically developing children and often exclude children with disabilities. This review identifies existing weight-management programs for children with disabilities, and examines their characteristics and outcomes.

Methods: A scoping review was conducted using rapid review principles. Three health and social science databases were searched using terms related to ‘disabilities’, ‘obesity’, and ‘weight management’, limited to 2007-2017. Articles meeting the inclusion criteria were summarized and analyzed thematically.

Results: Five articles met inclusion criteria, and described four different weight-management programs. All included children with intellectual disabilities, with one including children with physical disabilities. Programs had three characteristics in common: 1) utilizing a multidisciplinary team; 2) using technology to deliver the program; and 3) engaging the family
during the entire program. All articles reported that the programs reduced body mass index and resulted in positive lifestyle and behavioural changes.

**Conclusion:** The scarcity of programs designed to meet the unique needs of children with disabilities is alarming. Although a robust evidence base is lacking, current research provides some directions into components that should be considered when designing future interventions.

### 3.3 Background

OW/OB rates are high among Canadian children (22). OW/OB puts children at risk for developing numerous secondary health conditions (44,45) that affect both their immediate and future wellbeing (25,46). Further, having OW/OB frequently puts children at risk for experiencing weight stigma from peers, adults and HCPs, which threatens their psychosocial wellbeing and can lead to further weight gain (5,45). Both the physical and psychosocial consequences associated with OW/OB can be compounded when a child has a pre-existing disability, hindering independence, mobility and social participation (25,41). This is concerning considering children with disabilities experience OW/OB at two to three times the rate of their typically-developing peers (25,26,41,42).

Weight-management programs for children have been increasing across Canada over the past ten years (22,48). Such programs are instrumental in addressing the medical and psychological sequelae of obesity and providing support to children and families in making positive lifestyle and behavioural changes (48). However, these programs are generally designed to meet the needs of typically developing children. Some programs may explicitly exclude children with disabilities, or have challenges and barriers that prevent equitable access (28–30).

Given the increased prevalence of OW/OB in children with disabilities, it is concerning that this population is often explicitly excluded from weight-management programs and health promotion research more generally (28). It is therefore important to identify weight-management interventions that do exist for this population. To address this gap in the literature, a rapid
Scoping review was conducted to identify and synthesize literature on weight-management programs specifically designed to meet the needs of children with disabilities and higher weight.

3.4 Methods

Scoping review methodology with rapid review principles was selected to map out the field and gather relevant information on weight-management programs in a timely manner (79,80). The scoping review framework developed by Arksey and O’Malley (80) and updated by Levac and colleagues (81) was followed. The review was further guided by the World Health Organization’s guidance for conducting rapid reviews (79,82,83). Rapid reviews are gaining popularity in the health care field as a way of systematically reviewing the literature to explore and map out the field of study, but using clear parameters to ensure a feasible and efficient process (79). Using both principles of scoping literature reviews, in combination with the guidelines for rapid reviews, I identified three key databases, created a list of inclusion and exclusion criteria and generated a list of search terms (82,83). Our search strategy was developed with input from a Health Sciences Research Librarian and a Knowledge Translation Broker based in a pediatric rehabilitation academic health sciences centre. As is common with rapid reviews, our publication years were limited to the past ten years (2007-2017) and I did not search for grey literature (82).

3.4.1 Search Methods

The electronic databases searched in November 2017 included: Medline, Embase and PsycInfo. Search terms related to pediatrics and disability (6 terms), overweight and obesity (4 terms) and weight-management interventions (3 terms). An example search strategy is provided in table 1.

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<td>3 P?ediatric*.mp</td>
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<td>4 Pediatrics/</td>
<td>55398</td>
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Table 1: Search Terms in Medline

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<td>5088</td>
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</tr>
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</table>

3.4.2 Inclusion Criteria

As recommended by the World Health Organization’s guide to rapid reviews (79) a PICO question guided both our search strategy, our inclusion criteria and our article selection process. The population was children and adolescents (<19 years old) with a self-reported disability. In order to get a comprehensive understanding of programs available to young people with disabilities, I did not limit our search to specific diagnoses or types of disabilities. The intervention was any weight-management intervention or program. There was no comparison group specified. Lastly, the outcome of interest was change in Body Mass Index (BMI), skin fold thickness or waist circumference. Articles were therefore included if the following criteria were met: a) published between 2007-2017; b) available in English; c) full text was accessible online d) focused on children aged 2-19 with a self-reported disability and overweight/obesity; e) reported a weight-management intervention or program. Articles were excluded if they: a) described a review or study protocol and/or did not report empirical data; b) focused on prevention rather than treatment.
3.4.3 Study Selection

As outlined by Haby et al., (82), in a rapid review a single reviewer reviews articles and checks with a second reviewer. Consistent with these guidelines, a single reviewer (MW) first independently screened articles using titles. Both MW and ACM then reviewed the abstracts of the articles identified by title as potentially matching the inclusion criteria separately (inter-rater reliability of Kappa =.80). The full-text articles were examined in full by both MW and ACM. (See appendix 1 for the PRISMA flow diagram)

3.4.4 Data Extraction

A Microsoft Excel database was created to chart the information from each accepted article (80). Fields were determined collaboratively between the two authors. Extraction fields included: title, author, year, country, weight-management program, program details, population and outcomes of programs. Data were extracted by the first reviewer (MW) and checked by the second reviewer (ACM) for accuracy.

3.5 Results

Five studies met the inclusion criteria (see appendix 2). Studies originated from the United States of America (n=4) (30,78,84,85) and Hong Kong (n=1) (86). Articles were published in journals pertaining to pediatrics (n=3) (30,78,85), public health (n=1) (86) and technology (n=1) (84). Participants ages ranged from 2-19 (n=1), 8-16 (n=1), 2-18 (n=2) and 11-18 (n=1) (84). The majority of participants were diagnosed with intellectual disabilities, however Gillette et al. (30) and Pona et al. (85) also included children with physical disabilities. Three main themes captured commonalities between the programs. First, interdisciplinary professional teams were used to provide holistic programming and treatment plans for participants (30,78,85,86). Second, technology proved to be an effective way to engage participants in the programming (84,86). Lastly, was the families’ engagement and partnership in the programs (30,78,84–86).
3.5.1 Interdisciplinary Teams (n=3)

Three programs, discussed in four papers, utilized multidisciplinary teams when designing and implementing their programs (30,78,85,86). Gillette et al. (30) and Pona et al. (85) both reported on the effectiveness of the same Special Needs Weight Management Clinic (SNWMC), which employed an interdisciplinary team to meet with families and both plan and implement programming. The team working in the SNWMC consisted of a clinical child psychologist, a nurse practitioner or pediatrician, an occupational therapist, and a dietitian. The family and child would meet with all team members simultaneously and the most relevant team member for the topic being discussed would take the lead on guiding the conversations, while allowing other members to contribute to the discussion. Further, the occupational therapist conducted an assessment of the oral motor skills, swallowing, and oral sensory processing by watching the participant eat foods they both liked and disliked. At the end of the meeting, a plan was created together as a team (HCPs and family, collaboratively), to decrease the chances of contradictory recommendations by different health care professionals.

Lee et al. (86) conducted a six-month program extending a weight-management school-to-home program via technology, called the School Based Weight Management Program (SBWMP). The six-month program was implemented in schools and then extended to the home in hopes that the continuity of the program throughout settings would aid in the effectiveness. A physical activity specialist, dietitian, educational psychologist and two school nurses made up the interdisciplinary team (86). The team designed the program as well as ran sessions at a central location and communicated with families online via existing social media platforms.

Brown et al. (78) conducted a retrospective analysis of a clinical database from a tertiary-care pediatric weight-management program called Brenner FIT to determine the effectiveness of the program for children with disabilities. Similarly to SNWMC (30), and SBWMP (86), Brenner FIT is an interdisciplinary program involving regular meetings in a health care setting with pediatricians, family counsellors, dieticians, physical therapists and exercise specialists. The interdisciplinary team created plans for healthy eating, grocery shopping, exercise, meal tracking and beverage choices (78). Further, the team worked together with the family to create goals and identify steps to accomplish such goals.
3.5.2 Technology to Implement the program (n=2)

Two programs utilized technology to deliver the weight-management programs (84,86). Lee et al. (86) used technology to bring a school based weight-management program into the family home. There were 24 training sessions that focused both on healthy eating and regular exercising for the child. Through technological devices (computer tablets), parents were encouraged to virtually ‘attend’ seminars, regular dietary consultation sessions, as well as attend parent-child health promotion activities. While some of the support sessions took place in person (at the start of the program), Facebook, apps, email and phone calls were used as the main social support platforms for bringing the program from school settings to the home (86).

Technology played a more prominent role in Promeys et al.’s (84) study. All participants were randomized to one of two diet groups: a conventional reduced-energy diet (CD) or an enhanced stop light diet (eSLD). The CD group was instructed to consume a nutritionally balanced diet, with five servings of fruits and vegetables daily. Participants were advised on proper meal portions as well as given meal plan examples (84). The participants assigned to the eSLD were provided more strict guidelines to follow, based on Epstein’s original Stop Light Diet (84). The eSLD consists of two shakes and two entrees a day, and snacks were chosen from the stop light diet picture book on their tablet. Meals and shakes were selected by participants before the study and delivered to their homes prior to the start of the program. Participants were provided a tablet computer for the 8-week pilot study. The first session took place in the family home with a registered dietitian, and all future sessions occurred over online video chat (84). Further, both groups tracked their dietary intake using a mobile application called “Lose it!” and their physical activity levels using a FitBit connected to the tablet (84).

3.5.3 Family Engagement (n=4)

All four studies (written about in five articles) engaged the families in the entire course of their programs. The ways in which the families were engaged, however, differed between studies. Gillette et al. (30) and Pona et al. (85) included parents in the initial intake meeting with the
multidisciplinary team and had the families identify their goals for the program. Further, parents attended each follow up session with their child. The families’ goals were instrumental in both guiding and measuring the success of the program (30). At each session, the families’ goals were discussed and strategies were created to identify any unmet goals the families had. Lastly, the families worked alongside the participant to aid them in achieving each goal (30).

The rationale for Lee et al.’s study emphasized that parents are “agents of change” and therefore are instrumental in helping their child with lifestyle alterations (86). Thus, they asked parents to act as role models to reinforce and monitor their child’s health behaviours outside of school hours. Parents attended eight “parent skill training” sessions, and 16 additional sessions (both online and face-to-face) that focused on facilitating the participants’ health behaviour changes. Parents played an active role in facilitating the program, as well as aiding the participant in achieving positive lifestyle changes.

Parental involvement was also a critical component of Brown et al.’s Brenner FIT weight-management program (78). The multidisciplinary team met with the families biweekly. At the first meeting the team helped the family determine unhealthy behaviours and aided them in creating realistic goals for managing weight and changing behaviours (78). The families received instructions on family activities to create positive behaviour changes including: grocery shopping tips, meal tracking, beverage choices, and physical activity suggestions. The tips and instructions were all based on the families’ unique needs. Further, motivational interviewing was used with the entire family to help the families’ create goals while fostering an environment for positive and encouraging discussions (78).

One parent from each family in Ptomey et al.’s study was identified as a study helper and was required to be present during each online meeting. The parent was further required to help the participant track dietary intake and physical activity (84). The parent identified as the study helper was essential in helping the participant during the entire duration of the study.

### 3.5.4 Clinical outcomes

Gilette et al. (30) reported significantly reduced BMIz scores at the 6-month follow-up, although
the attrition rate between baseline and follow-up was 50%. They also reported a statistically significant increase in the variety of foods (fruits, vegetables and grains) that participants were willing to consume and include in their diets. The results suggested that the intervention may be stronger for younger children and females, however the effects did not reach statistical significance (30). Pona et al. also reported significant reductions in BMIz scores after the 12-month follow up from the same program. Further, when controlling for differences in participant populations, they only found that participant age moderated BMI, such that younger participants lost more weight. Type of disability (specific diagnosis), insurance coverage, sex and ethnicity did not affect change in BMIz scores. Of note is that type of disability (i.e. intellectual Vs physical) did not impact outcomes.

Lee et al. reported that the intervention group in their program had lower body weight, BMI, and skinfold thickness than the control group at 6-month follow up, yet these findings did not reach statistical significance (86). However, there were statistically significant improvements in quality of life, self-esteem, perceived body image, self-figure rating, and social relationships when compared with the control group (86).

When comparing data from children with and without cognitive disabilities, Brown et al. found that participants with cognitive disabilities had similar or better outcomes with regards to program attrition, and significantly greater reduction in BMIz (78).

Lastly, Ptomey et al. determined that participants in both the conventional diet group and those in the enhanced stop light diet group both lowered their BMI (84). Further, participants were successful 84% of the time with tracking their dietary intake. Participants in both groups increased time spent doing physical activity, however accelerometer data indicated that there was a significant decrease in time spent doing sedentary activities, but no significant increases in vigorous physical activity for either group (84).

### 3.6 Discussion

Given the high prevalence of OW/OB in children with disabilities (25,87), it is concerning that
only five articles were identified, which described four weight-management programs tailored to children with disabilities. Because of the limited literature on weight-management programs for children with disabilities, there are currently no official recommendations or guidelines for how to create, or adapt, programs for this population (78). This review, however, demonstrates that there are existing weight management programs for children with disabilities that report promising outcomes and have common features that should be considered further (30,78,84–86).

Three programs (discussed in four studies) emphasized the importance of multidisciplinary teams providing support during weight-management programs (30,78,85,86). These studies all emphasized the importance of having numerous perspectives on the team to ensure that families were being provided holistic advice supporting behavioural lifestyle changes. The multidisciplinary teams played a key role in supporting participants and families in creating behavioural changes by assessing numerous areas in their lives where change could be possible. Including team members with varied backgrounds allowed for the physical, social and psychological wellbeing of the child to be incorporated into lifestyle plans.

The use of technology seemed to contribute to the effective delivery of weight-management programming. Both Lee et al. (86) and Ptomey et al. (84) used technology as a key component of their study, however the way they employed it differed greatly. Social media platforms could potentially support and encourage parents, and provide a place for them to communicate with one another and the team’s professionals. This sort of forum could be a useful tool in other weight-management programs, especially for parents of children with disabilities who may want to consult with one another about disability-related challenges to weight-management. Using visual cues and dietary tracking via tablet computers may also be particularly helpful to support children with intellectual disabilities (84). Families of children with disabilities face a larger than usual set of barriers that prohibit them from accessing weight-management clinics and appointments, such as transportation, frequent medical appointments and financial burdens (78). Technology may therefore provide a solution to many of those barriers, as the program can happen in the home whenever it is most suitable for families.

All programs included the families during the entire duration of the program (30,78,84–86). The
authors all reported that this was instrumental in both the planning and delivery of the weight-management programs. According to the World Health Organization, addressing childhood and adolescent OW/OB cannot be done without considering the context of the environment in which the child is immersed (11), highlighting the need to address the family as a whole unit. This is especially important for children with disabilities who may struggle with behavioural changes, either because of physical impairments or cognitive challenges (78). Having the parents help co-create goals, meet with the team and support the child in making positive lifestyle changes was critical to the implementation and success of all four programs. Parental involvement is often suggested as a key factor in successful weight-management for typically developing children. However, Gillette et al. (30) suggest involving the family is of upmost importance when children have disabilities as their ability to participate fully in the program may be compromised by the involvements of their disability.

Pona et al. (85) did not find that type of disability (based on diagnosis) impacted the child’s success in the program. This is surprising considering that there are numerous disability-specific characteristics that put children at risk for higher weight, such as mobility limitations, food preferences, food selectivity, body composition variability and understandings of health and wellness (25). Therefore, it is unexpected that the specific disability of the child did not impact their success in the program. One possible explanation for this is that the program was designed in such a way that the team altered and accommodated the program for each child and family, depending on the child’s abilities and goals of the families. Thus, it is evident that tailoring the program to the individual is critical when working with populations of children with disabilities.

The four programs took differing approaches to the creation of their programs. Gillette et al. (30), Pona et al. (85) and Ptomey et al. (84) adapted existing pediatric weight-management programs to meet the specific needs of young people with intellectual disabilities (30,84,85), whereas Lee et al. (86) created a program specifically for children with intellectual disabilities. Lastly, Brown et al. (78) examined data from an existing weight-management program that serves both children with and without intellectual disabilities to examine the effectiveness of the program for children with disabilities. While all four programs took different approaches to their creation and design, they all were found to be effective in reducing the BMI of participants,
suggesting that perhaps there are key components that make programs successful for children with disabilities regardless of whether existing programs are accommodated or if new programs are created.

3.6.1 Limitations of Studies

3.6.1a Outcome measures employed
The primary outcome measure reported in all five papers was BMI. In Western society, BMI is the predominant way of diagnosing and categorizing an individual as having OW/OB (5,4); however, this anthropometric classification system does not provide an accurate understanding of broader aspects of health, wellbeing, and quality of life (4). In addition, BMI fails to account for muscle mass, distinguish between fat and muscle, or predict body fat distribution (88,47), all of which can differ in children with disabilities and offer useful insights into their health (89). Surprisingly, only one study examined changes in psychological wellbeing, including self-esteem, perceived body image and overall quality of life (86). This demonstrates that the focus of weight-management programs still is on BMI as the primary measure of health and weight, rather than a holistic approach examining the physical and psychological wellbeing of a child.

3.6.1b Theoretical Underpinning
Of the five studies, only one explained the theoretical underpinning of their program. Bandura’s social learning theory was the theoretical framework upon which Lee et al. grounded their weight-management program (86). Understanding an intervention’s theoretical framework is crucial to obtaining deeper insights into the creation, rationalization and desired outcomes of a study. It would have been helpful to understand the theoretical underpinnings of the other three studies.

3.6.1c Lack of consistent diet type
Across the studies, diet and nutritional intake was a crucial component. However, the type of diet differed across studies. In some studies, diet referred to discussions with families about food recommendations and working with families to manage feeding difficulties and integrate new foods (30,85). While in other studies, such as Ptomey et al. (84), participants in the eSLD group
pre-selected meals ahead of time and meals were then delivered before the start of the program. Participants doing the eSLD diet only ate two meals and two shakes a day. The varied approaches to diet makes it challenging to directly compare programs, and also to make recommendations for future programs.

3.6.1d Exclusion of children with physical disabilities

Across all of the studies, participants were reported to have intellectual disabilities (30,78,84,86). It is important to note that only one program (two studies) (30,85) included participants with physical disabilities, who may be at higher risk of OW/OB than children with intellectual disabilities (90). Children with physical disabilities face considerable environmental and physical barriers. Participating in sedentary activities is much more common in children with physical disabilities due to restrictions in physical environments and attitudinal barriers prohibiting full inclusion in physical activities (25). These two articles, however, did not discuss the differences in treatment plans for children with physical versus cognitive disabilities. Thus, it is important that future research is inclusive of other disabilities.

3.6.1e Failure to distinguish who was included in family unit

All studies discussed the involvement of families throughout the weight-management programs. However, the majority of the studies failed to distinguish who was involved in the family unit. When suggesting that goals were discussed as a family, it is unclear whether children were part of the goal creation process. Having personally-meaningful goals is a critical factor in behaviour change (91), and it is therefore important that children have a voice in the decision making process. Similarly, extended family members may play a key role in providing childcare and could usefully be involved in weight-management programs (92). More clarity when describing family involvement is needed to draw conclusions around the key ingredients of interventions.

3.6.2 Limitations of this review

As is protocol with rapid reviews, our review only spanned the literature from the past 10 years, and only searched three databases (79). Further, one investigator did the majority of the creation of inclusion/exclusion criteria and article searching. These are best practices of rapid reviews due
to the limited time frame such reviews are completed in, but may result in a less expansive search of the literature. However, for our specific research question, rapid scoping review methodology allowed for an efficient and feasible process to identify the emerging area of weight-management programs for children with disabilities (83).

3.6.3 Future steps

There is a scarcity of research exploring weight-management services and supports for children with disabilities (30). It is crucial that future research examines the supports and services children with disabilities require and desire, so that programs can be created or accommodated to meet their needs. Further, children with physical disabilities must be included in these studies. Using a range of outcomes to augment BMI would also allow a broader picture of health and wellness.

3.7 Conclusion

This review provides promising evidence that weight-management programs that include children with disabilities can be successful at both lowering BMIz scores and making positive behavioural and lifestyle changes. Including a multidisciplinary team, utilizing technology, and engaging the family are ways that the unique needs of children with disabilities can potentially be met. This review was an important first step in identifying the features of programs to support this population and how existing weight-management programs can make their program more inclusive of children with disabilities.
Chapter 4

*I work out, who cares if I’m bigger: What matters to children with ASD regarding weight and their bodies?*

4.1 Chapter Introduction

This chapter includes a manuscript that presents qualitative research conducted to explore the perspectives of children with ASD with regards to weight and their bodies.

4.2 Abstract

**Background:** Childhood overweight and obesity (OW/OB) rates have recently surpassed adult obesity rates. While weight alone is not an indicator of health, the prevalence of higher weight in combination with weight related stigma puts children at risk for the development of numerous physical and psychosocial conditions. Children with ASD are up to 30% more likely to have OW/OB than their typically developing peers. Health Care Providers (HCPs) play a key role in ensuring the health and wellbeing of this population. However, the ways in which HCPs discuss weight has the potential to greatly affect the health and wellbeing of this population. In order for HCPs to have these important conversations with this population, we need to know what the children themselves think is important to talk about.

**Methods:** Eight semi-structured interviews were conducted with children with ASD. Interviews were transcribed and analyzed using a phenomenological approach within an interpretive paradigm.

**Results:** One overarching theme, and two sub-themes emerged from the data. The overarching theme was that weight was not a concern for these participants. The first sub-theme was that the participants had a high sense of body image. The second sub-theme was that the children value being physically active.
Discussion: This work encourages a shift of focus from weight and body size to health and growth in order to promote child-centered care. Further, it encourages the inclusion of the child’s voice and opinions in matters relating to their care.

4.3 Background

According to the World Health Organization childhood and adolescent OW/OB continues to affect approximately one third of five to seventeen year olds in Canada (11,93). While OW/OB is frequently framed as a public health crisis and an epidemic (23), higher weight alone does not equate to ill health (12). Rather, OW/OB, and the resultant weight stigma, can put children at risk of developing numerous secondary physical and psychosocial health conditions, which are cause for concern and action (25).

As childhood OW/OB rates rise, so too does the prevalence of secondary health conditions (44,45) which affect both immediate and future wellbeing (25,46). The physical implications that can be caused by higher weight can impact a child’s immediate physical health, in addition to putting them at risk for future health conditions that persist into teenage and adult years (49). Physical complications include: increased fatigue, pain, high blood pressure, insulin resistance, hyperlipidemia (25), type 2 diabetes, cardiovascular disease, non-alcoholic fatty liver disease, hypertension, metabolic syndrome (47–49), asthma and sleep apnea (47). These health conditions can greatly impact physical mobility, function, and overall quality of life (48).

In addition to physical health, the psychosocial wellbeing of children with OW/OB can also be threatened through pervasive weight related stigma (5,45). Weight stigma refers to weight related attitudes, thoughts and assumptions that are demonstrated through bias, rejection, and prejudice towards people who have higher weight (5). In addition to the psychosocial consequences of weight stigma, experiencing weight stigma can also result in increased stress hormone levels, maladaptive eating behaviours and avoidance of physical activity (50,75), all of which may result in further weight gain.

Together, the physical and psychosocial consequences of OW/OB can affect any child. However, a population that is at escalated risk for developing OW/OB and related consequences, are
children with disabilities (15,16). This population is 2-3 times more likely to have OW/OB than their typically developing peers (25,26). Children with disabilities and OW/OB frequently experience more serious consequences resulting from higher weight (29), which can further limit mobility, exacerbate pain, limit abilities to provide self-care, increase social isolation and reduce independence (94).

One population that is at particular high risk of developing OW/OB is children with ASD (18,65) due to their unique set of characteristics and the complexity of their medical considerations, disability-related characteristics, and social/environmental barriers (63). Studies suggest that the prevalence of OW/OB may be up to 30% higher in children with ASD, than the general pediatric population (17–19).

ASD is a continuum or spectrum of neurodevelopmental conditions that affects one in 66 Canadian children (36). ASD can affect language development, social skills, social communication, and cause sensory and behavioural challenges (18,38). ASD ranges dramatically in severity, affecting each child quite differently.

Energy intake versus energy expenditure at the individual level is the main explanatory framework for weight gain (20). It is important, however, to explore alternative factors that may impact the weight of a child with ASD. ASD is associated with a spectrum of cognitive involvement, which may make children less aware of the potential physical, social and psychological health risks that can be associated with higher body weight (56,57). Furthermore, physical activity levels are low among children with ASD, with high levels of sedentary activities (38,65,66). This lack of physical activity may be due, in part, to compromised motor, balance, and coordination abilities (17,64). There may also be other disability-specific characteristics such as: limited attention span, difficulties engaging with certain stimuli (including auditory, visual and tactile), challenges forming and maintaining interpersonal relationships and specific, narrow interests (64), all of which can make participating in group activities more challenging.
Children with ASD are also often prone to altered food preferences. This usually takes the form of sensory responses, which can make children more sensitive to food textures (25,65,66), frequently leading to the development of atypical eating behaviours with preferences for a limited range of energy dense food (25,65,66). Further, between 30 and 60% of children with ASD take psychotropic medication to help with certain behavioural and emotional abnormalities (17). These psychotropic medications are frequently associated with considerable weight gain as one of the main side effects (58,59).

HCPs play a critical role in ensuring the health and wellbeing of children. However, as with the general population, HCPs can experience stigmatized thinking and actions towards patients with higher body weight (5,13,75,95). Whether intentionally or unintentionally, HCPs have the power and potential to reinforce weight stigma, which can have harmful repercussions. The choice of words used by HCPs around topics relating to weight can lead to children and families experiencing weight stigma and may result in the avoidance of care (95). Stigma perpetuated by HCPs can be detrimental for immediate and future wellbeing of children, impacting their physical, social, and psychological wellbeing (95). The stigmatization of people with OW/OB not only worsens physical, social, and psychological consequences caused by OW/OB, but can greatly impede on effective weight-management behaviours and treatments (13,76).

According to the United Nations Convention on the Rights of a Child, children have a legal right to fully participate in matters that affect their lives (96). With regards to health care, this right means that care should be provided in a way that is child-centered (97). To achieve this, HCPs need a thorough understanding of the child’s perspective on matters pertaining to their care (98). Frequently, adults (parents or HCPs) have provided their understanding of children’s needs or opinions as proxies in research, which does not truly provide the perspectives of children (97). To address this, including the first hand perspectives of the child has become more common in research to ensure that their perspectives are directly impacting the health care they receive (97,98). However, pediatric research is frequently aimed at typically developing children, resulting in a lack of research understanding the specific needs and viewpoints of children with disabilities (39). In fact, having an “existing disability” is frequently an exclusion criteria for research on health promotion and weight-management (28) which both excludes the opinions
and needs of children with disabilities and OW/OB and limits the generalizability of the research (99). It is important that we understand the perspectives of children about issues concerning their care to ensure that we respect their right to be included in matters affecting them and to provide them with child-centered health care (97).

It is therefore imperative that research engages the child’s voice to ensure that practices are informed by the key stakeholders. It is important that HCPs understand how children with ASD and higher weight think, talk and conceptualize weight and weight related matters, so that they best know how to meet the needs of this population. To address this, I conducted qualitative interviews with children with ASD on what matters to them with regards to weight and their bodies. Our results aim to help HCPs foster positive conversations and provide supports to children with ASD and higher weight, based on what they deem to be important.

4.4 Methods

4.4.1 Design

This study was situated within an interpretivist paradigm, going beyond simply describing the themes found in the data and further interpreting the data (31). Within an interpretivist paradigm, I place value on the expert knowledge of the researcher, and embrace the perspectives, knowledge, and experiences that the researcher brings to the study. Further, I value the co-construction of knowledge between the researcher and the participants (33). Ontologically, I am interested in participants’ subjective interpretations of the world (33,35). Methodologically, I assumed a phenomenological approach (100), focusing on the essence of human experiences (31). My methodological position reflects an inductive reasoning approach. Rather than generating and testing a hypothesis, I discern the findings and results from within the data (32).

4.4.2 Participants

The selected sample was children with a diagnosis of ASD and higher weight. I aimed to recruit 10 children with ASD. Inclusion criteria were: a) 10 to 18 years old; b) have higher weight (≥ 85 percentile on BMI growth chart); c) have a diagnosis of ASD; d) can communicate at least in
short phrases in English (either verbally or with a communication aid); e) have previously had a
discussion about weight with a HCP. Exclusion criteria included: a) the child was judged by
someone within their circle of care or the Research Coordinator (RC) to lack the cognitive ability
to participate in an interview (e.g. turn-taking, considering different perspectives, recalling
experiences); b) the child displayed behaviours that were deemed to be unsafe (towards
themselves or others) by the researchers (TC, MW, ACM).

I acknowledge that a diagnosis does not equate to being disabled. Thus, our choice of inclusion
based on diagnosis, rather than function and participation (101), simply acts as a screening tool.
Due to the high prevalence of OW/OB in children with ASD, and the noted impact it can have on
activity, participation, and physical function, the diagnosis acts as a valuable screening tool.

4.4.3 Recruitment

Prior to recruitment, I obtained Research Ethics Board (REB) approval from two pediatric
teaching hospitals (Holland Bloorview Kids Rehabilitation Hospital and McMaster Children’s
Hospital), in addition to administrative ethics review from the University of Toronto. I invited
children with ASD who were attending a weight-management clinic in Hamilton, Ontario, which
belongs to the Ontario Pediatric Bariatric Network. I also recruited participants through a
psychopharmacology clinic at Holland Bloorview Kids Rehabilitation Hospital. The
psychopharmacology clinic prescribes and monitors psychotropic medication to children under
19 with ASD. These two settings were selected as we could purposefully sample from children
with the lived experience that we were hoping to understand.

Invitation letters were sent to those meeting the age and diagnosis inclusion criteria identified
from clinic databases, followed by a 10-day opt out period where children or families could leave
a message on a dedicated voicemail number requesting no further contact. If they did not opt out,
the RC contacted families by phone to establish whether they met full inclusion criteria and to
explore their interest in participating in the study and answer any questions. If they wished to
participate, an interview was scheduled at a time and place most convenient for the family.
Before the interview took place, consent forms were completed by children where they
demonstrated capacity to consent (judged by the RC using a standard capacity assessment
process); otherwise parents signed the consent form and the child provided assent, either by signing an assent form or providing assent verbally.

4.4.4 Data Collection

Data were gathered using semi-structured interviews with children, using an interview guide informed by the study aims, existing literature, and the team’s multidisciplinary expertise. Questions explored topics such as perspectives on their bodies, experiences getting weighed and having weight related conversations with HCPs, and feelings related to having weight related conversations. The questions were tailored to the child’s age and cognitive ability (see Appendix 3 for the entire interview guide). The participants’ parent was allowed to remain in the room if they felt that the child required clarification about what was being asked. A pilot interview was conducted with a younger child (10 years old) and an older child (14 years old) before data collection started, to ensure that the interview schedule was feasible and acceptable to the target population.

Children with ASD can find it difficult to maintain eye contact. Therefore, I provided each child with a large piece of construction paper, markers and pencil crayons as well as numerous different “fidget” toys. Additionally, there were images of a: nurse, doctor, mother, father, classroom-teacher, gym-teacher, hospital, clinic, house, school and emotion-faces to help the child if they required prompting during the interview. Children had the option to draw as they answered questions, or play with the toys to help alleviate any pressure that comes from one-to-one interviews, as well as ease any pressure or concerns about making eye-contact. Drawing was a tool to aid in the facilitation of the interview, but drawings were not used for analysis.

A brief demographic questionnaire was completed by parents before the child was interviewed.

4.4.5 Analysis

Interviews were professionally transcribed and thematically analyzed using a phenomenological approach within an interpretative paradigm (102). The Master’s student (MW), and Supervisor (ACM) read all transcripts. The two supervisory committee members (JH and SN) both read a
subset of the transcripts. Emerging ideas were discussed by the entire team. As a result of those conversations, a flexible coding scheme was created and applied to the transcripts by MW. All sections of transcripts that were assigned the same code were broken into separate documents, from which a list of themes was created. Trustworthiness and methodological rigor were ensured by regular check-ins with the group, and routine discussions about the emerging codes and themes. As this study was done within an interpretive paradigm, post-contact “member checking” was not conducted (103). Throughout the research process a journal was kept with reflexive notes, which were incorporated into the analysis (104).

4.5 Results

Nine children were enrolled, with one later withdrawing from the study, leaving eight participants. All participants were recruited from the psychopharmacology clinic at one of the hospitals. Participants ages ranged from 10-18, with the median age of 13.5. Demographic characteristics of participants are outlined in Table 2.

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Table 2: Participant Demographics (n=8)

When discussing weight and weight related topics with participants, one overarching theme was identified: “It’s not about weight”, reflecting that weight was not a primary concern for the participants. Within this, two sub-themes emerged as topics that were of concern and valued to
the participants: “positive sense of body image” and “place high value on being physically active”.

4.5.1 It’s not about weight

In society, the normative notion is that higher weight can be a sensitive topic to discuss and there are prominent negative discourses that surround the topic. However, weight did not appear to be a sensitive or uncomfortable topic to discuss with the study participants. When asked about weight and related experiences, all but one of the participants demonstrated a marked lack of concern about their weight. Despite the purpose of each interview being an opportunity to talk about weight and weight related experiences, participants seemed uninterested in the topic. When asked about getting weighed at the doctor’s office and having follow up conversations with health care professionals, some participants felt indifferent, as exemplified in this exchange about getting weighed:

Interviewer: And how do you feel when that happens?
Participant: Feels normal because I get weighed all the time.
Interviewer: So you just feel okay with doing it?
Participant: Yeah.

(Peter, 12 years old)

Other participants spoke positively about the experience of getting weighed:

Interviewer: Do you ever stand on a scale and get measured?
Participant: yeah, sometimes
Interviewer: And how do you feel when that happens? Here are some emotion faces [Interviewer points to printed photos of different emotions]
Participant: It doesn’t even hurt! [Participant points to the happy emotion face]

(Nicole, 10 years old)

The typical response from participants when asked about getting weighed was that it ‘didn’t matter’ and they were unfazed by the experience. Their non-verbal responses mirrored their
verbal replies. No participants looked uncomfortable talking about these topics and their body language did not change when talking about these topics compared to more general rapport-building questions. While many participants felt indifferent to the experience of getting weighed, a few also conveyed a sense of pride in the experience as it symbolized growth. When asked when they weighed themselves or why, several participants reported wanting to see how much they had grown.

Participant: *I do it here [home] sometimes [referring to places he gets weighed]*

Interviewer: *How come?*

Participant: *To check how much I weigh. See how much I’ve grown!*

(Peter, 12 years old)

When asked about how they felt when HCPs or their parents raise the topic of weight, answers largely fell into two categories, either feeling “neutral or positively” or did not want to participate in these conversations as they were uninterested in the topic.

Many participants said they were “fine” with the conversations and didn’t mind them at all.

Interviewer: *And how do you feel when grown-ups talk to you about your weight?*

Participant: *I am happy.*

Interviewer: *You feel happy when you talk about weight?*

Participant: *Yeah!*

(Peter, 12 years old)

The other common response was that participants did not care for these conversations as they were uninterested in the topic or bored during those conversations. These participants suggested they would prefer if weight conversations were between the HCP and their parent:

Interviewer: *Why are the appointments boring?*

Participant: *Because they talk too much*

Interviewer: *And do they talk to you or to your mom?*

Participant: *To mom*
Interviewer: *Do you wish they’d talk to you more?*

Participant: *No, I don’t want them to talk to me.*

(Aleesha, 13 years old)

Even when mentioning they were not interested in these conversations and did not want to be included, it did not seem to be because the participant felt uncomfortable or embarrassed. Rather, the participants either seemed uninterested in the topic, or did not think that it was very important to talk about weight.

There was one participant who was an exception to this theme. Chris indicated that he was very engaged in weight related research and weight-management services. When Chris was asked about weight, weight related conversations, and the act of getting weighed, his answers were focused on losing weight and trying to be ‘thinner’. When asked how he felt about having weight related conversations, his responses typically mentioned negative feelings:

Interviewer: *So I am going to say, when I go to the doctor and they talk to me about my weight I feel…*

Participant: *A little bit happy and a little bit embarrassed [points to embarrassed emotion cut out]*

Interviewer: *So a little bit embarrassed?*

Participant: *Yes*

Interviewer: *And the first emotion was happy?*

Participant: *No, not the first one, I meant nervous.*

Interviewer: *Nervous?*

Participant: *Yeah.*

Interviewer: *So you feel a little bit nervous and a little bit embarrassed?*
Participant: *Yeah because I like I don't want anybody to insult my weight. Like “you’re so fat, you should go on a diet, you should get exercise”. I take those as insults.*

(Chris, 14 years old)

### 4.5.2 Positive sense of body image

With the exception of Chris, all participants felt confident and positively about their bodies. When asked about a time when they did not feel good about their bodies, there were two consistent responses. Some participants provided examples of when their bodies were in physical pain: ‘running because it’s painful’ (Aleesha), ‘getting cramps’ (Emma) or ‘having nightmares’ (Nicole).

The other common response was for participants to be unable to identify a time when they felt negatively about their bodies, as exemplified by Simon:

Interviewer: *Is there a time when something happened that made you feel bad about your body?*

Participant: *No, I feel really good*

(Simon, 14 years old)

The majority of participants did not discuss the size of their bodies or allude to thinking they had larger bodies. They reinforced that they felt “happy” with their bodies and that any negativity towards their bodies stemmed from painful physical experiences. Two participants did discuss having a larger body. One of them was Chris, who spoke about times when he felt badly about his body being larger. However, the other participant, Peter, rejected the common normative notion of a larger body being negative, unfit or unhealthy. He indicated that while his body was bigger, it did not bother him and he felt confident and positive about his size.

Participant: *The person down the street bullies me. So they call me fat but then I say, “Actually I work out a lot. It’s not my fault I might be heavier”.*

(Peter, 12 years old)
Of note, while this participant reported feeling good about his body and did not equate a larger body to being unhealthy or unfit, he went on to describe his health care provider holding a different view:

Participant: *She [HEALTH CARE PROVIDER] says I need to get my body together and start reading stuff and it’s bad for me. And I say, ‘That’s funny’.*

(Peter, 12 years old)

Peter seemed to dismiss the view from his HCP that having a larger body equates to being unfit and unhealthy. However, while Peter did not think negatively about his bigger body or discuss wanting to lose weight, Chris repeatedly referred to losing weight and his desire to be ‘skinny’. Chris did not think he currently had overweight or obesity but suggested that this was because he had recently lost some weight and was actively trying to avoid ‘getting obesity’. Chris took pride in losing weight, as demonstrated by this statement:

Interviewer: *Can you tell me about a time when you something happened that made you feel really good about your body?*

Participant: *When I lost 6 pounds... when I lost weight... it made me feel happy.*

*As you can see, if I gain weight, that smile turns upside down.*

(Chris, 14 years old)

### 4.5.3 High value on being physically active

Participants placed high value on moving their bodies. Despite differences in the actual activities that were important to them, exercise and physical activities were consistently raised as something the participants valued and enjoyed doing. When asked what they loved to do or their favourite activities, common answers were ‘basketball’, ‘exercising’, ‘biking’ and ‘swimming’.

Mother: *What do you do in the garage gym?*

Participant: *Lift weights.*

Mother: *I know. What’s your favourite lift?*

Participant: *Clean and jerk.*
Mother: *Clean and jerk? That’s cool.*

Interviewer: *That is cool.*

Mother: *Are you lifting big weights?*

Participant: *I am* 

(Sam, 18 years old)

Weight loss rarely came up as the rationale behind participants’ desire to be physically active. Most participants associated exercise with something that was fun and enjoyable, without relating it to their health. Chris mentioned that exercise is a ‘good for you thing’ but did not directly associate it with losing weight.

Participant: *I get a lot of exercise!*

Interviewer: *A lot of exercise? That’s great*

(Chris, 14 years old)

Many participants discussed different places they participated in physical activities and exercised. One common place, across participants, associated with physical exercise was gym class during school time. Gym class was deemed an important part of the day for many participants to engage with peers and participate in physical activities. Many participants got very excited when talking about gym class and explained different games they enjoy playing. Two participants, however, suggested that gym class was a time where they felt bored and disengaged. The first of the two participated in “special education” gym classes where the members of the class did exercises in isolation and did not engage in any group activities:

Interviewer: *Are there any games you play in gym that you like?*

Participant: *We- I don’t know, nothing much…. We don’t play anything*

Mother: *I think they do individual- they don’t- because it’s a special ed[ucation] thing, so they don't have like a formal gym class where we’re all doing basketball. It’s something- everybody gets to choose an activity I think. I think that’s how it works.*

(Emma, 16 years old)
The other participant who did not enjoy gym class suggested that she often sat out and was not encouraged to participate.

Interviewer: *Do you always participate or sometimes do you sit out?*

Participant: *I sit out sometimes.*

Interviewer: *A lot of the time?*

Participant: *Yeah.*

(Aleesha, 13 years old)

All participants, regardless of whether they were engaged and participating in their gym classes, suggested that they would like more opportunities to engage in activities and play. Some suggested that this would include access to a gym and track where they would work out, lift weights, and get formal exercise. Others suggested that they would like a place to play and be physically active with a group of peers. While the atmosphere, group, environment, and activities differed between participants there was a consistent focus on wanting more opportunities to move their bodies.

**4.6 Discussion**

This study explored what was important to children with ASD regarding weight and their bodies. Most prominently, I found that weight was not a central concern for most of these children. Within North American society, there is a dominant discourse that OW/OB is negative and unhealthy (23). This discourse carries assumptions about people with higher weight, including being unmotivated, lazy, unknowledgeable, and unhealthy (23). The children in our study rejected the association of higher weight being innately bad or negative; they did not care about their weight and were unfazed by being weighed or having conversations about their weight. Some participants associated getting weighed with growth and were excited about seeing how much they had grown. This positive association with being weighed indicates that the participants do not see their body size as something to be concerned about and getting bigger is something they wanted and were proud of, as it signifies growing- a milestone of childhood.
The participants in the study further rejected the notion that individuals should feel badly about having a bigger body size or higher weight. Within North America, there is a prevalent notion of excess weight and larger bodies being unwanted and the assumption is that people with OW/OB are unhappy with their bodies (105). The participants rejected this and shared their pride for their bodies. The participants felt confident and happy with their bodies and associated any negative feelings towards their bodies with times that they were physically in pain. Peter was the only participant who reported that he had been bullied for his body size. He denied the normative notion that a larger body equates to being unfit and uses the rebuttal that he is fit and works out and has a bigger body, thereby negating the bullies’ association of a bigger body being something negative.

All participants placed tremendous value on moving their bodies. However, physical activity for the purpose of weight loss was not discussed. Participants talked about games they enjoyed playing, parks and play structures they liked visiting, hikes they went on, and sports they participated in. Within the dominant discourse of OW/OB, people with higher weight are assumed to be lazy, unmotivated and not exercise (23). The participants, again, contradict this assumption with numerous examples of activities they loved. They valued moving their bodies and playing, not exercising to lose weight.

However, there was one participant who was an exception. Chris had long been engaged in weight-management treatments, programs and research at the children’s hospital where this research took place. Chris took up the common assumptions that OW/OB is “bad”, and highly valued weight loss and attempting to be “skinny”. He was particularly concerned and fixated on weight and fears gaining weight, while priding himself on losing weight. While he is concerned about weight and being thin, he does not seem to equate weight to health. He never mentioned fearing gaining weight because he was worried about any potential health consequences; rather, he seemed to be preoccupied by size alone. It could be interpreted that he has developed a fear of weight gain and a fixation on size through involvement in weight-management programs and services. Research suggests that a focus on size and weight loss may have a detrimental impact on behaviour and/or psychological outcomes. For example, young people with OW/OB may misinterpret weight-management messages and develop an eating disorder, as an attempt to eat
“healthy” and lose weight (106,107). This pre-occupation with weight loss, that can arise due to misunderstood messages on weight-management, can also lead to excessive exercise. Together, this can lead to an intense fixation on weight loss, which can lead to social isolation, fear of gaining weight, body image distortion (106), and depression (108).

The lack of concern and focus on weight, by our participants, and the great focus on health, growth, and enjoyment of physical activities, suggests that there is a need for HCPs to support healthful behaviours, rather than focus on size and weight alone. It is important that HCPs question their own assumptions about weight being inherently bad and a concern for all children and shift their priorities to that of health and psychosocial wellbeing.

The study’s findings contribute to a call to action to shift the normative thinking around weight and size to a focus on growth and health (23). By emphasizing growth and health, priorities can shift to overall physical, social, and psychological wellbeing, rather than a preoccupation with weight and size alone. By shifting our thinking, our language should also evolve to focus on the things that matter to children: growing and being healthy. By talking about health and growth the risk of stigmatizing by focusing on size and weight is reduced. This positive shift will reduce the reinforcement of weight stigma by HCPs, and hopefully decrease the ramifications impacting children.

4.6.1 Strengths and Considerations

Researchers have begun engaging key stakeholders to include their opinions, values and perspectives with regards to weight and weight related matters. In pediatric OW/OB research, this has mainly been the parent voice (65,97). While the perspectives and input of parents are valuable, so too is the voice of the child. Research shows that many children are willing to engage with the topic of weight (109,110), yet children and young people are often marginalized and excluded (43). Our research therefore provided children with the opportunity to share what matters to them, so that healthcare programs and services can reflect their needs. Arguably, the main strength of this research is the population whose voices were highlighted. Children with disabilities are frequently excluded from research (99). Our research included and valued the voices of this underserved population. I used fidget toys as well as drawing materials to the
children to provide an alternative to eye-contact (a common struggle for children with ASD), and to alleviate any pressure that can come with one-to-one interviews (111). Further, I used printed images and pictures of different emotions to support their communication. One participant was non-verbal. To address this, rather than exclude her, I used a white-board to communicate. I asked questions verbally and the participant wrote down her answers. These accommodations to include all children who wanted to participate and share their experiences allowed me to elicit the voices of children who are often silenced in research.

There are also some considerations within this research. First, all our participants came from the same psychopharmacology clinic at one children’s hospital. It is therefore possible that their experiences are a reflection of the ethos of that specific clinic. Second, I had a limited sample size. While qualitative research typically does not engage large numbers of participants due to the nature of the methodology (34), our goal of ten children was not reached due to recruitment challenges. However, the participants still provided rich insights into the phenomenon in question. Moreover, our population may not be fully representative of the spectrum of ASD as our participants were likely higher functioning due to the nature of participating in qualitative interviews. Another consideration is the role parents played in the interviews. For six out of the eight interviews, the parents were in the room with the participant. This was a valuable tool as parents could re-frame questions or provide the child with concrete examples relating to the question. However, it may have affected how and what the participants chose to share. Lastly, many of the participants struggled with questions that were too abstract or hypothetical. For example, the question: what is the best thing that doctors or nurses can do to help keep you healthy? This question required participants to think abstractly about services or supports they did not currently receive and were difficult for participants to answer.

4.6.2 Future Directions

Future research is warranted to explore a larger population of children with ASD to gain a broader understanding of what matters to children with ASD regarding weight and their bodies. While we chose to focus on ASD, research should also be conducted with children from other disability populations to understand what matters to them regarding weight and body, given the high risk of OW/OB seen with many other physical and developmental disabilities (25). Of
particular interest, would be a population of children with a physical disability, to compare and contrast between our findings with participants whose disability was more neurodevelopmental in nature. Future research on the perspectives of parents with regards to their child’s weight would also be valuable. Parents are key stakeholders in ensuring their child’s health and wellbeing. Parents may have differing views or concerns from their children and it is imperative that those perspectives are considered and valued. It is important that HCPs balance the needs and views of the parents with the needs and views of the child, and research should explore the perspectives of both populations to ensure HCPs are equipped with an understanding of the two populations with regards to weight and weight-management.

4.7 Conclusion

This study acts as a call to action to shift the normative thinking, especially in health care, from focusing on weight and size to focusing on health and growth. Our participants valued moving their bodies and felt good about their bodies. To promote these positive relationships with body image and with physical activity, it is vital that HCPs shift their focus to prioritize health and growth, rather than weight and size.
Chapter 5
Discussion and Conclusion

5.1 Chapter Introduction

This concluding chapter provides a summary of the findings from the three manuscripts presented in this dissertation. I will explain the importance of all three manuscripts and the ways that conceptualizing OW/OB differently across manuscripts has led to novel ways of considering higher weight in children with disabilities, specifically ASD. I also discuss the considerations/limitations of these three pieces of work and directions for future research.

5.2 Summary of Findings

The Ecological Systems Framework was explored and adapted to consider disability. This was specifically meant to encourage HCPs to consider a range of influencing factors that can contribute to OW/OB among children with disabilities. I explored the environment in which a child with a disability is immersed and the factors in each layer of the environment that can put them at risk for OW/OB. I reject the simplistic view that weight is the sole result of diet and exercise (i.e. ‘eat less, move more’), and encourage HCPs to consider the different ways the child’s environment impacts their weight and health. While the Ecological Systems Framework was designed to conceptualize contributing factors to higher weight specific to those experiencing a disability, its purpose was not to suggest that higher weight is innately bad or equates to ill health. Rather, it provides a novel way of conceptualizing risk factors so that if a child does require/desire supports, those supports and treatment plans are developed with consideration of the multitude of influencing factors in their life.

Further, if a child requires support in the form of a formal weight-management program, it is essential that those programs and services are available and accessible. The scoping review using rapid review methodology was conducted to identify what weight-management programs are currently available to meet the unique needs of children with disabilities. I identified only four programs in the published literature. Evaluations of these programs provide promising evidence...
of effectiveness at both lowering BMIz scores and positively modifying behaviours (30,78,84–86). Including interdisciplinary teams, utilizing technology, and engaging the family during the entire duration of the program were commonalities across the programs, which may have contributed to their success. I suggest that further empirical work is needed to examine and test these program factors in detail to inform future program design and delivery.

Lastly, I explored the viewpoints of one group of key stakeholders: the children themselves, who are often excluded in matters concerning their lives (97). With numerous ways of viewing and conceptualizing weight and OW/OB, I deemed it important to directly gather the viewpoints of the children using semi-structured interviews. I chose to solely focus on children with ASD as my population, due to the numerous influencing factors putting them at high risk for OW/OB (17,18). The results from our qualitative study indicated that the participants rejected the normative notion in society that OW/OB is inherently negative, and the associated assumptions that individuals with OW/OB have poor body image and do not engage in exercise. The positive views participants expressed about their body size and shape, and the value participants placed on physical activity suggests that a shift is needed in the way that society, most importantly HCPs, conceptualize children with higher weight. I suggest that HCPs need to recognize that not every child who has OW/OB experiences health complications, requires supports, or is unhappy with their weight. A paradigm shift is required from one that focuses on weight and size to one that values health and growth. This shift could potentially reduce weight related stigma and promote more holistic wellbeing of children.

5.3 Critiquing traditional ways of conceptualizing OW/OB

Across the three manuscripts, the way I conceptualized and framed OW/OB differed slightly as my thinking and findings evolved. Researchers working within the critical paradigm of fat studies promote an understanding that higher weight is a normal variation of the human population. They further suggest that higher weight is not a ‘negative’ condition nor is it equated to being unhealthy or unfit (112). Fat scholars propose that weight related stigma is the main concern causing negative psychological ramifications in individuals with higher weight. Fat studies purport that higher weight is not inherently a ‘problem’ and treating it as one is
stigmatizing (112). This contrasts with the more medicalized presentation of OW/OB, which suggests that OW/OB itself directly causes severe implications on physical and mental health (47). I value the critical paradigm from fat studies, but balance it with my medical understanding of OW/OB as a condition that, when combined with weight related stigma, can put children at risk for physical, social and psychological conditions (12). Thus, my conceptualization of OW/OB aligns closely with the researchers who created the Edmonton Obesity Staging System-Pediatric version (EOSS-P) (12), balancing the impact that weight can have on physical and mental health with the actual functioning and experience of the child.

The EOSS-P was created to reflect the understanding that OW/OB is complex and can impact the health, wellbeing, and function of individuals in numerous different ways (12) (see Figure 3). It also aimed to serve as a departure from the typical definition of OW/OB as a cut-off on the Body Mass Index. The EOSS-P combines body weight (measured by BMI) with broader comorbid functional, physiological or psychological conditions. The EOSS-P examines the contributors and consequences that may be present for an individual with higher weight and categorizes the child into different levels accordingly. The EOSS-P separates OB into four distinct stages, labelled 0-3 (12). Each category, is broken down into four sub-sections: Metabolic, Mechanical, Mental and Milieu. Metabolic complications include glucose dysregulation (including dyslipidemia, non fatty liver disease syndrome and type 2 diabetes) and hypertension. Mechanical difficulties may be apparent if a child has sleep apnea, musculoskeletal pain, gastroesophageal reflex disease or disordered sleep breathing. Mental health risks include depression and anxiety, dysregulated eating habits and body dissatisfaction. Lastly, Milieu encompasses difficulties faced by the child at home, school or in the community. The presence and severity of issues in each of these categories helps determine which ‘stage’ of OB a child is in. The stage of OB will help determine both the treatment and management plan (if any). At stage zero there are no apparent risk factors and therefore no need to intervene, regardless of BMI score. An individual with stage one OB would begin to present with some concerns under each category (metabolic, mechanical, mental and milieu). Each further stage presents with more concerns and health implications than the previous, with stage three considered the most serious.
The EOSS-P highlights the importance of recognizing that OW/OB indicated by BMI alone is not a medical health concern; rather it is the presence of secondary conditions impacting a child’s health and wellbeing that can be cause for concern. To provide the most appropriate care, it is essential that OW/OB is considered from such a holistic approach.

When considering how to holistically support a child, our Ecological Systems Framework can also serve as a valuable tool. Our Ecological Systems Framework helps support children with stage 1, 2, or 3 OB. If the child is experiencing physical or psychosocial consequences as a result of their weight, it is important that the factors contributing to those consequences are explored. Using the Ecological Systems Framework, HCPs can examine where supports can be implemented and where changes may be needed in the child’s life. This removes the individual “blame and shame” often associated with an individualistic approach viewing OW/OB as a sole result of diet and exercise, and proposes a more holistic understanding of the child, their environment, and where supports can be implemented. HCPs can explore their home life, their
school, and the community they live in. Thus, when proposing supports or suggesting lifestyle and behavioural modifications, the HCPs can ensure that they are addressing key factors that are contributing to weight gain.

For a child with stage 1, 2 or 3 OB who requires or requests supports to help with weight-management, our scoping literature review provides evidence that weight-management programs including children with disabilities can show positive outcomes. Given that OW/OB is more prevalent in children with disabilities and the consequences more often impact their health and wellbeing (25), it is critical that inclusive, evidence-based strategies are available for all children at stage 1, 2 or 3 OB.

5.4 Considerations

This section details factors that should be taken into account when interpreting the findings of this work. Below I outline a few study-specific considerations that should be considered in combination with the considerations outlined in each respective manuscript. Further, I outline broader factors to consider with regards to this dissertation as a whole.

When creating the Ecological Systems Framework, I focused broadly on “disability” in order to incorporate risk factors that could potentially affect children with different disabilities. While this allows the framework to be more generalizable, it also does not provide specific risk factors for each disability population who is at high risk of OW/OB. For example, children with Duchenne Muscular Dystrophy, due to the degenerative nature of their disability, may face numerous risk factors that other populations do not. Thus, applying the Framework to this population specifically would allow a deeper exploration of all factors to consider when working with this unique group.

While I deemed a rapid scoping review to be the most appropriate form of literature synthesis for exploring existing weight-management programs for children with disabilities, it may have limited our findings. As is best practice with rapid scoping reviews, only 10 years of literature from three key databases were searched, which may have resulted in limited return articles.
With regards to our qualitative study, I chose to focus upon children with ASD. Including a population of children with a disability more physical in nature, as well as ASD which is more neurodevelopmental in nature, could provide an interesting comparison between different group profiles. For example, I may have found differences between populations regarding body image, because children with physical disabilities may have additional considerations about their bodies due to the nature of their disability (41).

Throughout the dissertation, my way of conceptualizing higher weight and OW/OB changed and evolved. I did not begin this dissertation with one theory to frame the work I was doing. Due to the explorative nature of this work, different paradigms and frameworks informed different parts of the study. I used Bronfenbrenner’s Ecological Systems Framework as a way of conceptualizing the child within the context of their environment (24) when creating my Ecological Systems Framework. Further, reflecting on critical approaches such as fat studies, informed my understanding of weight being a variation of a human condition, and higher weight not being innately unhealthy (23). I also drew on more medical understandings of OB to understand how and when it can impact children’s health and wellbeing (22,25,87). These different approaches to conceptualizing the child and OW/OB informed separate parts of the manuscripts and dissertation as a whole.

5.5 Implications for Health Care Providers

The three manuscripts in this dissertation aim to help HCPs support children with disabilities and higher weight. While our focus was on children with disabilities, specifically ASD, I propose that some of our key findings may have relevance for how HCPs interact with all children around the topic of weight, growth, and health.

The overarching implication for HCPs is to consider their assumptions about weight and OW/OB. HCPs, like all individuals in our society, have assumptions about weight and body size that are innate and ingrained in our belief system. The assumptions HCPs have about weight may impact the way they discuss and support children with OW/OB, and it is therefore critical that they question their underlying assumptions, values and beliefs. While the medical approach to
OW/OB is one of a public health crisis and cause for alarm (1), our participants demonstrated that weight does not affect all children the same way and may not necessarily be perceived as cause for concern. The way our participants viewed their bodies, their enjoyment of physical activity, and lack of concern about their weight suggests that HCPs should challenge their own assumption that OW/OB always requires treatment and equates to ill health. I suggest that HCPs move towards a more holistic approach, considering the wellbeing of the child rather than just their weight. I also suggest that HCPs shift their focus from size and weight to growth and health, and also the way they discuss weight. By talking about health and growth, the conversations with children will reflect what matters most to the children themselves.

Approaching issues related to eating and physical activity should be done from a health promotion perspective, rather than weight perspective, as that may reduce the reinforcement of stigma.

The Ecological Systems Framework I adapted will be a useful tool for HCPs when children with disabilities and higher weight do require supports for their health. By exploring the environment of the child, HCPs avoid conceptualizing and perpetuating the idea that OW/OB solely stems from individual choices. If the child and their family deem formal weight-management programs to be the most appropriate course of support, our literature review provides useful tips as to how mainstream weight-management programs can be potentially accommodated to meet the needs of children with disabilities. It provides promising evidence suggesting weight-management programs specifically designed for youth with disabilities can be successful in lowering BMI and creating behavioural and lifestyle changes.

Together, these three manuscripts call for HCPs to reexamine normative assumptions of OW/OB in children, as outlined in Table 3.

<table>
<thead>
<tr>
<th>Assumption</th>
<th>Our Participant’s View</th>
<th>Considerations for HCPs</th>
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<tbody>
<tr>
<td>OW/OB is innately negative and unhealthy (23).</td>
<td>Not concerned about weight. Mostly did not discuss negative consequences of having higher weight or wanting their weight to</td>
<td>Recognize that not everyone with OW/OB experiences any negative consequences from their weight. Not every child with OW/OB</td>
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</table>
People with OW/OB are lazy and unmotivated to exercise (14).

- Valued physical activity and loved to move their bodies.
- Frequently engaged in physical activities, but not for the purpose of losing weight.
- Recognize that having OW/OB does not mean children do not participate in or enjoy exercise.

OW/OB equates to poor body image (105).

- Very high sense of body image and pride for their bodies.
- Carefully craft conversations about the child’s body size in terms of growth, not size/weight.

| People with OW/OB are lazy and unmotivated to exercise (14). | Valued physical activity and loved to move their bodies. | Frequently engaged in physical activities, but not for the purpose of losing weight. | Recognize that having OW/OB does not mean children do not participate in or enjoy exercise. |

Table 3: Re-examining assumptions through children’s perspectives

5.6 Future directions

Each manuscript outlined future directions specific to that particular study. The studies outlined in this thesis begin to address a gap in knowledge and help to inform future research in this area.

Conducting a larger study with children with a variety of disabilities on how they perceive weight and what matters to them regarding their bodies would be very valuable. While we acquired rich information and personal accounts from children with ASD, involving the viewpoints of other populations of children with disabilities would provide a more holistic understanding of the views of children with disabilities.

Exploring differences between identifying males and females would be important for future work. Typically, media and mass messages about body image and weight have been more geared towards females than males. Thus, exploring how body image in females with higher weight and a disability compares with males may provide useful information to HCPs about how they might provide tailored support.

While our inclusion criteria did not necessitate a child to be verbal, it did require them to be able to communicate in short phrases in English using a communication board or verbally. Many
children who do not use these modes of communication, and perhaps use sign language or point to images exclusively, may have rich insights into weight and their bodies and could inform practices. It would be valuable to include their voices in future studies.

5.7 Conclusion

Together, all three manuscripts suggest we need to challenge the prevalent discourse of higher weight in North American society and the related assumptions. The dominant notion of individual behaviours being the main impacting factors is challenged by our Ecological Systems Framework. The Framework dispels myths that position weight as an individual problem and poses weight as a result of factors located in a range of levels. Our scoping review determined existing supports for children with disabilities and higher weight, for those who require formal supports. Lastly, and arguably most impactful, children with ASD challenged the dominant discourses and assumptions about OW/OB. Results from the participants suggest that higher weight was not associated with lower body image or lack of enjoyment of exercise. Understanding higher weight in this way may allow for a more compassionate, empathetic, child-centered approach in health care.
References

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43. Holt NL, Moylan BA, Spence JC, Lenk JM, Ball GDC. Treatment Preferences of Overweight Youth and Their Parents in Western Canada. 2008;


103. Lopez KA, Willis DG. Descriptive Versus Interpretive Phenomenology: Their Contributions to Nursing Knowledge. Qual Health Res [Internet]. 2004;14(5):726–35. Available from:
Appendix 1: PRISMA Flow Diagram

Records identified through database searching:
- Psych Info (n = 54)
- Medline (n = 64)
- Embase (n = 76)
- Total (n = 194)

Records after duplicates removed (n = 185)

Title and abstracts screened

Records excluded (n = 154)
- Reasons:
  - a) participants were not considered "youth"
  - b) programs were preventative not management

Full-text articles assessed for eligibility (n = 7)

Studies included in qualitative synthesis (n = 5)
Appendix 2: Charted Article Summaries of Weight-Management Programs for Youth with Disabilities
<table>
<thead>
<tr>
<th>Title</th>
<th>Authors</th>
<th>n</th>
<th>Year</th>
<th>Country</th>
<th>Program</th>
<th>Details of the program</th>
<th>Population</th>
<th>Outcome Measures</th>
<th>Findings</th>
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<tr>
<td>Outcomes of a weight management clinic for children with special needs</td>
<td>Gillette M., Stough C., Beck A., Maliszewski G., Best C., Gerling J., Summar S</td>
<td>30</td>
<td>2014</td>
<td>USA</td>
<td>Special Needs Weight Management Clinic (SNWMC) -- multidisciplinary weight management clinic adapted for kids with disabilities</td>
<td>An interdisciplinary team met with families at the start of the program, and then at 1, 2, 3 and 6 months after initial appointment. Teams discussed the family goals, and made plans to help manage weight of the child including topics such as diet and exercise. Goals were discussed at each follow up sessions and plans created to help reach unmet goals.</td>
<td>Age 2-19 diagnosed with special health care need (down syndrome, ASD, and other developmental disabilities, or cerebral palsy).</td>
<td>The Baylor College of Medicine’s BMI-percentile-for-age Calculator was used for computing BMIz of participants.</td>
<td>Significant reductions in BMIz and an increase in the variety of foods the child would eat. However, while 63 were initially recruited only 30 participants remained in the program until the 6 month follow up session.</td>
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<td>The Impact of a School-Based Weight Management Program Involving Parents via mHealth for Overweight and Obese Children and Adolescents with Intellectual Disability: A Randomized Controlled Trial</td>
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<td>Lee R L-T., Leung C., Chen H., Louie L. H. T., Brown M., Chen J-L., &amp; Lee PH.</td>
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<td>Six-month school based weight management program (SBWMP) via mHealth. -- Provides parents with activities and lessons to aid in weight management for children with intellectual disabilities.</td>
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<td>The SBWMP was extended to the home providing structured weight management programming promoting healthy eating and regular exercise through training sessions at school and extended to the home via technology. Experts included: physical activity specialist, dietitian and educational psychologist and two school nurses).</td>
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<td>Age 8-16 with MID's based on IQ test and in grades 3-9 with OW/OB</td>
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<td>BMI was calculated by dividing body weight in kilograms by height in meters squared according to gender- and age-specific growth charts produced by the Centre for Disease Control. For psychosocial wellbeing the following scales were used: PedsQLTM, Rosenberg’s Self-esteem Scale (SES), Perceived Body Shape Scale, The Perceived Body Image Questionnaire, Stunkard Self-Figure Rating Scale, Children’s Self-Efficacy in Peer Interactions scale and Nutrition Self-Efficacy Scale</td>
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<td>Program was effective, resulting in behavioural change and lower BMIz. Also, children in the intervention group improved significantly in psychosocial wellbeing.</td>
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<td>Family-Based Obesity Treatment in Children with Disabilities</td>
<td>Brown C., Irby M., Houle T., &amp; Skelton, J.</td>
<td>111</td>
<td>2015</td>
<td>USA</td>
<td>Retrospective chart review was performed for patients enrolled in the Brenner FIT program (FIT= Families in Training). An interdisciplinary, family centered weight management clinic for children with and without disabilities. For 12 months children and their parents met regularly with pediatrician, family counselor, Physiotherapist, dietitian, and exercise specialist. The treatment team aided the family in determining unhealthy habits and provided guidance for goal setting and changing.</td>
<td>Age 2-18 with cognitive disability</td>
<td>BMI z-score and attrition at 4 month follow up were the primary outcome measures. Children with disabilities did the same or better than children without disabilities in the program, and resulted in lower BMIZ scores for children with disabilities. The program was also successful in altering healthy habits and behaviours of children with disabilities.</td>
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<td>Title</td>
<td>Year</td>
<td>Country</td>
<td>Study Design</td>
<td>Intervention</td>
<td>Participants</td>
<td>Main Findings</td>
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<td>The use of technology for delivering a weight loss program for adolescents with intellectual and developmental disabilities</td>
<td>2015</td>
<td>USA</td>
<td>8 week pilot program for adolescents with mild to moderate IDD. Participants assigned to either CD= conventional diet and eSLD: enhanced Stop Light Diet</td>
<td>Age 11-18 with IQ between 50-69 (mild) or 35-49 (moderate) BMI was calculated as weight (in kilograms)/height (in meters²). To assess physical activity levels, all participants wore an ActiGraph Model GT3ட (ActiGraph LLC) for 4 consecutive days (2 weekdays and 2 weekend days) at baseline and at the end of Month 2. The outcome variables were the average accelerometer counts per minute over the 4-day period and time spent sedentary and in light, moderate, and vigorous physical activity. The Healthy Eating Index-2010 (HEI-2010) was used to determine diet quality.</td>
<td>Children were randomized to CD or eSLD and participants were given an IPad to track diet and activity. At the start participants attended an in-home orientation by a nurse and then weekly at home education sessions that happened over video chat. eSLD: stop light diet originally created by Epstein for children. The diet includes lots of fruit and vegetables, and 2 entrees and 2 shakes per day. CD: the children were told to consume a nutritionally balanced diet. Physical activity: all participants were recommended to do 60 minutes a day/5 days of physical activity. Participants in both the conventional diet and those in the enhanced stop light diet both lowered their BMI. Further, participants were successful 84% of the time with tracking their dietary intake. Participants in both groups increased time spent doing physical activity, however accelerometer data indicated that there was a significant decrease in amount of time doing sedentary activity, but no significant increases in vigorous physical activity.</td>
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<tr>
<td>Long-Term outcomes of a multidisciplinary weight management intervention for youth with disabilities</td>
<td>Pona, A., Dreyer Gillette, M., Odar Sough, C., Gerling, J., &amp; Sweeney, B.</td>
<td>115</td>
<td>2017</td>
<td>USA</td>
<td>Special Needs Weight Management Clinic (SNWMC) -- multidisciplinary weight management clinic adapted for kids with disabilities</td>
<td>An interdisciplinary team met with families at the start of the program, and then at 6 weeks, 3 months, 6 months and 12 months after initial appointment. Teams discussed the family goals, and made plans to help manage weight of the child including topics such as diet and exercise. Goals were discussed at each follow up sessions and plans created to help reach unmet goals. One of the main goals of the study was to assess long-term outcomes as well as differential outcomes of the SNWMC based on patient characteristics (gender, disability, age and ethnicity).</td>
<td>Age 2-18 with a diagnosis of ASD, Down syndrome, intellectual or physical disabilities</td>
<td>A multilevel model (MLM) was used to test patient-level change in BMIz between the baseline and their 12-month follow-up.</td>
<td>Significant reductions in BMIz over the 12 month period. The only patient characteristic that impacted BMI reductions was age. Younger children were found to have greater decreases in BMI than older children. Other patient characteristics, such as disability, sex, ethnicity, did not affect BMI reductions.</td>
</tr>
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Appendix 3: Children’s Interview guide

**Overall goal:** Understand children’s expectations, experiences and recommendations around supports and strategies for weight management

**Objective 1:** Explore the experiences of children with disabilities around weight management

**Objective 2:** Identify what services and supports children with disabilities wish to receive for optimal weight management.

*Explain at the start of the interview that the art materials are here for them to use whenever they would like to. If they feel that drawing or using cut outs would help them tell me their experiences and answer any of the questions, they should use them. However, if they prefer not to use any of the materials they are not at all required to.*

I want to remind you that I will be audio recording our interview so that I don’t miss anything you say. Are you ready to begin?

<table>
<thead>
<tr>
<th>Warm-up/rapport-building</th>
<th>Questions</th>
<th>Probes*</th>
</tr>
</thead>
<tbody>
<tr>
<td>1a. Please tell me a bit about yourself</td>
<td>What do you like to do for fun? Tell me about something you are really good at. What would your super power be?</td>
<td></td>
</tr>
</tbody>
</table>
| Probes: (“how so”, “what else”, “what do you think?” “why do you think that”) | Can you tell me about: Home: Can you tell me a little bit about your home?  
- some activities you like to do at home?  
- Do you like to cook? (YES: what kind of things do you like to cook? Who do you like to cook with? NO: Who likes to do the cooking at home?)  
- What are your favourite snacks to have at home?  
- What sort of things to do you like to do after dinner at home? | |
<p>| b. | School: Can you tell me | |
| 2. | Can you tell me what you think it means to be healthy, and what it means to be unhealthy? | What are some things you think of when I say the word healthy/unhealthy? What are some healthy foods or unhealthy foods? |
| 3. | On this piece of paper here do you want to draw a picture of yourself in the middle of the page, or use one of these pre-cut outlines of a person to represent yourself? |  |
| 4. | Some kids say that they want their weight to go down, is that something you have ever thought about? |  |</p>
<table>
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<th></th>
<th></th>
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</thead>
<tbody>
<tr>
<td>5.</td>
<td>Can you tell me about a time when something happened that made you feel good about your body?</td>
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<tr>
<td></td>
<td>You can draw out the situation on the paper if that helps you tell me the story. Why did this situation make you feel good?</td>
</tr>
<tr>
<td>6.</td>
<td>Can you tell me about a time when something happened or someone did/said something that did not make you feel good about your body?</td>
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<tr>
<td></td>
<td>If you want to can you point to the face that best describes how you felt.</td>
</tr>
</tbody>
</table>

**Experiences around weight management (offer break)**

<p>| 5. | Who talks to you about things to do with your health? |
|    | E.g. parent, doctor, nurse etc. If struggling: *Here are some different places that people talk about health (picture of a school, home, hospital and doctor’s office)- have you had any conversations in any of these places about your health? |
| 6. | When you go to your doctor’s office, do you ever stand on a scale or get measured? |
|    | Where does this happen? Here are some different places where people might get weighed or measured (*pictures of a school, hospital, home and doctor’s office) |
|    | b) is there anywhere else that you get on a scale and get measured? |
| 7. | Do you ever talk about things like food or physical activity or weight? |
|    | Who talks to you about these things? (*pictures of a school, hospital, home and doctor’s office). What do you talk about? Where do you talk about it? |
| 8. | Do you think it’s important to talk about food or physical activity or weight? |
|    | Why/why not? On a scale of 1-10, how important is it to you? Why did you pick that |</p>
<table>
<thead>
<tr>
<th>number?</th>
<th>9. How do you feel when grown-ups talk to you about your weight?</th>
<th>(* have different emotion faces cut out that they can add to their picture if necessary)</th>
</tr>
</thead>
<tbody>
<tr>
<td>10. What sorts of things do you talk about?</td>
<td>What kind of words do they use? Can you tell me a story about a conversation you have had with a doctor, nurse, parent about your weight or healthy living?</td>
<td></td>
</tr>
<tr>
<td>11. Do you always understand the words the healthcare professionals (e.g. doctors or nurses) use in the appointment?</td>
<td>Why/why not? Have you ever asked them what things mean?</td>
<td></td>
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<tr>
<td>Experiences of weight management support</td>
<td></td>
<td></td>
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<tr>
<td>12. Who do you think is the best person to talk about things like weight, physical activity and food?</td>
<td>e.g. doctor, nurse, parent etc. Why do you think that they are the best person?</td>
<td></td>
</tr>
<tr>
<td>13. Who do you think the {person identified above} should talk to about these things?</td>
<td>Mom, Dad, family member, themselves. Do you want to be in the room when they talk about those topics?</td>
<td></td>
</tr>
<tr>
<td>14. When my doctor or nurse talks to me about my weight I feel…</td>
<td>Would it be helpful to draw this or choose a cutout to help you explain this to me?</td>
<td></td>
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<tr>
<td>15. If there was a special program that focused on weight management would you want to go? What kind of things would you want to do there?</td>
<td></td>
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<tr>
<td>Recommendations</td>
<td></td>
<td></td>
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<tr>
<td>16. What is the best thing doctors or nurses can do to help keep you healthy?</td>
<td>Talk about it, give food suggestions, help find physical activity options, not talk about it.</td>
<td></td>
</tr>
<tr>
<td>17. Do you have any creative ideas on how doctors or nurses could talk about weight and health to make it more interesting?</td>
<td>Pictures, video, storytelling, fact sheets. Don’t want to talk about it.</td>
<td></td>
</tr>
<tr>
<td>17. Who do you think is the best person to talk about things like weight, physical activity and food?</td>
<td>e.g. doctor, nurse, parent etc. Why do you think that they are the best person?</td>
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<tr>
<td></td>
<td>Question</td>
<td>Response</td>
</tr>
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<td>-------------------------------------------------------------------------</td>
<td>-------------------------------------------------------------------------</td>
</tr>
<tr>
<td>18.</td>
<td>Who do you think that person should talk to about these things?</td>
<td>Mom, Dad, family member, them. Do you want to be in the room when they talk about those topics?</td>
</tr>
<tr>
<td>19.</td>
<td>How often should * above person * talk about weight, physical activity, food?</td>
<td>Every time you see them? Only when they bring it up?</td>
</tr>
<tr>
<td>20.</td>
<td>When my doctor or nurse talks to me about my weight I feel…</td>
<td>Would it be helpful to draw this or choose a cutout to help you explain this to me?</td>
</tr>
<tr>
<td></td>
<td>• Go off this emotion… why does it make you feel this way?</td>
<td></td>
</tr>
<tr>
<td>21.</td>
<td>What kind of supports would you like to help keep you healthy? (explore the notion of supports: more options for physical activity, choices on healthy food, doctor conversations, special programs?)</td>
<td></td>
</tr>
</tbody>
</table>

**Summary**

22. Is there anything we didn’t talk about that you think I should know?

23. If you got to be the principal of your school for one day, what is something you would do? (something new you would bring? A new rule?)

* Standard probes: Tell me more about that. How so? What else? On a scale of 1-10... (why did you pick that number?), would it be helpful to draw this or choose a cutout to help you explain this to me?

**Materials that will be available:** paper, pencil, crayons, pre-cut shapes of: house, clinic, school, generic building, generic outlines of multiple body shapes, woman, man, nurse, doctor, in addition to cut outs of different facial expressions (happy, sad, worried, angry)
Appendix 4: Invitation Letter

RE: Families’ Experiences of Weight Management and Wellness in Children with Disabilities

<Date>
Dear Youth,

Researchers at Holland Bloorview Kids Rehabilitation Hospital wants to understand the experiences, expectations and recommendations of children and youth with Autism Spectrum Disorder (ASD) and their families around the support needed for weight management and wellness. The research team wants to explore the experiences of children and youth with Spina bifida and ASD and their parents around weight management. This information will help the research team to understand which services are available and desired by families.

You do not have to take part in this research study. Any decision you make will not affect the services you receive at Holland Bloorview Kids Rehabilitation Hospital. If you want to opt out of the research study, please contact 1-800-363-2440 ext. 3095 within 10 days of receiving this letter and leave a message for the Research Coordinator, Tasha Carter. Once you leave a message, no one will contact you to take part in this study.

If you choose not to opt-out, the Research Coordinator will call you to explain and review the study information and answer questions about what the study involves. At that time, you can still decide whether or not to take part. By talking with Tasha Carter you are not obligated to participate in the study. If you decide not to take part, that is okay. We will also be talking to your parents about the study however this does not obligate you to be in the study.

If you choose to participate, a Master’s student from the research team will work with you. You will be asked questions through an arts-based interview. You will be asked to tell your story through creative activities such as drawing and selecting pictures. The inclusion of arts in the interview is to help you to share your experiences in a comfortable and creative way, but you do not have to take part in the arts activity if you do not wish to.

Please see the attached information letter for more details about this research study. If you have any questions, you can contact the Research Coordinator, Tasha Carter at (416) 425-6220.

Thank you for thinking about helping us with this project.

Yours truly,