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Weight-related behaviors and outcomes in children and youth with intellectual and developmental disabilities

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Weight-related behaviors and outcomes in children and youth with intellectual and developmental disabilities

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Table of contents

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Editorial: Weight-related behaviors and outcomes in children and youth with intellectual and developmental disabilities

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Editorial on the Research Topic
Weight-related behaviors and outcomes in children and youth with intellectual and developmental disabilities

Poor diet, low physical activity levels, and high levels of sedentary behavior are associated with obesity and a host of other chronic diseases, including diabetes, coronary heart disease, hypertension, stroke, obstructive sleep apnoea, and many cancers. Childhood obesity rates in the general population have grown rapidly, increasing almost five-fold over the last several decades (1). Studies from around the world also demonstrate that children with intellectual and developmental disabilities (IDD) are at higher risk for obesity than those without IDD (2, 3).

Investigations in typically developing children suggest that changes in obesity prevalence have been fueled by changes in eating patterns, physical activity engagement, and sedentary behaviors. Although children with IDD are exposed to the same obesogenic environments as their typically developing counterparts, they appear to experience additional risk factors associated with their disability and structural disability-related barriers to a healthy lifestyle. These include food selectivity, medication use, feeding problems, behavioral challenges, body composition alterations, and individual- and community-level barriers to physical activity (4). Notably, the 2023 American Academy of Pediatrics Clinical Obesity Guideline emphasized the importance of screening and treatment for obesity in the IDD population (5).

This Research Topic was curated by the Healthy Weight Research Network (HWRN) for Children with Autism Spectrum Disorder and Developmental Disabilities, an interdisciplinary research network funded by the Maternal Child Health Bureau within the U.S. Health Resources & Services Administration (6). The mission of the HWRN is to promote the development of evidence-based solutions to achieve healthy weight in children with autism and other IDD, and to disseminate research findings to broad and diverse audiences. This diverse set of papers reflects the wide range of research questions, study designs, and disciplinary perspectives that characterize this important research area and adds to our understanding of weight-related behaviors in children with IDD. The papers in this Research Topic focus primarily on autistic children and children with Down syndrome.

Parents of children with IDD often experience challenges around eating and leisure time behaviors of their children beyond those of parents of children without IDD. Within this Research Topic we share three original articles on different aspects of parenting children with IDD. Magaña et al. describe associations of overweight/obesity status of Latino children with IDD with parenting practices around food and physical activity based on interviews with parent-child dyads. They found that greater parental use of controlling dietary strategies was associated with *lower* BMI percentile. A qualitative study by Blaine et al. contrasts parent and interdisciplinary health professionals' perspectives on priorities, barriers, and facilitators to nutrition-related care for autistic children. Among the findings from their thematic analysis was that parents tended to emphasize the importance of addressing food selectivity, behavioral eating challenges, sensory issues, and sleep disturbances affecting appetite. Caldwell et al. leveraged a triangulated qualitative approach to explore facilitators and barriers to healthy behaviors among young children (12–36 months old) with Down syndrome. Their in-depth reflexive thematic analysis revealed child-level facilitators (high activity and sound sleep) and barriers (co-occurring conditions and eating behaviors) as well as family and community factors that included role modelling, time constraints, and social support.

Parents and clinicians are eager for access to effective interventions to promote healthy weight-related behaviors. Our Research Topic includes four contributions that reflect innovative adaptations to meet the needs of children with IDD and their families. Ptomey et al. report a post-hoc secondary analysis of a successful randomized 18-month weight management trial to assess whether outcomes differed between adolescents with Down syndrome and adolescents with other IDDs. Study authors found no significant differences in weight loss or compliance with intervention elements post randomization. The remaining three investigations were conducted among participants with autism. Kral et al. assessed the initial efficacy of an mHealth nutrition intervention to encourage healthy foods and discourage less healthy choices over 3 months among autistic children aged 6–10 using a randomized design with a waitlist control. Initial findings suggested only participants who initially consumed few fruits and vegetables and were highly engaged with technology increased intake over 3 months. Remote delivery was also utilized in a 4-week beta-test of a single-arm exergaming intervention that adapted an existing approach. Hatfield et al. report high feasibility, acceptability, and engagement with the progressive exergame schedule, Fitbit step-tracking, health tip and exercise videos—supported with weekly telehealth coaching. Lastly, Atkins et al. conducted a qualitative study to inform the development of a family-based intervention that centers the family dog as a vehicle for weight-related behavior change in autistic children. Interviews with parent-child dyads illuminated the strong relationship between the child and the pet dog and the dog's active role in family life; challenges related to physical activity and nutrition; and positive views on potential intervention strategies.

This Research Topic also features the results of three original observational epidemiological studies that leverage population-based datasets employing an open-science model. Because the IDD population is relatively small, population-based studies of IDD require very large samples to yield adequate numbers of individuals with IDD for adequately powered investigations. Harris et al. identified a strong association between autism symptoms and eating problems at the between-person level, but little evidence for consistent longitudinal effects at the within-person level using five waves of childhood data gathered in the Generation R Study, conducted in the Netherlands. Two studies used baseline data from the Adolescent Brain and Cognition Development Study, a population-based longitudinal study conducted in the U.S. In their exploration of racial and ethnic obesity disparities and the potential mediating contributions of select social determinants of health among autistic boys, Magaña et al. found significant differences in some social determinants; only food insecurity mediated differences between Black and White children. A second cross-sectional analysis by Must et al. identified important differences in the screen time habits (passive screen time, videogame playing, and social screen time) between male and female pre-adolescents with and without autism, but their associations with obesity were similar in the two groups.

It is essential to assess body composition and energy expenditure in individuals with Down syndrome in order to determine energy needs and thereby prevent excess weight gain. In this Research Topic, Polfuss et al. share their innovative protocol to gather energy expenditure data using doubly-labeled water from youth with Down syndrome, using video cameras to monitor data collection remotely.

There is a recognized need for practice guidelines for the treatment and management of obesity in children and adolescents with IDD (ref AAP). Ptomey et al. assembled a workgroup to develop such guidelines that incorporate the specific physiological and cognitive needs of youth with Down syndrome with obesity. An expert panel then reviewed each recommendation and rated its strength and the strength of the evidence, resulting in eight recommendations available for clinicians to use with patients and their families.

Together, the studies that comprise this Research Topic contribute to the evidence base of well-designed studies and highlight pioneering approaches to research that seeks to promote healthy weight-related behaviors for children with IDD for their long-term health and well-being. With much investigation and translation to practice yet to be done, we hope this collection serves to inspire novel research questions, innovative approaches to implementation, and attract new investigators from a range of disciplines and training backgrounds.

Author contributions

AM: Writing – original draft. CC: Writing – review & editing. AB: Writing – review & editing. SB-F: Writing – review & editing. LB: Writing – review & editing.

Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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Weight loss in adolescents with down syndrome compared to adolescents with other intellectual disabilities enrolled in an 18-month randomized weight management trial

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Background: There is limited information on the efficacy of weight management interventions in adolescents with Down Syndrome (DS)

Objective: To compare weight change and intervention compliance between adolescents with DS compared to adolescents with non-DS related intellectual disabilities (ID) who were enrolled in an 18-month weight management trial.

Methods: Participants were adolescents (13–21 years) with mild to moderate ID and overweight or obesity. Participants were randomized in a 1:1:1 allocation to one of 3 intervention arms for an 18-month weight management trial: face-to-face/conventional diet (FTF/CD), remote delivery/conventional diet (RD/CD), or remote delivery/enhanced Stop Light Diet (RD/eSLD). Anthropometrics were assessed at baseline 6, 12, and 18 months by staff blinded to the intervention, and self-monitoring data was collected across the 18-month study. As an unpowered, post-hoc, secondary analysis, two-sample *t*-tests were used to compare the weight change across 6,12, and 18 mos. and compliance across 18 mos. between adolescents with and without DS randomized to each intervention arm.

Results: Adolescents with ID ($n = 110$) were randomized to one of three intervention arms: FTF/CD ($n = 36$, DS = 17, other ID = 19), RD/CD ($n = 39$, DS = 21, other ID = 18) or RD/eSLD ($n = 35$, DS = 15, other ID = 20). Body weight at 18 months was obtained from 82%, 76% and 73% of participants with DS and 84%, 83% and 75% of participants with other ID randomized to the FTF/CD, RD/CD, and RD/eSLD arms, respectively Weight change across 18 months was -0.2 ± 8.8 kg (–0.5%), -0.3 ± 5.3 kg (–0.7%), and -2.6 ± 5.0 kg (–4.0%) in adolescents with DS randomized to the FTF/CD, RD/CD and RD/eSLD arms, respectively. There were no significant differences in change in body weight or BMI across 18 months between adolescents with DS or those with other ID in any of the 3 intervention arms (all $p > 0.05$). Additionally, there were no significant differences in intervention compliance between adolescents with and without DS across 18 mos. (all $p > 0.05$).

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Conclusions: Adolescents with DS respond to a multi-component weight management intervention similar to those with others ID

KEYWORDS

down syndrome, diet, physical activity, remote delivery, body composition, weight loss, weight maintenance

Introduction

Down syndrome (DS), a genetic condition caused by extra chromosome 21 material in all or some cells, is the most common chromosomal abnormality associated with intellectual disability (ID) (1) with an estimated prevalence of 12.7 per 10,000 among children age 0–4 years in the United States (2). The prevalence of overweight (BMI-for-age 85th–94.9th percentile) and obesity (BMI-for-age ≥95th percentile) in youth with DS (age 2–18 years) is high and higher than rates observed in typically developing youth (3–7). For example, a 2016 literature review which included 45 papers published between 1988 and 2015 reported the combined prevalence of overweight and obesity in children and adolescents with DS ranged from 23% to 70% (6) while a 2021 report found the prevalence of overweight and obesity was 49% in a sample of 122 youth with DS living in the United States (4) compared with 39% in youth in the general population (8). Overweight and obesity in youth with DS increases the probability overweight and obesity in adulthood and obesity associated conditions including sleep apnea, type 2 diabetes, Alzheimer's disease, and increased mortality (9, 10). For example, a recent report demonstrated that overweight and obesity were associated with a 3-fold increase in risk for sleep apnea and a 2-fold increase in risk for type 2 diabetes in adults with DS (4).

The etiology of obesity in youth with DS is unclear (11); however, currently available evidence suggests that a combination of physiologic factors such as increased leptin, decreased resting energy expenditure, chronotropic incompetence and hypotonia, lifestyle factors including consumption of a high calorie diet and low levels of physical activity, and comorbidities associated with DS, including hypothyroidism and congenital heart defects, likely play an important role (6). Obesity typically develops in children with DS around 2 years of age with their BMI percentile remaining stable until puberty (∼ age 12) when significant increases in BMI percentile are frequently observed (3, 7, 12). The increases in BMI percentile are likely associated with decreased parental control over both dietary intake and physical activity resulting in increased consumption of high calorie unhealthy foods (12) and low levels of physical activity observed in adolescents with DS (13). These observations suggest that evidence-based treatments, such as multi-component weight management interventions which include recommendations for decreased energy intake, increased physical activity and education/behavioral counseling, are warranted for adolescents with IDD and overweight or obesity. Physiological characteristics associated with DS including hypotonia, hypothyroidism, decreased resting energy expenditure, increased leptin, chronotropic incompetence and altered gait may impact the effectiveness of weight management interventions in individuals with DS; however, data regarding the impact of weight management interventions in individuals with DS is extremely limited. Although several previous trials have demonstrated the effectiveness of multi-component interventions for weight management in samples of children, adolescents, and young adults with a variety of IDs including DS, results have not been reported by specific ID diagnosis (14–19). Data relative to the effectiveness of multi-component weight management interventions specifically for individuals with DS is limited to one small sample trial which compared weight change across 6 and 12 months in adolescents and young adults with DS (age 13–26 years) randomized to a 6 month nutrition and physical activity education intervention ($n = 10$) or a nutrition and physical activity education plus parent-supported behavioral intervention ($n = 11$), followed by a 6-month no contact follow-up (20). Weight change across both 6 and 12 months was minimal; however, significantly greater weight change at 6 and 12 months was observed in the parent supported (6 mos. = −3.4%; 12 mos. = −2.4%) compared with the non-parent supported arm (6 mos. = + 0.6%; 12 mos. = + 2.2%). We are unaware of any publications which have compared the response to weight management interventions between adolescents and young adults with DS with adolescents and young adults with other types of ID.

Our group recently completed an 18-month weight management trial (6 mos. weight loss, 12 mos. weight maintenance) designed to compare diet [conventional meal plan diet (CD) vs. enhanced Stop Light diet(eSLD)] and delivery strategy [individual face-to-face home visit (FTF) vs. individual remote *via* FaceTime^{TM} (RD)] in 110 adolescents and young adults with ID randomized to one of three intervention arms: FTF/CD, RD/CD, RD/eSLD. A detailed description of the rationale, design, and methods for this trial (21) and the results for our primary outcomes, weight change at 6 and 18 months, have been published previously (22, 23). Weight loss at 6 months was clinically relevant and significantly greater in the eSLD compared with the CD arms when both interventions were delivered remotely: RD/eSLD (−6.4%) vs. RD/CD (−2.4%, $p = .01$). However, 6-month weight loss in the CD arms was minimal and did not differ by delivery strategy: FTF/CD (−0.2%) vs. RD/CD (−2.4%, $p = 0.20$). Weight change across 12 months differed significantly by diet (RD/eSLD: −7.0% vs. RD/CD: −1.1%, $p = .002$) but not by delivery strategy (FTF/CD: +1.1% vs. RD/CD: −1.1%, $p = 0.21$). Weight change across 18 months was minimal in all intervention arms and did not differ by diet (RD/eSLD: −2.6% vs. RD/CD: −0.5%; $p = 0.28$) or delivery strategy (FTF/CD: +1.6% vs. RD/CD: −0.5%; $p = 0.47$). The secondary analysis reported herein compares weight change across 6,12, and 18 months between participants with DS ($n = 53$) and participants with other types of ID ($n = 57$) randomized to the FTF/CD, RD/CD, and RD/eSLD arms.

Methods

Participant eligibility

Participants satisfying the following criteria were eligible for this trial: *Inclusion*: Age 13–21 years with mild to moderate ID (IQ 40–74), as verified by a primary care physician, body mass index (BMI) ≥85th percentile on CDC growth charts (age ≤19 years) or ≥25 kg/m^2 (age >19 years), or waist circumference to height ratio > 0.5 which indicates excess central adiposity in children and adolescents (24, 25) and is commonly observed in youth with DS (26), sufficient functional ability to understand directions, communicate through spoken language, living at home with a parent or guardian, and internet access in the home. *Exclusion*: Type 1 diabetes, or Type 2 diabetes treated with insulin, Prader-Willi Syndrome, participation in a weight management program involving diet and physical activity in the past 6 months, eating disorders, serious food allergies, consuming special diets, or the inability to participate in moderate to vigorous physical activity. To enhance the generalizability of our results individuals who used medications for prevalent conditions associated with obesity or other medications commonly prescribed for individuals with ID were allowed to participate. Clearance from a primary care physician was required for all participants.

Recruitment/randomization

Participants were recruited through contact with local community programs serving adolescents with ID and using print and web advertisements in the target area. Participants were randomized to intervention arms after providing signed informed parental consent/adolescent assent and written physician clearance. Randomization was stratified by BMI percentile (<95th percentile vs. ≥ 95th percentile) for participants aged 19 and younger and by BMI (25.0–29.9 kg/m^2 vs. ≥30 kg/m^2) for participants 19 and over. For adolescents with DS, BMI percentile was calculated using the standard CDC growth chart rather, rather than the DS specific growth chart (27) since the DS specific growth charts do not appear to provide better classification of weight status or health risk for youth with DS over the age of 10 compared to the standard CDC growth chart (28, 29). This trial, which was approved by the University's Institutional Review Board and registered on clinicaltrials.gov (NCT02561754), was conducted in the University's local metropolitan area from November 2015 to May 2021.

Intervention components

Diet

Energy intake

Energy intake for weight loss (0–6 mos.) was prescribed at 500–700 kcal/d below total daily energy expenditure estimated using the Dietary Reference Intake (DRI) total energy intake equation for overweight boys/girls (30). Recommended energy intake for weight maintenance (7–18 mos.) was estimated using the DRI equation based on participant weight at 6 months with consideration for adolescent growth and development and adjusted as required based on observed changes in weight across the weight maintenance intervention.

Enhanced stop light diet (eSLD)

Participants randomized to the eSLD arm were asked to follow the Stop Light Diet (SLD) (31), which categorizes foods by energy content: green (low energy, consume freely), yellow (moderate energy, consume in moderation), and red (high energy, consume sparingly). The SLD was enhanced by encouraging the consumption of high volume, low energy portion-controlled entrées and shakes (HMR Weight Management Services Corp, Boston, MA) and fruits and vegetables. Participants were encouraged to consume a minimum of 2 entrées (200–270 kcal each), 2 shakes (∼100 kcal each), and 5 one-cup servings of fruits and vegetables each day, as well as lower energy foods (green/yellow) from a chart with pictures of foods that were color-coded based on the SLD system.

Conventional meal plan diet (CD)

Participants randomized to the CD arms were asked to consume a nutritionally balanced, reduced energy diet which followed the recommendations found on the USDA website ChooseMyPlate.gov (32) and the Dietary Guidelines for Americans (33). Participants were provided with examples of meal plans consisting of suggested servings of grains, proteins, fruits and vegetables, dairy, and fats based on their energy needs and were counseled on appropriate portion sizes required to achieve the prescribed level of energy reduction. During weight maintenance, participants were asked to continue using a CD as recommended during weight loss; however, suggested servings of grains, proteins, fruits and vegetables, dairy, and fats were recalculated based on their energy needs for weight maintenance.

Physical activity

Participants in each intervention arm were asked to reach a target of 60 min./day of moderate-to-vigorous intensity physical activity at least 5 days/wk. (total 300 min/wk.) as recommended by the United States Department of Health and Human Services (34). The recommendation progressed from 15 min/day-3 days/wk. at week one (or current activity level if higher) to 60 min/day-5 days/wk. at week 12 and remained at that level through 18 months.

Education/behavioral counseling

Health educators

Participants were assigned to an individual health educator for the duration of the study. Health educators were registered dietitians, occupational therapists, and individuals with a degree in exercise Science, kinesiology, psychology, or applied behavior analysis. All health educators receive IDD specific training by two dietitians who specialize in working with individuals with IDD. Additionally, they received weight management specific training by shadowing a comprehensive weight management clinic with physicians, nurse practitioners, physician assistants, and dietitians certified in obesity and weight management for 3–6 months. Health educators were randomly assigned to participants in each of the 3 intervention arms to diminish the potential for health educator bias. All health educator/participant sessions were recorded, and intervention fidelity was assessed by comparing recordings with a check list of content to be delivered. On average, behavioral education sessions delivered 96% of the scheduled content. Eighty percent or more of scheduled content was delivered in all behavioral sessions.

Education sessions

Participants and parents in all intervention arms were asked to attend ~30–45 min. sessions with a health educator twice each month for the first 12 months, and monthly during months 13–18. All participants received an iPad® (Apple Inc, Cupertino, CA), provided by the trial. The RD arms were delivered using FaceTime™ on an iPad® while the FTF arm was delivered during a home visit. Behavioral session content and duration were identical in all 3 intervention arms and included strategies to improve weight loss, e.g., social support, self-monitoring, planning, environmental control, self-efficacy, etc. In addition to the lesson, health educators reviewed self-monitoring data for diet, physical activity, and weight in order to answer questions, problem-solve, and provide support). COVID-19 restrictions prohibited FTF contacts with participants between March and June 2020. Therefore, during this period all sessions with participants in the FTF arm were conducted by telephone. Participants who were uncomfortable with attending FTF meetings following the lifting of the COVID-19 restrictions were allowed to continue with telephone meetings from July 2020 through the completion of the trial (May 2021).

Self-monitoring

RD arms

Participants, with the help of a parent (if needed), were asked to record all food and beverages consumed on the iPad® using the Lose It! app (Fitnow, Boston MA). Self-monitoring of physical activity was completed using a Fitbit® Charge HR wireless activity tracker (Google, LLC, Mountain View, CA) worn on the wrist. To provide feedback regarding weight change, participants in the RD arms were weighed during the FaceTime™ education/behavioral counseling sessions using a calibrated wireless digital scale (Model: WS-30, Withings Inc. Cambridge, MA). Self-monitoring data was accessible to health educators to inform participant counseling during behavioral sessions.

FTF arm

Participants, with the help of a parent (if needed), were asked to record daily number of servings of each food group consumed, minutes of daily physical activity, and the number of steps each day assessed by pedometer provided by the trial (Omron HJ-320, Lake Forest, IL) using a hard copy sheets which were developed for individuals with ID (21, 35) and contained pictorial representations of each food category for assistance. Body weight was monitored using a calibrated digital scale (Model #PS6600, Belfour, Saukville, WI) during each behavioral session. FTF participants who completed behavioral sessions by telephone, i.e., COVID protocol, verbally provided self-monitoring data to the health educator; however, body weight, typically obtained during FTF sessions, was unavailable for sessions conducted by telephone. Self-monitoring records were reviewed with participants during each behavioral session to provide feedback and counseling.

Outcome assessments

Demographics/ID diagnosis

Parents completed a brief survey to obtain participant age, race/ethnicity, sex and ID diagnosis. The parent reported ID diagnosis was verified by the participant's primary care physician who also provided medical clearance for participation in the intervention.

Anthropometrics

Weight, height, and waist circumference were assessed during FTF home visits at baseline, 6, 12, and 18 months by trained staff blinded to the intervention arm. Weight was measured in duplicate to the nearest 0.1 kg using a calibrated digital scale (Model #PS6600, Belfour, Saukville, WI) with participants wearing shorts and a t-shirt. Standing height was measured in duplicate with a portable stadiometer (Model #IP0955, Invicta Plastics Limited, Leicester, UK). BMI was calculated as weight in kilograms divided by height in meters squared (kg/m^2) and BMI- z score was calculated using the Center for Disease Control's (CDCs) growth charts (36).

Process outcomes

The percentage of behavioral sessions attended, and the percentage of days participants provided self-monitoring data for diet and physical activity across the 18-month intervention were calculated from health educator records.

Analysis

This is an unpowered post-hoc analysis to compare weight loss and intervention compliance between adolescents with and without DS. Sample characteristics and outcomes were summarized using means and standard deviations for continuous variables and frequencies and percentages for categorical variables. Separate two sample *t*-tests were used to compare the changes in body weight and BMI between adolescents with DS ($n = 53$) and those with other ID ($n = 57$, 42 Autism, 15 other ID) randomized to the FTF/CD, RD/CD, and RD/eSLD arms across 6,12, and 18 months. Differences between adolescents with DS and other ID for changes in BMI-z score were not analyzed as BMI-z score has been shown to be a poor indicator of change in weight status in children and adolescents (37). Between group differences in session attendance and self-monitoring of both diet and physical activity in each intervention group across 18 months were also evaluated using two-sample *t*-tests. All analyses were conducted using SAS 9.4 (Cary, NC).

Results

Participants

Adolescents with ID ($n = 110$) were randomized to one of three intervention arms: FTF/CD ($n = 36$, DS = 17, other ID = 19), RD/CD ($n = 39$, DS = 21, other ID = 18) or RD/eSLD ($n = 35$, DS = 15, other ID = 20). **Figure 1** illustrates the participant flow in the three intervention arms across the 18-month trial. Body weight at 18 months was obtained from 82%, 76% and 73% of participants with DS and 84%, 83% and 75% of participants with other ID randomized to the FTF/CD, RD/CD, and RD/eSLD arms, respectively. Baseline characteristics of participants with DS or other ID by intervention arm are presented in **Table 1**. Participants were~16 years of age, 52% female, 88% white with a BMI of~32 kg/m^2. Baseline weight was significantly greater in adolescents with other ID (92.6 ± 26.5 kg) compared with those with DS (71.1 ± 17.6 kg, $p = 0.004$); however, there were no significant baseline differences between groups in BMI or BMI-z scores.

Comparison of weight change between adolescents with DS or other ID (Table 2, Figure 2). We observed no significant differences in change in body weight or BMI across 6, 12 or 18 months between adolescents with DS or those with other ID in any of the 3 intervention arms (all $p > 0.05$). Six-month weight change was 0.2 ± 3.4 kg (0.5%), −1.8 ± 3.1 kg (−2.8%), and −5.1 ± 4.2 kg (−7.5%) in adolescents with DS and −0.7 ± 6.1 kg (−0.7%), −1.8 ± 4.9 kg (−2.0%) and −4.9 ± 7.1 kg (−5.6%) in adolescents with other ID randomized to the FTF/CD, RD/CD, and RD/eSLD arms, respectively. Weight change across 12 months was −0.6 ± 5.5 kg (−0.4%), −0.5 ± 4.1 kg (−2.0%), and −4.0 ± 6.1 kg (−6.4%) in adolescents with DS and −2.8 ± 9.8 kg (2.3%), −1.0 ± 5.4 kg (−1.5%) and −6.4 ± 6.6 kg (−7.6%) in adolescents with other ID randomized to the FTF/CD, RD/CD and RD/eSLD arms, respectively. Weight change across 18 months was −0.2 ± 8.8 kg (−0.5%), −0.3 ± 5.3 kg (−0.7%), and −2.6 ± 5.0 kg (−4.0%) in adolescents with DS and +2.8 ± 10.6 kg (+2.6%), +0.4 ± 8 kg (+0.1%), and −1.8 ± 8.9 kg (−1.5%) in adolescents with other ID randomized to the FTF/CD, RD/CD and RD/eSLD arms, respectively. **Figure 3** demonstrates a high degree of individual variability in weight change across 6, 12, and 18 months that is similar in both participants with DS and other ID across the three intervention arms.

Adherence to intervention components (Table 3). Adherence with intervention components was general high and ranged from 78% to 88% for attendance at education/behavioral counseling sessions, 65% to 85% for self-monitoring of diet, and 68% to 81% for self-monitoring of physical activity. There were no statistically significant differences between participants with DS and those with other ID for these adherence measures in any of the three intervention arms (all $p > 0.05$).

Discussion

The results of this analysis indicate that weight change, attendance at educational/behavioral counseling sessions and compliance with self-monitoring of diet and physical activity in response to an 18-month weight management intervention did not differ significantly between adolescents/young adults with DS and adolescents/young adults with other types of ID. Similar results were observed across two energy reduced diets (CD vs. eSLD) and two strategies for the delivery of educational/behavioral counseling (FTF vs.

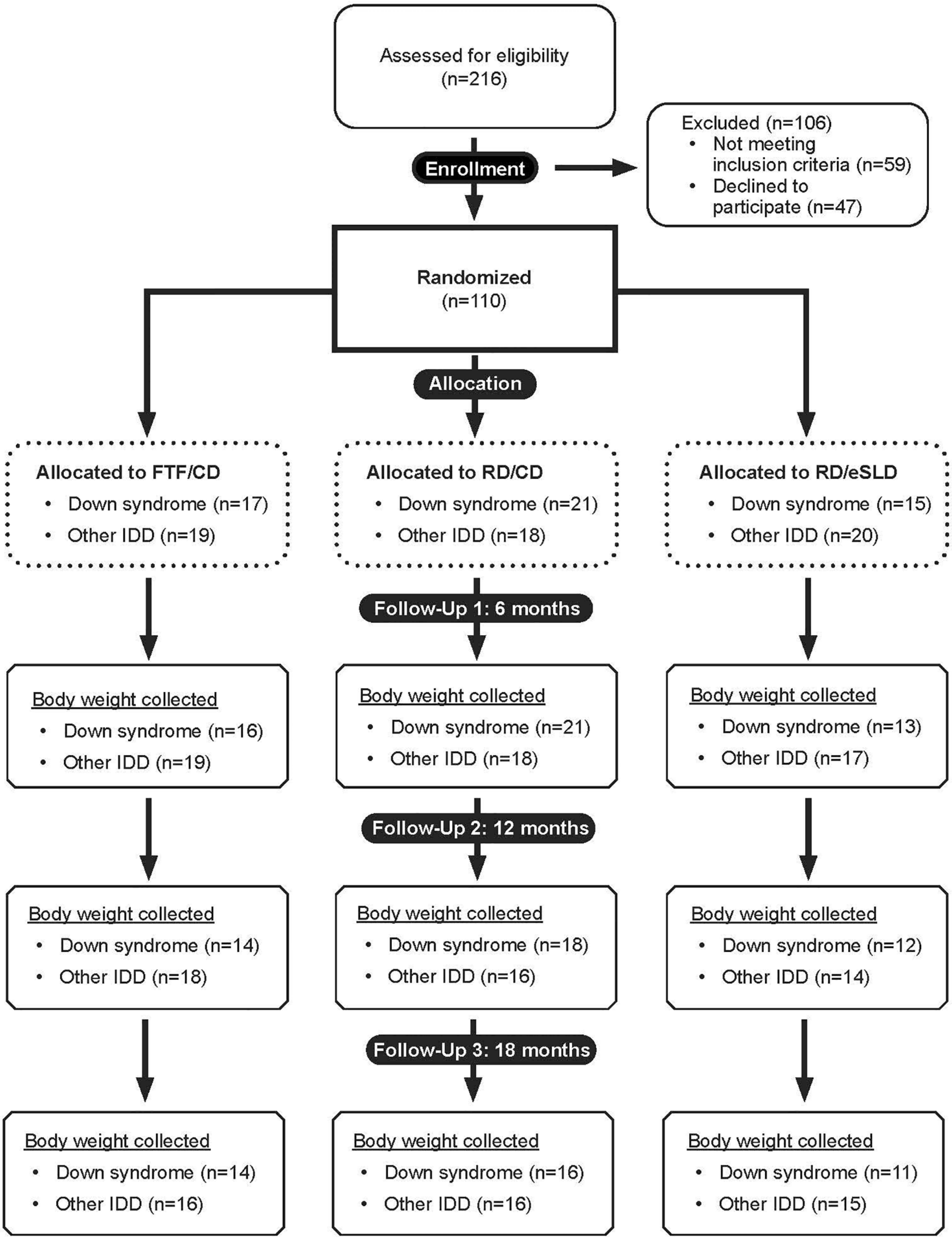

FIGURE 1
Consort diagram.

FaceTime^{TM}). Our results suggest weight loss across 6 (−7.5%), 12 (−6.4%) and 18 months (−4.0%) of a magnitude potentially associated with clinical benefits (e.g. lower blood pressure, LDL, fasting glucose) (38) can be achieved in both adolescents with DS and other types of ID who complete a multi-component weight management intervention using an eSLD with remotely delivered education/behavioral counseling (RD/eSLD). Weight loss was achieved in

TABLE 1 Baseline characteristics of adolescents with down syndrome (DS) or other intellectual disabilities (ID) by intervention arm.

	Face-to-face/conventional diet		Remote delivery/conventional diet		Remote delivery/enhanced stop light diet	
	DS (*n* = 17) *M* ± *SD*/% (*n*)	Other ID (*n* = 19) *M* ± *SD*/% (*n*)	DS (*n* = 21) *M* ± *SD*/% (*n*)	Other ID (*n* = 18) *M* ± *SD*/% (*n*)	DS (*n* = 15) *M* ± *SD*/% (*n*)	Other ID (*n* = 20) *M* ± *SD*/% (*n*)
Age (years)	16.2 ± 3.2	16.4 ± 2.2	15.7 ± 1.7	15.6 ± 1.7	17.1 ± 2.5	16.5 ± 2.5
Sex						
Male	47% (8)	63% (12)	29% (6)	50% (9)	47% (7)	50% (10)
Female	53% (9)	37% (7)	71% (15)	50% (9)	53% (8)	50% (10)
Race						
White	88% (15)	79% (15)	95% (20)	100% (18)	80% (12)	85% (17)
Black	12% (2)	5% (1)	0% (0)	0% (0)	13% (2)	10% (2)
Two or more Races	0% (0)	16% (3)	4.8% (1)	0% (0)	7% (1)	5% (1)
Ethnicity						
Not Hispanic/latino	88% (15)	100% (19)	91% (19)	100% (18)	93% (14)	85% (17)
Hispanic/latino	12% (2)	0% (0)	9% (2)	0% (0)	7% (1)	15% (3)
Weight (kg)	72.9 ± 24.2	105.0 ± 29.7	67.2 ± 13.8	84.2 ± 17.8	72.1 ± 15.9	89.4 ± 31.5
BMI (kg/m^2)	31.9 ± 10.1	36.2 ± 7.0	30.7 ± 5.6	31.2 ± 7.5	30.1 ± 6.3	32.3 ± 8.9
BMI z-score[a]	1.86 ± 0.57	2.24 ± 0.56	1.78 ± 0.42	1.87 ± 0.63	1.86 ± 0.45	1.98 ± 0.56

[a]Calculated for participants ≤ 19 years of age (FTF/CD = 30, RD/CD = 38, RD/eSLD = 27).

TABLE 2 Change in weight and BMI across 6, 12 and 18 months in adolescents down syndrome (DS) and other intellectual disability (ID) by intervention arm.

	Face-to-face/conventional diet					Remote delivery/conventional diet					Remote delivery/enhanced stop light diet				
	DS		Other ID		*p*-Value	DS		Other ID		*p*-Value	DS		Other ID		*p*-Value
	n	*M* (*SD*)	*n*	*M* (*SD*)		*n*	*M* (*SD*)	*n*	*M* (*SD*)		*n*	*M* (*SD*)	*n*	*M* (*SD*)	
Across 6-months (0–6 mos.)															
Δ Weight (kg)	16	0.2 (3.4)	19	−0.7 (6.1)	0.63	21	−1.8 (3.1)	18	−1.8 (4.9)	0.99	13	−5.1 (4.2)	17	−4.9 (7.1)	0.93
Δ Weight (%)	16	0.5 (5.1)	19	−0.7 (5.8)	0.52	21	−2.8 (4.8)	18	−2.0 (5.5)	0.66	13	−7.5 (6.3)	17	−5.6 (9.0)	0.55
Δ BMI (kg/m^2)	16	−0.2 (1.5)	18	−0.5 (1.8)	0.58	18	−1.0 (1.3)	18	−0.8 (2.0)	0.77	12	−2.3 (2.2)	17	−2.1 (2.7)	0.81
Across 12-months (0–12 mos.)															
Δ Weight (kg)	14	−0.6 (5.5)	18	2.8 (9.8)	0.26	18	−0.5 (4.1)	16	−1.0 (5.4)	0.77	12	−4.0 (6.1)	14	−6.4 (6.6)	0.36
Δ Weight (%)	14	−0.4 (8.0)	18	2.3 (9.9)	0.41	18	−0.8 (6.4)	16	−1.5 (6.7)	0.74	12	−6.4 (8.2)	14	−7.6 (7.7)	0.68
Δ BMI (kg/m^2)	14	−0.8 (2.3)	15	−0.1 (2.6)	0.46	18	−0.5 (2.0)	12	−1.1 (2.5)	0.49	10	−1.9 (3.0)	12	−2.6 (2.7)	0.61
Across 18-months (0–18 mos.)															
Δ Weight (kg)	14	−0.2 (8.8)	16	2.8 (10.6)	0.42	16	−0.3 (5.3)	16	0.4 (8.0)	0.76	11	−2.6 (5.0)	15	−1.8 (8.9)	0.79
Δ Weight (%)	14	−0.5 (13.0)	16	2.6 (12.1)	0.65	16	−0.7 (8.2)	16	0.1 (9.5)	0.80	11	−4.0 (7.2)	15	−1.5 (12.5)	0.55
Δ BMI (kg/m^2)	10	−0.4 (4.2)	16	0.1 (2.6)	0.74	14	−0.4 (2.3)	16	−0.6 (2.8)	0.87	10	−1.5 (2.5)	15	−1.2 (2.9)	0.82

adolescents with DS in spite of the presence of potential obesogenic physiologic characteristics associated with DS including hypotonia, hypothyroidism, decreased resting energy expenditure, increased leptin, and chronotropic incompetence. However, additional trials will be required to evaluate strategies to minimize weight regain after 12 months that was observed in both adolescents with DS and other types of ID in the RD/eSLD arm. In contrast to our results using the eSLD, weight change across 6, 12 and 18 months was minimal (<3%) in both adolescents with DS and other types of ID using a CD delivered either remotely or FTF.

We are unaware of previous trials which have compared weight change between adolescents with DS and those with other types of ID in response to a multi-component weight management intervention. The minimal weight loss across 6 and 12 months observed in adolescents with DS in the

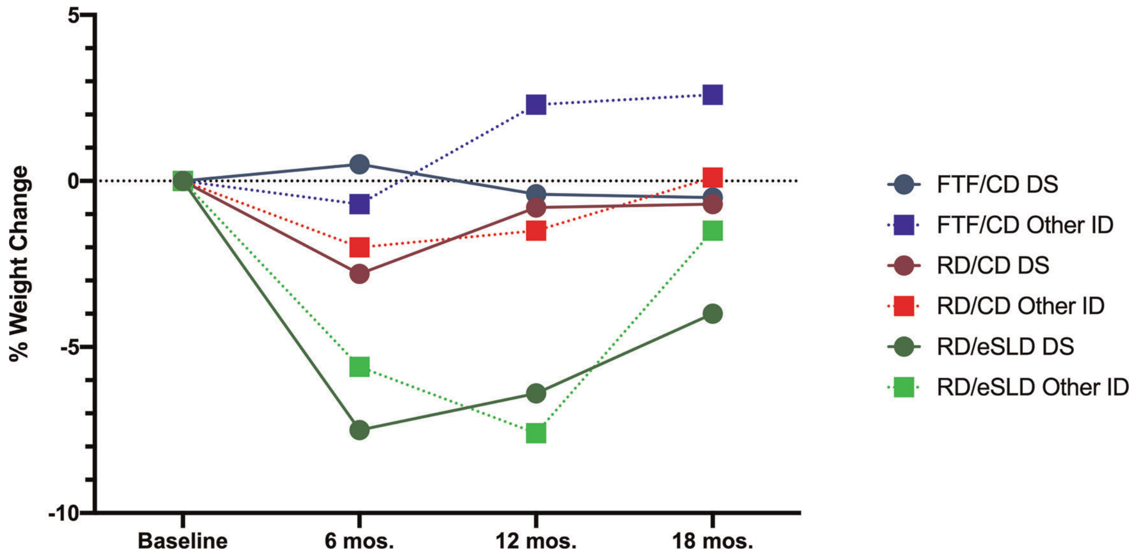

FIGURE 2
Percent weight change in adolescents with down syndrome (DS) or other intellectual disability (ID) across 18-months by intervention arm.

current trial using a CD delivered both FTF and remotely is consistent with the results reported by Curtin et al. (20) who observed minimal 6 and 12 month weight loss in 21 adolescents and young adults randomized to a CD with (6 mos. = −3.4%; 12 mos. = −2.4%) and without parental support (6 mos. = + 0.6%; 12 mos. = +2.2%). Our observation of similar weight change in adolescents/young adults with DS and those with other types of ID are in agreement with results from a previously published secondary analysis of data (39) from an 18-month multi-component weight management intervention (6 mos. weight loss, 12 mos. maintenance) in adults with ID (age ∼37 years., BMI ∼37 kg/m^2) completed by our group (40, 41). For this analysis we estimated a propensity score for the probability of having DS or other types of ID for each participant using a logistic regression model including the following baseline variables as covariates: age, sex, race/ethnicity, BMI, and original study randomization group (eSLD or CD). The analytic cohort included 124 participants, 21 with DS and 103 with other ID. Successful propensity matches were obtained for 20 of the 21 participants with DS. Results indicated weight loss across 18 months was clinically relevant (≥5%) and did not differ significantly between adults with DS (−5.2%) or other types of ID (−6.8%; $p = 0.39$). Thus, the limited available evidence suggests that adolescents with DS or other types of ID respond to multi-component weight management interventions in similar manner.

Strengths of this analysis include the use of data from long-term intervention (18 mos.) that was tailored to the cognitive abilities of adolescents with ID and included both a weight loss (6 mos.) and weight maintenance phase (12 mos.), a similar number of adolescents with DS ($n = 53$,48%) and other types of ID ($n = 57$, 52%), and a high rate of participant retention which ranged from 94% at 6 months to 80% at 18 months. This paper describes results from an unpowered secondary analysis from a randomized trial in a sample of 110 adolescents ($n = 53$ DS, $n = 57$ other ID) that was not specifically designed to evaluate differences in weight change between adolescents with DS and other types of ID. Thus, our sample size for comparisons of weight change between adolescents with DS and other types of ID was small averaging 15 participants with DS and 17 participants with other types of ID within each of the three intervention arms at 6, 12, and 18 months which represents a potential limitation. Additionally, our results are based on a sample of adolescents with mild-to-moderate ID and overweight/obesity living at home with a parent, who volunteered to participate in a weight management trial. Thus, these results may not be generalizable to adolescents with more severe ID, those living in group homes or other living arrangements, or outside of the context of a research trial.

In summary, despite physiologic characteristics associated with DS that may contribute to the development of obesity and hinder the ability to lose weight, the results of this analysis suggest that adolescents with DS can achieve potentially clinically meaningful weight loss across 18 months in response to a multi-component weight management intervention tailored to their cognitive ability using an eSLD with remotely delivered education/behavioral counseling. Additional trials/analyses to confirm these results and to evaluate the influence of factors such as ID severity and living arrangement and to explore strategies to minimize weight regain observed during the final 6 months of the weight maintenance intervention are warranted.

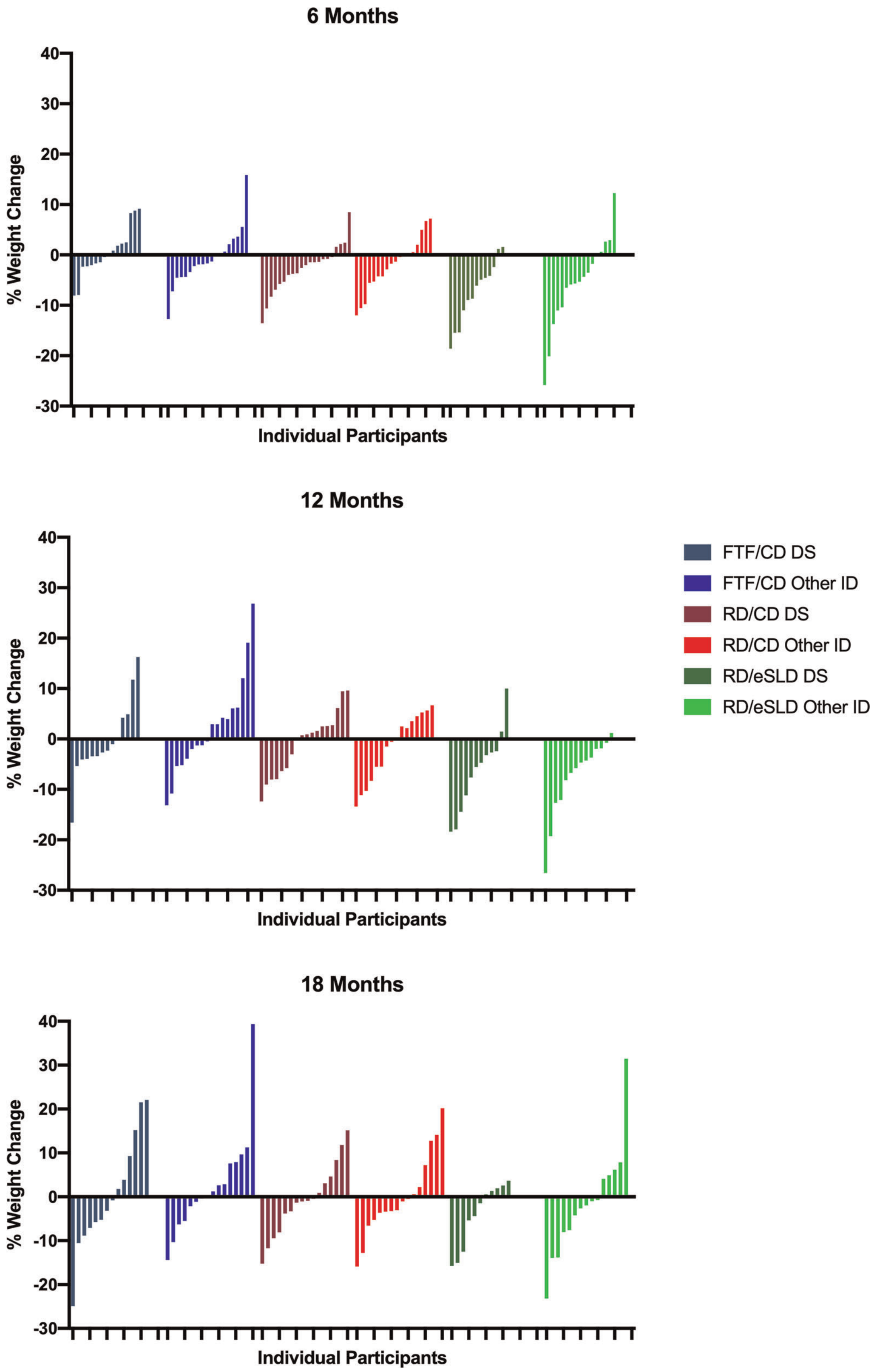

FIGURE 3
Individual percent weight change at 6, 12 and 18 months in adolescents with down syndrome (DS) or other intellectual disability (ID) by intervention arm.

TABLE 3 Adherence to intervention components in adolescents with down syndrome (DS) or other intellectual disability (ID) across 18-months by intervention arm.

	Face-to-face/conventional diet			**Remote delivery/conventional diet**			**Remote delivery/enhanced stop light diet**		
	DS	**Other ID**	***p-Value***	**DS**	**Other ID**	***p-Value***	**DS**	**Other ID**	***p-Value***
	M (SD)	***M (SD)***		***M (SD)***	***M (SD)***		***M (SD)***	***M (SD)***	
Behavioral session attendance	88% (11%)	83% (11%)	0.45	78% (23%)	82% (14%)	0.50	87% (15%)	83% (18%)	0.46
Dietary self-monitoring	85% (25%)	69% (35%)	0.22	65% (32%)	75% (26%)	0.31	80% (27%)	69% (35%)	0.37
Physical activity self-monitoring	81% (25%)	73% (32%)	0.47	73% (28%)	68% (25%)	0.59	80% (25%)	73% (32%)	0.50

Data availability statement

Deidentified individual participant data (including data dictionaries) will be made available, in addition to study protocols, the statistical analysis plan, and the informed consent form. The data will be made available upon publication to researchers who provide a methodologically sound proposal for use in achieving the goals of the approved proposal. Proposals should be submitted to the corresponding author at *lptomey@kumc.edu*.

Ethics statement

The studies involving human participants were reviewed and approved by The University of Kansas Medical Center Institutional Review Board. Written informed consent to participate in this study was provided by the participants' legal guardian/next of kin.

Author contributions

LTP, RAW, and JPD conceptualized and designed the study, coordinated and supervised data collection drafted the initial manuscript, and reviewed and revised the manuscript. AMG, AEB, KBS, BCH, AMR, and MH designed the data collection instruments, collected data, carried out the initial analyses, and reviewed and revised the manuscript. All authors contributed to the article and approved the submitted version.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Publisher's note

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Weight management recommendations for youth with Down syndrome: Expert recommendations

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Youth with Down syndrome (DS) have a higher prevalence of overweight and obesity compared to the general youth population. Due to physiological and cognitive differences observed in youth with DS, weight management recommendations developed for the general population, may not be suitable for youth with DS. However, there are no recent recommendations for weight management in youth with DS. A workgroup of clinicians and researchers with extensive experience working with youth with DS came together to give clinicians and families guidance for weight management in youth with DS. Recommendations were developed by the workgroup *via* a methodical, deliberative process. After the initial development of the recommendations, they were shared with an expert review panel and caregivers who rated the strength of the recommendation and strength of the evidence. The workgroup moved forward the recommendations which the review panels rated as strong. Eight recommendations were developed which focused on screening for overweight and obesity, screening for health conditions that may impact dietary intake and physical activity, screening for feeding difficulties, setting appropriate recommendations for dietary intake and physical activity, and well as prevention and treatment of overweight and obesity using evidence-based strategies. These recommendations can be implemented by clinicians working with youth with Down syndrome as well as the family, school, and other relevant entities.

KEYWORDS

weight loss, weight gain, obesity, dietary intake, exercise, physical activity, down syndrome, intellectual disability

1. Introduction

Obesity is one of the most prevalent chronic conditions, nearly one out of every five (19.3%) youth in the US are obese according to recent national statistics (1). Obesity disproportionately affects minority populations and people living in low-income communities (1). Being obese during youth increases the risk of being obese during adulthood (2) and has both short-and long-term health consequences (3). Children with obesity are at increased risk for: cardiovascular conditions including high blood pressure and high cholesterol, metabolic dysregulation including impaired glucose tolerance and Type 2 diabetes, breathing complications including asthma and sleep apnea, gastroesophageal reflux, gallstones, joint pains, fatty liver disease, low self-reported quality of life, low self-esteem, mental health problems including depression and anxiety, difficulties with academic performance, and social problems including stigma and being bullied (4, 5). Obesity can also increase the risk of complications for infections like influenza and COVID-19 (6). Beyond the individual, obesity has substantial societal effects by increasing healthcare costs – the combined annual direct and indirect costs of obesity in the United States totaled over $147 billion in 2008 (7). Finding ways to improve obesity treatment and self-management is therefore imperative.

Down syndrome (DS) is a genetic condition caused by extra chromosome 21 material in all or some cells of the body (8). The prevalence of DS among children aged 0–4 years in the United States is about 12.7 per 10,000 (9). Youth with DS have high risks for cardiac, metabolic, musculoskeletal, endocrine, respiratory, neurologic, and mental health conditions (10, 11). As well as a higher prevalence of overweight and obesity compared to the general youth population (12–16) which may further contribute to health risks (17). A 2016 review by Bertapelli et al. (18) reported that the combined prevalence of overweight [body mass index (BMI)-for-age 85th–94.9th percentile] and obesity (BMI-for-age ≥95th percentile) varied between studies from 23%–70%. A 2021 report in 122 youth with DS living in the United States, estimated the prevalence of overweight and obesity in youth with DS was 49% (14) compared to 39% in the general youth population (19). The onset of obesity in children with DS occurs around 2 years of age (12, 16). BMI rankings remain stable until puberty (∼12 years of age) when there appears to be an increase (12, 16). The etiology of obesity in youth with DS is unclear (20), but Bertapelli et al. (18) suggest the increased rates of obesity are associated with both physiological factors, such as increased leptin, decreased resting energy expenditure (REE), hypotonia, DS associated comorbidities, and lifestyle factors such as an unhealthy diet, and low physical activity levels.

Overweight and obesity in individuals with DS may contribute to health risks commonly observed in DS (21, 22). Controlling and monitoring weight status in youth with DS may reduce health risks during the growing years and possibly in adulthood. Weight management recommendations have been developed for the general pediatric population (23) as well youth with Autism (24); however, these recommendations may not be appropriate for adolescents with DS. Youth with DS have unique needs and challenges that make them vulnerable to risk factors in the obesogenic environment not shared by those in the general population by virtue of their limited cognitive abilities (25). Youth with DS have limitations with reasoning, money management, memory, and decision making, and require assistance from parents/guardians to complete activities of daily life (26). Additionally, parents/guardians of youth with DS report high levels of stress (27, 28), and often neglect their own health as they prioritize the needs of their children (29, 30). Additionally, individuals with DS have physiological profiles that may contribute to obesity and could impact weight loss (e.g., hypotonia, decreased REE, increased leptin, cardiac chronotropic incompetence). Thus, the daily life experience of adolescents with DS and their families is vastly different from their typically developing peers. Qualitative data indicate that clinicians face uncertainties when providing weight management for youth with DS, and many report lack of resources on the topic. In 2010, Murray and Krause published Recommendations for Obesity Management in Children with Down Syndrome (31); however, the evidence base on this topic has significantly increased in the decade following this publication. Additionally, these recommendations were developed specifically for clinicians, and do not provide families with any guidance. The goal of this paper is to equip clinicians and caregivers with updated accessible state-of-the-science recommendations for behavioral weight loss and the prevention of excess weight gain in youth with DS.

2. Development of weight management recommendations

A workgroup of clinicians and researchers with extensive experience working with youth and adults with DS came together in 2021 to develop recommendations that offer guidance to clinicians and families for behavioral weight management in youth with Down syndrome. This workgroup consisted of 1 Doctor of Medicine, 2 Registered Dietitians, one who is an expert in weight management, 1 non-profit foundation scientist, and 1 physical activity specialist, all with at least 10 years of experience working with individuals with DS. Two of the workgroup members were primarily clinicians, 2 were primarily researchers, and 1 had about equally split roles as clinician and researcher.

The following recommendations were developed *via* a methodical, deliberative process. Workgroup members participated in monthly conference calls between May 2021 and April 2022. They reviewed relevant extant research that focused on obesity in youth with DS, weight management interventions for youth with DS, co-occurring conditions in DS that could impact dietary intake and physical activity, and weight management guidelines for typically developing youth. Clinical consensus was achieved iteratively; the workgroup held extensive discussions focused on developing guidance for clinicians and families considering the lack of evidence-based weight management or weight loss approaches developed specifically for youth with DS. The workgroup consulted with other clinicians who provided either general medical care or weight management for individuals with DS to review standard of care, best practices, and clarify practices that deviated from published literature. For example, the workgroup consulted a special needs weight management clinic, a DS medical clinic, and authors of key peer-reviewed publications.

Using peer-reviewed literature, data collected from external clinicians, and their own experiences working with youth with DS, the group initially developed 9 recommendations. These recommendations were then shared with an expert review panel, who are members of the Down Syndrome Medical Interest Group (US-DSMIG). Each member of the expert panel was asked to read each recommendation and give feedback on both the strength of the recommendation and strength of the evidence. We also conducted a focus group with the expert panel in which they provided additional feedback on aspects of the recommendations to refine, clarify and, in some cases, to expand upon. Recommendations which did not demonstrate strength of the recommendation and strength of the evidence were removed ($n = 1$). The remaining 8 recommendations were updated based on feedback from the expert panel (e.g., providing additional detail or modifying the language). The remaining recommendations were shared with two panels of caregivers who provided feedback on the clarity of the recommendations. The caregivers were also asked to comment on how feasible it would be to implement the recommendations based on their lived experiences. The recommendations were again modified based feedback from caregiver panel and included adding additional details about physical activity.

3. Recommendations

3.1. Recommendation #1. Youth with down syndrome should be screened routinely for overweight and obesity

For youth with DS under the age of 2, clinicians should monitor weight and follow weight-for-length trends at each health care visit. The infant's growth should be plotted on the Down syndrome-specific charts (32, 33) for weight, length, weight for length, and head circumference and reviewed with the family (34).

For youth with DS 2 years of age or older, weight and height should respectively be measured on a standard stadiometer and scale, ideally with the individual in a gown without shoes on and plotted on the Down syndrome-specific charts for weight and height. Universal calculation and classification of body mass index (BMI), calculated as weight (kg)/height(m)^2, is recommended for routine visits, and at least annually starting at the age of 2 years (23). BMI is correlated with more direct measures of body fat, and BMI classification serves as the first step in assessment of obesity (23). Weight status classifications are based on BMI. For children in the United States, sex-specific BMI-for-age percentiles are calculated relative to the 2000 US Centers for Disease Control and Prevention (CDC) growth reference (35). The BMI can then be classified as underweight (<5th percentile), healthy weight (5th to <85th percentile), overweight (85th to <95th percentile), and obesity (≥95th percentile). Severe obesity is defined as a BMI ≥120% of the age- and sex-specific 95th percentile or an absolute BMI ≥35 kg/m^2, whichever is lower (25, 36). Additionally, specialty growth charts are available for youth with DS (32); however, while the DS specific growth charts are useful in comparing youth with DS to their DS peers, they do not appear to provide better classification of weight status or health risk for youth with DS over the age of 10 compared to the standard CDC growth chart (33, 34). Thus, as recommended by the 2022 Health Supervision Guidelines for Children and Adolescents with Down Syndrome, BMI should be plotted on the DS-specific growth chart for youth up to age 10, and for children over the age of 10, BMI should be plotted on both the DS-specific growth chart and the CDC growth chart (34).

Given that youth with DS have altered body composition including a higher prevalence of central adiposity compared to youth without DS (37) and that the extent to which BMI captures excess body adiposity in youth with DS is not known (33), the use of BMI alone may not be accurate enough to detect excess adiposity in this population. Thus, waist circumference should be measured routinely and at least annually. Waist circumference should be measured at the midpoint between the lower margin of the least palpable rib and the top of the iliac crest, using a stretch-resistant tape that provides a constant 100 g tension (38). The waist circumference to height ratio should also be calculated – a weight circumference to height ratio of >0.5 indicates excess central adiposity and is associated with higher risk of metabolic syndrome (37, 39).

3.2. Recommendation #2: clinicians and families should be aware of health conditions and risk factors that are common in down syndrome and may impact the development of obesity

DS is associated with several health conditions that have independent associations with dietary intake and physical activity pattern of youth with DS (40), and may contribute to the development of obesity (18). Clinicians working with youth with DS should screen for and monitor these health conditions to aid in the prevention or treatment of obesity, and families should be aware of how these risk factors may influence diet or physical activity. **Table 1** lists medical conditions associated with DS and the condition's potential impact on weight management.

3.3. Recommendation #3: clinicians should screen for feeding difficulties in all youth with down syndrome

Feeding difficulties are common among infants, children, and adolescents with DS (41). Feeding difficulties, changes in feeding, or changes in respiratory symptoms with feeding should be reviewed during medical visits (34).

Early feeding difficulties can result in protein-calorie malnutrition or inadequate fluid intake, and may require increased calories, modified textures, modified consistency, or alternative methods of feeding to achieve adequate weight gain with minimal aspiration risk (41–43). Older children with DS may continue to have difficulty with hard textures, foods with multiple consistencies or those that require more chewing or sensory tolerance like raw vegetables, unpeeled fruit or less-processed cooked meats or fish (43).

Maladaptive mealtime behaviors can make weight management harder. Caregivers of youth with DS report high frequency of food selectivity, continued eating in the presence of food, swallowing without enough chewing, and eating (or drinking) large amounts of food (or caloric beverages) in short periods of time (43–45). Eating large amounts of food in a short period of time is a predictor of rapid weight gain and higher body fat in preschool-age children (46). Youth with DS should have early and continued access to support for developing and maintaining skills in functional chewing, food preparation, and self-feeding, with focus on less processed alternatives to ultra-processed foods.

3.4. Recommendation #4: clinicians should include assessments of dietary intake and physical activity at every visit

Collection of dietary intake and physical activity are essential for prescribing appropriate energy intake for both weight loss and maintenance, providing feedback to participants in weight management programs, describing changes over time, and determining the effectiveness of the program.

TABLE 1 Health conditions and risk factors common in youth with Down syndrome that can impact weight control *via* either diet or physical activity.

Medical condition	Impact on weight management	Impact on dietary intake	Impact on physical activity
Sensory Input			
Visual Impairment	• Glaucoma, visual field defects, and keratoconus are diseases of the eye that can limit vision. Limited vision can impact feeding and participation in exercise and sports.	☑	☑
Oral and Digestive System			
Dental Disease	• Certain dental conditions including delayed tooth eruption and missing teeth can make eating healthy foods more difficult.	☑	
Esophageal and Swallowing disorders	• Esophageal disorders causing strictures along with other esophageal motility disorders can lead to food avoidance and result in decreased eating due to inability to properly swallow foods.	☑	
Intestinal obstruction, Hirschsprung Disease, Congenital Duodenal Atresia	• Intestinal disorders characterized by obstruction can cause loss of appetite. • Children with a prior surgical repair of the intestinal tract, such as a repaired congenital duodenal atresia, can develop a late-term complication called intestinal strictures, which can decrease intestinal motility and may consequently result in food avoidance.	☑	
Celiac Disease	• Poorly controlled Celiac disease can cause inflammation of the cells lining the intestinal tract, resulting in poor absorption of nutrients and inadequate calorie absorption. Poorly controlled Celiac disease can also cause changes in bowel habits including increased stooling frequency and diarrhea, which can cause weight loss. Slight weight increases along with decreased appetite gain can also be the result of abdominal bloating, another symptom of poorly controlled Celiac disease. • Following a gluten-free diet may result in low intake of fiber, Vitamin D, Vitamin B12, and folate. • Many gluten-free food alternatives (e.g., gluten free cookies) are high in saturated fat, added sugar, and calories, promoting weight gain.	☑	
Endocrine			
Thyroid Disease	• Inadequately controlled hypothyroidism can result in changes in appetite and weight changes. An under-functioning thyroid can cause fatigue and a decreased desire to engage in physical activity.	☑	☑
Cardiovascular			
Congenital heart disease	• Uncorrected congenital heart disease can lead to decreased physical activity and participation in sports due to fatigue with exertion. • Active congenital heart disease can lead to fluid retention presenting as weight gain.		☑
Acquired heart disease	• Diseases of the heart valves can develop during childhood and adolescence that may cause fatigue and a decreased desire to engage in physical activity. • Heart valve disease can cause fluid retention presenting as weight gain.		☑
Moya-Moya Disease	Strokes associated with Moya-Moya disease can limit physical activity.		☑
Vascular ring	• Aberrant right subclavian artery can sometimes cause compression of the esophagus, limiting solid food intake.	☑	
Pulmonary			
Pneumonia and Bronchitis	• Acute lung infections can cause systemic symptoms, including loss of appetite and when severe can result in decreased physical activity capacity.	☑	☑
Obstructive Sleep Apnea	• Inadequately controlled sleep apnea can result in daytime fatigue and a decreased desire to engage in physical activity. • Inadequately controlled sleep apnea may result in a lower metabolism, which can lead to weight gain. • Use of CPAP may also lead to slight weight gain by decreasing your basal metabolic rate.		☑
Musculoskeletal			
Hypotonia (Low Muscle Tone)	• Poor muscle tone can make participating in exercise and sports difficult, resulting in less physical activity. • Low muscle tone can result in a decreased metabolism with lower daily energy requirements.	☑	☑

(*continued*)

TABLE 1 Continued

Medical condition	Impact on weight management	Impact on dietary intake	Impact on physical activity
Arthritis (Joint Disease)	• Arthritis and joint pain can limit physical activity. • Some classes of medications used to treat inflammatory type arthritides, including steroids, can cause increased appetite as well as weight gain.		☑
Joint stability and Posture	• Loose ligaments (ligament laxity) and other causes of poor joint stability can limit physical activity capacity. • Poor or misaligned posture from flat feet and other common foot, ankle, and hip conditions can cause pain that limits physical activity.		☑
Osteoporosis	• Low bone density is common in individuals with DS. Increased consumption of foods rich in calcium and vitamin D, as well as regular weight bearing physical activity can increase bone density and decrease the risk for bone fractures in individuals with DS.	☑	☑
Atlanto-axial instability (AAI)	• Some sports and activities are contraindicated in individuals with atlanto-axial instability/subluxation.		☑
Neurologic			
Seizure disorder	• Certain medications used to treat seizures can cause either loss of appetite or weight gain.	☑	
Regression disorder in DS	• A decrease in global activity results in decreased eating and decreased physical activity.	☑	☑
Developmental Delay	• Autism Spectrum Disorder can impact eating and physical activity levels.	☑	☑
Psychiatric			
Mental Health (Anxiety, Obsessive Compulsive Disease, Depression, Schizophrenia)	• Emotional eating can be seen with Anxiety and Depression which is often associated with increased caloric intake and consumption of unhealthy foods. • Depression can cause a decreased desire to engage in physical activity. • Antipsychotic medications can cause increased appetite and weight gain.	☑	☑
Cancer			
Leukemia, Testicular cancer	• Cancer treatments can cause appetite loss and weakness resulting in decreased physical activity levels. • Steroid medications can lead to increased appetite and weight gain.	☑	☑

A typical approach is to obtain a dietary intake is to have a parent or caregiver record all foods and beverages consumed for the 3-days prior to the medical visit using a simple diet journal or a smart phone app such as *Lose it!* or *MyFitnessPal*. Clinicians can then review the food record to estimate the patients average daily caloric intake, macronutrient intake, and the quality of the diet (for example daily servings of fruits and vegetables). This information should be used to create individualized diet goals; for example, increasing fruit and vegetables intake from 3 to 4 servings per day, reducing the number of sugar sweetened beverages (juice, soda) consumed from 3 to 1 per day, reducing the consumption of fast food or highly processed foods to 1 time per week, or reducing overall energy (calorie) intake. Additionally, the dietary record can be used to identify food aversions and food selectivity, such as rejecting certain foods based on color or consuming only certain textures, which can lead to nutritional deficiencies (47).

Assessment of physical activity can be done with self-reported questionnaires when a patient comes into the clinic or having the youth with DS wear a physical activity tracker. There are pros and cons to each method. While the use of a questionnaires is easy, can be done in clinic, and is inexpensive, the accuracy of these questionaries in youth with DS is unknown. Youth are less likely to make accurate self-report assessments due to developmental differences, especially in the ability to perform detailed recall and understand concepts regarding physical activity duration and intensity (48). This may be amplified in youth with DS who may have difficulties with cognitive functioning, memory, and attention. Recently, the American Academy of Pediatrics opted to not recommend a specific physical activity assessment tool because of limitations to existing questionnaires (49).

Conversely, physical activity trackers have grown in popularity; these include simple pedometers as well as wrist-worn physical activity trackers. Pedometers provide step-counts as a quantity of physical activity and can often be purchased at a low-cost; however, pedometers do not provide information regarding time or intensity of physical activity, and it may be difficult to obtain long-term data as most pedometers can only store 1–7 days of activity. Recently, wrist-worn physical activity trackers have become popular. These devices often combine an accelerometer to measure minutes of physical activity and steps as well as a heart rate monitor to measure physical activity intensity. These devices often sync with an app on a smart phone so the user can see physical activity data, including daily minutes of physical activity, steps, resting heart rate, and heart rate during exercise. These data can then be shared with the medical team of youth with DS. However, these trackers can be costly, and the heart rate and intensity data provided by the devices may not be accurate as youth with DS have chronotropic incompetence (50) and increased heart rate variability (51).

The physical activity data obtained by either questionaries or devices should than be used to determine level of physical activity, set goals for increased activity, review barriers to physical activity for families, and provide feedback regarding change in physical activity since the last visit.

3.5. Recommendation #5. Clinicians and families should set appropriate recommendations for dietary intake

Determining nutrition and energy (calorie) requirements is challenging because these vary depending on the severity of intellectual disability, mobility status, age, medications, and feeding problems (52). When determining energy requirements, it is important to individualize the requirements based on all these considerations, as well as monitor the individual and make changes to the plan of care as needed. Predictive equations, that rely on the individual's height and/or weight, are often used to determine the energy needs of an individual. However, youth with DS may have a significantly lower resting metabolic rate and total daily energy expenditure relative to body size and composition (53, 54); thus, many predictive equations overestimate the energy requirements for adolescents with DS. Recent literature (55) demonstrates that the estimated energy requirement equations developed for children by the National Academy of Medicine, previously the Institute of Medicine (IOM) (56) provides the most accurate prediction of energy needs in youth with DS. The IOM equations include both an equation for general use (i.e., applied only to healthy weight participants) or overweight/obese specific equation (i.e., used for participants who were overweight or obese). **Table 2** provides the difference predictive equations by sex and weight status.

TABLE 2 The Institutes of Medicine estimated energy requirement equations.

Stratification	Predictive Equation
Healthy weight male	79 − 34.2 × age + 730 × height + 15.3 × weight
Healthy weight female	322 − 26 × age + 504 × height + 11.6 × weight
Overweight/obese male	420 − 33.5 × age + 418.9 × height + 16.7 × weight
Overweight/obese female	516 − 26.8 × age + 347 × height + 12.4 × weight

Once resting energy expenditure calculated using the IOM equations are calculated, it needs to be multiplied by an activity factor to yield total daily energy needs. The clinician should choose the best activity factor for the youth with DS based on the physical activity assessment collected during screening.

- For girls, use 1.1 for sedentary/non-active; 1.3 for active (3 or more days of vigorous activity of at least 20 min/day, OR 5 or more days of moderate-intensity activity or walking or at least 30 min/day); and 1.5 for very active (5 or more days of vigorous activity of at least 30 min/day, OR 5 or more days of moderate-intensity activity or walking or at least 60 min/day).
- For boys, use 1.1 for sedentary/non-active; 1.25 for active; and 1.4 for very active.

This will yield the approximate daily calories needs for weight maintenance. If weight loss is a goal, 250–500 calories should be subtracted from the total to get approximate needs for weight loss.

Currently, there is no evidence demonstrating that the macronutrient (i.e., fat, protein, carbohydrates) needs of youth with DS are different than youth without DS. Thus, it is recommended to refer to the national dietary recommendations when providing dietary recommendations for youth with DS. The 2020–2025 Dietary Guidelines for Americans were published in December 2020 (57). These Guidelines expand previous versions that provided a roadmap for chronic disease prevention through adequate nutrition and address the role of the food environment, including access to ultra-processed foods and the ease of preparing and consuming them. Furthermore, the 2020–2025 Dietary Guidelines now stress the importance of maintaining healthy dietary patterns across the lifecycle. According to the 2020–2025 Dietary Guidelines, starting at age 2 years, youth should limit added sugars to less than 10% of calories and saturated fat to less than 10% of total daily calories. Added sugar and added fat tend to be sources of "empty calories," leaving less space for more nutrient-dense foods. Additionally, calories from sugary drinks make it difficult to maintain a healthy meal pattern and weight (58). Younger children should avoid foods and drinks with added sugars. Water should be offered (not juice or juice drinks) for the whole family with introduction at 6 months or as directed by a medical team. There is not one menu to solve the challenge of healthy eating. A diversity of nutrient-dense ingredients and foods can support a healthy eating pattern. This is true for all youth including those with DS even with personal preferences and cultural traditions considered.

3.6. Recommendation #6. Clinicians and families should set appropriate recommendations for physical activity

When developing a physical activity program as a component weight control in youth with DS, health professionals should consider current recommendations. The U.S. Department of Health and Human Services launched the second edition of the Physical Activity Guidelines for Americans in 2018, affirming that physical activity improves a wide range of health outcomes including but not limited to weight status and body composition in youth aged 3–17 years (59). The guidelines are generally the same for youth with and without disabilities. Children aged 3–5 years should perform a variety of physical activities throughout the day and should engage in active play such sports and interactive activities involving running, jumping, climbing, and crawling, among others. It is also recommended that youth aged 6–17 years obtain ≥60 min of moderate-to-vigorous physical activity daily accumulated in bouts of different durations and should include vigorous physical activity, muscle-strengthening activity, and bone strengthening activity at least 3 days/week. The guidelines call for physical activities that are age-appropriate, enjoyable, and offer variety.

Most youth with DS across the lifespan do not meet recommendations for physical activity and have high levels of sedentary behavior (60–62). While youth with DS should be encouraged to meet the recommendations, this may not be immediately attainable for some youth with DS. Thus, physical activity programs must have gradual progression in frequency, duration, and total weekly amount of physical activity (59). **Table 3** provides an example of a gradual exercise progression plan for youth aged 6–17 years which has been previously implemented in youth with DS (63). Most of the proposed amount of physical activity shown should involve moderate aerobic activity (e.g., brisk walking, hiking, and bicycle riding), but also include three times per week (a) vigorous aerobic activities (e.g., running and sports), (b) muscle-strengthening activities (e.g., resistance exercises using body weight), and (c) bone-strengthening activities (e.g., hopping, skipping, and jumping rope). Importantly, physical activities should be enjoyable. Enjoyment during physical activity may be achieved by affording youth with opportunities for engaging in preferred activities (e.g., if someone enjoys music, have dance parties with favorite songs), acquiring movement skills, interacting with others, and gaining positive feelings through movement, while avoiding pain, frustration, and an emphasis on competition (64, 65).

Furthermore, parents and clinicians should be aware that the minimum recommended amount of physical activity is intended for attaining general health benefits, but they are not specific for weight loss in youth with obesity. However, physical activity is associated with increased cardiovascular fitness (66), muscular strength and endurance (67), and reduced risk of chronic disease (68) in youth with DS. These benefits are independent of its impact on weight, and any increases in physical activity or decrease in sedentary behaviors, such as screen time, may have health benefits (69, 70).

Prior to recommending physical activity programs, especially of vigorous intensities, health professionals should conduct an evaluation of current physical activity levels with signs and symptoms of cardiovascular, metabolic, and other health conditions. Based on this preparticipation screening, medical clearance may be required prior to starting the exercise program. It is also important for clinicians and families to address the barriers to physical activity youth with DS face and consider their physical activity preferences. Barriers within the person include acute health problems, low physical fitness levels, low motor skills, orthopedic anomalies, lack of energy, and boredom (60, 71, 72). Parental barriers include family structure (marital status, other siblings, etc.), lack of self-efficacy for encouraging activity in their adolescent, time constraints, lack of affordable/accessible transportation, and low rates of parental physical activity (73, 74). Environmental barriers include lack of accessible, inclusive, and adapted programs, limited assistance by professionals, negative attitudes towards people with DS, and limited friendships (60, 71, 72). Physical activity in youth with DS may be facilitated by health care professionals knowledgeable in designing programs, family members who understand their roles in modeling physical activity, and programs that are accessible, structured, adapted to the needs and abilities of youth with DS, and ones that promote social interactions and enjoyment (71, 73). Families should ensure their children wear well-fitting shoes with proper arch support to avoid complications of foot anomalies. Additionally, youth with DS, family members, and clinicians should be educated to recognize warnings of cardiac distress, such as palpitations, syncope, lightheadedness, and dyspnea. Commonly performed activities among individuals with DS are walking, dancing, swimming, bowling, and team sports, but there is variation in physical activity types around the world (60, 71, 72). Overcoming barriers and identifying facilitators and preferences of physical activity for youth with DS may increase the success of physical activity programs for weight control.

TABLE 3 Example of an exercise progression plan for youth with Down syndrome 6–17 years of age.

Week	Days/week	Min/day	Min/week
1	3	15	45
2	3	20	60
3	4	20	80
4	4	25	100
5	4	30	120
6	5	25	125
7	5	30	150
8	6	30	180
9	6	35	210
10	6	40	240
11	7	40	280
12	7	45	315
13	7	50	350
14	7	60	420

3.7. Recommendation #7. Clinicians should provide multi-component behavioral weight management treatment programs specific to the needs of youth with down syndrome and with overweight or obesity

Behavioral weight Management strategies for youth with DS are based on those for the general youth population. However, clinicians working with youth with DS must consider their specific needs and the needs of their families. The quality and quantity of data to base recommendations for effective weight management specifically for youth with DS is limited (25, 75–77). Most behavioral weight management interventions have been conducted in youth with intellectual and developmental disabilities and were comprised of physical activity alone (75–80), a combination of diet and physical activity (81), and multi-component interventions which included diet, physical activity, and behavioral/education strategies (25, 63, 82–88). This literature suggests that the most effective behavioral weight management interventions are multi-component interventions that include changes to diet and physical activity and behavioral strategies such as self-monitoring of diet and physical activity, mindfulness, and goal setting. Clinicians should provide guidance and direct families towards multi-disciplinary treatment programs when weight management is required to maintain health goals. It is important that this guidance be empathetic, inclusive, and honest to empower families to make informed decisions. The following are specific recommendations that should be considered when providing multi-component treatment programs for youth with DS.

3.7.1. Contact hours

The US Preventive Services Task Force Recommendation Statement on Screening for Obesity in Children and Adolescents recommends ≥26 contact hours over 12 months to improve weight status in typically developing children and adolescents (89). However, the cost and scalability of high contact programs may be limiting factors in the feasibility of this approach. A study in adolescents with intellectual disabilities ($n = 110$, 48% with DS, age 13–21 yrs) that included 30–45-minute individual sessions with participants and parents twice per month across 12 months, a total of ∼18 h across 12 months which is less than the ≥26 contact hours over 12 months, still resulted in weight loss (63). This suggests that intervention programs with fewer contact hours may still be effective for weight loss in youth with DS.

3.7.2. Delivery format

Limited evidence in typically developing children and adolescents with overweight/obesity suggests that weight loss achieved with tele-health behavioral interventions may be minimal (90) and that a combination of face-to-face and remotely delivered sessions may be required to elicit clinically relevant weight loss (91, 92). However, recent research in adolescents with intellectual and developmental disabilities including DS demonstrates that weight management can be successfully delivered in-person or by tele-health (45, 63, 74, 85). In a 2021 study, adolescents attended behavioral lifestyle sessions with a trained health educator every 2 weeks across a 6 month period (63). Participants enrolled in the in-person delivery arm met with a health educator during individual home-visits and self-monitoring of diet and physical activity was completed by participants using pencil and paper records. Participants in the tele-health arms met with a health educator remotely using FaceTime™ video conferencing and self-monitoring was completed using a web-based app for diet (Lose it!) an activity tracker for physical activity (Fitbit®). Results of the study found no differences in weight loss between the in-person or tele-health formats, suggesting that remote delivery is just as effective as face-to-face delivery. Additionally, tele-health may be useful in this population as it eliminates the need for parents to provide transportation to the intervention site and eliminates the time associated with travel.

3.7.3. Family-Based

Multiple studies in youth with DS involved a designated study helper who worked with the participant and engaged in the intervention themselves through attendance to meetings or sessions (25, 81–83, 85). Other studies were family-based trials (25, 82, 84, 87), which included significant parental involvement in family exercise, nutritional education sessions, as well as behavioral or motivational education sessions to assist with making healthier lifestyle changes at home. One study (25) compared an intensive 16-week educational approach that included nutrition and physical activity education with the same approach, but with increased parental support and training in 21 adolescents with DS. The rigorous parent training intervention guided parents to work with their adolescent son or daughter with DS to track diet and physical activity, set specific weekly goals for both, participate in a weekly phone call from the interventionist to track progress on both, report and discuss results with fellow parents and a behavioral therapist weekly, and receive feedback and reinforcement. Results of that study indicated that significant involvement of family members yields greater weight loss. A subsequent trial (86) examined the long term changes in weight after use of the increased parental support and training intervention in a sample of youth with intellectual disabilities ($n = 24$, 56% DS, age 14–22 yrs.) and included three 45-minute in-person group sessions per month (2–5 participants and parent) and one monthly 45-minute session with participants and parents separately during weight loss and 2 sessions per month during weight maintenance which alternated between 90-minute in-person group sessions (participants and parent) and 30-minute individual parent sessions, in a group setting. Participants who followed the intensive family-based program for 12 months had a mean weight loss of 6.1 kg, 6 months after ending the intervention, suggesting that the family-based approach is successful for both weight loss and long-term weight maintenance.

Research findings also indicate that family members significantly influence the physical activity levels of their children with DS. A recent cross-sectional review examined different intrapersonal, interpersonal, and environmental factors associated with device-measured physical activity in 92 adolescents with intellectual disabilities (55% DS, 11–21 years) and determined that the factor that most influenced physical activity levels of adolescents with intellectual disabilities was parental physical activity (93). Results suggest that for every 10 min of moderate to vigorous physical activity the parent performed, adolescents with intellectual disabilities achieved 6 min of moderate to vigorous physical activity. Notably, the correlation between parental physical activity and adolescent physical activity was higher in adolescents with DS compared to those with other intellectual disabilities. It should be noted that parents of youth with DS face emotional and physical challenges that exceed those of parents caring for typically developing adolescents. Thus, clinicians should assess family stressors and consider the family environment before making recommendations for family-based weight management treatments.

3.7.4. Dietary components

Nearly all the evidence for effective weight management interventions in youth with DS includes components that focus on healthy eating and physical activity. The specific dietary recommendations vary widely among studies, so no one unified approach has demonstrated superiority over another. Common components of successful diet interventions in youth with DS are: providing specific recommendation for the number of servings from each food group; encouraging foods with low energy density (e.g., fruits, vegetables, and lean meats) and limiting foods with high energy density (e.g., sweet and fried foods); avoiding dietary restriction; allowing individuals to have their favorite foods in moderation; and tracking dietary intake using simple pictorial displays (25, 52, 63, 84, 86). Additionally, portion-controlled meals have been shown to be effective for weight loss in youth with DS (63, 85). For example, portioned lunch boxes or single-serve containers that are a “just right” size for the individual can help families and caregivers support the routine of adequate nutrition at home. A dietitian can provide individualized assessment and provide guidance specific to any child or adolescent. Specific recommendations for portion sizes may vary from individual to individual based on physical activity level, age, gender, weight status, and height (as discussed earlier). This is one reason that healthy eating and physical activity promotion are effective partners in weight management. **Table 4** provides some online resources that can help with the promotion of healthy eating specific to those with DS.

3.7.5. Physical activity components

Increased physical activity in conjunction with a reduced energy diet and behavioral counseling to assist participants with adherence to the diet and moderate to vigorous physical activity, is an important part of current multicomponent weight loss recommendations (94). However, data on the changes in physical activity in youth with DS participating in weight management interventions are limited. General physical activity education strategies, such as providing individuals with weekly physical activity recommendations, providing education around physical activity, and encouraging self-monitoring of physical activity using physical activity trackers, have not demonstrated effectiveness in promoting change in physical activity (82, 95, 96). Conversely, educating parent/caregivers (25, 97), providing greater structure and implementing scheduled activities for exercise rather than leisure exercise (80), and participating in remote group exercise classes (98), have demonstrated some effectiveness in increasing physical activity levels of adolescents with DS. **Table 4** provides some online resources for increasing physical activity specific to those with DS.

3.7.6. Multidisciplinary team

Youth with DS experience nutrition and medical challenges across their lifespan, such as increased risk of comorbidities, feeding/mealtime issues, and food insecurity, which may be further complicated by lack of insurance. Multidisciplinary teams which may include the primary care clinician/pediatrician, speech language pathologist, occupational therapist, physical therapist, therapeutic recreation specialist, and dietitian, are critical for long-term-care and effective weight management. For example, a weight management program that was delivered at a children's hospital and involved sessions with a child psychologist, nurse practitioner/pediatrician, dietitian, and an occupational therapist, yielded significant reductions in BMI z-score (0.02 units/month, $p < 0.001$) in 115 youth with intellectual disabilities (88).

3.7.7. Self-Monitoring of diet and physical activity

Self-monitoring of diet and physical activity has been shown to be associated with decreased weight in typically developing youth (99) and in youth with DS (100). Traditional methods of self-monitoring of dietary intake include written food diaries, and traditional methods of self-monitoring of physical activity include the use of pedometers and tracking steps. However, as stated previously, these methods may be not accurate in youth with DS. In the last decade, several technology-based tools have been developed for self-monitoring of diet and physical activity which may be more appropriate for youth with DS. In typically developing youth, technology based self-monitoring of diet and physical activity may be a more effective approach than traditional paper records (99, 101). In youth with DS, compliance with self-monitoring using technology vs. paper records has been shown to be similar (63). It is recommended that families of youth with DS self-monitor diet and physical activity at least once a week for general health, and daily when actively working to lose weight. Self-monitoring can be done in whatever method works best for each family, decreases burden of tracking, and is affordable. **Table 4** presents a list of technology-based tools for self-monitoring of diet and physical activity.

3.7.8. Treatment limitations

There are many known limitations for families to access and participate in comprehensive, multi- component obesity treatment. These limitations include the lack of treatment programs and clinicians with experience in pediatric obesity treatment in youth with DS. Additionally, many families struggle with transportation issues, loss of school or work time, and caregiver burn-out. However, tele-health may help to increase the reach of many treatment programs as well as overcome barriers related to transportation and time. The following recommendation provides strategies that parents may be able to implement in the home.

TABLE 4 Technology based tools for self-monitoring and online programs for the promotion of health eating and physical activity.

DIET	PHYSICAL ACTIVITY
Tools for Self-Monitoring of Diet	***Tools for Self-Monitoring of Physical Activity***
MyFitnessPal (app)	Fitbit Tracker
Lose it (app)	Garmin Vivofit Tracker
	Apple Watch
	Any Smart Phone
Online Tools for Promotion of Healthy Eating	***Online Tools for Promotion of Physical Activity***
The Accessible Chef: https://accessiblechef.com/	Special Olympics Fit 5: https://resources.specialolympics.org/health/fitness/fit-5
Gigi's Kitchen Online: https://gigisplayhouse.org/gigisathome/programs/teen-and-adult-13/#	Special Olympics School of Strength: https://www.specialolympics.org/school-of-strength
MGH Down Syndrome Program: https://www.massgeneral.org/children/down-syndrome/patient-handouts	Gigi Fit Live Online Workouts: https://gigisplayhouse.org/gigisathome/

3.8. Recommendation #8. Families should work to promote healthy eating and increased physical activity at home and school

The recommendations for healthy eating and increased physical activity in youth with DS are similar to those for youth without DS. As stated above, common components of weight management in youth with DS are: providing specific recommendation for the number of servings from each food group; encouraging foods with low energy density (e.g., fruits, vegetables, and lean meats) and limiting foods with high energy density (e.g., sweet and fried foods); avoiding dietary restriction; allowing individuals to have their favorite foods in moderation; and tracking dietary intake using simple pictorial displays (25, 63, 84–86). However, key factors for successful weight management in youth with DS is family involvement and family modeling (25). Table 5 provides specific strategies for families to consider in support of their children with DS adopting health-promoting behaviors. Of note, youth with DS will have individualized needs and goals; thus, working with a registered dietitian or multidisciplinary health care team could

TABLE 5 Strategies for families to support their children with down syndrome to adopt health-promoting behaviors.

Promoting Healthy Eating	Promoting Physical Activity
At Home:	**At Home:**
Act as role models in eating healthy foods.	Build exercise into the weekly routine, and schedule when you will do it
Avoid using food as a reward.	Consider remote physical activity programs designed for youth with DS.
Involve children in planning meals, food shopping and cooking (if able).	Consider ways to be active as a family: dance to music, take walks/hike, play outside games.
Introduce 1–2 new foods every week.	Consider involving the child in physical chores such as raking leaves or sweeping or carrying groceries as a way to promote movement in a positive way: helping!
Include at least one safe food that the child likes in every meal.	Engage in and teach the family about active living - using the surrounding streets and buildings to be active every day: walk to school and work, walk to stores and restaurants, take the stairs, get off one stop early when using public transportation and walk the rest of the way to the destination.
Avoid pressuring child to try the new foods	Get involved in Special Olympics or community-based physical activity groups.
Don't stress if the child does not eat the food right away, it can take many attempts for a child to accept a new food.	**At Childcare or School:**
Limit energy dense foods such as sweets and chips to 1–2 times a week.	Explore ways to increase physical activity during the school day., e.g., movement breaks as sensory accommodations and travel training as a way to practice independence and improve tolerance for walking.
Offer a fruit or vegetable with every meal, including snacks.	Request PT/OT (physical therapy/occupational therapy) services to address readiness to access the K-12 physical education (PE) curriculum in Early Intervention years and for preschool IEP.
Portion snacks in advance.	Recommend that a physical education teacher be included on the child's IEP team and include physical therapy and/or physical activity goals in the child's IEP that support them accessing the K-12 physical education (PE) curriculum
Offer water instead of sugar-sweetened beverages (Soda, juice, chocolate milk)	Request an assessment for adaptive physical education (APE) services if a child is not successful in the general PE program.
Use positive language when talking about food or body weight.	Be sure recess is not limited or taken away as a punishment or to provide services.
Eat meals together as a family.	
Remove screens (TVs, tablets, and phones) when eating.	
Offer the child choices at each meal (Do you want blueberries or strawberries with dinner?)	
Consider modifying the texture of foods that align with the child's texture preferences and swallowing abilities.	
At Childcare or School:	
Review monthly school menus and pack a lunch/snack if needed. Pack water or flavored water instead of juices for lunch/snack.	
Include healthy eating goals and alternatives to food rewards in Individual Education Plan (IEP) and Transition Plans. For example, request food not be given as a reward in school settings.	
Develop behavior plans that do not use food as a reward. Document specific alternatives to food-based rewards.	

TABLE 6 Summary of weight management recommendations for youth with Down syndrome.

Recommendation 1: Youth with Down syndrome should be screened routinely for overweight and obesity.
Children with Down syndrome should be screened annually for overweight and obesity. Weight and height should be measured on a standard stadiometer and scale, ideally with the individual in a gown without shoes on.
BMI should be plotted on the Down syndrome-specific growth chart for youth up to age 10, and for children over the age of 10, BMI should be plotted on both the Down syndrome -specific growth chart and the CDC growth chart.
Recommendation 2: Clinicians and families should be aware of health conditions and risk factors that are common in Down syndrome and may impact the development of obesity.
Down syndrome is associated with several health conditions that have independent associations with dietary intake and physical activity pattern of youth with Down syndrome.
Clinicians working with youth with Down syndrome should screen for and monitor these health conditions to aid in the prevention or treatment of obesity, and families should be aware of how these risk factors may influence diet or physical activity
Recommendation 3: Clinicians should screen for feeding difficulties in all youth with Down syndrome.
Feeding difficulties are common among infants, children, and adolescents with Down syndrome.
Feeding difficulties, changes in feeding, or changes in respiratory symptoms with feeding should be reviewed during medical visits
Recommendation 4: Clinicians should include assessments of dietary intake and physical activity at every visit.
Collection of dietary intake and physical activity are essential for prescribing appropriate energy intake for both weight loss and maintenance, providing feedback to participants in weight management programs, describing changes over time, and determining the effectiveness of the program.
Assessment of dietary intake can be done by having a parent or caregiver record all foods and beverages consumed for 3-days prior to the medical visit using a simple diet journal or a smart phone app such as Lose it! or MyFitnessPal.
Assessment of physical activity can be done with self-reported questionnaires when a patient comes into the clinic or having the youth with DS wear a physical activity tracker.
Recommendation 5: Clinicians and families should set appropriate recommendations for dietary intake.
Youth with Down syndrome may have a significantly lower resting metabolic rate and total daily energy expenditure relative to body size and composition.
The estimated energy requirement equations developed for children by the National Academy of Medicine, previously the Institute of Medicine, provides the most accurate prediction of energy needs in youth with Down syndrome.
The macronutrient (i.e., fat, protein, carbohydrates) needs of youth with Down syndrome are not different than youth without DS. Thus, it is recommended to refer to the national dietary recommendations when providing dietary recommendations for youth with Down syndrome.
Recommendation 6: Clinicians and families should set appropriate recommendations for physical activity.
When setting goals for physical activity clinicians should consider current youth recommendations but take into consideration youths with Down syndrome current activity levels, sedentary time, cardiovascular health, and intrapersonal, parental, and environmental barriers to physical activity.
Physical activity programs should be enjoyable, accessible, structured, adapted to the needs and abilities of youth with Down syndrome, and should promote social interactions.
Recommendation 7: Clinicians should provide multi-component behavioral weight management treatment programs specific to the needs of youth with Down syndrome and with overweight or obesity.
The US Preventive Services Task Force Recommendation Statement on Screening for Obesity in Children and Adolescents recommends ≥ 26 contact hours over 12 months to improve weight status in typically developing children and adolescents. However, intervention programs with fewer contact hours may still be effective for weight management in youth with DS
Weight management can be provided to youth with DS using either face-to-face delivery or tele-health. However, tele-health may help to increase the reach of many treatment programs as well as overcome barriers related to transportation and time.
Interventions should be family based; however, clinicians should assess family stressors and consider the family environment before making recommendations for family-based weight management treatments.
Common components of successful diet interventions in youth with Down syndrome are:
Providing specific recommendation for the number of servings from each food group
Encouraging foods with low energy density (e.g. fruits, vegetables, and lean meats) and limiting foods with high energy density (e.g. sweet and fried foods)
Allowing individuals to have their favorite foods in moderation
Use of simple pictorial displays
Use of portion-controlled meals
Physical activity promotion efforts need to go beyond just recommending increased physical activity and should include structure exercise and increased parent involvement.

(*continued*)

TABLE 6 Continued

Multidisciplinary teams which may include the primary care clinician/pediatrician, speech language pathologist, occupational therapist, physical therapist, therapeutic recreation specialist, and dietitian, are critical for long-term-care and effective weight management
Families of youth with Down syndrome should self-monitor diet and physical activity at least once a week for general health, and daily when actively working to lose weight. Self-monitoring can be done in whatever method works best for each family.
Recommendation 8: Families should work to promote healthy eating and increased physical activity at home and school.
The recommendations for healthy eating and increased physical activity in youth with DS are similar to those for youth without DS.
Parents and caregivers should:
Act as role models in eating healthy foods.
Avoid using food as a reward.
Involve children in planning meals, food shopping, and cooking (if able).
Introduce 1–2 new foods every week and include at least one safe food the child likes in every meal.
Avoid pressuring child to try the new foods.
Limit energy dense foods such as sweets and chips to 1–2 times a week.
Offer a fruit or vegetable with every meal, including snacks.
Offer water instead of sugar-sweetened beverages (Soda, juice, chocolate milk)
Use positive language when talking about food or body weight.
Build exercise into the weekly routine
Consider remote physical activity programs designed for people with Down syndrome.
Consider ways to be active as a family: dance, take walks or hike, play outside.
Involve the child in physical chores such as raking leaves or sweeping.
Get involved in Special Olympics, team, community-based, or school sports.
Be sure to include physical education and physical activity goals in the child's IEP.

help caregivers prioritize and further individualize health goals and health promotion strategies for their family and child.

4. Discussion

Youth with DS are at increased risk for obesity due to both behavioral and biologic reasons. While we await the results of additional research on the etiology of obesity and on evidence-based weight management practices in youth with DS, these recommendations can be implemented by clinicians working with youth with DS as well as the family, school, and other relevant entities. These recommendations should be revised and updated as additional evidence-based practices are developed. Table 6 provides a summary of all recommendations.

There are several limitations to be considered when reviewing these recommendations. First, most interventions have been conducting in adolescents with DS and may not be effective in younger children who are more reliant on caregivers and who have unique considerations for growth. Next, the present recommendations are for behavioral weight management, thus, other obesity treatment options, such as pharmacotherapy and bariatric surgery, were not included in our recommendations and could be considered for weight management. Finally, we did not include recommendations for specific laboratory assessments to be included during clinical screening as these have been covered in detail in the Health Supervision for Children and Adolescents with Syndrome Guidelines (34).

The current recommendations highlight that weight management interventions for youth with DS are not drastically different than those for typically developing youth, clinicians should consider the unique characteristics of youth with DS, such as the increased prevalence of DS-related health conditions that may impact diet and physical activity, feeding difficulties, difficulty assessing dietary intake and physical activity, challenges and barriers for increased physical activity, and increased reliance on parents and caregivers who often experience increased stress. While youth with DS are at increased risk for obesity, recent findings demonstrate that weight management for this population is feasible with proper screening and intervention strategies. Clinicians and families should work together to determine what strategies works best for each person and their family.

Author contributions

All authors were workgroup members who participated in monthly conference calls reviewed, relevant extant research, developed the recommendations, and revised the recommendations. LP and SA drafted the initial manuscript. All authors contributed to the article and approved the submitted version.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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Effects of a mobile health nutrition intervention on dietary intake in children who have autism spectrum disorder

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Background: Children who have Autism Spectrum Disorder (ASD) show preferences for processed foods, such as salty and sugary snacks (SSS) and sugar-sweetened beverages (SSB), while healthier foods, such as fruits and vegetables (FV), are consumed less. Innovative tools are needed that can efficiently disseminate evidence-based interventions and engage autistic children to improve their diet.
Aim: The aim of this 3-month randomized trial was to test the initial efficacy of a mobile health (mHealth) nutrition intervention on changing consumption of targeted healthy (FV) and less healthy foods/beverages (SSS, SSB) in children who have ASD, ages 6–10, who were picky eaters.
Methods: Thirty-eight parent-child dyads were randomly assigned to either an intervention (technology) group or a wait list control (education) group. The intervention included behavioral skills training, a high level of personalization for dietary goals, and involved parents as "agents of change." Parents in the education group received general nutrition education and the dietary goals but did not receive skills training. Children's intake was assessed at baseline and at 3 months using 24-hour dietary recalls.
Results: While there were no significant group-by-time interactions ($P > 0.25$) for any of the primary outcomes, we found a significant main effect of time for FV intake ($P = 0.04$) indicating that both groups consumed more FV at 3 months (2.58 ± 0.30 servings/day) than at baseline (2.17 ± 0.28 servings/day; $P = 0.03$). Children in the intervention group who consumed few FV at baseline and showed high engagement with the technology increased their FV intake by 1.5 servings/day ($P < 0.01$). Children's taste/smell sensitivity significantly predicted their FV intake ($P = 0.0446$); for each unit of *lower* taste/smell sensitivity (indicating greater sensory processing abnormalities), FV intake increased by 0.13 ± 0.1 servings/day.
Discussion: This mHealth intervention did not yield significant between-group differences for changing consumption of targeted foods/beverages. Only children who consumed few FV at baseline and highly engaged with the technology increased their FV intake at 3 months. Future research should test additional strategies to expand the intervention's

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Abbreviations
mHealth, mobile health; BMI, body mass index; ASD, autism spectrum disorder; SSS, salty and sugary snacks; SSB, sugar-sweetened beverages; FV, fruits and vegetables.

impact on a wider range of foods while also reaching a broader group of children who have ASD. This trial was registered at clinicaltrials.gov as NCT03424811.

Clinical Trial Registration: This study was registered at clinicaltrials.gov as NCT03424811.

KEYWORDS

mobile health intervention, technology, nutrition, children, autism

Introduction

Children who have Autism Spectrum Disorder (ASD)[1] are five times more likely to have mealtime challenges (4–6) and be picky eaters (7–10), which in part has been attributed to restrictive and ritualistic behaviors and heightened sensory sensitivity (7). Picky eating among autistic youth has been shown to not be associated with a lack of appetite as many parents report that their children show a healthy appetite for the foods that they like (7), which often include highly processed foods (9–13). Consumption patterns that favor energy-dense, nutrient-poor foods and beverages in lieu of healthier options put children on the autism spectrum at an increased risk for excess weight gain. In fact, children who have ASD show a four-fold increased risk for overweight and obesity (14) and are over three times more likely to develop metabolic syndrome (15) than children with neurotypical development.

Children on the autism spectrum have been reported to show preferences for highly processed foods, such as salty and sugary snacks (SSS) and sugar-sweetened beverages (SSB), while healthier foods, such as fruits and vegetables (FV), are consumed less often (9–13). There is strong evidence for an independent role of SSB intake (16–18) and increased snacking frequency (19–22) in the promotion of obesity in youth. Increased FV consumption has been shown to reduce dietary energy density (23, 24), moderate energy intake (25, 26), and play an important role in the prevention and treatment of childhood obesity (27, 28). Reducing consumption of SSB and SSS and increasing consumption of FV in children are therefore considered important targets for intervention.

The pronounced core impairments of social and communication skills and presence of restricted and repetitive behaviors in children who have ASD complicate traditional treatment options for healthy eating available to children with neurotypical development. While behavioral interventions are considered effective treatments overall and, in particular, for selective eating in children who have ASD (29–31), it is often behavioral therapists, and not parents or caregivers, who work with children one-on-one in highly structured clinical settings, which are highly resource dependent and less generalizable to everyday life without structured mealtimes. Parents are often removed from the treatment initially and then trained to re-enter mealtimes as discharge approaches [see Sharp and colleagues (31) for a review of the most common intensive multidisciplinary interventions]. Evidence suggests that treatments that involve family members as treatment providers are effective and may be more applicable to the home environment (32, 33). A small number of studies exist aimed at teaching caregivers, during in-person sessions, behavior modification strategies which they can use to address feeding problems in their children. While some of these interventions indicated a high degree of social validity and caregiver satisfaction, many showed limited success in changing child mealtime behaviors or dietary variety, included small sample sizes, and suffered from high attrition rates (34–38). Barriers to parent-directed interventions include high time commitment and transportation costs, shortage of trained professionals, and lack of childcare (39). New and innovative tools are needed that are scalable, can efficiently disseminate evidence-based parent interventions, and effectively engage children who have ASD.

The use of mobile technology is rapidly increasing in children, including for those on the autism spectrum, across all ages. Children who have ASD, in particular, are engaging with mobile devices on a daily basis and technology has been shown to help with their learning and communication by providing structure and dependability and opportunities for visual learning (40, 41). Research has shown that multisensory interactions and the ability to individualize instructions are some of the features that can assist children who have ASD when working with technology (42) and smart technologies are effective tools for improving social, functional, and communications skills (40, 43). We aimed to harness the lure of technology by developing an innovative, evidence-based mobile health (mHealth) nutrition intervention to teach children who have ASD about healthy eating and to motivate them to make healthy food choices in their daily lives. mHealth technologies provide opportunities for remote coaching and skills training, which has proven to be an effective and efficient training tool for parents of autistic youth (44, 45).

Core behavior change strategies that have been used in family-based nutrition and childhood obesity prevention research in children with neurotypical development include the specification of target behaviors, self-monitoring, goal setting, stimulus control, positive parenting strategies, and promotion of self-efficacy and self-management skills (46, 47). Parents and caregivers act as important "agents of change" for promoting healthy eating among their children. There are parallels in the application of similar core behavior strategies in providing supports for autistic children (48, 49) and many parents are already being trained in these behavior change strategies to address behavioral and communication challenges their children experience (50, 51). Our study is among the first to empirically test the efficacy of incorporating these same

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[1] A growing literature has highlighted how language and terminology used to describe autism may reflect and further ableist beliefs (1). Particular attention has been paid to whether person-first (e.g., children with ASD) or identity first (e.g., autistic child) language should be used (2, 3). Out of respect for divided opinions among autistic stakeholders themselves, both approaches to terminology are used.

core behavior change strategies into a mHealth nutrition intervention to affect changes in the intake of targeted healthy and less healthy foods and beverages in children on the autism spectrum who are picky eaters.

The aim of this 3-month randomized controlled trial was to test the initial efficacy of a mHealth nutrition intervention on changing consumption of targeted healthy (FV) and less healthy foods (SSS) and beverages (SSB) in children on the autism spectrum who were picky eaters. We hypothesized that, by the end of the intervention, children in the technology (intervention) group, but not children in the education (wait list control) group, would show a significant increase (expressed as % change from baseline) in intake of FV and a decrease in calories consumed from SSS and SSB.

Methods

Study design

In this exploratory 3-month trial, parent-child dyads were randomly assigned to either a mHealth intervention group (technology group) or a wait list control group (education group) using a randomized block design to produce groups that were comparable in weight status. Parent trainings in both groups were matched for in-person contact time. All study visits were conducted in families' homes to reduce burden and increase child comfort. The study protocol, including screening and recruitment procedures, was approved by the Institutional Review Boards of the University of Pennsylvania and The Children's Hospital of Philadelphia (CHOP). Parents and children were asked to provide voluntary informed consent (parents) and assent (children) to participate in the study by signing the consent and assent forms. During the informed consent/assent process, families were informed that they will be randomized into one of two groups (technology or education group) for the duration of the study. Families were also informed that if they were assigned to the education group, they would be given access to the mobile app for free after their participation in the study ended.

Study population

Participants for this study included boys and girls with ASD, ages 6–10 years, and their parent or legal guardian (referred to as "parent" for ease of use). This age range is consistent with ages that children would engage in similar technology. Parents had to be the children's primary caregiver (i.e., person responsible for grocery shopping and/or feeding). For this exploratory trial, we recruited a well-defined, homogenous group of children to determine the efficacy of this intervention. Only children without significant intellectual disability (see definition in *Recruitment and Screening Process*) were enrolled to increase the likelihood of comprehension and engagement with the technology. Children with a range in weight were included to explore if the intervention is equally effective in children with normal weight, overweight, and obesity.

A power analysis was conducted (PASS software, Version 11, NCSS LLC, Kaysville, UT) for the primary aim using 3-month changes in intake of targeted healthy foods (FV) as primary outcome variable. The estimated mean (± SD) for baseline FV intake (2.57 ± 1.20 servings/day) was derived from our pilot work with children on the autism spectrum (52). Based on this estimate, a sample size of 46 children with an attrition rate of 10% yielded 80% power to detect a statistically significant increase in FV intake of 1.1 servings/day (or 43%) in the intervention group relative to the control group at an alpha level of 0.05 based on a 2-sample t-test. The magnitude of this increase is comparable to that achieved in behavioral interventions in children with neurotypical development (28, 53) and represents ∼one-fifth of the Recommended Dietary Allowance (RDA) of FV for children of that age (54).

Recruitment and screening process

Recruitment of study participants was carried out in collaboration with the CHOP Center for Autism Research (CAR). Our multi-pronged recruitment plan utilized the following strategies: (a) CAR's research study page of its website, social media accounts, and email listserv; (b) the CHOP Recruitment Enhancement Core, which leverages recruitment *via* the electronic medical record system; and (c) community-based organizations.

Interested families completed a telephone screening. Parents provided information about their child's age, sex, height, weight, autism diagnosis, medical and developmental history, and medication use and provided verbal authorization per the Health Insurance Portability and Accountability Act (HIPAA) for the phone screening and to have their child's medical information and previous diagnostic evaluations reviewed. Parents were asked to complete the Picky Eating subscale of the Child Feeding Questionnaire (CFQ) (55), which consisted of the following items: (1) "My child's diet consists of only a few foods"; (2) "My child is unwilling to eat many of these foods that our family eats at mealtimes"; (3) "My child is fussy / picky about what she eats." The items on this subscale have shown adequate internal consistency ($\alpha = 0.85$). Parents were asked follow-up questions to confirm that a child's pickiness was related to the intervention's targeted healthy and less healthy foods to ensure that the intervention goals would be relevant. Picky eating was confirmed if parents endorsed at least two out of the three items on this subscale.

To be included in the study, children had to be between ages 6 to 10 years; fluent in English; have an ASD diagnosis using the DSM-IV-TR or DSM-5 criteria (56, 57) and cognitive skills within the low average (or higher) range with IQ scores of ≥80 and comparable verbal ability; meet the definition of picky eater with pickiness related to the intervention's targeted healthy and less healthy foods; and have access to a mobile device. Medical records were reviewed to confirm documentation of ASD diagnosis by an expert clinician (i.e., developmental pediatrician, clinical psychologist) as well as cognitive and language ability at a level sufficient for comprehension of and engagement with the mHealth technology. When specific IQ or language assessment scores were not available in medical records, school records such as Individualized Education Program documents were reviewed by the expert clinician, and descriptions of skills across academic domains and educational goals were used as a proxy.

Children were excluded from participation in the study if they had moderate-severe hearing/visual or motor impairment (e.g., were non-ambulatory); were taking antipsychotic medications which may be associated with uncontrolled eating; were on a special diet (e.g., gluten/casein-free diet); or had underweight [i.e., body mass index (BMI)-for-age <5th percentile].

Technology intervention group

Description of the behavioral intervention

Parents and children in the technology group received the mHealth nutrition intervention plus training in behavior change strategies. The intervention incorporated core behavior change strategies that have been tested extensively in family-based behavior modification research, including obesity prevention trials (46), and were familiar to families with children who have ASD (58, 59). The unique features of this mHealth intervention were that it (1) reinforced healthy food choices in autistic youth by using behavioral strategies tailored to the specific needs and learning styles of children on the autism spectrum (e.g., visual depictions, concrete descriptions with "scripts", and routines for abstract concepts), (2) included a high level of personalization to align dietary goals with individual food preferences and sensory sensitivities, and (3) involved parents as "agents of change." Specifically, children were reinforced for making healthy food choices while limiting less healthy food choices in their daily lives by earning points towards a prize. Targeted *healthy* foods included fresh, canned, and frozen FV. Parents were instructed to omit energy-dense toppings and sauces on FV. Targeted *less healthy* foods included SSS (e.g., all types of chips, popcorn, pretzels, party mixes, ice cream, candy, cookies, cakes/pies, sweet rolls, pastries) and SSB (e.g., sugar-sweetened sodas, fruit drinks/punches and fruit juices, sport drinks, and energy drinks).

The intervention also included behavioral training for children *via* an interactive nutrition education game to facilitate healthier food choices. This involved a "Nutrition Ninja" virtual character, which was directed by the parent and interacted by the child to set and reinforce dietary goals. The inclusion of this virtual character who acted positively towards the child aimed to make the child feel comfortable with technology-mediated communication and offer support for performing the desired behavior, consistent with the Proteus effect (60–62). The goals were very prescriptive and were tailored to children's food preferences and sensory sensitivities by letting them customize dietary targets (e.g., add dip to a vegetable, eat a vegetable raw or cooked, have it served hot or cold). Even small goals, such as touching or smelling a novel food before tasting it, were encouraged. Children received frequent visual and personalized feedback and positive reinforcement to support their unique learning styles. The individual training components for parents and children are summarized in **Table 1**.

Description of the mHealth technology

The technology-based intervention, a mobile application, was developed in collaboration with Skyless Game Studios, a Philadelphia-based software company. We used an iterative design process for prototype development, testing and refining of the intervention during which stakeholders (i.e., parents and caregivers of children with autism and children with autism) and technology developers were engaged and asked to provide continuous feedback on the functionality and acceptability of the intervention during the development process.

During the baseline study visit, trained research staff assisted families with downloading and installing the mobile application onto their smartphones or tablets. They also provided families

TABLE 1 Training components for parents and children in the intervention group.

Training type	Training components
Parent training	
Behavioral skills training	• Specifying target behaviors and goal setting • Self-monitoring • Stimulus control • Positive reinforcement • Self-efficacy
Nutrition training	• Explanation of nutritional goals and targeted foods and beverages[a] • Training on how to present feeding opportunities during meal and snack times • Substitute unhealthy target foods and beverages for healthier options • Strategies to overcome resistance in children trying new foods using differential attention and positive reinforcement • Strategies for promoting children's intake of healthy target foods and limiting intake of unhealthy target foods and beverages daily for 3 months
Technology training	• Explanation of the layout and functions of the mHealth technology • Setting dietary goals, selecting rewards, and awarding points • Adding custom foods • Reviewing child's progress, goals, and rewards
Child training	
Behavioral skills training	• Specifying target behaviors and goal setting • Positive reinforcement
Nutrition training	• Explanation of the health benefits of fruits and vegetables and undesirable properties of sugary drinks and salty and sugary snacks • Explanation of nutritional goals and targeted foods and beverages • Explanation of "Go" and "Whoa" foods and beverages
Technology training	• Explanation of the layout and functions of the mHealth technology • Setting dietary goals and selecting a reward • Learning how to play the educational Nutrition Ninja game • Communicating with the Nutrition Ninja • Reviewing their progress

[a]This was the only training component which participants in the waitlist control (education) group received.

with a brief technology tutorial which explained to the parent how (1) to view, create, and edit rewards and goals; (2) view their child's progress and award points for eating and drinking goal foods/beverages; (3) add or edit custom foods; and (4) view and send messages to the child. The tutorial explained to the child how to (1) choose their goals; (2) select their reward; (3) send messages to the "Ninja" (i.e., parent) about a food they ate or ask for a food or drink for their next meal; (4) view their progress and awarded points; and (5) play the Nutrition Ninja educational game. Parents and children were also instructed to view a training module, which was built into the app and explained the nutritional targets of the intervention and provided behavioral skills training. Throughout the training, parents and children completed quizzes which reinforced the training content. Parents and children were encouraged to engage with the mHealth technology on a daily basis for 3 months to promote children's intake of the healthy target foods and limit their intake of the less healthy target foods and beverages. Examples of targeted healthy and less healthy target foods were incorporated in the mHealth technology. **Figure 1** provides examples of screenshots from the mHealth intervention. The mHealth technology provided research staff with an activity log, which they accessed regularly. For families who showed no activity with the mHealth technology for some time, research staff followed up with them *via* email (after 2 weeks) or a phone call (after 3 weeks) to assess if they had any technical difficulties with the mobile app and reminded them of the goals of the study.

Education control group

Parents in the Education group received a printed handout which provided general education about healthy eating and explained the nutritional goals and targeted foods and beverages but did not provide any skills training. Parents were encouraged to promote children's intake of healthy target foods and limit intake of unhealthy target foods daily for 3 months. Examples of targeted healthy and less healthy target foods were included on the handout. Families were offered access to the mHealth intervention after they completed the study.

Families in both groups were instructed to try increasing their children's intake of FV and decreasing their intake of SSS and SSB for the 3-month study duration. They were not instructed on what to purchase and make available to their children specifically because we wanted to give families the flexibility to tailor the food and beverage choices to their children's preferences and sensory sensitivities.

Assessment of child dietary intake

Children's intake was assessed at baseline (before the first study visit) and at the end of the 3-month intervention using the telephone-based 24-hour dietary recall method; the gold standard for self-reported intake (63). Each assessment consisted of three unannounced recalls (two weekdays, one weekend day), conducted

- For **Go Foods! (Healthy)**, **more** servings = more points
- For **Whoa Foods! (Less Healthy)**, **fewer** servings = more points

I shouldn't need to praise or reinforce something I already expect my child to do.

- Healthy food
- Full of vitamins
- Fiber helps your body digest foods
- Eat lots of fruits and vegetables!

FIGURE 1
Sample screenshots of the mobile health (mHealth) intervention including goal setting (panel A), parent behavioral skills training (panel B), and child nutrition training (panel C).

by research dietitians from the CHOP and Penn Dietary Assessment Unit at the Center for Human Phenomic Science. Dietitians were blinded to families' group assignment. During each recall, they asked parents, with help from their child, to describe all foods and beverages consumed by their children during the prior 24 h and to provide detailed information about portion sizes and preparation method.

Individual food items were manually coded to derive SSS, SSB and water intake. Data were analyzed for the primary outcomes measures which included daily FV intake (servings/day) and calories consumed per day from SSB and SSS using the University of Minnesota Nutrition Coordinating Center's Food and Nutrient Database. All data were averaged across the three days.

Assessment of child weight status

During both study visits (i.e., at baseline and at the end of the intervention), children had their heights and weights measured using a digital scale (SECA 876, Chino, CA) and portable stadiometer (SECA 217, Chino, CA). Measurements were taken in triplicate by a trained staff member in children's homes with children wearing light clothing (no shoes). Child age- and sex-specific BMI percentiles and z-scores were calculated using the CDC Growth Charts 2000 (64). Children were classified as normal-weight (BMI-for-age 5–84th percentile), overweight (BMI-for-age 85–94th percentile), or obese (BMI-for-age ≥95th percentile) (65).

Questionnaires

Demographic questionnaire

During the baseline home visit, parents completed a demographic questionnaire which included questions about their age, race/ethnicity, marital status, education, household income, and food security status. Families' food security status was assessed using the 6-item short form of the U.S. Household Food Security survey module (66). The survey's raw score, which is the sum of affirmative responses to the six survey questions, describes four levels of food security: high food security (i.e., no indications of food access problems or limitations); marginal food security (i.e., 1–2 indications of food access problems such as anxiety over food sufficiency or shortage of food in the house); low food security (i.e., reports of reduced quality, variety, or desirability of diet); and very low food security (i.e., reports of multiple indications of disrupted eating patterns and reduced food intake) (67). This short form of the U.S. Household Food Security survey module has shown to have acceptable conceptual validity, specificity (99.5%) and sensitivity (85.9%) for determination of overall food insecurity for households with children (66) as well as good internal consistency (Cronbach's alpha = 0.86) (68).

Sensory profile

Parents were also asked to complete the 38-item Short Form Sensory Profile (69), which measures children's sensory processing. For this study, we limited the analysis to the taste/smell sensitivity domain only, which is comprised of the following items: "Avoids certain tastes or food smells that are typically part of children's diets," "Will only eat certain tastes," "Limits self to particular food textures/temperatures," and "Picky eater, especially regarding food textures." Parents were asked to indicate, on a 5-point scale ranging from "always" (1) to "never" (5), the frequency with which their child responds to these sensory experiences. Using a reverse scoring system, lower scores corresponded to more frequent child behavioral responses. Children were categorized into "Typical Performance," "Probable Difference," or "Definite Difference" in oral sensory sensitivity based on the classifications specified by Dunn (70). Construct validity has been established for the Short Form of the Sensory Profile (71) and the tool has been shown to have acceptable reliability and excellent validity (72).

Statistical analysis

Data were analyzed using the statistical software SAS (Version 9.4; SAS Institute Inc, Cary, NC). The Shapiro-Wilk test was used in combination with histograms and summary statistics to confirm normal distribution of all outcome variables. Outcome variables included intake of fruits and vegetables (servings/day; with and without French Fries); vegetables (servings/day; with and without French Fries); fruit (servings/day); sweet and savory snacks (kcal/day); sweet snacks (kcal/day); savory snacks (kcal/day); sugar-sweetened beverages (kcal/day and fl oz/day); and water (fl oz/day). Participants' baseline demographic, clinical and anthropometric characteristics and dietary intake were compared between the technology and education group using Chi-Square and t-tests for categorical and continuous variables, respectively.

To test the primary aim, an intent-to-treat approach was used. We constructed separate linear mixed effects models for each outcome measure with an unstructured covariance matrix to account for within-subject variance. The effects of time (baseline, 3-month follow-up) and treatment group were included in all models. A time-by-group interaction was included to assess changes in outcomes over time by group. Furthermore, we created adjusted models which controlled for children's age, BMI z-score, and level of taste/smell sensitivity.

Secondary analyses assessed the intervention utilizing a dose-response approach. We explored the extent to which level of engagement with the technology impacted participants' dietary outcomes. In this exploratory analysis, we assessed both planned behavior (i.e., completion of nutrition training and setting goals) and performed behavior (i.e., number of points earned for meeting goals). We then categorized children into those with a high planned engagement (i.e., children who completed the nutrition training and set at least one goal) and those with low or no engagement (i.e., children who completed the nutrition training but did not set any goals or children who neither completed the nutrition training nor set any goals). In terms of performed behavior, we categorized children's engagement with the technology using a tertile split (low/no, medium, high). Analyses tested the effect of children's level of engagement with the technology and the time-by-engagement interaction on dietary outcomes. Analyses were conducted with participants in the education (control) group included in the statistical model; their

TABLE 2 Child and parent demographic and clinical characteristics by group.

Characteristic	Technology group (*N* = 19)	Nutrition education group (*N* = 19)	*P*-value
Children			
Age (years), *mean ± SD*	8.9 ± 1.2	8.4 ± 1.4	0.26
Sex, *male/female, n (%)*	18 (94.7%)/1 (5.3%)	18 (94.7%)/1 (5.3%)	1.00
Race, *n (%)*			
Asian	0	2 (10.5%)	0.16
Black or African American	4 (21.1%)	1 (5.3%)	
White	11 (57.9%)	15 (78.9%)	
More than one race	3 (15.8%)	1 (5.3%)	
Unknown	1 (5.3%)	0	
Ethnicity, *n (%)*			
Hispanic or latino	4 (21.1%)	1 (5.3%)	0.20
Not hispanic or latino	12 (63.1%)	17 (89.5%)	
Unknown	3 (15.8%)	1 (5.3%)	
Weight status, *n (%)*			
BMI z-score, *mean ± SD*	0.8 ± 1.36	0.6 ± 1.35	0.64
BMI-for-age percentile, *mean ± SD*	68.1 ± 34.2	63.1 ± 37.2	0.67
Has normal weight	10 (52.6%)	9 (47.4%)	0.82
Has overweight	2 (10.5%)	4 (21.1%)	
Has obesity	7 (36.8%)	6 (31.6%)	
Sensory profile (score), *mean ± SD*			
Taste/Smell Sensitivity	9.7 ± 4.9	11.9 ± 4.0	0.14
Taste/smell sensitivity classification, *n (%)*			
Typical performance	4 (21.1%)	5 (26.3%)	0.48
Probably difference	3 (15.8%)	6 (31.6%)	
Definite difference	12 (63.2%)	8 (42.1%)	
Parents			
Academic degree, *n (%)*			
High school	3 (15.8%)	4 (21.1%)	1.00
College	8 (42.1%)	8 (42.1%)	
Master’s	6 (31.6%)	6 (31.6%)	
Doctorate	2 (10.5%)	1 (5.3%)	
Household income, *n (%)*			
<$50,000	2 (10.5%)	4 (21.1%)	0.73
$50,000–$100,000	4 (21.1%)	5 (26.3%)	
$100,000–$150,000	5 (26.3%)	5 (26.3%)	
>$150,000	8 (42.1%)	5 (26.3%)	
Marital status, *n (%)*			
Single	2 (10.5%)	0	0.54
Married, remarried	15 (78.9%)	17 (89.5%)	
Divorced, separated, widowed	2 (10.5%)	2 (10.5%)	
Food security status, *n (%)*			
High/marginal food security	18 (94.7%)	16 (84.2%)	0.74
Low food security	0	2 (10.5%)	
Very low food security	1 (5.3%)	1 (5.3%)	

level of engagement was set to “low/no engagement” because they did not have access to the technology.

Additional exploratory analyses examined the effects of the intervention on changes in dietary outcomes with the sample stratified into low or high consumers at baseline based on a median split in intake. Stratified analyses were conducted for analyses of both the primary predictor (intervention group) and secondary predictor (engagement level) with and without controlling for participants’ age, BMI z-score, and level of taste/smell sensitivity. All analyses were evaluated at the alpha level of 0.05 and are considered exploratory. Results are presented as model-based means (± standard error).

Results

Child and parent characteristics

Child and parent demographic and anthropometric characteristics are shown in Table 2. The majority of children were male (95%), and many were White (68%); 13% were Hispanic. Half of the children had either overweight (16%) or obesity (34%), respectively. Among parents, 84% were married; 42% had a college degree; and 61% had household incomes greater than $100,000. Groups did not differ significantly in any demographic or anthropometric characteristics ($P > 0.14$), nor in their baseline intake of the target foods ($P > 0.099$).

Efficacy of mHealth intervention on changing target dietary behaviors

Table 3 shows participants’ mean intake of FV, SSS, and SSB (primary dietary outcomes) at baseline and at 3 months (end of

TABLE 3 Model-based mean (± SEM) intake of primary dietary outcomes at baseline and month 3 (end of intervention).

Intake	**Technology ($N = 19$)**		**Nutrition education ($N = 19$)**		**Results from mixed-model analysis**	**Between-group comparison at baseline**
	Baseline (mean ± SEM)	**Month 3 (mean ± SEM)**	**Baseline (mean ± SEM)**	**Month 3 (mean ± SEM)**		
Fruits and vegetables						
Fruits and vegetables, *servings/day*	1.79 ± 0.40	2.16 ± 0.43	2.56 ± 0.40	3.01 ± 0.41	Group*Time: $P = 0.82$; Group: $P = 0.15$; Time: $P = 0.04$	$P = 0.15$
Fruits, *servings/day*	0.82 ± 0.36	0.84 ± 0.40	1.48 ± 0.36	1.54 ± 0.37	Group*Time: $P = 0.93$; Group: $P = 0.18$; Time: $P = 0.84$	$P = 0.18$
Vegetables (french fries included), *servings/day*	0.97 ± 0.20	1.26 ± 0.25	1.08 ± 0.20	1.45 ± 0.21	Group*Time: $P = 0.83$; Group: $P = 0.55$; Time: $P = 0.08$	$P = 0.66$
Vegetables (french fries excluded), *servings/day*	0.71 ± 0.21	0.84 ± 0.25	0.95 ± 0.21	1.29 ± 0.21	Group*Time: $P = 0.53$; Group: $P = 0.19$; Time: $P = 0.19$	$P = 0.32$
Salty and sugary snacks						
Salty and Sugary snacks, *kcal/day*	401.6 ± 49.0	420.8 ± 58.4	456.9 ± 49.0	385.7 ± 51.0	Group*Time: $P = 0.25$; Group: $P = 0.87$; Time: $P = 0.50$	$P = 0.42$
Sugary snacks, *kcal/day*	252.8 ± 38.2	225.3 ± 45.7	251.9 ± 38.2	244.3 ± 39.9	Group*Time: $P = 0.74$; Group: $P = 0.85$; Time: $P = 0.56$	$P = 0.99$
Savory snacks, *kcal/day*	148.8 ± 34.8	195.3 ± 41.8	205.0 ± 34.8	141.9 ± 36.3	Group*Time: $P = 0.06$; Group: $P = 0.98$; Time: $P = 0.77$	$P = 0.22$
Beverages						
Sugar-sweetened beverages, *fl oz/day*	7.8 ± 1.6	7.6 ± 1.7	7.1 ± 1.6	7.3 ± 1.6	Group*Time: $P = 0.75$; Group: $P = 0.83$; Time: $P = 0.95$	$P = 0.78$
Water, *fl oz/day*	16.1 ± 3.1	17.5 ± 3.5	21.5 ± 3.1	22.9 ± 3.2	Group*Time: $P = 0.99$; Group: $P = 0.21$; Time: $P = 0.45$	$P = 0.24$

intervention) by group. There were no significant group-by-time interactions ($P > 0.25$) for any of the primary dietary outcomes. There were also no significant main effects of group for intake of FV, SSS, SSB ($P > 0.15$) or time for intake SSS and SSB ($P > 0.83$). We did find a statistically significant main effect of time for FV intake ($P = 0.04$) indicating that all participants, irrespective of random assignment, on average, consumed significantly more FV at the end of the intervention (2.58 ± 0.30 servings/day) than at baseline (2.17 ± 0.28 servings/day; $P = 0.03$). This change over time in FV intake remained significant after adjusting the model for children's age, BMI z-score and taste/smell sensitivity. When analyzing fruit intake and vegetable intake as separate outcomes and including or excluding French fries in the vegetables category, the main effect of time was not statistically significant ($P > 0.08$). We also explored potential changes in water intake over the course of the intervention but did not find a significant group-by-time effect ($P = 0.99$) or main effects of group or time ($P > 0.21$) on participants' water intake.

Individual differences in response to nutrition intervention

Overall, the results also remained consistent when adding participants' BMI z-score, age, or taste/smell sensitivity as covariates to the statistical models. We, however, did find that taste/smell sensitivity significantly predicted children's intake of FV when French Fries were included ($P = 0.0446$); for each unit of *lower* taste/smell sensitivity (indicating greater sensory processing abnormalities), estimated mean FV intake increased by 0.13 ± 0.1 servings/day. We also found a significant effect ($P = 0.03$) of BMI z-score on intake of SSB indicating that for each unit increase in children's baseline BMI z-score, estimated mean SSB intake increased by 1.86 ± 0.8 fl oz/day during the study.

Exploratory stratified analyses revealed that among children who were high consumers of savory snacks at baseline, those in the education group showed a significant *decrease* in calories consumed from savory snacks over time (296 ± 37 kcal/day vs. 165 ± 37 kcal/day; $P = 0.02$) while children in the technology group showed a trend for a significant *increase* in calories consumed from savory snacks over the course of the intervention (286 ± 43 kcal/day vs. 439 ± 61 kcal/day; $P = 0.06$; Group*Time: $P = 0.007$).

Efficacy of technology-based intervention by engagement

In this exploratory analysis, we assessed the extent to which level of participants' engagement with the technology impacted their dietary outcomes by examining both planned behavior (i.e., completion of nutrition training and setting goals) and performed behavior (i.e., number of points earned for meeting goals).

Exploratory stratified analyses revealed that among children who were low consumers of FV (with French Fries excluded) at baseline, those who showed high performed engagement with the technology-based intervention significantly increased their FV intake by 1.5 servings/day over the course of the intervention (engagement-by-time: $P < 0.01$) even when adjusting for children's age, BMI z-score and taste/smell sensitivity (**Figure 2**).

With respect to savory snacks, findings related to performed and planned engagement were consistent with those seen when using treatment group as predictor. That is, among children who were high consumers of savory snacks at baseline, those who were engaged with the technology exhibited an increase in calories consumed from savory snacks, while those who were not engaged with the technology exhibited a decrease in savory snacks (performed engagement-by-time interaction: $P = 0.01$; planned engagement-by-time interaction: $P = 0.02$).

Further, we found a statistically significant planned ($P = 0.04$) and performed ($P = 0.03$) engagement-by-time interaction for water intake in our stratified analysis. That is, among children who were low consumers of water at baseline, those who showed little planned or performed engagement with the technology exhibited a significant *increase* in water intake over the course of the intervention (adjusted pairwise comparison for planned ($P = 0.001$) and performed ($P = 0.002$) engagement).

Discussion

This exploratory trial was among the first to test the preliminary efficacy of a technology-based mHealth intervention for improving dietary intake among autistic youth who are picky eaters. While this technology intervention produced few between-group differences in the consumption of targeted foods and beverages, subgroup analyses revealed that some children, namely those who consumed few FV at baseline but showed high engagement with

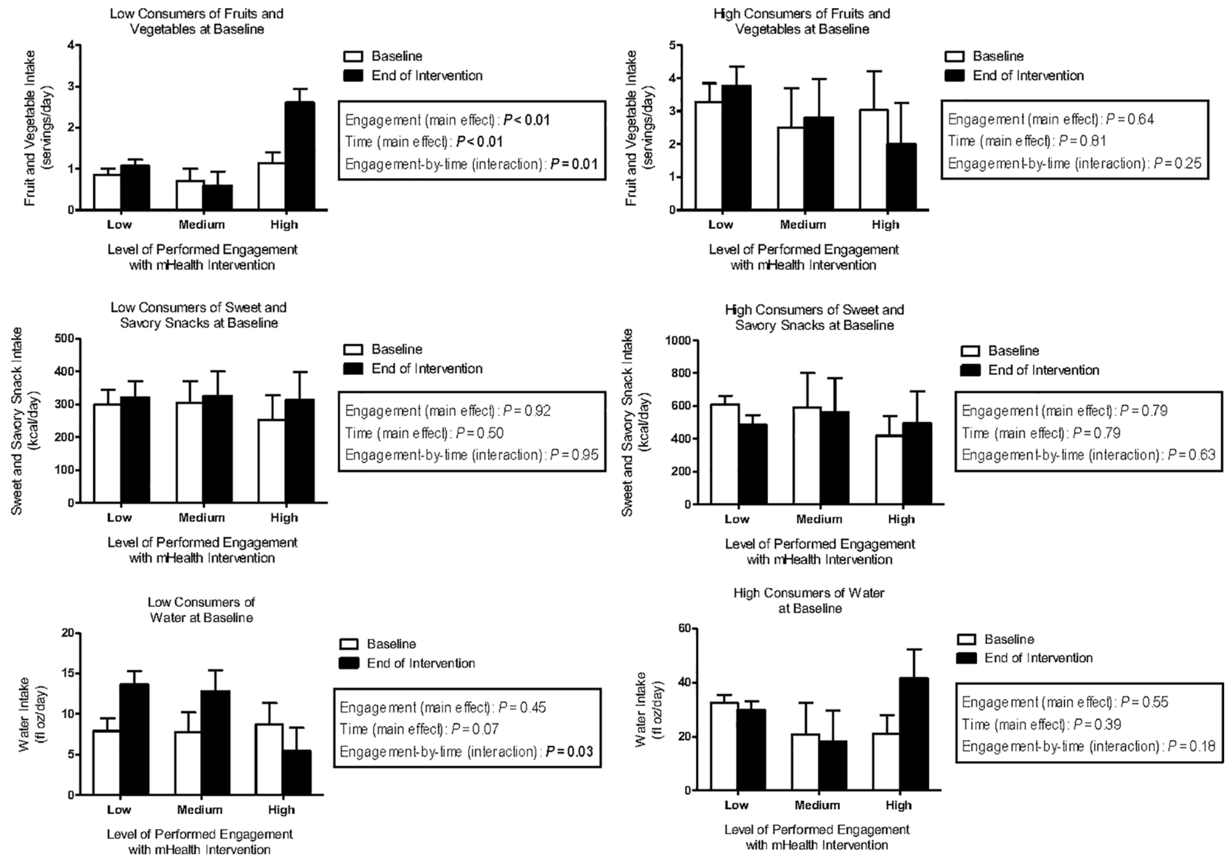

FIGURE 2
Model-based means (±SEM) of fruit and vegetable intake (servings/day), sweet and savory snack intake (kcal/day), and water intake (fl oz/day) for children in the technology group ($n = 19$) by level of performed engagement (low, medium, high) with the technology and consumption status (low, high) at baseline and at the end of the intervention.

the technology, significantly increased their FV intake by the end of the intervention. These findings remained significant when adjusting for taste and smell sensitivity, which was identified as a significant predictor of FV intake among the study sample. Exploratory stratified analyses further revealed that among children who were high consumers of savory snacks at baseline, those in the education group showed a significant *decrease* in calories consumed from savory snacks over time while children in the technology group showed a trend for a significant *increase* in calories consumed from savory snacks. Also, among children in the intervention group who were low consumers of water at baseline, those who showed little engagement with the technology exhibited a significant *increase* in water intake over the course of the intervention.

Contrary to our hypotheses, we did not find a significant group-by-time interaction for any of the primary dietary outcomes. We did, however, find a statistically significant increase in FV intake by 0.4 servings/day (or 19%) in both groups over the course of the intervention. The magnitude of this increase is approximately one third smaller than that seen in behavioral interventions in children with neurotypical development (53, 73, 74) and represents approximately one-sixth of the FV intake recommendations for children of that age (75). The finding that children in the control group also increased their FV intake was unexpected. It is possible that providing families in the control group with a brief nutrition education and printed handout which summarized the dietary targets, having groups matched for research staff contact time, and simply being part of a nutrition research study led to improvements in FV intake among children who did not receive the technology intervention. The finding may also suggest that even low-level efforts and outreach on topics related to public health and nutrition may be useful for making a small but meaningful impact on health behaviors in this population.

With respect to individual differences in children's response to the intervention, we found that children's taste and smell sensitivity significantly predicted their intake of FV for all participants. That is, for each unit of *lower* taste/smell sensitivity, FV intake increased by 0.13 ± 0.1 servings/day. These data are in agreement with findings from prior research. For example, Coulthard and Blissett (76) reported that children with neurotypical development who were more sensitive to taste and smell stimuli, as measured by the Sensory Profile, consumed fewer FV. A similar relationship between sensory sensitivity and FV intake has been found previously in children who have ASD (77, 78). Thus, promoting healthy eating is likely particularly challenging for children with increased sensory sensitivities. Future interventions should consider intervening at both the level of support for sensory sensitivities (e.g., occupational therapy, exposure and desensitization, sensory-specific diets) and the level of accommodation by parents (e.g., skills training for parents to modify the taste and/or texture of foods and meals through creative preparation and cooking methods).

We further found a significant effect of BMI z-score on intake of SSB indicating that for each unit increase in children's baseline BMI z-score, SSB intake increased by approximately 2 fl oz/day over the course of the intervention. Several systematic reviews and meta-analyses point to a significant positive association between intake of SSB and BMI during childhood (17, 79–81). Even though SSB intake was a dietary target in the current research, the mHealth intervention did not lead to a reduction in SSB. In our stratified analysis, however, we found statistically significant planned and performed engagement-by-time interactions for water intake. Children who drank little water at baseline significantly increased their water intake over the course of the intervention, even in the absence of engaging much with the technology. Given that SSB intake did not decrease over the course of the intervention, it can be assumed that water intake added on but did not replace SSB among children. Additional efforts will be needed for future intervention design and refinement that target the substitution of SSB with water, especially among children with a higher weight status.

In an exploratory analysis, we tested if children in the technology group who were more engaged with the mHealth intervention showed greater improvements in their intake of the target foods and beverages when compared to children who were less engaged with the technology. With respect to healthy target foods and beverages, we found that children who were low consumers of FV at baseline and showed high performed engagement with the technology-based intervention significantly increased their FV intake by 1.5 servings/day over the course of the intervention. Interestingly, we also found that among children who were low consumers of water at baseline but showed little planned or performed engagement with the technology also significantly increased their water intake over the course of the intervention. This suggests that (a) participating in a mHealth nutrition intervention may be particularly useful for children with low baseline intakes of the target foods and (b) having children engage even a little with the technology-based intervention can lead to significant improvements in intake (as was the case with water intake). Indeed, prior research in adults has confirmed that engagement with a mHealth technology was a significant predictor of dietary intake behavior change (82). It will be critically important to identify components of the mHealth intervention, such as increased interactivity, personalization, or individual feedback, which keep children and families engaged with the technology long-term (83).

With respect to unhealthy target foods and beverages, children in the technology group who were (1) high consumers of savory snacks at baseline and (2) showed high planned and performed engagement with the technology exhibited a significant *increase* of 352 calories consumed from savory snacks over the course of the intervention, while children who were not engaged with the technology showed a decrease in calories consumed from savory snacks. Interestingly, we also showed that children in education group, who did not have access to the technology and were high consumers of savory snacks at baseline, showed a significant *decrease* of 131 calories consumed from savory snacks over time. Reducing children's intake of less healthy foods or substituting unhealthy foods for healthy foods may represent a more challenging intervention target. While this intervention showed some improvements in increasing intake of healthy foods and beverages (e.g., FV, water), the benefits of this increased intake will be limited if there is no concomitant decrease in intake of less healthy foods (e.g., SSB, SSS) and may actually increase overall energy intake.

The strengths of the study include the racial/ethnic diversity of our study sample and the inclusion of children with a range in weight status (~50% with overweight/obesity). To our knowledge, this study is also among the first to test a technology-based nutrition intervention in autistic youth who are picky eaters. The study also had limitations. One, enrollment of study participants fell short of our recruitment goal (83%) and had a higher attrition rate (18%) than anticipated due to the restrictions of the COVID-19 pandemic (e.g., social distancing, stay-at-home orders) which took place towards the later part of the study. Some families were unable to complete their final visits due to stay-at-home orders, and others indicated that priorities had shifted given new childcare, etc. demands. Not reaching our recruitment goal likely impacted the statistical power for the study. While the current analyses should therefore be regarded as exploratory, it still provides important effect size estimates which will help inform future technology-based interventions. Second, the mHealth technology included a larger number of examples for both healthy and less healthy foods and beverages than did the handout for the education group. This may have differentially affected families' food choices. Also, given the fairly short duration and low intensity of the current intervention, it will be important for future studies to determine if any changes seen in children's dietary intake are maintained long-term. In addition, future studies that aim to promote healthier eating and increased water intake should also evaluate gastrointestinal function in children.

In summary, this mHealth nutrition intervention did not yield a significant increase in intake of targeted foods and beverages among children in the technology group relative to a waitlist education group. Subgroup analyses, however, revealed that some children, namely those who consumed few FV at baseline but showed high engagement with the technology, significantly increased their FV intake by the end of the intervention. Future research should test additional strategies to expand the intervention's impact on a wider range of foods while at the same time reaching a broader group of children who have ASD.

Data availability statement

Deidentified data will be made available upon publication to scientists who provide a methodologically sound proposal for use in accomplishing the aims of the approved proposal. Proposals should be sent to the corresponding author at tkral@nursing.upenn.edu.

Ethics statement

The studies involving human participants were reviewed and approved by Institutional Review Boards of the University of Pennsylvania and the Children's Hospital of Philadelphia. Parents and children were asked to provide voluntary informed consent (parents) and assent (children) to participate in the study by signing the consent and assent forms.

Author contributions

The authors' responsibilities were as follows – TVEK: study design, interpretation of the results, and writing of the manuscript; LOM, KJ, TB: data collection, interpretation of the results, and critical revision of the manuscript; JC, RJQ: statistical analysis, interpretation of the results, critical revision of the manuscript; and JPM, SEL, GT, ESK: study design, interpretation of the results, and critical revision of the manuscript. All authors contributed to the article and approved the submitted version.

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Conflict of interest

TVEK discloses a financial conflict of interest related to the intellectual property of the mHealth nutrition intervention that was tested as part of this clinical trial. The conflict was managed by the University of Pennsylvania and all research data collection, data management, and statistical analyses were carried out by individuals who had no related conflicts of interest. JGT is a member of the Scientific Advisory Board and receives consulting fees from Lummé Health, Inc. and Medifast, Inc.

The remaining authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Skyless Game Studios, the software company which developed the technology, did not provide funding for the study and did not receive data from this study to support its marketing.

Publisher's note

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Interrelated development of autism spectrum disorder symptoms and eating problems in childhood: a population-based cohort

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Eating problems, such as food selectivity or picky eating, are thought to be an epiphenomenon of autism spectrum disorders (ASD). Yet eating problems are also common in the general pediatric population and overlap with ASD symptoms. However, the temporal association between ASD symptoms and eating problems is poorly understood. This study examines the bidirectional association between ASD symptoms and eating problems across child development, and investigates whether these associations differ by child sex. Participants ($N = 4{,}930$) were from the population-based Generation R Study. Parents reported their child's ASD symptoms and eating problems using the Child Behavior Checklist at 5 assessments from toddlerhood to adolescence (1.5 to 14 years, 50% girls). A Random Intercept Cross-Lagged Panel Model was used to examine the lagged associations between ASD symptoms and eating problems at the within-person level, controlling for stable, trait-like differences at the between-person level. At the between-person level, there was a strong correlation between ASD symptoms and eating problems ($\beta = .48$, 95% CI: 0.38 to 0.57). Controlling for these between-person effects, there was limited evidence for consistent, predictive effects of ASD symptoms and eating problems at the within-person level. Associations did not differ by child sex. Findings suggest that ASD symptoms and eating problems may represent a cluster of traits that are highly stable from early childhood to adolescence, which have a minimal reciprocal effect at the individual-level. Future research could focus on these trait-like qualities to inform the development of supportive, family-focused interventions.

KEYWORDS
ASD symptoms, autistic traits, eating problems, food selectivity, picky eating, random-intercept cross-lagged panel model, autism spectrum disorder

1. Introduction

Autism spectrum disorders (ASD) are neurodevelopmental conditions characterized by social communication deficits, and restrictive and repetitive behavioral patterns (1). Some features inherent to ASD, such as impaired sensory processing and rigid behavior, may manifest in eating problems (2). Children with ASD are five times more likely than neurotypical children to have eating problems (3) which may persist into adolescence (2) and possibly young adulthood (4). Indeed, Suarez et al. (5) showed persistence of eating problems over a 20-month time period in children with ASD ($n = 52$). On the other hand, Bandini et al. (6) showed that some aspects of eating problems, such as food refusal or frequency of problematic mealtime behaviors (e.g., tantrums about food), improved over a longer time period from childhood to adolescence (6.8 to 13.2 years, $n = 18$). Eating problems may predispose children with diagnosed and even subclinical ASD symptoms to poor diet quality (7) and suboptimal nutritional intake (8). While eating problems are presumed to be an epiphenomenon of ASD, eating problems may also modulate diet to influence the severity of ASD-associated symptoms (9, 10). Cumulating evidence from population-based cohorts suggest that eating problems observed in infancy and toddlerhood may be an early indicator of elevated ASD symptoms in mid-childhood (11, 12). However, no epidemiological studies to date have investigated the potentially interrelated development of ASD symptoms and eating problems from early childhood to adolescence.

Although eating problems are common in childhood, the definition of eating problems varies widely in the literature (2). Eating problems may be characterized by, although not limited to, food selectivity, food refusal, poor dietary intake or nutrient inadequacy (13), disruptive or problematic mealtime behavior (14), slow eating and food neophobia (15). Food selectivity is the most common eating problem experienced by children with ASD, where only a narrow variety of food is consumed (3). Many neurotypical children also experience eating problems in the preschool years, although this is a temporary phase for most children (16). Yet eating problems are thought to be more prevalent, more severe, and more enduring in children with ASD (3). Regardless of the type, source or duration of eating problems they can be a significant source of concern for parents (17), and could indicate the need for behavioral, nutritional or lifestyle interventions.

What is currently known about the association between ASD and eating problems has generally been derived from studies that compare children with a clinical diagnosis of ASD to neurotypical children. However, there are several limitations to this approach which obfuscate the understanding of ASD and eating problems. Firstly, emerging evidence suggests an overlap between the severity of ASD symptoms and eating problems, like food selectivity, not only at the level of children with clinically-diagnosed ASD (18) but also at the population-level (19). Case-control studies comparing children with diagnosed ASD to neurotypical children tend to overlook the evolving continuum of ASD symptoms in the general population. Secondly, researching children who have already received an ASD diagnosis precludes the testing of temporal associations between ASD symptoms and eating problems as they emerge (20). Recent meta-analytic evidence suggests that some dietary components could play a role in the expression of ASD-associated symptoms in those with ASD (10), although it is unclear whether this finding can be generalized to community-based samples. Finally, while there is a male-bias in ASD prevalence, studying populations with clinically-diagnosed ASD under-represents girls who are relatively underdiagnosed or who may present with different symptoms compared to boys (21). Evidence from population-based samples suggest that ASD symptom trajectories may differ by child sex—typically emerging later in childhood for females—although sex differences may disappear into adolescence (22). Thus, examining children diagnosed with ASD may potentially bias eating-related research to males. A dimensional approach to assessing ASD symptoms in population-based samples over time can shed light on the developmental etiology of ASD and eating problems.

A combination of repeated measures taken throughout child development and appropriate statistical modelling techniques are key in understanding whether eating problems precede ASD symptoms, or vice versa. Testing temporal directionality of associations has traditionally been undertaken using the Cross-Lagged Panel Model (CLPM), which examines the mean-level, lagged associations between constructs within a population (23). However, this model does not disaggregate stable, trait-like between-person differences from state-like, within-person changes over time. The Random Intercept Cross-Lagged Panel Model (RI-CLPM) is an extension of the CLPM that controls for stable, between-person differences to isolate the lagged effect of the temporal deviation from an individual's mean score on one construct to the temporal deviation from their mean score on another construct (23). This statistical approach better aligns with child developmental processes and is growing in popularity in the pediatric literature (24). Exploring the directionality of associations between ASD symptoms and eating problems using the RI-CLPM could be leveraged for hypothesis-generating, building theoretical frameworks and guiding future research to understand when and how (if possible) to best intervene in the course of eating problems and ASD symptoms.

This exploratory, population-based study had two aims. Aim 1 was to investigate whether ASD symptoms predict later eating problems or vice versa within individuals, or whether these behaviors remain stable, yet related, across child development. Aim 2 was to explore whether within-individual lagged associations between ASD symptoms and eating problems differed by child sex. Unravelling these pathways has the potential to inform early identification processes and intervention strategies to support parents in managing eating problems in children with a high-level autistic trait phenotype.

2. Methods

2.1. Study design and participants

The Generation R Study (25) is a population-based cohort on health and development from fetal life onwards. All pregnant women living in Rotterdam, the Netherlands, with an expected delivery date between April 2002 and January 2006 were invited to participate ($N = 9{,}778$; participation rate: 61%). Ethical approval was granted by the Medical Ethical Committee of the Erasmus Medical Center Rotterdam. Written informed consent was obtained from parents of all children. Full consent for participation up to the age of 14 years was obtained from $n = 5{,}447$ children and their parents. The current study uses data collected from 5 waves, when children were 1.5, 3, 6, 10 and 14 years old. Children with ≥2 repeated measures of both eating problems and ASD symptoms were included in this study ($n = 4{,}930$). Included children were more likely to have a Western ethnicity, greater birth weight, a lower Body Mass Index (BMI) z-score at 14 years; and have older mothers with higher levels of education and a lower pre-pregnancy BMI (all $p < .001$) compared to those excluded.

2.2. Measures

An overview of all the measures used at each wave is provided in **Supplementary File Table S1**.

2.2.1. ASD symptoms

In the current study, we assessed symptoms of ASD rather than clinically diagnosed ASD. At child age 1.5, 3 and 6 years, parents (90%–96% mothers) completed the Child Behavior Checklist (CBCL)/1.5–5 (26). The DSM-Oriented subscale "Pervasive Developmental Problems" (PDP; 13 items) was used as an indicator for ASD symptoms (27). Cohort T-scores of the PDD are available in **Supplementary File Table S2**. At child age 10 and 14 years, parents completed the CBCL/6–18 (28). However, a standard subscale for assessing ASD symptoms has not been constructed in this version for older children. Two independent studies (29, 30) of Dutch children have shown that elevated scores on 10 items from the CBCL/6–18 can adequately discriminate between children with and without an ASD diagnosis (example item: "*repeats certain acts over and over*", other items shown in **Supplementary File Table S3**). To investigate the construct validity of this 10 item ASD symptoms subscale (29) in the current sample, we examined the correlation between this subscale and the 18 item Social Responsiveness Scale (SRS) short form (31). The SRS is an autism screening questionnaire which covers all domains of the DSM-5 ASD diagnostic criteria, including social cognition, social communication and autistic mannerisms (31) and shows good diagnostic validity (32, 33). Parents reported the SRS at child age 14 years. The Pearson's correlation coefficient between the SRS and the 10-item CBCL/6–18 ASD symptoms subscale at 14 years was $r = .58$, $p < .001$. Parents responded to all items on the CBCL on a scale of 0 (*Never*) to 2 (*Often*) and items were averaged to produce mean item ASD symptoms scores at 1.5, 3, 6, 10 and 14 years.

2.2.2. Eating problems

Eating problems in the current study is operationalized as "poor dietary intake" and/or "food refusal". At child age 1.5, 3 and 6 years, parents reported on their child's eating problems using two items from the CBCL/1.5–5 (26). Parents were asked to indicate how frequently their child "*does not eat well*" or "*refuses to eat*". Item responses were anchored on a scale of 0 (*Never*) to 2 (*Often*) and items were averaged to produce mean item eating problem scores at 1.5, 3 and 6 years. These items have been used previously in this cohort to characterize picky eating trajectories (16). At child age 10 and 14 years, parents reported on a single item ("*does not eat well*") from the CBCL/6–18 to indicate eating problems (28). The second eating problem item (i.e., "*refuses to eat*") was dropped in this version for older children. Therefore, the single item responses were used to assess eating problems from 0 (*Never*) to 2 (*Often*) at these waves, rather than a mean score. Previous research by Prosperi et al. (34) have also used this single CBCL item as a broad indicator of eating problems in children with ASD. For descriptive purposes, we examined correlations between the single eating problem item and an indicator of "food selectivity", one of the most common eating problems experienced in children with ASD (3). Food selectivity was assessed with the 4-item picky eating subscale from the Stanford Feeding Questionnaire (35). Pearson's correlation coefficients indicated moderate associations between eating problems and food selectivity at 10 ($r = .37$, $p < .001$) and 14 years ($r = .36$, $p < .001$).

2.2.3. Sociodemographic characteristics

Information on child sex, birth weight and gestational age was obtained from hospital/midwife registries. Child ethnicity (Western or non-Western) was based on the country of birth of both biological parents. Children's height and weight were measured by research assistants at the research center visit at 14 years and converted into sex- and age-adjusted BMI z-score using Dutch reference growth curves (36). Mothers' age at enrolment, pre-pregnancy BMI and highest level of education obtained was collected via postal questionnaire during pregnancy.

2.2.4. Statistical analysis

All analyses were carried out in R statistical software, version 4.1.1. Descriptives of the sociodemographic characteristics of the study population are presented in proportions (%) or means. The ASD symptoms and eating problems subscales, even those using 1 item, were treated as continuous scores throughout all the analyses. As a preliminary step, multiple linear regression analyses were used to examine the wave-on-wave longitudinal relationships for both variables separately, e.g., ASD symptoms at 1.5 years predicting eating problems at 3 years, controlling for eating problems at 1.5 years. Covariates were imputed using multiple imputation by chained equations (MICE) using 20 imputed datasets. Pooled linear regressions showed that adjusting for child sex, birthweight, ethnicity, and maternal age at recruitment and education did not significantly alter the results. Therefore, models were not adjusted for covariates in the main analysis to facilitate model parsimony. Correlations and intra-class correlations (ICCs) across ASD symptoms and eating problems were calculated.

To address the first aim, an RI-CLPM analysis was performed to explore the intra-individual, cross-lagged association between ASD symptoms and eating problems from early childhood and adolescence. RI-CLPM analyses disaggregate stable, between-person differences (i.e., trait-like factors) from within-person fluctuations over time by inclusion of a factor with all loadings constrained to 1 (i.e., a random intercept) (23, 37). RI-CLPM analyses were performed using the *lavaan* package (38). Missing data on ASD symptoms and eating problems were handled using Full Information Maximum Likelihood (FIML). To account for the skewed data, parameters were estimated using the Maximum Likelihood estimator with Robust standard errors (MLR). Overall goodness of fit of the models was determined using cut-offs including Tucker-Lewis index (TLI) and the Comparative Fit Index (CFI) values > 0.95; and root-mean-square error of approximation (RMSEA) < 0.06 (39). The time intervals between waves varied throughout the study, therefore, we did not constrain the model to test whether the dynamics of processes are time invariant (37). We additionally adjusted for multiple testing using the Benjamini-Hochberg False Discovery Rate (FDR) to account for the number of parameters tested. In addition to the primary analysis, we ran a multi-group analysis to test if the cross-lagged effects were equal for boys and girls following the procedure outlined by Mulder and Hamaker (37). First, we estimated a multi-group RI-CLPM with unconstrained cross-lagged pathways by child sex using the “group” function in *lavaan*. We then estimated a multi-group RI-CLPM in which the cross-lagged pathways were invariant (e.g., constrained to be equal) across child sex. The model fit of the unconstrained and constrained models was compared using the Satorra–Bentler adjusted χ^2 difference test. We also ran two sensitivity analyses. Firstly, we reran the model using only 1 item assessing eating problem (*“does not eat well”*) so that the measure in waves 1 to 3 were equivalent to the measure in waves 4 and 5. Secondly, we reran the model with eating problems dichotomized at every timepoint as “no eating problems” vs. “any eating problems” (defined by mean score > 0 from ages 1.5 to 6 years or “Sometimes” and “Often” at ages 10 and 14 years), to check whether skewness of the eating problems measure influenced our findings.

3. Results

There was an equal proportion of boys to girls in the sample (see **Table 1** for sociodemographic characteristics). Most of the children in the sample had a Western background (77%) and had mothers who were university educated (58%). Pearson’s correlations showed that ASD symptoms were positively correlated across all 5 waves (rs ranging from .17 to .61), as were eating problems (rs ranging from.08 to.43; see **Supplementary File Table S4** for study measures descriptive statistics). Spearman’s Rank Order Correlation tests were also run to account for the non-normality of the data, and results were the same as the Pearson correlations. Paired samples Wilcoxon sign-ranked tests were used to examine the wave-on-wave differences in ASD symptoms or eating problems. For ASD symptoms, mean individual scores significantly increased from wave to wave ($p < 0.05$). For eating problems, mean individual scores significantly decreased from wave-to-wave ($p < 0.01$) with the exception of eating problems from 10 to 14 years, which significantly increased ($p < 0.001$).

TABLE 1 Sociodemographic characteristics (*N* = 4,930).

Child	% or M ± SD	*n*
Boys (%)	49.7	2,452
Birth weight, grams (M ± SD)	3,430.7 ± 570.7	4,926
Gestational age, weeks (M ± SD)	39.8 ± 1.8	4,913
Ethnicity (%)		
Western	77.0	3,778
Non-Western	23.0	1,126
BMIz score at 14 years (M ± SD)	0.17 ± 1.1	3,838
Mother		
Age at inclusion, years (M ± SD)	31.5 ± 4.6	4,930
Pre-pregnancy BMI (kg/m^2) (M ± SD)	23.5 ± 3.9	3,729
Highest level of education (%)		
University educated	57.6	2,703
Not university educated	42.4	1,989

Multiple linear regression analyses showed that eating problems were positively associated with ASD symptoms at every subsequent wave while adjusting for baseline ASD symptoms, with the exception of eating problems at 6 years which were not associated with ASD symptoms at 10 years (see **Supplementary File Table S5** for the longitudinal multiple linear regression models). ASD symptoms were also associated with eating problems at every subsequent wave while adjusting for baseline eating problems, with the exception of ASD symptoms at 6 years which were not associated with eating problems at 10 years. ICCs showed that 74% of the variance in ASD symptom score was explained by between-person differences (or stable traits). For eating problems, 67% of the variance was explained by between-person differences. Therefore, the RI-CLPM indicated how the within-person fluctuations in ASD symptoms and eating problems (i.e., 26% and 33% of the variance, respectively) predicted each other while controlling for stable, between-person differences.

The RI-CLPM model fitted well with the data, CFI = 0.984, TLI = 0.966 and RMSEA = 0.036 (**Figure 1**). At the between-person level, there was a moderate to strong positive association between ASD symptoms and eating problems (β = .48). Therefore, individuals with higher average ASD symptoms scores reported higher average eating problems scores across the 5 measurement waves. At the within-person level, the positive autoregressive effects for ASD symptoms indicate that individuals with an elevated ASD symptom score at one occasion also showed an elevated ASD symptom score at the next occasion, relative to their own average score (e.g., ASD symptoms from 1.5 years to 3 years: β = .27). Similarly, positive autoregressive effects were also observed for eating problems (e.g., eating problems from 1.5 years to 3 years: β = .27). Positive concurrent associations between ASD symptoms and eating problems were also observed, indicating that children who scored higher than their average ASD symptoms score also scored higher than their average eating problems score at the same wave (e.g., concurrent association at 1.5 years: β = .21). Evidence of a small, positive bidirectional association was observed between ASD symptoms and eating problems from 1.5 years to 3 years (e.g., eating problems at 1.5 years to ASD symptoms at 3 years: β = .06). From 3 years to 6 years, there was a positive lagged effect from eating problems to

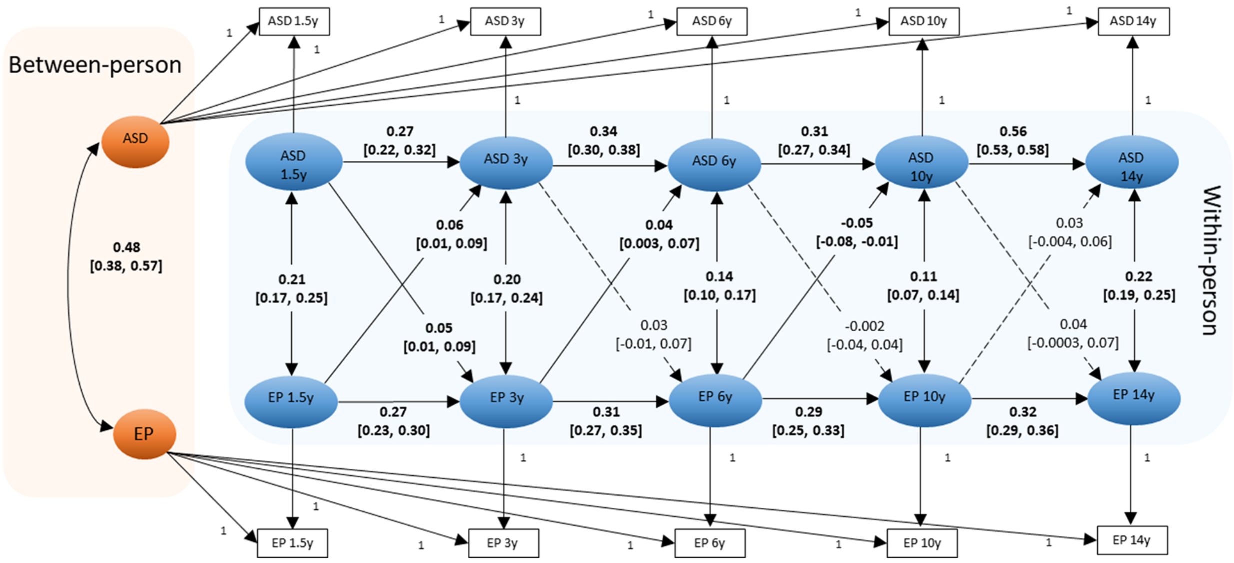

FIGURE 1
Diagram of the RI-CLPM examining the *between-person* and *within-person effects* between ASD symptoms and eating problems ($N = 4{,}930$). Standardized beta coefficients and [95% Confidence Intervals] for pathways are shown. Statistically significant paths are shown in solid lines (and coefficients are bold); dotted lines show the non-significant paths. ASD: ASD symptoms; EP: eating problems. Residuals are omitted for clarity of presentation.

subsequent ASD symptoms (β = .04). From 6 years to 10 years, there was a negative lagged effect from eating problems to ASD symptoms (β = -.05). All associations remained statistically significant after adjusting for multiple testing. Constraining the cross-lagged parameters to be invariant across child sex did not significantly worsen the model fit [$\Delta\chi^2(8) = 9.49$, $p = .30$]. This indicates that parameter estimates were similar for boys and girls.

In the first sensitivity analysis, associations remained in the same direction when using the 1 item indicator of eating problems in waves 1 to 3. However, some cross-lagged associations changed in significance, likely due to the decreased variation in eating problems and smaller effect sizes. In the second sensitivity analysis whereby eating problems were dichotomized, the results were similar to those of the primary analysis (not shown, but available upon request).

4 . Discussion

This is the first study to explore intra-individual, reciprocal associations between ASD symptoms and eating problems in a population-based cohort. Study findings suggest that ASD symptoms and eating problems are highly correlated at the latent-trait level throughout child development. That is, children with higher average ASD symptom scores also had more eating problems from 1.5 to 14 years. Once controlling for the stable, trait-like association between ASD symptoms and eating problems, there was limited evidence for reciprocal longitudinal associations at the intra-individual level between these factors. Findings of lagged associations between ASD symptoms and eating problems should be interpreted in light of their small effect sizes in addition to the large sample size of the study. Toddlers (1.5 years) with higher than their average level of ASD symptoms had higher subsequent eating problems at 3 years, and vice versa. In the preschool years, elevated eating problems at 3 years preceded a subsequent increase in ASD symptoms. In early to mid-childhood, elevated eating problems at 6 years preceded a subsequent decrease in ASD symptoms at 10 years. These within-person, cross-lagged associations did not differ by child sex. It is worth noting that these findings speak to the directionality of parent-reported associations in an observational setting, and firm conclusions about causality cannot be established. Further research is warranted to ascertain whether intervening on eating problems in the general pediatric population, for example, will result in changes in the subsequent expression of ASD symptoms using experimental study designs.

Findings from the current study suggest that ASD symptoms and eating problems are temporally stable and strongly correlated at the population-level. This adds significant knowledge to the current understanding of ASD and eating problems, with implications for research and practice. While it is widely accepted that children with ASD experience disproportionate eating problems (3), our results suggest that subclinical ASD symptoms at the population-level are also associated with more eating problems. ASD symptomology and eating problems may represent a constellation of phenotypes grounded in shared characteristics, such as atypical sensory sensitivities and cognitive rigidity, found in clinical and general populations and across ages (40). Future research could investigate the potential shared etiology of ASD symptoms and eating problems. Such research might include the examination of overlapping heritability of ASD symptoms and eating problems. Furthermore, network analysis could be leveraged to identify the specific phenotypic features common between ASD symptoms (i.e., social and communication problems or repetitive, stereotyped behavior) and eating problems (i.e., food selectivity, or disruptive mealtime behavior). It is important to increase health service providers' awareness of the shared characteristics of ASD features and eating problems and ensure that nutrition-related behaviors are evaluated and communicated within the multidisciplinary team where treatment is accessed. Additionally, it would be useful for providers, when working with families, to frame eating as a complex skill for some children to master, which could require ongoing management through development.

The small bidirectional association between ASD symptoms and eating problems in toddlerhood years suggest the need to further investigate this developmental stage as a window of opportunity for early screening and intervention. The early years mark an important period for brain growth, where atypical connectivity associated with ASD emerges (41). More frequent food refusal is common during this time, although this gradually subsides over time for most children (16). Children with atypical sensory sensitivities, delays in motor development (i.e., oral-motor eating skills), difficulties in communicating their preferences to caregivers and a need for "sameness" may find eating more challenging, which could reinforce early eating problems (11, 12). Eating is also a social activity that is embedded within the daily family routine. Mealtimes could therefore present a tangible platform to identify early ASD-like behaviors and to intervene in problematic eating behaviors. Children with less severe ASD symptoms may be more difficult to identify but may still benefit from nutritional intervention (42). Our results suggest a need to develop and test age-appropriate tools in toddlerhood to assist in identifying specific eating problems which could be indicative of mild ASD, and tailor interventions accordingly. While early interventions typically focus on cognitive, language and behavioral outcomes, eating problems are rarely addressed in early interventions for ASD (43). It is critical to understand if addressing early eating problems improves children's and parents' ability to cope with atypical sensory sensitivity and the social demands of mealtimes.

The unidirectional findings of eating problems on subsequent ASD symptoms from 3 years to 10 years were surprising and are difficult to explain. More eating problems at 3 years predicted a subsequent increase in ASD symptoms at 6 years, which may reflect that eating problems could be an indicator of developmental delay during this time period. Alternatively, this finding could be suggestive of a relation in which poor eating habits may exacerbate ASD symptoms. This speculation is in line with research showing the role of diet in influencing the severity of ASD-associated symptoms (9, 10). However, more eating problems at 6 years predicted a subsequent *decrease* in ASD symptoms at 10 years. The most likely explanation for this peculiar finding may be related to the change in CBCL measures between these two waves. This change in CBCL measure may also explain the lack of a significant longitudinal association of ASD symptoms at 6 years with later eating problems. Changes in measurement tools used is an undeniable, major limitation of the current study. That said, a change in the direction of an effect is possible when disaggregating between-person from within-person processes (24). If this is the case, a potential explanation for this finding could be related to how families manage or accommodate eating problems, or could reflect families prioritizing treatment-seeking in other areas related to core autistic traits (such as academia). Nevertheless, we strongly recommend replication of this finding using identical, repeated measures across waves to support or refute this association.

Limitations of this study include the use of parent-reported measures, and some inconsistency in measures of ASD symptoms and eating problems. Although a moderate correlation between the recently developed ASD symptoms scale and the SRS was observed (31), the internal reliability for the ASD symptom scale was below acceptable levels (29). Furthermore, the test-retest reliability of this scale has not been examined and further research is required to examine longitudinal measurement invariance over time. Moreover, we used a broad indicator of eating problems, which was only moderately correlated with the "picky eating" subscale from the Stanford Feeding Questionnaire. We suggest exercising caution when interpreting the results, and future research could consider specifying the types of eating problems, which may be age- and sex-dependent (12, 44). Finally, findings may not be applicable to clinical ASD cohorts with potentially different trajectories of symptom severity and eating problems (45). Strengths of our study include the novel exploration of reciprocal associations between ASD symptoms and eating problems at the between- and within-person level. The large sample size enabled us to detect small effect sizes. However, the clinical significance of these small effect sizes in the general population is unknown, and it is possible that small mean differences, particularly early in life, may reflect larger individual differences (46). Finally, we also took a dimensional approach to investigating ASD symptoms with a continuous indicator, therefore providing more information about the broader autism spectrum.

This is the first exploratory study to begin unravelling pathways of development between ASD symptoms and eating problems in the general pediatric population. ASD symptoms and eating problems appear to be mainly stable and highly correlated traits from ages 1.5 to 14 years. This suggests that ASD symptoms and eating problems may form part of a cluster of phenotypes based on underlying, shared characteristics. There was limited evidence for an intra-individual associations between ASD symptoms and eating problems. Replication of these findings are recommended, and further research is required to understand to the potentially shared etiology of ASD symptoms and eating problems in community-based samples.

Data availability statement

The data analyzed in this study is subject to restrictions. Data described in the manuscript, code book, and analytic code can be made available upon request to datamanagementgenr@

erasmusmc.nl and will be discussed in the Generation R Study Management Team.

Ethics statement

Ethical approval was granted by the Medical Ethical Committee of the Erasmus Medical Center Rotterdam. Written informed consent was obtained from parents of all children.

Author contributions

HH contributed to the conceptualization and design of the analyses, carried out the initial analyses, drafted the initial manuscript, and reviewed and revised the manuscript. ID assisted with carrying out the analyses and interpreting results and reviewed and revised the manuscript. PP, AL, and MH assisted in the interpretation of results and critically reviewed the manuscript for important intellectual content. PJ contributed to the conceptualization and design of the analyses, supervised the analyses, assisted with the interpretation of results, and reviewed and revised the manuscript. All authors contributed to the article and approved the submitted version.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Publisher's note

Supplementary material

The Supplementary Material for this article can be found online at: https://www.frontiersin.org/articles/10.3389/fped.2023.1062012/full#supplementary-material.

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Passive and social screen time in children with autism and in association with obesity

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Background: Screen time has been identified as a risk factor for childhood obesity, but the media landscape has evolved rapidly. Children with autism tend to be heavy users of screens and have an elevated prevalence of obesity. We know little about screen use patterns among children with autism vs. typically developing (TD) peers and in association with obesity.
Methods: Baseline data from 10,842 participants in the Adolescent Brain Cognition Development Study was used to characterize time spent with child-reported passive screen use (television/movies/watching videos), playing video games, and using social media. Duration of screen time by autism status and gender was summarized as mean time per day; obesity was defined using CDC/WHO criteria. A propensity score analysis was used to create a matched dataset for analysis.
Results: Overall, 1.7% of children were was identified as having autism. Significant mean differences were observed by autism status and gender for both passive viewing and playing video games. Compared to TD children, boys with autism spent more time (2.9 vs. 2.3 h, $p < 0.001$) watching TV, movies or videos, as did girls (3.0 vs. 2.0 h, $p = 0.002$). Compared to TD peers, boys with autism reported more video game time (102.7 vs. 77.5 min, $p = 0.001$), as did girls with autism (64.4 vs. 37.9 min, $p = 0.03$); girls with autism also spent more time on social media sites or video chat (45.5 vs. 21.9 min, $p = 0.04$). Overall, obesity prevalence increased with increasing screen time duration, significantly for passive screen time (p-value = 0.002) and texting (p-value = 0.02). Associations between obesity and screen time duration did not differ by autism status.
Discussion: Children with autism spend more time playing video games and on passive and social screen activities than their TD peers, with some variations by gender. High rates of social media use among girls with autism and multiplayer video game use among both boys and girls with autism may challenge the notion that the high levels of screen time reflect social isolation in the group. Given potential positive aspects of screen time in children with autism movement to focus on content and context is appropriate.

KEYWORDS
autism spectrum disorder, screen time, obesity, gender, electronic media

1. Introduction

The first decades of the new millennium have been characterized by an explosion in the types of screens, their availability, and the proportion of leisure time that children are spending engaging with them (1). With this marked increase in screen use, concerns about the impact of this growing pastime on aspects of child health have ensued. Early foci included the association of screen time with the development and maintenance of obesity in children and the impact of screen use on children's social and emotional development (2).

Child obesity is a multifactorial disease with risk factors operating at the level of the individual, family, community, and beyond. At the individual level, the key factors that appear to be causal include dietary intake, physical activity, sedentary behavior, and possibly sleep duration. Certain frequently prescribed medications that induce weight gain represent an additional risk factor (3). With respect to sedentary behavior, screen time has emerged as a major contributor to overall sedentary time. Screen time may operate directly on energy balance, given that it requires relatively low energy expenditure. It may also exert its effect on energy balance indirectly, by supplanting time spent sleeping, especially for youth. Early studies that established screen time as an obesity risk factor relied on time spent watching television or videos. The key mechanisms proposed included displacement of physical activity, snacking while viewing, exposure to food advertisements, and interference with the quality and quantity of sleep. However, the nature of screens has evolved rapidly over the last two decades, with the addition of social screen time (e.g., Facebook, Twitter, Instagram), video games that include active and social/multi-player games, video chatting, and texting. Whether these other types of screen time are associated with obesity is less clear. Historically, the American Academy of Pediatrics (4), Canadian Pediatric Society (5) the German Federal Health Ministry (6), have recommended limiting total recreational daily screen time to 2 h, but did not make any distinctions by screen time source. Likewise, unlike passive consumption of movies and television, many new screen types involve elements of socialization (7), although their associations with social development remain unclear.

Children with autism are more likely to have obesity than their typically developing peers (8, 9). Autism is a neurodevelopmental disability characterized by persistent deficits in social communication and social interaction across contexts. Autism has seen increasing prevalence over the last several decades (10, 11). Current data suggest approximately 2% of the pediatric population has autism with an estimated male-to-female ratio of about 4 to 1 (12). Several studies have documented higher levels of screen time in children with autism compared to their typically developing peers (13). The impairments in behavior, intellectual capacity, social communication, and/or social interactions that characterize autism may make participation in structured and unstructured forms of physical activity more difficult, potentially increasing the amount of time spent in sedentary behaviors. Specifically, restricted, repetitive patterns of behavior, interests, or activities as described in the DSM-5 for autism may explain elevated time with electronic screens (DSM-5) (14, 15). However, more research is needed to understand additional drivers for screen affinity in this population, including social isolation and self-stimulation. Screen use may also be considered an area of particular strength or skill, given the high levels of engagement and preference for screen-based modalities among individuals with autism (16). Additionally, inasmuch as the large majority of children with autism are male, they dominate the samples of children with autism, with the result that girls with autism are underrepresented in clinical and population research. Growing evidence suggests that autism presents differently in girls than in boys, emphasizing the need for robust samples that can support gender-specific investigations.

The Adolescent Brain Cognitive Development (ABCD) Study is a longitudinal multisite study enrolling a large sample of US school children aged 9 and 10 years. Their open science model (17, 18) provides access to this unique data set and the opportunity to explore how screen use types differ between boys and girls with autism and typically developing children, and to assess whether any associations between autism status and obesity differ by screen time. We hypothesized that the magnitude and direction of differences in the duration of screen time by autism status would vary by screen type reported in ABCD, which include passive screen use (TV, movies, videos), video gaming, and social media/video chatting, and texting. We further hypothesized that the pattern of associations of screen time with obesity would be similar in children with autism and typically developing children.

2. Methods

2.1. Study population

We used baseline data from the ABCD study of children enrolled from 21 study sites between September 2016 and October 2018. Within study sites, consenting parents and their assenting children were recruited largely from public and private schools. The geographic locations that comprise the ABCD research sites are nationally distributed and generally represent the range of demographic and socio-economic diversity in the US. Information about the sample design, recruitment, measures, and compensation is detailed elsewhere (17, 19). The de-identified data set was deemed non-human subjects research by the Tufts University Institutional Review Board.

2.2. Screen time

Screen time was measured using the Youth Screen Time Survey (20). Children answered questions about typical hours per day spent on six different screen activities, separately for weekdays and weekend days. The 7-point scale responses (none, <30 min, 30 min, 1 h, 2 h, 3 h, and 4+ hours) were converted to corresponding count measures for the purpose of analyses (0, 15, 30, 60, 120, 180, and 240 min). In calculating screen time, the six screen activities were classified into four categories: passive viewing (watching television, movies, or videos), playing video games, social media (visiting social networking sites, such as Facebook, Instagram and video-chatting); and texting. For each category, daily screen time was calculated from the weighted average of the weekday and weekend screen time activities: [(sum of weekday activity × 5) + (sum of weekend day activity × 2)]/7.

2.3. Autism status

We defined autism status (yes/no) based on a single question on the ABCD screening questionnaire completed by parents, "Has your child been diagnosed with autism spectrum disorder?" ABCD Study inclusion criteria required children to be in regular (mainstream) classes at school; we have classified these children as typically developing.

2.4. Weight status

Body mass index (BMI) was based on measures of height and weight, which were taken as the average of up to 3 separate measurements. BMI was calculated as weight in kg divided by height in meters squared. Sex and age-specific BMI z-scores were referenced against the Center of Disease Control 2001 (21). BMI z-scores and classified as obese (≥95th percentile) or not (<95th percentile).

2.5. Covariates

Race/ethnicity categories were defined as Hispanic, non-Hispanic White, non-Hispanic Black, non-Hispanic Asian, and non-Hispanic other/multi-race. Individual socioeconomic position (SEP) scores were calculated from a weighted combination of four highest household education levels and four household income levels (22). The SEP scores range from 1 to 10, with higher scores corresponding to higher socioeconomic positions.

2.6. Statistical analyses

A propensity score analysis was used to create a matched data set for the analyses. The propensity of being a child with autism was estimated using a generalized linear model with generalized estimation equations. The data were modelled using a binomial distribution with a log link, and included child age, gender, and race/ethnicity, as well as household socioeconomic position as covariates. A compound symmetry correlation structure was used to account for the within-site clustering of observations. The propensity score was used to perform a nine-digit match of one child with autism to five typically developing children using a greedy matching algorithm (23). As propensity score matching ensured comparable distributions of characteristics between children with autism and typically developing children, adjustment for covariates in multivariable regression analyses were unnecessary. Means and proportions were used to summarize continuous and categorical variables, respectively.

Generalized linear models using generalized estimation equations were used to derive the estimates and inferences for duration of screen time analyses. As screen time was considered to be count data and was positively-skewed, a Poisson distribution with a log link yielded the best fitting models. A compound symmetry correlation structure was used to account for the within-site clustering of observations. For each category of activity, the model consisted of two fully-crossed factors (gender and autism status). Durations of screen times were summarized as mean hours per day or minutes per day. Ratio of means with corresponding 95% confidence intervals were used to compare duration of screen time between autism status, separately for boys and girls.

For analyzing obesity, generalized linear models using generalized estimation equations were used to derive the estimates and inferences. The data were modelled using a binomial distribution with a log link. A compound symmetry correlation structure was used to account for the within-site clustering of observations. For each category of activity, the model consisted of two fully-crossed factors (three-category screen time duration and autism status). Prevalence ratios with corresponding 95% confidence intervals were used to compare the prevalence of obesity across categories of screen time duration. All statistical analyses were carried out using SAS 9.4 (SAS Institute Inc., Cary, NC), and results with p-values < 0.05 deemed statistically significant.

3. Results

A total of 10,842 children from the ABCD study were included in the analyses, of which 187 (1.7%) were reported to have been diagnosed with autism. Propensity score matching yielded a data set consisting of 186 children with autism and 930 typically developing children. One child with autism could not be matched and therefore was excluded from further analyses. The resulting demographic characteristics of the participants were well-balanced (**Table 1**). Mean (standard deviation) age of participants was 10.0 (0.6) years. The sample was predominantly male (85.5%) and White (53.8%), with 15.6% being Hispanic, 13.4% Black, and 1.6% Asian. Parents were well-educated, with 87.6% reporting post-secondary school educational attainment. Reported household income varied widely, with approximately one-third reporting less than $50,000 annual income and one-third reporting annual income that exceeded $100,000. Among the 186 children with autism, 35 (18.8%) met the definition for obesity compared to 134 of 930 (14.4%) typically developing children.

Overall, children spent an average of 2.4 h per day watching television or movies or videos, 76.3 min playing video games,

TABLE 1 Demographic characteristics of the propensity score matched sample.

	Autism (*N* = 186)	Typical (*N* = 930)
Age of child, *n* (%)		
9 years old	84 (45.2)	420 (45.2)
10 years old	102 (54.8)	510 (54.8)
Gender of child, *n* (%)		
Boy	159 (85.5)	795 (85.5)
Girl	27 (14.5)	135 (14.5)
Ethnicity/race of child, *n* (%)		
Hispanic	29 (15.6)	145 (15.6)
White, non-Hispanic	100 (53.8)	500 (53.8)
Black, non-Hispanic	25 (13.4)	125 (13.4)
Asian, non-Hispanic	3 (1.6)	15 (1.6)
Other or Multi, non-Hispanic	29 (15.6)	145 (15.6)
Highest household education, *n* (%)		
Grade school	1 (0.5)	7 (0.7)
High school	22 (11.8)	109 (11.7)
College or vocational	57 (30.7)	273 (29.4)
University or postgraduate	106 (57.0)	541 (58.2)
Household income, *n* (%)		
<$50,000	70 (37.6)	326 (35.0)
$50,000 to $74,999	9 (4.8)	78 (8.4)
$75,000 to $99,999	25 (13.5)	131 (14.1)
$100,000 or greater	69 (37.1)	331 (35.6)
Don't know	5 (2.7)	35 (3.8)
Refused to answer	8 (4.3)	29 (3.1)
Socioeconomic position, *n* (%)		
Low range	23 (12.4)	115 (12.4)
Medium range	50 (26.9)	250 (26.9)
High range	113 (60.7)	565 (60.7)

17.1 min visiting social networking sites or video chat, and 12.4 min texting.

Significant differences between boys and girls and between children with autism and typically developing children were observed for both passive viewing (watching TV, movies or videos) and playing video games (**Table 2**). In comparison to typically developing children, boys with autism spent 26% more time (2.9 vs. 2.3 h) and girls with autism spent 50% more time (3.0 vs. 2.0 h) watching TV, movies or videos, while both boys and girls with autism significantly played about 25 more minutes of video games per day than their typically developing peers. The only other statistically significant screen time difference was among girls with autism who spent 108% more time (45.5 vs. 21.9 min) visiting social networking sites or video chatting. Daily duration of texting was low and was similar across groups.

Considering all children (**Table 3**), the prevalence of obesity increased significantly with increasing duration of passive viewing ($p = 0.002$), playing video games ($p = 0.05$), and texting ($p = 0.04$). A similar pattern of increased obesity occurrence was also observed for visiting social networking sites and/or video chat, but did not reach statistical significance. There were no significant interactions between autism status and screen time duration in relation to obesity (all p-values > 0.05); therefore **Tables 4**, **5** show similar patterns of increased prevalence of obesity with increasing duration of different types of screen time for both children with autism and typically developing peers.

4. Discussion

We sought to leverage the detailed screen use data in the ABCD Study of 9- and 10-year-olds to understand how screen use types differed between boys and girls with autism and their typically developing peers. Passive screen time, video games, social screen time, and texting time were explored separately. We also assessed whether any associations between screen time and obesity differed by autism status. Compared to typically developing children, we observed that boys and girls with autism reported more passive screen time. At the same time, both boys and girls with autism played more video games than their typically developing peers. Finally, social screen time and texting were far less frequent overall, but social screen time appeared to be elevated among girls with autism compared to their typically developing girls.

The world of screens has evolved substantially since the early published reports of television viewing and obesity in 1980s (24, 25) with the introduction of social media and mobile technologies. These newer forms of electronic media may function differently with respect to obesity risk. Specifically, playing video games is not likely to be accompanied by excess snacking as is the case with passive viewing, in part because play requires continual manual interaction. Further, to the extent that high levels of exposure to food advertising fuel snack consumption, advertising-free viewing options have increased (26). Importantly, playing video games is more physiologically demanding than passive viewing, as reflected in energy expenditure and other physiologic responses (27). Additionally, active video games demand far greater expenditures of calories compared to passive video games, up to four times greater in one study (28). The explosion of social play options for video games and multiplayer video games has also changed the social-emotional dynamics of screen-based gaming, allowing youth to interact with friends, family, and meet new people while playing. This may alter the implications of high video game play time among youth with autism, as it may be less associated with social isolation and more associated with socialization. Engagement with social media, texting, and chatting may be done in shorter time intervals. Finally, users of handheld devices, smart phones, and tablets may not be sitting; as such, these activities do not comprise sedentary behaviors.

4.1. Differences by screen time type and by gender

Mixed findings with respect to differences in screen time patterns in children with autism and typically developing children may reflect the aforementioned changes in the contemporary landscape of digital media as well as the broad age

TABLE 2 Comparison of mean daily screen times by type, gender, and autism status.

Type	Gender	Status	Sample size	Mean	Ratio of means	95% CI	*P*-value
Watch TV, movies or videos hours per day	Boy	Autism	159	2.9	1.26	(1.13–1.42)	<0.001
		Typical	795	2.3			
	Girl	Autism	27	3.0	1.50	(1.17–2.01)	0.002
		Typical	135	2.0			
Play video games minutes per day	Boy	Autism	159	102.7	1.32	(1.12–1.56)	0.001
		Typical	795	77.5			
	Girl	Autism	27	64.4	1.70	(1.04–2.77)	0.03
		Typical	135	37.9			
Social and video chat minutes per day	Boy	Autism	159	16.9	1.09	(0.67–1.76)	0.74
		Typical	795	15.5			
	Girl	Autism	27	45.5	2.08	(1.01–4.28)	0.04
		Typical	135	21.9			
Texting minutes per day	Boy	Autism	159	11.4	0.91	(0.61–1.36)	0.65
		Typical	795	12.5			
	Girl	Autism	27	14.6	1.06	(0.63–1.77)	0.83
		Typical	135	13.8			

TABLE 3 Prevalence of obesity by type and duration of screen time for all children.

Duration per day	Sample size	Prevalence *n* (%)	Prevalence ratio	95% CI	*P*-value
Watch TV, movies or videos—all children (overall *p*-value = 0.002)					
Less than 2 h	584	61 (11.0)	Reference		
2 to 3.99 h	306	53 (17.5)	1.59	(1.12–2.26)	0.009
4 h or more	226	55 (23.7)	2.15	(1.40–3.31)	<0.001
Play video games—all children (overall *p*-value = 0.05)					
Less than 30 min	320	35 (11.6)	Reference		
30–59 min	253	35 (14.2)	1.23	(0.90–1.67)	0.19
60 min or more	543	99 (18.3)	1.58	(1.09–2.29)	0.01
Social and video chat—all children (overall *p*-value = 0.58)					
0 min	670	96 (14.8)	Reference		
1–44 min	338	53 (16.0)	1.08	(0.80–1.46)	0.61
45 min or more	108	20 (17.8)	1.20	(0.84–1.73)	0.32
Texting—all children (overall *p*-value = 0.04)					
0 min	671	98 (15.2)	Reference		
1–29 min	306	40 (13.3)	0.88	(0.66–1.17)	0.37
30 min or more	139	31 (21.5)	1.42	(1.00–2.01)	0.05

TABLE 4 Prevalence of obesity by type and duration of passive screen time, and autism status.

Duration per day	Sample size	Prevalence *n* (%)	Prevalence ratio	95% CI	*P*-value
Watch TV, movies or videos—children with autism (overall *p*-value = 0.29)					
Less than 2 h	69	10 (14.9)	Reference		
2–3.99 h	59	10 (16.9)	1.13	(0.46–2.76)	0.79
4 h or more	58	15 (25.4)	1.70	(0.83–3.47)	0.14
Watch TV, movies or videos—typically developing (overall *p*-value = 0.007)					
Less than 2 h	515	51 (10.5)	Reference		
2–3.99 h	247	43 (17.6)	1.68	(1.14–2.49)	0.009
4 h or more	168	40 (23.1)	2.21	(1.35–3.63)	0.002
Play video games –children with autism (overall *p*-value = 0.16)					
Less than 30 min	36	3 (9.0)	Reference		
30–59 min	40	6 (14.4)	1.60	(0.43–5.92)	0.48
60 min or more	110	26 (23.5)	2.62	(0.64–10.8)	0.18
Play video games—typically developing (overall *p*-value = 0.11)					
Less than 30 min	284	32 (11.9)	Reference		
30–59 min	213	29 (14.2)	1.19	(0.84–1.70)	0.33
60 min or more	433	73 (16.9)	1.42	(1.02–1.98)	0.04

TABLE 5 Prevalence of obesity by type and duration of social screen time, and autism status.

Duration per day	Sample size	Prevalence *n* (%)	Prevalence ratio	95% CI	*P*-value
Social and video chat—children with autism (overall *p*-value = 0.82)					
0 min	119	21 (17.6)	Reference		
1–44 min	45	9 (20.0)	1.13	(0.49–2.62)	0.77
45 min or more	22	5 (22.8)	1.29	(0.56–2.98)	0.54
Social and video chat—typically developing (overall *p*-value = 0.80)					
0 min	551	75 (14.2)	Reference		
1–44 min	293	44 (15.3)	1.08	(0.77–1.53)	0.65
45 min or more	86	15 (16.6)	1.17	(0.69–1.97)	0.56
Texting—children with autism (overall *p*-value = 0.42)					
0 min	121	20 (16.6)	Reference		
1–29 min	45	10 (22.3)	1.34	(0.78–2.30)	0.29
30 min or more	20	5 (23.9)	1.44	(0.59–3.47)	0.42
Texting—typically developing (overall *p*-value = 0.01)					
0 min	550	78 (14.8)	Reference		
1–29 min	261	30 (11.7)	0.79	(0.55–1.13)	0.19
30 min or more	119	26 (21.1)	1.42	(0.97–2.08)	0.07

ranges in prior studies. In an analysis of the 2011–2012 National Survey of Children's Health, Montes et al. found no difference between children aged 6–17 with and without autism in total screen, media, or computer/mobile device time or in adherence to the recommendation to limit screen time to less than two hours daily. Interestingly, in a separate report using the same dataset, Gillette et al. reported that children with autism were more likely to be "never users" of electronic devices than children without autism (29). Two systematic reviews also reached conflicting conclusions. A systematic review that covered the years 2005–2016 and included the Montes et al. report, described mixed findings in the 17 studies reviewed that focused on comparisons of children with and without autism (30). It is noteworthy that in several of the studies, the comparison group comprised children with other developmental disabilities. The more recent systematic review covering publications through 2018 was more conclusive, finding that in 14 of 16 studies, children with autism used more screen media than those without autism (29). Our analysis, which focused on a narrower age range of 9- and 10-year-olds found that passive viewing, videogaming, and social media/video chatting were more frequent among children with autism than among typically developing children, with some notable differences by child gender.

Our study is among the first to report screen time patterns separately for boys and girls with and without autism. Because the ratio of males to females with autism is estimated at a little over 4 to 1 (12), most studies do not report estimates for boys and girls separately. Of the 16 studies included in the 2019 systematic review of screen use and autism, none reported gender-specific results (29). An earlier review of 47 studies also reported no findings separately by gender (13). One notable exception is an investigation by Mazurek et al. that studied a sample of 202 youth with autism aged 8 to 18 years and their typically developing siblings (31). With a broad age range and a sample size of 166 boys and 31 girls with autism, they found that compared to their typically developing siblings, television time was significantly higher in girls with autism but not different in boys with autism (31). Compared to their typically developing siblings, youth with autism of both genders also reported higher levels of video game time, but lower levels of social media use (31). We found elevated passive screen time levels for both genders: boys with autism had 26% more passive screen time and girls with autism had 50% more passive screen time than their typically developing peers. Although social screen time was a less common activity for both genders, there appear to be important gender differences. Whereas we saw no difference by autism status in average social screen time levels for boys, twice the level of social screen time was observed among girls with autism compared to typically developing girls.

Our understanding of gender differences in autism is emerging, with reports that girls with autism are better able to mask their social deficits than are boys. A large meta-analysis study of children with autism found that compared to boys, girls evidenced less repetitive and stereotyped behavior after age 6 but were similar in the domains of social behavior and communication (32). In a mixed methods observational study of playground behavior, girls and boys with autism were found to play differently; girls were more likely to situate themselves near social circles, where even if less likely to engage in talking, they maximized the opportunity for social interaction. In contrast, boys with autism tended to be solitary and did not participate in the structured games that engaged typically developing boys (33). The higher levels of social screen time we observed in girls with autism seems consistent with this desire for social interaction. Social screen time may feel safer than in-person social interactions—i.e., the screen may provide a buffer that facilitates social encounters with peers. This may also drive higher rates of video game use among boys and girls with autism vs. their typically developing peers. Anecdotal evidence from participants in our current exergaming intervention with adolescents with autism suggests they are drawn to engage with peers in online video games. More research is needed in this area to better elucidate the types of video games children with autism are engaging in, including the amount and types of social interaction required and/or chosen.

4.2. Associations with obesity

Cross-sectional and longitudinal studies have linked screen time, usually captured as television viewing time, to obesity in typically developing children (25, 34). Positive results of a randomized clinical trial suggest that the association is causal (35). A 2018 meta-analysis of 16 studies estimated that, compared to children watching fewer than 2 h daily, children watching two or more hours were 67% more likely to have obesity (36). Less is known about these associations in children with autism. We previously reported elevated relative weight (BMI z-score) in association with weekend, but not weekday, screen time in a convenience sample of 53 children with autism and 58 typically developing children, aged 3 to 11 years (37). In the present study, we did not find evidence that the association between screen time duration and obesity in 9- and 10-year olds differed by autism status. Although not statistically significant, the patterns of estimates were similar in children with autism and their typically developing peers, with evidence of increasing obesity prevalence with increased passive screen time and time playing videogames or video chatting. We previously identified an age-dependent divergence in obesity by autism status in children ages 10 to 17 years in the nationally representative National Survey of Children's Health 2011–2012 (38). Obesity prevalence at age 10 did not differ by autism status (prevalence ratio = ∼1) but rose steadily to a prevalence ratio of ∼3 at age 17 (37). Given the longitudinal design of the ABCD study, further exploration of these associations as these children go through adolescence is warranted—one might expect differences to emerge over the adolescent developmental period (39, 40).

Beyond concerns that excess screen time will impair academic or social development, compromise physical activity engagement, or contribute to obesity, managing the screen behavior of children with autism can be source of considerable conflict and stress for parents (40). The classic restrictive and repetitive characteristics that define autism are readily reflected in viewing certain videos repeatedly or playing video games in ways that parents deem excessive (31, 41, 42). Youth may play video games late at night instead of sleeping—which itself is often particularly problematic for this population (42). However, the potential adverse impact on child health and family dynamics associated with screen time should be considered in the contexts of its benefits, particularly for children with autism. These children may use screens in many positive and beneficial ways. In addition to the social interaction afforded by social screen time and some video games as discussed above, interventions have been successful using video to model appropriate behavior (43). In our study of leisure time activities in transition-aged individuals with autism, participants favored videogames and other electronic media, reporting these activities were enjoyable and contributed to their feelings of competence and independence (44). In therapeutic settings, preference for passive viewing and video games are effective motivators or positive reinforcers (30). Parents also view screens as a source of wellbeing for their children with autism, providing essential downtime that their children need to decompress after a day at school (30). Viewing television, movies, and videogames can also serve as a positive shared family activity (30, 45).

4.3. Limitations and strengths

There are several noteworthy limitations of our study. First, the autism status of participants was based on parent-reported screening questionnaire, which may be subject to misclassifications. Screen time information was child-reported separately for screen time types. This approach is known to result in overestimations because of the difficulty in separating out the different screen activities as well as multi-tasking (e.g., texting while watching television) (46). Furthermore, we lack information regarding the proportion of videogaming that is active or played online with others (and therefore, social). To the extent that any misclassification of autism status or screen time is random, it would make differences more difficult to discern. Second, although BMI is an indirect measure of obesity, it correlates with more direct measures of body fatness. In addition, examining obesity, rather than overweight as the outcome of interest, minimizes misclassification. Third, one of the eligibility criteria for inclusion in the ABCD Study was being enrolled in regular classes. This criterion likely resulted in the exclusion of children with developmental or behavioral characteristics that would preclude their full inclusion in mainstream programming, such as those with little or no functional communication, and/or children with a co-occurring intellectual disability. The prevalence of autism in the sample, at 1.7%, is lower than the current estimated prevalence in the general population of 2.3% (12). Nonetheless, the size of the study produced a sample of 186 children with autism, including 27 girls. This sample size was adequate to support our planned analyses, but does limit generalizability to populations of children with autism who have greater support needs.

Our study also had several strengths. Screen time was reported by the children themselves, and reported in many distinct categories, supporting a comprehensive investigation. Although, as noted above, the reporting task has its challenges, parents are particularly ill-suited to provide this information. Parents are unlikely to know what their children are watching/doing, especially in the late evening hours when children may be playing video games while their parents believe they are sleeping (47). All participants were 9 or 10 years old, which is an important developmental period for obesity risk (48), and the narrow age range enhances interpretability, particularly for our findings in girls. The design of the study, with 21 recruitment sites located throughout the US, generally represents the range of sociodemographic characteristics of the 9- and 10-year school children nationally. Finally, the propensity score analysis created a dataset that resulted in well-balanced demographic characteristics between the two groups of children, thus not requiring the need for multivariable regression analyses to adjust the results for confounding factors as is required in an observational study.

5. Conclusions

Overall, we found that passive screen and video game use was higher among both boys and girls with autism relative to their typically developing peers. Our study identified some important gender differences in viewing patterns by screen time type. In particular, we found higher levels of social screen time in girls with autism compared to typically developing girls. We did not find evidence that the modest association of screen time with obesity in the sample of 9- and 10-year-olds differed between children with and without autism. It will be important to assess these associations longitudinally as children move through adolescence.

Highly prescriptive guidelines (e.g., limiting total leisure screen time to <2 h/day) promulgated by medical professional organizations have largely been replaced by a more balanced approach to screen use policies. The American Academy of Pediatrics updated their guidance for parents in 2016 and now counsel parents to work collaboratively with their children to create a family media use plan that moves beyond setting time quotas (49). The Canadian Pediatric Society 2022 guidelines for young children emphasize quality over quantity (50). These recommendations seem particularly appropriate for families with a child with autism who need support as they consider electronic media content, implications for social interaction, and the context in which their child engages, in addition to being attentive to the total time spent.

Data availability statement

Publicly available datasets were analyzed in this study. Data are available on The National Institute of Mental Health Data Archive (NDA) website.

Author contributions

AM contributed to the conceptualization and design of the analyses, drafted the initial manuscript, and reviewed and revised the manuscript. ME designed and conducted the analyses, and reviewed and revised the manuscript. HS, LB, CC, and AB contributed to the conceptualization of the study, assisted with the interpretation of results, and reviewed and revised the manuscript. All authors approved the final manuscript as submitted and agree to be accountable for all aspects of the work. All authors contributed to the article and approved the submitted version.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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Racial and ethnic disparities in obesity and contributions of social determinants of health among boys with autism spectrum disorder

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Children with autism spectrum disorders (ASD) are at greater obesity risk compared to typically developing peers. Although many potential risk factors for this relationship have been identified, the causal chain must be better understood, particularly modifiable social determinants of obesity risk in ASD, and especially for children with ASD from minoritized racial/ethnic groups. We aimed to: (1) examine racial/ethnic disparities in obesity status in boys with ASD; (2) assess associations between social determinants of health and obesity status; and (3) understand if social determinants of health factors mediate the relationship between race/ethnicity and obesity status for these youth. We used data for 124 boys, aged 9–10 with ASD enrolled in an ongoing longitudinal study. Social determinants of health explored included socioeconomic position, Area Deprivation Index, neighborhood safety, food and housing insecurity, and racial/ethnic discrimination. The racial/ethnic distribution was: 17.1% Black, 14.6% Latino, and 68.3% White; average age was 10 years. Both Black (PR 2.57, 95% CI: 1.26–5.26) and Latino boys (PR 2.08, 95% CI: 1.08–4.03) with ASD were more likely to be obese than their White peers. While there were significant differences in some social determinants of health by race/ethnicity, only food insecurity mediated associations between race/ethnicity (Black vs. White) and obesity. The striking disparities in obesity and differences in social determinants of health between Black and Latino children with ASD compared to White children emphasize the need to identify factors that contribute to healthy weight among these children and to address these factors in practice.

KEYWORDS

obesity, weight status, race, ethnicity, health disparities, autism spectrum disorder, social determinants of health

1. Introduction

Obesity prevalence is high among children, and puts them at risk for myriad poor physical health outcomes including Type 2 diabetes, hypertension, and orthopedic conditions (1). Childhood obesity has also been associated with mental health risks, such as decreased social support and depression (2, 3). These health outcomes are linked to the development of chronic disease in adulthood (1, 4). At the same time, an emerging body of research suggests that children with autism spectrum disorders (ASD) have higher prevalence of obesity compared to typically developing (TD) children; for example, a recent meta-analysis found an increased risk of obesity among children with ASD compared to their TD peers (5). Differing associations with obesity by sex or gender among youth with ASD are likely, as are observed among TD youth (6). However, because approximately four males are diagnosed with ASD for every female diagnosed (7), most studies to date have been underpowered to examine moderation by sex and have relied on statistical adjustment to control for sex differences. This is problematic, as such adjustment provides a summary estimate and may mask important differences in the magnitude or direction of associations.

There are a multitude of factors that have been shown to contribute to higher rates of obesity among children with ASD. For example, screen time is higher among youth with ASD (8), and physical activity lower compared to TD youth (9) due to a variety of barriers (10) including a lack of inclusive physical education, sports, and community recreation programs (11). Children with ASD are more likely to display selective eating patterns, which can result in low fruit and vegetable consumption, eat more foods that are high calorie and have low nutrient density, and have higher intake of sugar sweetened beverages (12–14). Importantly, psychotropic medications used to treat many children with ASD, such as second-generation antipsychotics, are associated with significant, and often rapid weight gain (15).

A variety of social determinants of health may affect obesity risk among children with ASD. For example, perceived discrimination and decreased social support have been shown to be associated with increased adiposity in TD youth (16) and both of these domains are elevated in populations with ASD (17). Also, well established social determinants of health, such as socioeconomic status, food insecurity, and housing insecurity maybe more prevalent among families of autistic children, given the increased resource demands they face, such as caregiving and medical costs. For example, Karpur et al. found that households that included a child with ASD had twice the risk of food insecurity of households with TD children only (18). However, to our knowledge, no study to date has investigated whether these social determinants are associated with obesity in children with ASD.

Importantly, there are established disparities in obesity for Black and Latino TD children compared to non-Latino White TD children which are related to social determinants of health. By adolescence, prevalence of overweight and obesity in the United States is approximately 9% higher among African American boys and 14% higher among Latino boys relative to their white counterparts (19). These disparities emerge in early childhood, increase over time (19), and are particularly pronounced in the southeastern United States (20). Important contributors to these disparities include gaps in socioeconomic status, accessibility and affordability of healthy foods, and access to green, safe, and walkable neighborhood environments (21). However, there is also emerging evidence that prenatal adversity (22), high allostatic load, and perceived discrimination in childhood may contribute to obesity development in childhood, particularly among African American and Latino youth whose parents were not US-born (23).

The research on obesity among racial and ethnic minoritized children with ASD is sparse but suggestive of poor outcomes compared to their counterparts with ASD and non-Latino white children. Data from the National Health Interview Survey found that Black adolescents with ASD had a higher risk than their same-race counterparts without ASD (24). Similarly, A meta-analysis found that non-White children with ASD had higher obesity rates than their typically developing counterparts, while this was not true for non-Latino White children (5). A study using data from the Autism Treatment Network found that Latino children had a higher risk of obesity compared to non-Latino White children with ASD (25). The intersection between ASD and minoritized status when studying childhood obesity is important. In addition to the factors that contribute to obesity among children with ASD, Black and Latino children with ASD are likely to face additional factors associated with social determinants of health, as they are more likely to live in poverty, have higher barriers to physical activity and health eating, and have increased risk of social isolation and perceived discrimination.

To address this gap in the literature, we analyzed a national sample of boys who were of the same ethnicity and race as their parent to address the following research questions: (1) Are there racial/ethnic disparities related to weight status for Black and Latino boys with ASD compared to non-Latino White boys?, (2) What social determinants of health are associated with weight status among boys with ASD?, and (3) Do social determinants of health mediate the relationship between race/ethnicity and weight status?

2. Methods

2.1. Study population

We used data from the Adolescent Brain Cognition Development (ABCD) Study, an ongoing longitudinal study of 9 and 10 year-old children. The baseline sample was recruited from 21 study sites from September 2016 to October 2018. At each study site, consenting parents and their assenting children were recruited largely from public and private schools. Eligibility criteria required that children be attending regular (mainstream) classes in school. The geographic locations comprising the ABCD research sites are nationally distributed and generally represent the range of demographic and socio-economic diversities in the United States. Information about the sample design, recruitment, measures, and compensation is detailed elsewhere (26, 27).

2.2. Measures

2.2.1. Autism status

We included only participants with ASD, defined based on a single question on the screening questionnaire, by parents answering yes to the following question: “Has your child been diagnosed with autism spectrum disorder?”

2.2.2. Weight status

Body mass index (BMI) was based on measures of height and weight, which were taken as the average of up to 3 separate measurements. BMI was calculated as weight in kg divided by height in meters squared. Sex and age-specific BMI z-scores (BMIz) were referenced against the Center of Disease Control 2001 (28). BMIz scores were used to define obesity (≥95th percentile) or not (<95th percentile).

2.2.3. Demographic characteristics

Parents answered questions about their age, gender, birth country (outside US versus US born), marital status, number of individuals living in the household, as well as their child's age and gender. Parent-reported ethnicity and races were categorized as Latino, non-Latino White, non-Latino Black, non-Latino Asian, and non-Latino other/multi-racial.

2.2.4. Social determinants of health

Individual socioeconomic position (SEP) scores were calculated from a weighted combination of four highest household education levels and four household income levels, combining education and income into a socioeconomic position score for use in studies of health inequalities (29, 30). The SEP scores range from 1 to 10, with higher scores corresponding to higher socioeconomic positions. An area deprivation index (ADI) was calculated for each household that measures socioeconomic disadvantage from a composite of 17 census variables that include education, income, employment, housing, and household characteristics (30). The ADI scores are percentiles that range from 0 to 100, with higher scores corresponding to higher levels of area deprivation. Neighborhood Safety was measured by 3 yes/no questions to parents: I feel safe walking in my neighborhood, day or night; violence is not a problem in my neighborhood; and my neighborhood is safe from crime. Food and housing insecurity was measured by two yes/no questions to parents asking if there was time in the past 2 months when the family couldn't afford food, or to pay rent or mortgage. Racial/ethnic discrimination was assessed by a single yes/no question.

2.2.5. Statistical analyses

Bivariable analyses consisted of comparing continuous variables among the three race and ethnic groups using analyses of variance and comparing categorical variables using chi-square tests. Generalized linear models using generalized estimation equations were used to derive the estimates and inferences for the BMIz scores and obesity analyses. An autoregressive (1) correlation structure was used to account for the repeated BMIz and weight status measures over time, as well as including the primary parent's and son's baseline ages as covariates in the models. For analyzing BMIz, a normal distribution with an identity link was specified in the models. Adjusted mean differences with corresponding 95% confidence intervals were used to compare the three groups. For analyzing obesity, a binomial distribution with a log link was specified in the models. Adjusted prevalence ratios with corresponding 95% confidence intervals were used to summarize the results. Mediation analyses were conducted to determine the extent that social determinants of health (ADI, neighborhood safety, food and housing insecurity, and racial/ethnic discrimination) explains (i.e., mediates) the relationship between measures of weight status and the three categories of race and ethnicity. For BMIz, the percentage mediated was calculated as the relative difference between the unadjusted and adjusted mean differences. For obesity, the percentage mediated was calculated as the relative difference between the unadjusted and adjusted prevalence ratios. All statistical analyses were carried out using SAS 9.4 (SAS Institute Inc., Cary, NC), and results with p-values < 0.05 deemed statistically significant.

3. Results

The ABCD dataset consisted of 11,876 individuals, of which 201 (1.7%) reported their "child been diagnosed with autism spectrum disorder". Four individuals were excluded because of missing age, gender, ethnicity, or race data, and 13 were excluded because the area deprivation index percentile was missing. Among the 184 children with ASD, 158 (85.9%) were males, of which 123 (77.8%) had the same racial and ethnic identity as their primary parent. The racial and ethnic distribution of the parent-son dyads was: 21 (17.1%) Black, 18 (14.6%) Latino, and 84 (68.3%) White. Given that families were followed longitudinally, annual measurements of weight and height were available from a majority of children. Black children contributed 56 measurements, Latino children contributed 45 measurements, and White children contributed 217 measurements to the BMIz and obesity analyses.

Demographic characteristics of the dyads are reported in **Table 1**. The mean (standard deviation) age of the children at baseline was 10.0 (0.6) years. Black and Latino parents were significantly less educated and financially poorer than White families. These observations are supported by significantly lower mean socioeconomic position scores and higher ADI percentiles among Black and Latino families (p-value < 0.001). No child reported experiencing discrimination based on their race or ethnicity.

To answer research question 1, we examined BMIz scores and obesity by race and ethnicity. Although mean BMIz scores were significantly different among the three racial/ethnic groups (p-value $= 0.02$), the observed differences were primarily in comparison to White children (**Table 2**). Mean differences between Black and Latino children were non-significant. A similar pattern was observed for the obesity results (**Table 2**). Both Black and Latino children were significantly more than twice as likely to be obese compared to White children.

To answer research question 2, we examined whether social determinants of health were associated with BMIz and with obesity (**Table 3**). Socioeconomic position and the ADI were not significantly associated with BMIz despite the mean BMIz scores being almost twice as high among disadvantaged families. Consistent with the BMIz findings, prevalence of obesity almost twice as likely among disadvantaged families (SEP $p = 0.05$ and ADI $p = 0.04$). None of the neighborhood safety measures were associated with either BMIz or obesity. Food insecurity and housing insecurity were significantly associated with both BMIz

TABLE 1 Sociodemographic characteristics and social determinants of health by race and ethnicity.

	Black ($n = 21$)	Latino ($n = 18$)	White ($n = 84$)	*P*-value
Sociodemographic variables				
Age of child (years), mean (standard deviation)	10.2 (0.5)	9.9 (0.5)	9.9 (0.6)	0.12
Age of primary parent (years), mean, (standard deviation)	38.7 (8.2)	39.3 (7.9)	41.8 (6.3)	0.11
Gender of primary parent, *n* (%)				
Female	18 (85.7)	16 (88.9)	79 (94.0)	0.40
Male	3 (14.3)	2 (11.1)	5 (6.0)	
Birth country of primary parent, *n* (%)				
United States	19 (90.5)	9 (50.0)	83 (98.8)	<0.001
Outside United States	2 (9.5)	9 (50.0)	1 (1.2)	
Marital status, *n* (%)				
Not married nor partnered	11 (52.4)	7 (38.9)	19 (22.6)	0.02
Married or partnered	10 (47.6)	11 (61.1)	65 (77.4)	
Number living in household, median, (interquartile range)	5 (4–6)	4 (3–5)	4 (4–5)	0.02
Highest household education, *n* (%)				
Grade school	1 (4.7)	0 (0.0)	0 (0.0)	< 0.001
High school	6 (28.6)	7 (38.9)	5 (5.9)	
College or vocational	6 (38.6)	5 (27.8)	24 (28.6)	
University or postgraduate	8 (38.1)	6 (33.3)	55 (65.5)	
Highest household employment status				
Not working	9 (42.9)	4 (22.2)	11 (13.2)	0.03
Part-time working	1 (4.8)	0 (0.0)	5 (5.9)	
Full-time working	11 (52.4)	14 (77.8)	68 (80.9)	
Household income, *n* (%)				
<$50,000	15 (71.4)	12 (66.7)	24 (28.6)	0.004
$50,000–$74,999	1 (4.8)	1 (5.5)	4 (4.8)	
$75,000–$99,999	0 (0.0)	0 (0.0)	15 (17.9)	
$100,000 or greater	4 (19.0)	3 (16.7)	37 (44.0)	
Refused to answer	1 (4.8)	2 (11.1)	4 (4.7)	
Socioeconomic position score, mean (standard deviation)	5.0 (3.1)	4.8 (3.0)	7.5 (2.7)	<0.001
Socioeconomic position score 4 or lower, *n* (%)	13 (61.9)	11 (61.1)	19 (22.6)	<0.001
Area Deprivation Index percentile, mean (standard deviation)	69.3 (32.9)	39.9 (24.2)	31.4 (22.1)	<0.001
Area Deprivation Index at 85th percentile or higher, *n* (%)	11 (52.4)	1 (5.6)	3 (3.6)	<0.001
National Walkability Index, mean (standard deviation)	12.3 (4.4)	12.1 (3.9)	10.1 (3.8)	0.02
National Walkability Index 10 or lower, *n* (%)	6 (28.6)	5 (27.8)	49 (58.3)	0.008
Neighborhood safety				
I feel safe walking in my neighborhood, day or night, *n* (%)	14 (66.7)	12 (66.7)	66 (78.6)	0.37
Violence is not a problem in my neighborhood, *n* (%)	10 (47.6)	12 (66.7)	61 (72.6)	0.09
My neighborhood is safe from crime, *n* (%)	8 (38.1)	10 (55.6)	49 (58.3)	0.25
Food and housing security				
In the past 12 months, there has been a time when the immediate family needed food but couldn't afford to buy it or couldn't afford to go out to get it, *n* (%)	4 (19.1)	3 (16.7)	8 (9.5)	0.40
In the past 12 months, there has been a time when the immediate family didn't pay the full amount of the rent or mortgage because they could not afford it, *n* (%)	5 (23.8)	3 (16.7)	11 (13.1)	0.47
Discrimination				
In the past 12 months, I have felt discriminated against because of race, ethnicity, or color, *n* (%)	0 (0.0)	0 (0.0)	0 (0.0)	1.00
Total visits contributed to weight analyses, *n*	56	45	217	
Baseline, *n* (%)	21 (37.5)	18 (40.0)	84 (38.7)	0.98
1-year follow-up, *n* (%)	21 (37.5)	17 (37.8)	76 (35.0)	
2-year follow-up, *n* (%)	14 (25.0)	10 (22.2)	57 (26.3)	

and with obesity; food insecurity was associated with a more than 3-fold increase in obesity prevalence and housing insecurity with a nearly 2-fold increase.

To address research question 3, Table 4 presents the results of the mediation analyses, which quantify the extent that each social determinant of health explains the association between race/ethnicity and BMIz and obesity for those determinants that were significantly associated with weight outcomes. In general, the social determinants of health were found to be weak mediators. Only food insecurity reached the level of being a partial

TABLE 2 Body mass index and obesity status by race and ethnicity.

	Black ($n = 56$)	Latino ($n = 45$)	White ($n = 217$)	*P*-value
BMIz, mean (se)	1.17 (0.31)	1.04 (0.25)	0.38 (0.14)	0.02
Mean difference	0.79	0.66	Reference	
95% confidence interval	(0.08–1.49)	(0.09–1.24)		
P-value	0.03	0.02		
Obese, *n* (%)	21 (40.3)	15 (32.6)	36 (15.7)	0.02
Prevalence ratio	2.57	2.08	Reference	
95% confidence interval	(1.26–5.26)	(1.08–4.03)		
P-value	0.01	0.03		

Estimates and *p*-values were derived from generalized linear models using generalized estimating equations and adjusted for primary parent's and son's baseline ages.

mediator, explaining approximately one-quarter of the association between race/ethnicity and obesity.

4. Discussion

In this paper, we examined racial and ethnic health disparities among boys with ASD in relation to an important health outcome for children: obesity. Health disparities are differences in health-related outcomes and services that are associated with social and economic disadvantage (31). It is important to identify such disparities in order to take actions to increase health equity for all. Using a US-based national sample, we found striking disparities in obesity between Black and Latino children compared to White children with ASD. Black and Latino boys had significantly higher rates of obesity compared to White boys with ASD, and Latino boys had significantly higher rates of obesity compared to White boys. While these findings are not surprising, it is disturbing. We know that among typically developing populations, Black and Latino children have higher rates of obesity compared to White children (19). There is also robust evidence that children with ASD have higher rates of obesity compared to typically developing peers (5). However, this is the first time to our knowledge that racial and ethnic disparities in obesity have been examined in a sample of boys with ASD, which eliminates residual confounding due to sex.

In order to work towards equity, identifying modifiable and structural factors that may contribute to higher rates of obesity among Black and Latino children with ASD is crucial. Therefore, we examined the relationship of selected social determinants of health to BMIz and obesity among the children in our study and assessed the extent to which any of the social determinants of health explained the observed disparity. We observed strong associations between socioeconomic status, area deprivation, food insecurity, and housing insecurity and obesity among boys with ASD of all races and ethnicities, consistent with findings in TD populations (19, 32–35). In contrast, we did not observe associations with community safety variables such as neighborhood walkability, which had been identified as an obesity risk factor in many studies of TD children (36, 37). Our incongruent findings may reflect the additional safety concerns parents have regarding

TABLE 4 Percentage of BMIz and obese relationships with race and ethnicity mediated by selected social determinants of health.

	BMIz Black vs. White	BMIz Latino vs. White	Obese Black vs. White	Obese Latino vs. White
Socioeconomic position score 4 or lower (vs. 5 or higher)				
Percentage mediated	11.3%	12.2%	18.7%	13.3%
P-value	0.14	0.24	0.20	0.10
Area Deprivation Index at 85th percentile or higher (vs. lower than then 85th)				
Percentage mediated	0.0%	0.0%	0.0%	0.0%
P-value	1.00	1.00	1.00	1.00
In the past 12 months, there has been a time when the immediate family needed food but couldn't afford to buy it or couldn't afford to go out to get it (vs. not)				
Percentage mediated	5.9%	6.5%	29.1%	22.7%
P-value	0.18	0.25	0.02	0.18
In the past 12 months, there has been a time when the immediate family didn't pay the full amount of the rent or mortgage because they could not afford it (vs. not)				
Percentage mediated	6.7%	0.4%	6.2%	15.1%
P-value	0.19	0.42	0.13	0.42

Estimates and *p*-values were derived from generalized linear models using generalized estimating equations and adjusted for primary parent's and son's baseline ages.

TABLE 3 Association of social determinants of health with BMIz and with obesity.

	BMIz mean and mean difference ($n = 318$)	*P*-value	Obesity prevalence and prevalence ratio ($n = 318$)	*P*-value
Socioeconomic position score 4 or lower (vs 5 or higher)	0.91 vs 0.45 0.46	0.08	0.32 vs 0.18 1.78	0.05
Area Deprivation Index at 85th percentile or higher (vs lower than then 85th)	0.98 vs 0.56 0.42	0.24	0.39 vs 0.20 1.94	0.04
National Walkability Index 10 or lower (vs 11 or higher)	0.52 vs 0.70–0.18	0.46	0.25 vs 0.20 1.27	0.43
I feel safe walking in my neighborhood, day or night (vs not)	0.59 vs 0.68–0.09	0.77	0.22 vs 0.22 1.00	0.98
Violence is not a problem in my neighborhood (vs not)	0.60 vs 0.64–0.04	0.87	0.19 vs 0.28 0.69	0.22
My neighborhood is safe from crime (vs not)	0.61 vs 0.62–0.01	0.97s	0.22 vs 0.23 0.96	0.89
In the past 12 months, there has been a time when the immediate family needed food but couldn't afford to buy it or couldn't afford to go out to get it (vs not)	1.52 vs 0.48 1.04	0.006	0.58 vs 0.18 3.26	< 0.001
In the past 12 months, there has been a time when the immediate family didn't pay the full amount of the rent or mortgage because they could not afford it (vs not)	1.15 vs 0.51 0.64	0.03	0.38 vs 0.19 1.96	0.03

Estimates and *p*-values were derived from generalized linear models using generalized estimating equations and adjusted for primary parent's and son's baseline ages.

independent physical activity in their children with ASD, which make typical neighborhood safety characteristics less salient (38, 39).

To assess whether any of the social determinants of health helped to explain disparities in obesity, we first examined whether the determinants differed by race/ethnicity. We found that Black and Latino children scored significantly higher on the ADI, and that Black and Latino parents were more likely to feel that violence as a problem in their neighborhood compared to White parents; these findings parallel the literature on the general US population (21). We did not identify significant racial/ethnic differences in food or housing insecurity or in children's perception of racial/ethnic discrimination; no child reported that they felt discriminated against because of their race, ethnicity, or color. However, these findings should be interpreted with caution given the small sample size and their lack of consistency with other studies. When we examined whether any of the social determinants of health mediated the relationship between race/ethnicity and obesity, only food insecurity among Black autistic boys emerged as a significant mediator of this relationship. Taken together, this suggests that while Black families with an autistic child may not be at greater risk of food insecurity compared to Whites in this sample, such insecurity may play a larger role in diet quality through mechanisms such as food deserts. This would be consistent with the worse area deprivation scores we found among Black families.

Some noteworthy limitations of our study warrant discussion. Autism status was based on parent report on a screening questionnaire rather than a neuropsychological assessment or multi-item measure. This may have resulted in inclusion of boys who would not have met diagnostic criteria. Similarly, the social determinants of health measures we relied upon are subject to misclassification. However, we would not expect any measurement error to differ by race/ethnicity. While the ABCD data is large national study, the number of children identified with ASD is small, limiting the power to detect group differences, especially between Black and Latino boys. A larger sample may allow us to better explain the association of social determinants on obesity among children with ASD for example. Further, because of the small sample and 4-to-1 male to female ratio, the sample did not have an adequate number of girls for a separate analysis.

In conclusion, our findings suggest substantial racial/ethnic disparities exist among children with ASD, mirroring the disparities observed in neurotypical youth. Additional research is needed to better elucidate unique social determinants of obesity risk in these populations and further study is needed in girls with ASD. Given the myriad health consequences of obesity for all children, more attention needs to be paid to the maintenance of healthy weight of Latino and Black boys with ASD and to identifying and addressing modifiable factors that are associated with unhealthy weight among children with ASD from Black and Latino communities.

Data availability statement

Publicly available datasets were analyzed in this study. Data are available on The National Institute of Mental Health Data Archive (NDA) website.

Author contributions

All authors contributed to the conceptualization and design and interpretation of the analyses and collaborated on the initial draft and revisions to the manuscript. ME designed and conducted the analyses. All authors contributed to the article and approved the submitted version.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Publisher's note

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Parental perception of facilitators and barriers to health among young children with down syndrome: a qualitative study

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Background: Despite high rates of obesity and weight-related conditions observed in children with Down syndrome, little is known about how to prevent these conditions.
Purpose: The purpose of this study was to identify parent-perceived facilitators and barriers to health for toddlers (12–36 months old) with Down syndrome.
Materials and methods: We conducted in-depth, semi-structured interviews with the mothers of 25 toddlers with Down syndrome. All interviews were conducted using Zoom Video Technology, audio recorded and transcribed before being coded in NVivo software using a structured protocol. Thematic analysis was used to identify themes in perceived facilitators and barriers to health at the level of the child, family, and community. Data were triangulated using reflective journaling, video review of child meals, and member-checking techniques.
Results: We identified unique themes for facilitators (on the move and sound sleep) and barriers (co-occurring conditions and eating behaviors) at the level of the child. At the level of the family and community, overarching themes that were viewed as either a facilitator or barrier, depending on the context, were identified (role models matter, time is critical, the importance of place, and social support).
Conclusion: These themes can help clinicians and researchers tailor their health promotion interventions to meet the unique needs of children with Down syndrome by using strength-based approaches and providing families with the tools to overcome barriers.

KEYWORDS
Down syndrome, toddler, early childhood, obesity, health, thematic analysis

Introduction

Children with Down syndrome have an elevated risk for obesity due to altered body composition and reduced exercise capacity and energy needs (1–5). Health disparities in weight-related health outcomes during childhood include obstructive sleep apnea syndrome, gait dysfunction, non-alcoholic fatty liver disease, and adverse cardiovascular risk factor levels (1, 2, 6, 7). Despite these risks, very little information is available about preventing obesity for children with Down syndrome or other developmental disabilities (8). What is known is that individuals with Down syndrome are more likely to be physically inactive (9, 10), demonstrate poorer diet quality (11, 12), and have more sleep problems (13, 14) than their peers. Very few studies examine the health behaviors of children with Down syndrome during the first 3 years of life (15, 16). However, the preferences, habits, and behaviors established during these critical first years influence developmental trajectories and health outcomes later in life (17, 18). Because rapid weight gain has been observed in children with Down syndrome between 2 and 6 years, it is imperative that we understand how early habits are formed in this population (19). Therefore, the purpose of this study was to describe parents' perspectives on health behaviors and the development of healthy habits in children with Down syndrome during the first 3 years of life. We were specifically interested in facilitators and barriers to health to inform the design of an intervention to reduce the risk of obesity and rapid weight gain among children with Down syndrome.

The Institute of Medicine (IOM) has prioritized helping parents promote healthy eating, increase physical activity, decrease sedentary behavior, and promote age-appropriate sleep duration during their children's early years to prevent obesity (20). In response to the high rates of obesity in children, several obesity prevention programs have been developed to promote healthy habits during early childhood in typically developing children and children at risk due to socioeconomic factors (21–24). However, we predict that these programs will need to be modified to best meet the needs of families of young children with developmental disabilities. Children with Down syndrome face barriers that traditional obesity prevention approaches may not address. For example, because toddlers with Down syndrome commonly experience oral motor delays, swallowing issues, and other feeding problems (e.g., picky eating) (25, 26), it may be more difficult for them to meet the World Health Organization recommendation to consume 400 g, or five or more servings, of fruits and vegetables per day (27). Similarly, children with Down syndrome frequently experience sleep problems (28) and gross motor delays (29, 30) that may hinder their ability to meet recommendations related to sleep duration and engagement in physical activity early in life. There is a pressing need for interventions to help families of young children with Down syndrome build healthy routines that consider co-occurring conditions and offer creative ways to promote health regardless of developmental trajectory.

To successfully promote health and prevent obesity in children with Down syndrome, clinicians must understand the facilitators and barriers to healthy habits families experience daily. Our primary research question was: What do parents of children with Down syndrome perceive as facilitators and barriers to building healthy routines and habits? We anticipate that barriers that are unique to Down syndrome will emerge through the thematic analysis of semi-structured interviews with parents. After themes of facilitators and barriers to healthy habits are identified, they can be used to guide the tailoring of existing obesity prevention strategies. Based on the socioecological model of obesity risk for children with developmental disabilities (8), we anticipate that approaches may require modification at the level of the child, the family, and the community. The overarching goal of this study was to describe parents' perspectives on healthy habits as they relate to their young child with Down syndrome. We used a qualitative approach to gain a deeper understanding of how parents viewed facilitators and barriers to health for their children.

Materials and methods

Study setting and design

We conducted a qualitative study using semi-structured interviews and thematic analysis (31, 32). All interviews were conducted remotely using Zoom technology (Zoom Video Communications, San Jose California). The university Institutional Review Board approved all research procedures, and all participants provided informed consent. This study was part of a larger mixed methods project to characterize the health behaviors of young children with Down syndrome. Recruitment and interviews occurred between June 2020 and March 2021.

Participants

We recruited a convenience sample of 25 parents of young children with Down syndrome through social media, newspaper ads, and email blasts from specialty clinics and organizations that serve individuals with Down syndrome in the United States. To be included, parent participants had to (1) be 18 or older, (2) speak English, and (3) have a child aged 12–36 months with Down syndrome. Parents were excluded if their child used a feeding tube as their primary source of nutrition at the time of data collection. Participants were told that the interview was being conducted to help the team understand the routines and habits of families with children with Down syndrome to inform the development of a new health-promoting intervention. Interested participants completed an online survey (Qualtrics, Provo, Utah) to determine participation eligibility and provide the research team with contact information. Informed consent documents were emailed to participants before meeting with the principal investigator (via phone or video conference). After reviewing procedures and making sure all parent questions were answered, those still interested in participating were given the option to sign the informed consent document electronically and return it via email or sign a printed copy and return it in a self-addressed, stamped envelope provided by the research team. After informed consent, interviews were scheduled at times convenient for participant parents. All parent participants completed a demographic survey on REDCap and received $50 on a pre-paid university-based debit card for completing an in-depth interview.

Semi-structured zoom interviews

Individual, in-depth interviews (35 min–60 min) were conducted via Zoom, audio-recorded using an external device, and transcribed by a qualitative data coding service at the university.

TABLE 1 Semi-structured interview script.

Question	Potential probes
1. Can you describe what a typical day looks like for your child?	– *Can you tell me more about your child's sleep behavior?*
	– *Can you tell me more about your child's eating and nutrition?*
	– *Can you tell me more about your child's physical activity?*
	– *Can you tell me more about your child's use of screens?*
	– *Can you tell me more about times when your child's movement is restricted?*
2. What kind of things influence your family's daily routines and activities?	– *Can you tell me about things that influence what you do each day or week?*
3. Could you tell me a little bit about how COVID-19 has changed your activities and routines in each of these areas?	
4. People often think about changing things in their lives. Can you talk to me about whether or not there are things you would like to change?	– *In what ways do you think these changes would impact your family?*
5. If you were thinking about making changes, what kind of things would get in the way?	– *Do you feel you have the resources you need?*
	– *Can you tell me more about your community?*
	– *Are there other things that take up your time?*
6. What things would help you be successful at making changes?	– *Are there programs that you think might help?*
	– *How do you prefer to receive training or education?*
	– *Do you have access to resources that might help?*
7. In terms of your health, what types of behaviors or habits do you consider to be healthy ones?	– *What does "being healthy" mean to you?*
	– *What kinds of things does a "healthy" person do?*
8. Would you describe healthy behaviors or habits differently when thinking about your child with Down syndrome?	– *Can you tell me more about why/why not?*
9. Is there anything else you would like to share with us about your family or child's health and routines?	

The semi-structured interview script and probing questions (**Table 1**) were developed to align with the IOM's obesity prevention priorities (20) and the Socioecological Model of Obesity Risk for children with developmental disabilities (8). As a form of member-checking, participant responses were paraphrased before probing questions were posed, to provide an opportunity for participants to clarify meaning and support valid interpretations. Data saturation was achieved, with no new codes or themes emerging in the data during the final rounds of thematic analysis.

The principal investigator and first author, AC, conducted all interviews. AC is a clinician-scientist and occupational therapist with 15 years of clinical expertise working with families of children with Down syndrome and interviewing families. AC acknowledges that confirmation bias based on previous experiences may have influenced the probing questions posed to families. During each interview, a second research team member was present to take field notes and offer an alternate perspective. In addition, before each interview, we sent participants a camcorder and requested that they video-record three child meals.

Data analysis

Transcripts were uploaded into QSR International's NVivo 12 qualitative data analysis software (Burlington, MA) for coding. The four coders had experience working with families of children with disabilities and education and training in occupational therapy. They represented diverse racial, cultural, and socioeconomic backgrounds, and each interview was coded by at least three coders using a codebook with flexibility for open coding as needed. An initial draft of the codebook was developed based on the four areas of health behaviors prioritized by the IOM (healthy eating; sleep; physical activity; and sedentary behavior). We also adapted the Socioecological Model of Obesity Risk for children with developmental disabilities (8) to include factors most relevant to children with Down syndrome. Each phrase coded was labeled as either a potential facilitator or barrier at the level of the child, family, or community.

To analyze the qualitative data, four trained coders used a coding protocol that followed the six-step process for thematic analysis (32, 33). They read each transcript to familiarize themselves with the data (step 1) prior to assigning and generating initial codes (step 2). After independently coding each interview via NVivo, coders participated in reflective journaling to take notes on key messages from each interview. Next, the team met weekly over 8 months to discuss facilitators and barriers at different levels (i.e., child, family, community) for each family and compare the findings across the families to identify potential emerging themes (step 3). The research team created a series of mind maps, visual tools to show connections or relationships of codes (34), to facilitate synthesis of codes, and to identify emerging themes. The analysis team (coders and principal investigator) met weekly to review emerging themes (step 4) and those flagged by the NVivo software system. Open codes were reviewed, and the codebook was updated iteratively over the course of data analysis to incorporate the interim findings. The analysis team held two workshops (halfway through coding and when coding was complete) to identify and define overarching themes (step 5) of facilitators and barriers before reporting the final themes (step 6). A recursive review of the initial themes was conducted in the workshops by identifying the most significant or frequently mentioned codes and combining the codes into higher-order meaningful themes. After the thematic analysis was completed, a member of our team viewed the video recordings of meals to identify child behaviors consistent with themes related to eating behaviors. Five participants representing diverse socioeconomic, racial, and ethnic backgrounds also reviewed a draft of the results of the thematic analysis, confirmed themes, and provided recommendations to improve clarity as a form of member checking.

Results

Participants

Of the 25 parents who participated in semi-structured interviews, all were mothers (23 biological, 2 adoptive), and most were white ($n = 22$), non-Hispanic ($n = 20$), and married at the time of the interview ($n = 23$). While diverse educational, employment, and income levels were represented (Table 2), most ($n = 14$) reported household income greater than $100,000. They ranged in age from 28 to 51 years (mean = 37). More than half of the children with Down syndrome being discussed were female ($n = 14$), and the vast majority had received early intervention services ($n = 22$). Most children had at least one sibling in the home ($n = 21$), ranging from zero to six siblings in our sample. All children with Down syndrome were between 12 and 36 months, with an average age of 25 months at the time of the interview. We received usable video-recorded child meals from 22 of 25 participants; two participants did not record child meals, and one participant's recordings were inaccessible due to a memory card error.

TABLE 2 Participant characteristics.

Parent demographics	*N*	%
Gender		
Female (Mother)	25	100
Race		
White	23	92
Black	1	4
Asian	1	4
Ethnicity		
Non-Hispanic/Non-Latina	20	80
Hispanic/Latina	5	20
Marital status		
Married	23	92
Education level		
High school	3	12
Vocational/Associate	5	20
Bachelor's	8	32
Graduate Degree	9	36
Employment status		
Full-time	11	44
Part-time	4	16
Stay-at-home Parent	10	40
Family income		
<$40,000	2	8
$40,000–$60,000	3	12
$60,000–$80,000	2	8
$80,000–$100,000	3	12
>$100,000	14	56
Age (years)		
Mean = 36.9; SD = 6.11; Range = 28–51		
Child demographics	***N***	**%**
Gender		
Female	14	56
Male	11	44
Race		
White	20	80
Black	1	4
Asian	1	4
Pacific Islander	1	4
Multi-racial	2	8
Ethnicity		
Non-Hispanic/Non-Latino	20	80
Hispanic/Latino	5	20
Number of siblings		
0	3	12
1–2	20	80
3+	2	8
Age (months)		
Mean = 25.6; SD = 7.6; Range = 12–36		

SD, Standard deviation.

Child-level factors

We identified unique themes for facilitators and barriers to healthy habits for children with Down syndrome at the level of the child. The following themes were identified as facilitators of healthy habit formation: (1) on the move and (2) sound sleep. The barriers included: (1) co-occurring conditions and (2) eating behaviors.

Facilitator—on the move

Parents described their toddlers with Down syndrome preferring active play and exploring their environment.

One mother whose child had recently mastered going up and down stairs explains,

> "…we did go to [museum] like last month, and they have that new toddler section set up, and so it's like stairs, and she just went up and down, and up and down, and up and down the stairs. I mean, she would've probably done it for a whole hour all by herself just up and down; she loved it" (P4, White mother of a 31-month-old).

This theme persisted among toddlers who were not yet walking, as described by another mother,

> "And he's very active… he's all over… everywhere. We have baby guard—really—he's not walking by himself yet, but he's crawling everywhere" (P24, Asian mother of an 18-month-old).

Many parents also discussed using music and dancing to motivate physical activity. When asked about her child's favorite activities, one mother responded,

> "She loves music—any kind of music, she just starts rocking. She loves to dance." (P25, Hispanic mother of a 23-month-old).

Facilitator—sound sleep

Regardless of sleep apnea, a strong theme of sound sleep emerged: parents described their toddlers with Down syndrome as good sleepers. A mother of three explained,

> "She sleeps great… she's my only child who has slept great" (P18, White mother of an 18-month-old). Similarly, another mother of three children shared, "… he sleeps through the night… of all my kids, he taught himself to fall asleep on his own" (P17, White mother of a 27-month-old).

In addition to sleeping through the night, mothers reported their children fell asleep quickly, with one sharing,

> "she does really good about staying in bed at nighttime. And she usually falls asleep within five minutes" (P7, Hispanic mother of a 29-month-old).

Barrier—co-occurring conditions

Parents' most frequent barriers to healthy habits were related to co-occurring medical conditions. Despite reports of sound sleeping, parents described medical concerns related to sleep apnea. One mother explained,

> "…the doctor told me that she [has] progressed to like severe sleep apnea. So, she's sleeping; at some point, she's not able to breathe. She sleeps well, but I don't think she's getting any quality sleep because of the sleep apnea because she's tossing and turning a lot. But other than that, she's a good sleeper compared to my other kids" (P8, Black mother of a 36-month-old).

Other co-occurring conditions parents discussed as barriers to the development of healthy habits included dysphagia, reflux, and gastrointestinal issues. One mother shared,

> "she has dysphagia…she's had multiple swallow studies, and she's still aspirating quite a bit… she's on thickeners, so she cannot take anything just straight liquid she also has some GI issues, some constipation, she has really bad reflux, so she [takes] medicine in her bottle" (P15, Hispanic mother of a 15-month-old).

Another mother described fears related to repeated choking associated with dysphagia,

> "she is more prone to choking…I don't feel like her skills are quite there yet. And we've had a couple of choking incidents, and it's not any fun to have to give your child back blows to get that thing out of their throat, so we proceed with caution" (P7, Hispanic mother of a 29-month-old).

Episodes of gagging and choking were confirmed upon review of video-recorded child mealtimes submitted by parents.

Barrier—eating behaviors

While parents often described their children as "good eaters," they also described eating behaviors that served as barriers to creating healthy habits. Parents describe their children with Down syndrome as lacking appropriate satiety signals and tending to eat whatever amount of food they are offered. One mother explained this,

> "…[she] loves to eat… She doesn't really have a… I guess I would say like a full sensor that we're aware of, she will just keep asking to *eat and eat and eat*" (P7, Hispanic mother of a 29-month-old). Another mother shared a similar experience, "he'll never tell us to stop. Like he'll just *eat and eat and eat*. …we have to read a lot from his cues, too. Like we can tell, he's done when he starts to play around. Or when he just starts to get really slow" (P9, White mother of a 27-month-old).

One mother described feeling like she needed to stop her child from eating,

> "when she starts eating, I feel like she keeps eating. And there are times where she'll tell us that she's all done, but I feel like a lot of times she might just keep eating, and we have to cut her off" (P22, White mother of a 19-month-old).

Parents of toddlers with Down syndrome also described strong food preferences and picky eating behaviors. One mother explained,

> "all she wants is carbs and sugar. So like, if we just gave her 500 mini muffins, that's all she would eat. But we try to make her eat other things" (P25, Hispanic mother of a 23-month-old).

Another mother expressed frustration relying on formula for nutrition,

> "she is such a picky eater… usually, her lunch consists of SpaghettiOs or Chef Boyardee, which we're trying to expand off of, because I don't want her to just be eating that. …a lot of the nutrients [are] coming from this formula, so we kind of really rely on that" (P3, White mother of a 30-month-old).

One mother described increased pickiness over time,

> "So, she used to eat all sorts of things and has since become very picky. She loves carbs, of course…and fruits. Has trouble with meats and vegetables" (P14, White mother of an 18-month-old).

Video review of child mealtimes confirmed the tendency for children in this sample to eat carbohydrates and starches first during meals.

Family-level factors

Two major themes emerged as factors influencing the development of healthy habits among children with Down syndrome early in life: (1) role models matter, and (2) time is critical. Interestingly, these themes were described in competing ways as both facilitators and barriers depending on the family context.

Role models matter

Parents, siblings, and extended family members were all described as role models that could positively or negatively influence child health behaviors. We have highlighted examples of this theme related to nutrition, physical activity, and the use of screens.

Regarding nutrition, siblings were described as powerful role models for mealtime behaviors. One mother who described her child's restricted eating behaviors also provided a strategy she used to increase dietary variety,

> "she's a major imitator… she never liked strawberries. So… I'll have her sister eat—start eating it, and after she sees her eating, and then she'll start saying, "eat, eat," that means she wants some" (P8, Black mother of a 36-month-old).

On the other hand, not all parents described positive role models for nutrition. A mother who described deep ties to her community explained how the foods valued in her culture could serve as a barrier to healthy habits,

> "Mexican families especially that love refried beans, they love all the good delicious things that are maybe not so great to eat all the time… On both sides of our family, there's, you know, health issues, things related to weight… that run in our families: heart disease, things like that, you know?" (P15, Hispanic mother of a 15-month-old).

Many parents expressed a desire to be positive role models in terms of physical activity. One mother explained,

> "I want us…to be examples for her so that she can see, 'Mom and dad go for walks, let me do the same thing… my sister is playing a sport… let me, you know, find my thing so I can do it too" (P15, Hispanic mother of a 15-month-old). Another parent described how her family had prioritized physical activity, "…my husband and I are very into being active, exercising…so we…one thing we've really tried to do just even with the kids as they're little, just go outside at least once a day and do something: walk, you know, ride bikes, something like that" (P14, White mother of an 18-month-old).

Alternatively, another mother admitted,

> "I'm addicted to my phone. She's seen me on it, and so she discovered, 'Oh, Mom's got [her phone] in her pocket.' … that whole day was terrible, 'cause then all she wanted to do was grab our phones" (P4, White mother of a 31-month-old).

Time is critical

Families also described how work setting (home vs. office) and other competing demands influenced the time available to build healthy family routines, both as a facilitator and a barrier.

A mother who worked full-time described commute time as a barrier,

> "Traffic really affects us in our house because we both commute to work, and so if there's a wreck on the interstate, that could really cause problems getting home at night" (P7, Hispanic mother of a 29-month-old).

Whereas another described the flexibility of working in the home and a short commute as facilitators,

> "I'm a stay-at-home mom, so my schedule is very flexible. My husband right now— 'cause we live on base, so he doesn't have much of a commute; he can come home for lunch, that helps a lot" (P4, White mother of a 31-month-old).

Many parents reflected on a recent transition to working from home due to the COVID-19 pandemic. One mother shared,

> "I'm mostly working from home, so I have—you know, my husband and I have more time to have things ready… and she's not like overly hungry waiting for dinner at this point… the kids are sitting down eating at the same time" (P14, White mother of an 18-month-old).

Parents of young children with Down syndrome also described balancing several weekly appointments and other scheduling conflicts as competing demands for time, thus serving as a barrier to healthy habit development. One mother explained how this takes away from other responsibilities,

> "Sometimes things like how busy I am on my day off, if [child] has a lot of…like if she has her therapies, and then if she has

> other afternoon appointments, sometimes I don't have time to do all the things that I would like to do on my day off, like go grocery shopping, clean the house, that sort of thing" (P7, Hispanic mother of a 29-month old). Another mother shared similar experiences, "…our schedule is insane. Let's see. My daughter has activities—my other two kids go to school. Some days are in person; some days are remote. So, I work in the schools here, so I'm gone every day. My husband's here working from home. The other two are coming and going depending on the day. In the evenings, my daughter has dance three nights a week… It's just crazy. I'm still in college. When I'm at home, it's just crazy" (P25, Hispanic mother of a 23-month-old).

Community-level factors

Regarding community factors, two themes emerged that could serve as either a facilitator or a barrier depending on family context: (1) the importance of place and (2) social support.

Importance of place

Parents of young children with Down syndrome acknowledged the critical role of their place (proximity to resources and the state policies related to health services) as factors that influence their ability to support their child's health.

Families described the types of community in which they resided (e.g., urban, rural) as a potential facilitator or barrier. One mother describes the benefits of living in a walkable, suburban community,

> "the daycare is right up the street, so… we always try to stay outside, and you know, stay active, and like walk to the playground or the park, or ride her little bike around. So, we do have access to those sorts of things" (P14, White mother of an 18-month-old). Another shared similar benefits, "Our community has a lot of really great walking trails. They have a pool. They have playgrounds" (P15, Hispanic mother of a 15-month-old).

One mother described barriers experienced living in a rural community,

> "We have parks, but unfortunately, this area is very rural, so like there's no… group meetings. And before I had [child] I was an OB nurse, and nobody ever talked about Down syndrome… there are a few people in the area that are older that have Down syndrome, but… they were in group homes, like you never saw them in the community" (P13, White mother of a 26-month-old).

Parents also discussed the proximity of specialists and access to care based on state policies as influencing the health of their toddler with Down syndrome. A mother who had recently moved described variations between states,

> "[former state] is our only place that we've experienced special needs support, and they were outstanding. So going from there to here has been somewhat of a disappointment. They have resources, but they're harder to come by. And speech therapists, they're very hard to come by around here" (P2, White mother of a 31-month-old).

Another mother described barriers to accessing virtual services across state lines,

> "normally, you'd see the whole pediatric team, and they'd evaluate like, you know, physical therapy, speech, occupational therapy, but because we're out of state, like we —we could only meet with [the physician]" (P17, White mother of a 16-month-old).

Many parents described feeling satisfied with their services, expressing their areas had access to "so many resources," or that their providers were "super, super, super knowledgeable."

Social support

Parent participants also cited the presence of social support as a facilitator and a lack of social support as a barrier to healthy habit formation. A mother of seven children describes how her son's weekly appointments have added complexity to their schedule,

> "…as a homeschooling family, it's been hard… ideally, we've been trying to find… a co-op or something one day week, [so] I had a day to focus on him and his doctor's appointments and therapies" (P19, White mother of a 19-month-old).

Many parents described a desire to connect with other families. One mother explains,

> "I would love… to have like playdates for him, whether with, you know, [other children with] Down syndrome or, you know, the same type of playgroups I did for my daughters" (P17, White mother of a 16-month-old).

Others described the importance of having the support of grandparents to help them promote healthy habits. One mother explained,

> "they were seeing their grandparents pretty regularly, and some of their aunts and uncles, and… I feel like that has helped a lot with development, and stress, and just, you know, trying to stay healthy and have a good attitude about things" (P4, White mother of a 31-month-old).

TABLE 3 Facilitators (+) and barriers (−) by socioecological level.

Themes	Sub-themes	Type	Exemplar codes	Definitions
Child-level				
On the move	Prefers active play	+	Activity level	Description of the child's activity level
	Loves to dance	+	Dance	Child preference for music and dancing
Sound sleep	Sleeps through night	+	Sleep quality	The onset of sleep or ability to stay asleep
	Falls asleep quickly	+	Sleep quantity	The duration of sleep (how long)
Co-occurring conditions	Risk of sleep apnea	−	Obstructive sleep apnea	A condition characterized by repeatedly interrupted breathing during sleep (symptoms include loud snoring, pauses in breathing, restless sleep)
	Swallowing issues	−	Pharyngeal functions	Swallowing function of a child; factors that impact efficient swallowing and airway protection (e.g., aspiration, choking, cough)
Eating behaviors	Lack of satiety	−	Control of eating	Whether the child can voluntarily stop eating when they feel full or not
	Prefers carbohydrates	−	Preferred foods	The childs preferred foods
	Restricted diet	−	Food refusal, picky eating	Eating a limited variety of foods or unwillingness to try new foods, despite the ability to eat a broader diet
Family-level				
Role-models matter	Siblings as motivators	+	Sibling effect	The impact of the sibling on the child with Down syndrome
	Parents as models	+	Family physical activity	Family activity routine, such as walking or going to a park
	Traditional foods	−	Family screen use	Description of family screen use influencing screen time of the child with Down syndrome
		−	Family meals	Types of foods that family commonly eats at home, whether they eat together or not
Time is critical	Flexible work setting	+	Family dynamics	Distinct factors of family function/roles that influence child health (e.g., work situation, marital status, travel)
	Competing demands	−	Competing time demands	Limited time to build healthy habits for child with Down syndrome (e.g., work responsibilities, other children, other appointments)
Community-level				
Importance of place	Proximity to resources	+/−	Access to inclusive facilities	Access to places to engage in physical and recreational activity for children with varying abilities.
	Access to services	+/−	Access to specialists	If family can access inclusive providers, early intervention services, medical specialists
	Financial strain	−	Cost	How much resources cost is described (e.g., services, food, opportunities for activity)
Social support	Presence or absence of social support	+/−	Community and others	Local community factors that influence parent and child health (e.g., peers, family, friends, respite providers)

Themes at the level of the family and the community represented a spectrum of experiences perceived as either facilitators or barriers based on contextual factors. It is important to acknowledge that at the level of the child, not all participants reported the same barriers. For example, not all parents said their toddlers experienced feeding problems. Similarly, a few parents reported that their toddler did not sleep soundly and frequently woke at night. Each parent participant described unique and unifying experiences that influenced the health behaviors of toddlers with Down syndrome. We have focused on overarching themes (Table 3), but varying experiences highlight the ongoing need for family-centered strategies that are tailored to each child and family.

Discussion

Using semi-structured in-depth interviews with parents and thematic analysis guided by a socioecological framework, we aimed to identify facilitators and barriers to building healthy habits and routines for young children with Down syndrome. In the category of child factors, a preference for active play (*on the move*) and a tendency to sleep through the night (*sound sleep*) emerged as facilitators that helped parents promote healthy routines for their toddlers with Down syndrome. *Co-occurring conditions* (e.g., sleep apnea, dysphagia, heart conditions) and dysfunctional *eating behaviors* (e.g., lack of satiety signals, restricted diet, picky eating, preference for starches) emerged as barriers that impeded parents' ability to build healthy routines for their toddlers with Down syndrome.

At the levels of the family and community, overarching themes emerged that were discussed as either facilitators or barriers based on each family's unique context and perspective. Specifically, the themes of *role models matter* and *time is critical* emerged as central to promoting healthy behaviors at the family level. Community themes revolved around access, with the importance of place and social support being highlighted by the parents in our sample. Ease of access to parks, walking trails, specialists, and opportunities to promote health was valued. The level of social support from friends, family, and other parents of young children with Down syndrome also emerged as a key contributor to building healthy habits. Parents lacking access and social support viewed these as community-level barriers, whereas those with access and support reported these as community facilitators.

The findings in this study support existing research that has identified co-occurring conditions, family role models, access to inclusive services, and time (i.e., competing demands) as factors that influence the health behaviors of individuals with Down syndrome (35–37). Social support has been linked to health-related quality of life and parenting stress among caregivers of children with Down syndrome (38–40). Therefore, it is not surprising that social support emerged as an important theme, but our study suggests parents perceive social support as being a critical component to health promotion for the entire family, including their child with Down syndrome.

Eating patterns and feeding problems have been linked to nutrition-related problems, such as obesity, among individuals with Down syndrome (1, 25, 26). The parents in our sample raised several concerns about eating behaviors that they viewed as barriers to healthy habit formation. Notably, many parents described their child as unable to regulate their own food intake; several reporting that their child would continue to eat preferred foods until the food was gone or taken away. Increased levels of leptin have been observed in children and youth with Down syndrome, potentially influencing leptin resistance and an ability to suppress appetite and regulate body weight (41). Our findings suggest that toddlers with Down syndrome may already be experiencing problems regulating appetite and satiety. This idea aligns with emerging evidence that children at increased risk for obesity may be less able to regulate caloric intake than their peers (42–44).

It is widely established that individuals with Down syndrome do not meet recommendations for physical activity and engaged in less physical activity than peers throughout childhood (10, 45). Furthermore, the duration and intensity of physical activity declines as children with Down syndrome get older (10, 45). Nevertheless, high levels of physical activity emerged as a perceived facilitator to healthy habit development for young children with Down syndrome in our thematic analysis. Our finding is consistent with other qualitative studies that found that children with Down syndrome prefer active play during early childhood. However, these same reports indicate that this preference for active play shifts to a preference for sedentary tasks during middle childhood (46, 47). Future research is needed to explore why children with Down syndrome appear to shift from more active to more passive activities as they develop. Nonetheless, innovative interventions are needed to support ongoing interest, motivation, and opportunities for children with Down syndrome to engage in physical activity.

It was surprising that parents in our sample overwhelmingly described their toddlers with Down syndrome as good sleepers. Children with Down syndrome are prone to sleep issues, including high rates of obstructive sleep apnea (48), lower sleep efficiency (49), higher incidences of night awakenings, and higher duration of wake after sleep onset (50). Many parents reported a history, current diagnosis, or increased risk for obstructive sleep apnea, despite good sleeping behaviors. This aligns with prior research that found parent-reported child sleep problems are not predictive of the severity or presence of sleep apnea (51, 52). Others acknowledged that sleep quality may be impacted by obstructive sleep apnea and other medical issues. That sleep emerged as a facilitator of healthy habits is noteworthy, as the disconnect between sleep health and parent-reported sleep behavior may indicate that there are fewer behavioral manifestations of sleep problems among toddlers with Down syndrome. Additional research is needed to understand the relationships between sleep behaviors and sleep outcomes (e.g., duration, night waking, sleep onset) among toddlers with Down syndrome.

Our findings should be viewed in the context of some study limitations and strengths. We acknowledge that the biases and experiences of the analysis team, each of whom has experience providing therapy to young children with developmental disabilities, can impact several aspects of study implementation and analysis. It is a limitation that the former experiences of the study team likely influenced interview questions, coding, and the identification of themes. We attempted to minimize bias by developing an interview guide, informing participants of our expertise and motivation, and following a detailed coding protocol. Another limitation of our study is that, like most qualitative studies, we report qualitative data on a convenience sample of participants; inferences to the greater population are not supported. Furthermore, our sample of families was largely recruited through specialty clinics at the beginning of the Covid-19 pandemic. This is a limitation, as those who volunteered to participate during this unusual time may be inherently different from other parents of young children with Down syndrome. Finally, our findings are further limited by the lack of diversity of our sample with respect to parent gender, race, and marital status. Therefore, our analyses may not represent the experiences of fathers and non-white or non-married mothers. Future work is warranted to understand the lived experiences of families of young children of Down syndrome within minoritized communities. Study strengths include: (1) diversity of backgrounds and perspectives of members of the research team, (2) use of member checking and video recordings to confirm the thematic analysis, and (3) a rigorous protocol for coding and thematic analysis that included weekly meetings and workshops.

In summary, we have described parent perceptions of facilitators and barriers to promoting healthy habits and routines for young children with Down syndrome. Parents described child sleep and preference for active play as facilitators and co-occurring medical conditions and eating behaviors as barriers at the level of the child. Positive role models and time to build routines emerged as facilitators, whereas negative role models and lack of time emerged as barriers at the level of the family. Finally, access to resources and social support emerged as facilitators, with lack of resources and lack of support representing barriers, at the level of the community. Additional research is needed to understand the underlying mechanisms of the child behaviors reported by parents. Understanding the factors that cause or contribute to dysregulated hunger and satiety signals, declining levels of physical activity over time, and sleep problems among children with Down syndrome are necessary to prevent obesity and weight-related health issues. Based on these themes, it is clear that existing obesity prevention interventions will require modification for children with Down syndrome to address child-level feeding issues and integrate tailored strategies to promote healthy habits for children with co-occurring conditions, such as obstructive sleep apnea. Also evident is the need for community-level interventions to improve inclusivity by increasing access to resources, building accessible spaces for physical activity, and educating leaders on how to include children with Down syndrome and their families in community activities. Future research is needed to adapt existing obesity prevention interventions and to develop toolkits and other appropriately tailored supports to meet the needs of families of young children with Down syndrome and other developmental disabilities.

Data availability statement

The datasets presented in this article are not readily available because the data collected that informed this study are qualitative in nature, inclusive of videos and interview transcripts. To protect the privacy of the participants, we do not have truly anonymous data to share. Requests to access the datasets should be directed to Angela Caldwell (ARL78@pitt.edu).

Ethics statement

The studies involving human participants were reviewed and approved by University of Pittsburgh Institutional Review Board. Written informed consent to participate in this study was provided by the participants' legal guardian/next of kin.

Author contributions

AC conducted all semi-structured interviews, participated in thematic analysis, and drafted the manuscript. YK led the thematic analysis, developed the codebook, and assisted in writing the manuscript and creating tables. NA, KR, and TD participated in the coding and thematic analysis and contributed to reviewing and editing the manuscript. KV, RB, JD, and LT assisted with conceptualization of the study, provided guidance on research procedures throughout, and participated in manuscript review and editing. AM served as the senior author and provided expertise and guidance on using the Socioecological Model of Obesity Risk, actively participated in manuscript development, writing, and edits. All authors contributed to the article and approved the submitted version.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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Exploring health behaviors and the role of pet dogs in households with autistic children: the DANE study

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Introduction: Autism spectrum disorder (ASD) often presents a unique set of risk factors that impact healthy eating and physical activity. Animal-assisted interventions (AAI) are a promising approach for autistic children. There is growing evidence for the positive impact of AAIs on self-regulation, which is necessary for initiating and maintaining behavioral changes. Pet dogs offer several potential advantages as a vehicle for an AAI focused on health behaviors. However, little is known about the experiences of autistic children and their families with respect to dog ownership and the mechanisms through which such an AAI might operate.

Methods: We conducted interviews with ten parent-child dyads to explore the role of pet dogs in the lives and lifestyle habits of families with an autistic child. Interview guides were designed to explore the relationship between the autistic child and the pet dog and the role of the dog in family life; attitudes and practices related to physical activity and nutrition; and thoughts about intervention strategies. We used a directed qualitative content analysis approach for analysis.

Results: Themes indicate a strong bond between the child and the dog, the child's enjoyment in caring for their dog, and successful integration of dogs within family routines. In contrast, minor themes emerged around the challenges that owning a pet dog posed for families with an autistic child. In terms of nutrition and physical activity, a major theme among children was that healthy eating and exercise were important for both them and their dogs. However, minor themes suggest challenges with healthy eating and exercise and room for improvement for these behaviors. Parents held favorable views toward an intervention that would incorporate the family dog to teach children about nutrition and physical activity, although they expressed some concerns about feasibility.

Discussion: This exploratory work suggests that AAIs to improve nutrition and physical activity could build on the strong bond that children have with their pet dogs, but should consider the specific needs of each family, including the needs of the pet dog.

KEYWORDS

autism spectrum disorder, animal-assisted intervention (AAI), human-animal interaction (HAI), nutrition, physical activity

1. Introduction

Increasing evidence suggests that children with autism spectrum disorder [ASD; person- and identity-first language is used intentionally in the remainder of this paper in recognition of the autistic community's right to self-determination (1)] are at greater risk for obesity compared to their neurotypical counterparts (2–5). This disparity may be mediated in part by behavioral and sensory challenges that impact eating and physical activity behaviors. For example, atypical eating patterns, food rituals, and hypersensitivity to tastes, textures, and smells are manifestations of ASD that are likely to contribute to poor diet quality (6). Notably, autistic children tend to choose foods that are higher in calories and lower in nutrients and fail to meet recommendations for fruit and vegetable intake (7). Moreover, physical activity may be avoided because of difficulties with gross motor skills (8), the social interactions that are required for many activities (9), and the intense sensory and visual stimuli that are typical in settings where physical activity occurs (10). Very few obesity prevention interventions exist that are designed to take into consideration the attributes of ASD (11–13), and fewer still offer family-based lifestyle programming. Novel approaches are needed to address this gap.

Animal-assisted interventions (AAI) are a broad category of interventions that use various animal species to benefit humans, and can include therapies, education, or activities (14). There is a growing body of research on the positive impact of animal-assisted interventions (AAI) on self-regulation (15, 16), which is necessary for initiating and maintaining behavioral changes (17), including changes in diet and physical activity (18). In addition to enhancing self-regulation, an AAI may promote physical activity and healthful nutrition behaviors in several ways that could help address the specific barriers faced by autistic children. For example, an AAI could introduce nutrition-related concepts with an emphasis on the animal's health to increase nutrition knowledge and awareness in a less stressful way since the focus is not on the child's eating behaviors; or an animal's non-judgmental attitude and patience could be emphasized with a child with gross-motor skill deficits, encouraging participation in physical activity.

While certified therapy animals are often used for AAIs, they are often inaccessible and costly. Pet dogs are an alternative to certified therapy animals for use in AAIs that may be more practical, and as members of the family environment they remain after an intervention concludes, potentially resulting in greater sustainability (19). There is some correlational evidence from the general population that dog ownership may promote physical activity among children (20).

While AAIs that incorporate pet dogs for obesity prevention in families with an autistic child represents a promising and novel approach, given a lack of literature in this area, formative work is needed to understand the household dynamics and the best approaches to such an intervention (19, 21). The purpose of this qualitative study was to gain insights into children's relationships with their pet dog to understand if it might be leveraged in an AAI focused on health behaviors; how the pet dog integrates into households with an autistic child to determine the appropriateness and feasibility of an AAI that would involve the family dog to help promote healthy nutrition and physical activity among autistic children; and parent reactions to this type of AAI.

2. Methods

The multidisciplinary team included a PhD-level researcher with expertise in community-based strategies for improving dietary intake and physical activity as well as expertise in qualitative methods, including adapting methods to meet the needs of autistic people (SCF); a student pursuing a doctorate in nutrition interventions, communications, and behavior change (JA) who was trained in qualitative methods by the qualitative expert; a PhD-level pediatric psychologist who has extensive expertise in the diagnosis and treatment of ASD and physical activity promotion in ASD (CMM); a board-certified veterinary nutritionist with knowledge and experience in AAI and pet obesity (DL); a PhD-level researcher who focuses on observational and intervention studies of obesity in vulnerable populations, with an emphasis on youth with developmental disabilities (AM); and a PhD-level behavioral economist whose work focuses on the economic aspects of behavior around food and nutrition, including how children behave when engaging in autonomous food purchasing activities, who is also the parent of an autistic child (SBC).

We conducted interviews with a purposive sample of ten parent-child dyads to better understand the role of pet dogs in the lives of families with a child who is diagnosed with ASD and the potential to conduct an AAI on health behaviors that involves the pet dog. This sample size helped assure that we would achieve data saturation (22). To be eligible for the study, the dyads were required to live with a pet dog, be English-speaking, and have a child between 8 and 18 years of age with an ASD diagnosis and intelligence quotient score greater than 70. We recruited the dyads through recruitment emails to veterinary school and a therapy dog organization listservs, social media (e.g., Facebook), and targeted recruitment of clinic patients who were known to be autistic.

The research team collaborated with stakeholders to develop semi-structured interview guides (21). The stakeholder panel included: a provider of AAI; two Board Certified Behavior Analysts (BCBAs); two parents of autistic children; and an autistic young adult, along with his mother. The interview guide for children included three topic areas. The first was designed to understand the child's relationship with the pet dog to help assess the appropriateness of an AAI that incorporates the pet dog might and how an AAI might be best designed to build on the existing relationship. In this area, we also asked about responsibilities for taking care of the dog and activities with the dog to understand how lessons about nutrition and physical activity might be incorporated into these activities. The second topic area was about the eating and exercise habits of the dog and the child. This topic area was designed to help shape the informational content that would be most relevant in an AAI. It was also designed to understand children's attitudes toward healthy eating and physical activity for themselves and for their dogs as this would form the basis for motivation to participate in an AAI on these topics. In the third topic area, children were asked directly for their thoughts on learning more about physical activity and nutrition for their dogs. The interview guide for parents covered the same topic areas, and in addition: perceptions about the effect of autism on child-dog interactions, fitting the dog into the family routine, the impact of the dog on the family, and reactions to a potential AAI. The questions about fit with the family routine and impact of the dog on the family were included to help understand the appropriateness and feasibility of an AAI the includes the pet dog. Because of the timing of the study, we also asked parents about the impact of the COVID-19 pandemic on these areas. See **Supplementary Tables S1A and S1B** for major topics and questions for both guides. Demographic data were collected during screening to help characterize the sample.

The interviews were conducted from August 2020 to December 2020 using the Zoom videoconferencing app. The parent interviews were conducted by a graduate student on the team (JA), and the child interviews were conducted by the qualitative expert (SCF) with experience interviewing autistic youth. The study was approved by the Tufts University Social, Behavioral and Educational Research Institutional Review Board. Parents provided verbal informed consent for themselves and their child prior to the interviews. Child assent was obtained verbally prior to each child interview. Interviews were designed to last no longer than 1 h, and each dyad received a $50 gift card and dog toy upon completion of their interviews.

All interviews were audio-recorded on Zoom and transcribed verbatim. We used a directed qualitative content analysis approach. We developed an initial codebook based on the interview guides and added codes based on review of the transcripts. NVivo 12 (QSR International Pty Ltd., 2018) was used to assist with the analysis. Primary coding was done by JA under the supervision of SCF. These team members established inter-coder reliability based on double-coding of one child transcript and one parent transcript. Satisfactory agreement was established (average Cohen's kappa was >0.9 for both the transcripts). Minor differences were discussed, and the codebook was revised accordingly, mainly by clarifying code definitions. The codebook remained stable at this point, reflecting code saturation (22). Major themes were developed based on similarities in responses in at least six of the ten transcripts, and minor themes were based on similarities in 3–5 of the transcripts. To finalize the themes and interpret results, findings were discussed with the study team and stakeholders.

3. Results

3.1. Participants

Fifteen parents contacted the study in response to recruitment efforts. Two did not meet eligibility criteria. Of the 13 eligible parents, two did not respond to scheduling follow-ups and one indicated that the study procedures would be difficult for her child and therefore declined to participate. Interviews were scheduled and completed with the remaining ten parent-child dyads. The characteristics of the participants are described in **Table 1**. Of the child participants, the median age was 9 years; 8 were male, 1 was female, and 1 was other. Of the parent participants, all were female and non-Hispanic white, 8 were married, and 2 were divorced. Three of the parent-child dyads were eligible for free or reduced lunch, and the number of children in the household ranged from 1 to 6. The breed of the dogs varied. Dyad 2 was the only family that had more than one dog. All families had acquired their dog at least one year ago except Dyad 2, which had acquired a second dog six weeks prior to the interviews.

3.2. Themes

The directed qualitative content analysis approach is largely deductive, and most themes arose directly from the questions asked. Based on the data, we combined our findings topically into three major domains: (1) child's relationship with the family dog; (2) the role of the dog in families with an autistic child; and (3) eating and exercise habits, including reactions to a potential AAI involving the pet dog. A summary of findings is provided in **Table 2**. For clarity we have underlined names and pronouns within quotes when they refer to the pet dog.

TABLE 1 Characteristics of parent-child dyads.

Dyad #	Child age (years)	Child gender	Parent gender	Parent race/ethnicity	Parent marital status	No of children in household	Free/reduced lunch eligible?	Pet dog breed and sex
1	8	Male	Female	Non-Hispanic white	Married	1	No	Rottweiler, male
2	8	Female	Female	Non-Hispanic white	Married	2	No	Pit bull mix, female
3	9	Male	Female	Non-Hispanic white	Married	2	No	Boxer mix, male
4	17	Male	Female	Non-Hispanic white	Divorced	1	Yes	Lab chow coon mix, male
5	8	Male	Female	Non-Hispanic white	Divorced	1	No	Pomeranian, male
6	13	Male	Female	Non-Hispanic white	Married	6	No	Australian cobberdog, female
7	9	Male	Female	Non-Hispanic white	Married	2	No	Chihuahua maltese mix, male
8	10	Other	Female	Non-Hispanic white	Married	2	No	Goldendoodle, male
9	16	Male	Female	Non-Hispanic white	Married	3	Yes	Lab mix, female
10	9	Male	Female	Non-Hispanic white	Married	2	Yes	Mini poodle, male

TABLE 2 Summary of themes.

Domain	Sub-domain	Themes	
Child's relationship with the dog	Positive	Child, major	Spending time with dog makes them happy
		Parent, major	Child has a strong bond with the dog
		Parent, minor	Helps with challenges related to autism
	Negative	Child, major	Some negative aspects to playing with dog (e.g., love biting and licking)
		Parent, minor	Autism negatively impacts interactions with dog (e.g., getting frustrated easily)
Role of the dog in families with an autistic child	Integration with family routine	Parent, major	Typical part of family routine; schedule fits well
		Parent, minor	Some challenges to having a dog (e.g., added responsibilities)
	Caring for dog	Parent, major	Children view caring for dog as part of routine and enjoyable
		Child, major	Taking care of dog is important—member of the family
		Parent, minor	Taking care of dog makes child feel proud
Eating and physical activity	Nutrition and physical activity and the dog	Child, major	Nutrition and physical activity are very important for the dog
	Nutrition and the child	Child, major	Eating healthfully is important
		Parent, major	Healthfulness of child's diet is good, but room for improvement
		Parent, minor	Pandemic increased food intake and decreased quality of foods eaten
	Physical activity and the child	Child, major	Physical activity is important
		Child, minor	Physical activity is unpleasant
		Parent, minor	Child does not enjoy physical activity
		Parent, minor	Child enjoys physical activity but needs encouragement to participate
	Potential AAI	Child, major	Interested in learning more about nutrition and physical activity for the dog from parents or reading materials
		Parent, major	Favorable perception of this type of program
		Parent, minor	Concerns with specifics of implementation

3.2.1. Domain 1: child's relationship with the family dog

A major theme among children was that playing with and spending time with their dog makes them feel happy. This was often because children perceived their dogs as cute and comforting.

> *"He's really cute. He comes into my bed every morning. When he doesn't find me, he goes around looking around the entire house. He goes and gets my parents. He's just the cutest. I love him because every time I'm feeling down or something…he comes over and lays on me and licks me. That's the dog he is. We look out for each other." (Child, Dyad 1)*

Like the children, parents also spoke positively about the relationship between their child and the family dog, and the major theme among parents was that there was a strong bond between the child and the dog, due mainly to the protective, attentive, and gentle nature of their dogs. They also said that their children enjoyed the dogs' calming nature and love.

> *"I think the fact that they're both very loving [contributes to the strength of their bond]. Chloe is a very loving and affectionate dog and [child] happens to be a very loving and affectionate kid. She really likes that affection, so she seeks it regularly. I think that's one of the reasons why she loves Chloe so much because Chloe is so interested in her and so affectionate with her, so she gives that mutual affection back if that makes sense." (Parent, Dyad 2)*

> *"Toby's gentleness and his tolerance [contribute to the strength of the bond]. He doesn't bark at kids or he doesn't whimper or growl, or anything like that when you're petting him. He's very, very calm." (Parent, Dyad 3)*

> *"They play together. [Child] lays on the bed with him and while he's listening to music on his phone, he lays by the side of Bruce. …Very close bond." (Parent, Dyad 4)*

A minor theme among parents was that the dog's attention, companionship, and bonding time helped their children with the challenges resulting from autism.

> *"[My child] is more verbal now. We've only had Oreo since May, so he's had the verbal skills pretty steadily. In the past, the verbal was really, really difficult for him." (Parent, Dyad 5)*

> *"I think [autism's effect on their relationship] is just positive…I think he feels really judged by others, and she doesn't judge him. She loves everybody and she wants to be with everybody, and she loves anybody's attention. There's always positive feedback that she gives him that he doesn't get from everybody else necessarily." (Parent, Dyad 6)*

Although the major themes indicate a very positive relationship between the child and the dog, most children also described some negative aspects to playing with their dog. These varied and included leash tugging, love biting and licking, playing rough with toys, and taking up free time. A minor theme among parents was that autism negatively impacts their children's interactions with the dog. Problematic behaviors included picking at the dog's face, walking loudly, or getting frustrated easily.

> *"I think that the autism and some of the behaviors, like just being a little bit louder, more physically, where he's not really*

> *aware of his physical body, sometimes he comes into a room and the arms are doing this [physical gesture], and it just scares the dog. I feel like I'm constantly managing the relationship between the two of them." (Parent, Dyad 7)*

> *"I think the only time if there's any problematic things is sometimes she'll get frustrated if Chloe won't come over to her. She has really low frustration tolerance." (Parent, Dyad 2)*

Since this study took place during the COVID-19 pandemic, parents also gave insight on how the relationship between their child and family dog had changed due to the pandemic. Many of them mentioned that their child spent more time with the dog, and they were trying to spend more time outside. According to the parents, most children enjoyed the extra time and reported that their child spends a range of 10 min to 4 h per day with the family dog.

> *"[Their relationship] is probably just stronger. They spend more time together and there are fewer distractions or opportunities for us to do something that Enzo wouldn't be included in. We haven't been to a museum or a shopping trip for an out-of-town weekend trip in almost a year. They are just spending more time together and getting that much closer." (Parent, Dyad 1)*

3.2.2. Domain 2: role of the dog in families with an autistic child

A major theme among parents was that the pet dog is a typical part of the family's routine, and their dog's schedule fits well with the family's. Parents stated that they take the dog with them wherever they can, which includes outdoor activities such as walks around the neighborhood, hikes, and going to the park. Parents described facilitators to fitting the dog into the routine, which included the dog's temperament and size, aligning the dog's schedule with the family's schedule, and placing a high importance on including the dog in family activities.

> *"[The dog fits into our routine] really nicely actually. [chuckles] …You get up, you go to the bathroom, you take the dog out. You eat breakfast and feed the dog. It added an additional step to learn, but it fits into the flow. Right after lunch, take the dog out. Right after school, take the dog out. It was a step that we added but it fit in pretty regularly." (Parent, Dyad 8)*

> *"There are certain activities that we can't include him in, like swimming in a pool but we live two or three blocks from [lake] so there were plenty of days over the summer that we would walk down to the beach and take him off his leash and he swam with us." (Parent, Dyad 1)*

> *"She walks very nicely on a leash, she's a very good listener. She'll literally walk right beside you on the leash." (Parent, Dyad 2)*

> *"He's easy to take with, he's very small. As far as when we go walking, it's mainly on the property here, we don't go too far out." (Parent, Dyad 5)*

Although the ready integration of the dog within the family's routine was a major theme, there was also a minor theme related to challenges. These included added responsibilities, financial concerns, and managing the dog and child's relationship.

> *"Obviously, financially, that's a concern… she just had heart surgery, so that was quite an expense. That was fine. Where we are, it was okay, but it was still an added expense. I can't think of anything else." (Parent, Dyad 6)*

> *"[Having a dog] is a lot of extra life skills as a parent. I don't think I anticipated how much longer it would take [the child] to understand it. That's really the only challenge, is the repetition to get [the child] to understand the process, but that's partly just [child]'s limitations. He's not a multiple-step kiddo. Feeding a dog is sometimes multiple steps, which is hard." (Parent, Dyad 8)*

In terms of children caring for the dog, a major theme among parents was that their children view this as part of a routine and enjoyable. Among the children, a major theme was that taking care of their dog is important because the dog is a part of the family whom they care about. Parents said they help their child, or their child is expected to help them, with feeding, watering, walking, and/or brushing the dog. From the children's perspective, their main responsibility was playing with the dog. Of the ten parent-child dyads, only one child stated that they do not take care of the family dog at all.

> *"[I take care of my dog by] giving her some food, playing outside with her sometimes." (Child, Dyad 6)*

> *"They're responsible for feeding, brushing, walking. When we do a bath, they're responsible for at least helping towel-off afterwards. It's hard for a 10, almost 11-year-old, to do those responsibilities, but it's part of ownership." (Parent, Dyad 8)*

A minor theme among parents was that the dog care responsibilities made their child feel proud and better about themselves.

> *"I think he enjoys [his responsibilities], especially now being home gives him something to do and being responsible. I think it helps him feel better about himself." (Parent, Dyad 4)*

> *"I think [feeding and watering the dog] makes him feel good, but it's also just very normal at this point. Like the same way that he is expected to get himself breakfast, he knows that Enzo needs to eat too. There's a little bit of pride involved, but it's also just part of his routine at this point, which is a big thing for him." (Parent, Dyad 1)*

3.2.3. Domain 3: eating and physical activity for the child and their dog

A major theme among children was that good nutrition and physical activity are very important for the family dog.

> *"Yes, [it's important for Bailey to eat healthy foods]. A dog's health is one of the most important things when it comes to pet care." (Child, Dyad 9)*

> *"[It's important for my dog to exercise] because he needs to have big, strong dog bones to be healthy so he could become an even better boy and take over the world." (Child, Dyad 7)*

> *"I think it's important for him to get exercise. Like I said, he needs it to develop his growth. I can tell you he also really enjoys it. It helps build up him wanting to be outside more and more." (Child, Dyad 1)*

Children also felt that healthy eating is important for themselves because it keeps their body healthy.

> *"When it comes to my condition, I see [healthy eating] as a very important thing because nutrition is one of the most essential things when it comes to growth of the body and enhancement of your internal systems." (Child, Dyad 9)*

> *"Yes, [it's important to eat foods that are good for me]. It helps my body stay healthy" (Child, Dyad 5)*

However, children generally did not enjoy eating healthy foods as much as they felt it was important. Among parents, a major theme was that the healthfulness of their child's diet was good but could be better. Introducing new foods and textures and getting their child to choose healthy foods on their own was a common challenge. When asked about how the pandemic may have impacted eating habits, a minor theme was that the children's food intake increased due to a lack of structured school mealtimes and being at home.

Similar to the theme around eating healthfully, a major theme related to physical activity for children was that it is important because it keeps them healthy and helps them grow.

> *"For me, [exercise] is really important because if a human doesn't get exercised, then, as I said, their muscles could get really weak." (Child, Dyad 10)*

Children and parents described a range of physical activities that children engaged in, which commonly included bike riding and playing outside. When asked about the impact of the pandemic, families were divided between those reporting that their child got less physical activity due to the lack of structured activity at school and being inside more often, and those saying their child increased their physical activity because of being at home more and making an extra effort to get moving. A minor theme was that physical activity is unpleasant: some children said it makes them tired, they would rather be doing other things, they are not good at it, or they simply do not like it. Parent perceptions were generally consistent with their children's. A minor theme among parents was that their children enjoy exercise but need some encouragement to participate.

> *"If something naturally incorporates exercise, he loves it. If you make something to him look like and sound like exercise, he doesn't want to do it, but if you have the same exact activity but call it a relay race or call it an obstacle course, he's all about it." (Parent, Dyad 10)*

Parents and children were asked to provide their thoughts about programming that would incorporate the family dog to help teach children about nutrition and physical activity. Children were asked whether they would be interested in learning more about nutrition and physical activity for their dogs, since the potential program would be designed to introduce nutrition and physical activity-related concepts through the lens of the dog's health. A major theme was that children were interested in learning more, either from their parents or by practicing or reading about it. For the few children who were not interested, reasons were that the children are not primary caretakers of the dog, or the child felt that their dog is in a good place regarding healthy eating and exercise.

> *"I think maybe [learning more about how to feed Bailey healthy foods] is something important. That actually sounds interesting. I'll go with that. I care about her as much as anyone else." (Child, Dyad 9)*

> *"Yes, [I would like to learn more about how to feed Cooper healthy foods]. I would like to learn what dogs eat and how much food you should give a little dog. (Child, Dyad 10)*

> *"[I'm] not exactly [interested in learning more about how to feed my dog healthy foods] because I don't exactly care for him that much." (Child, Dyad 7)*

It was similarly a major theme among parents that they liked the idea of this type of program. Many couldn't think of any potential drawbacks, and some felt that it would also teach their child about responsibility. The parents whose child had an Applied Behavior Analysis (ABA) therapist liked the idea of the therapist implementing the program.

> *"Right now, [doing the program] would be hard because it's over Zoom and she's [ABA therapist] not in person but the benefits would be great. They would really teach him responsibility and self-confidence and self-esteem." (Parent, Dyad 3)*

> *"[The benefits of the ABA therapist doing the program is], it's not mom and dad. It's not the primary caregiver. It's not someone else asking them almost like a chore. It's a, "Hey, let's try." It becomes a game and fun and something a little more treat-based or exciting-based for them because it*

> *wouldn't be mom or dad or aunt or uncle, grandma, grandpa, whoever they're living with." (Parent, Dyad 8)*

Although reaction to the program was largely positive, parents expressed some concerns about implementation. For parents with an ABA therapist, there was some concern about the relationship between the therapist and the dog: the therapist would need to feel comfortable and would also need to understand how to best care for the dogs' needs as well as the children's. Some parents without an ABA therapist perceived the potential for the program to be overwhelming if they were the ones implementing it. Parents offered advice on program development, such as making sure that parents had information on the goals of the program as well as finding a way to make the program specific to each child but also generalizable.

> *"[Information I want as a parent] is specific ideas on exactly what we should be doing. Tell me specifically what you want me to do. I just think it's so hard sometimes to come up with– If you're trying to incorporate nutrition and exercise with kids and how that works with the dog, just tell me what should I be doing. You want me to go outside with them? Do you want me to do this activity? Maybe some ideas. Give me some activities that you want me to try, and how do I incorporate the nutrition aspect with the dog? That's a little bit confusing to me." (Parent, Dyad 7)*

> *"[I want] those step-by-step instructions so I can learn more information about it." (Parent, Dyad 4)*

> *"The more information that you guys could give to the family about how this can benefit the family as a whole, I think would probably be good information to have." (Parent, Dyad 10)*

4. Discussion

Findings from our qualitative study suggests a positive role that pet dogs have for families with an autistic child. Children enjoy the bond with their dog and the dog's affection and attention while parents value how the dog integrates well into family life. Leveraging this relationship and the unique role of pet dogs in the family may be a promising approach to improving nutrition and physical activity among children with autism, and findings suggest several ways an AAI might be implemented.

Our findings suggest that an AAI that incorporates pet dogs to teach children about nutrition and physical activity is likely to be feasible and appropriate, at least in some families. While a pet dog could potentially introduce additional responsibilities and burden to families with an autistic child, a major theme was that pet dogs are a typical part of the family's routine and their dog's schedule fits well with the family's. Parents said that it was relatively easy to align the family schedule with the dog's, and that they often prioritized activities that could include the dog. Similarly, several studies have found that pet dogs have a positive impact on parent stress and family functioning in families with an autistic child (23–25), lending support to the appropriateness of an AAI. However, the minor theme related to challenges of having a dog are consistent with Carlisle et al. (26), in which they identified time and cost of care as challenges related to dog ownership. In implementing an AAI, it may be important to consider the strain that the dog may already be adding to some families.

Our findings related to the child-dog relationship is consistent with other literature and further suggests the appropriateness of an AAI that incorporates the pet dog. Studies with typically developing children have similarly found that children have a strong bond with the family pet (27). While there is scant literature on the relationship between autistic children and their pets, our findings are consistent with four studies in which parents also reported children's strong bonds with their pets, including dogs (26, 28–30). In one study, however, children who had lived with a pet (dogs, cats, or rodents) since birth demonstrated less bonding than children who acquired one later (31). In terms of an AAI, the children's concern for the dog's health could provide a strong motivator for participation in such a program. The strong bond with pet dogs could also offer an avenue to indirectly model healthy eating and physical activity behaviors for their child companions. However, this approach may not be feasible for children who feel less connected to or responsible for their dog's health and well-being. Some parents in our study also identified a need to manage the relationship between the dog and the child as a challenge; problematic behaviors such as meltdowns and invasion of the dog's personal space have been noted in other studies as well (29, 32). In considering an AAI involving the family dog, it will be critical to consider the relationship between the child and the dog, including any history of negative interactions, to ensure the safety of both. It is also important to consider the temperament and needs of the pet dog to help ensure that an AAI is a good fit and safe for both the child and the dog. As in our study, other studies indicate that it is common for autistic children to be responsible for some aspects of the care of their pets (26, 30, 31). Although not conclusive, some evidence suggests that taking responsibility for pets could increase social functioning (31) and decrease depressive symptoms (30). In terms of developing an AAI, children's involvement with their dog's care, including feeding and walking, could provide an opportunity for lessons about nutrition and physical activity for both dogs and humans.

Most parents liked the idea of a dog-assisted nutrition and physical activity intervention for their child, but some were concerned about time constraints and possibly feeling overwhelmed if they were to implement it themselves. In contrast, parents liked the idea of an ABA therapist delivering the program. A program delivered by ABA therapists could be beneficial if a standardized program is integrated into therapists' typical workflows. This integration could allow for nationwide dissemination and impact among families with children with autism. However, factors to consider are the uniqueness of each family and the skill and comfort level of the ABA therapist, who would need to address safety for both the child and the dog.

This study helps address a lack of literature on the role of the pet dog in a family with an autistic child. It also provides information to help assess the appropriateness of an AAI on nutrition and physical activity that incorporates pet dogs and to help shape what such an AAI might entail. The study team included a comprehensive range of expertise relevant to the study question. It also included members with lived experience, both on the study team and in the stakeholder panel that helped inform the work. Another strength of the study was the inclusion of both children and parents. Most qualitative studies have relied solely on parents to provide their own and their children's perspectives (33). The sample size is deliberately small in this qualitative study as we sought to gain in-depth insights. We also achieved code saturation (22), suggesting the robustness of themes among the voices included in our sample. The sample included perspectives from families in several U.S. states, as well as a range of voices in terms of child age and family structure and socio-economic status. The gender identities of the children are reflective of the ASD population (34, 35). However, the sample was limited to the inclusion of mothers only. Fathers of autistic children have been underrepresented in the literature and their perspectives may be different. The sample was homogeneous in terms of race/ethnicity and therefore not reflective of the general population of families with autistic children in this way (34). Future studies are needed to gain perspectives from participants that more fully represent the ASD population. The study sample was limited to children with the verbal skills to participate in the interview and who did not have an intellectual disability. The inclusion of children with more significant verbal communication challenges would have required adaptations to the qualitative methodology that was beyond the resources of this study. However, it will be important to work toward adapting the methodology so that a greater range of stakeholders may be included in future work. In this study, we also chose to limit the sample to children for whom the type of AAI being proposed would be most appropriate. Future work may consider how to develop an AAI to promote healthy eating and physical activity for a broader range of autistic children, although it may be appropriate to involve other types of animals or trained therapy dogs rather than pet dogs. Another limitation of this study is that by nature of the interview topic, our sample may be biased toward families that were more likely to have had positive experiences with the family dog in the context of nurturing the growth and development of an autistic child. It is important to note that a nutrition and physical activity AAI may be appropriate and feasible when a pet dog is already well-integrated into the family and the child has bonded well with the dog. It would not necessarily be advisable to incorporate a new dog into families for the purpose of such an AAI, especially if the autistic child exhibited aggressive behaviors toward or a dislike of animals, or if a pet dog would pose a greater burden to the family.

This study contributes an understanding of the experiences of autistic children and their families with respect to dog ownership and the potential mechanisms through which an AAI on nutrition and physical activity that incorporates pet dogs might work. Findings lend support to the potential of incorporating the family dog into an AAI, an approach that is potentially more accessible and sustainable than AAIs that use therapy animals. Future studies may build on this foundation to develop and test AAIs for obesity prevention among autistic children.

Data availability statement

The datasets presented in this article are not readily available because raw data may not be shared outside of the research team per IRB. Requests to access the datasets should be directed to sara.folta@tufts.edu.

Ethics statement

This study was approved by the Tufts University Social, Behavioral and Educational Research Institutional Review Board. Parents provided verbal informed consent for themselves and their child prior to the interviews. Child assent was obtained verbally prior to each child interview.

Author contributions

All authors contributed to the conceptualization of the study and the interpretation of findings. JA and SF collected and analyzed the data. All authors contributed to the article and approved the submitted version.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Publisher's note

Supplementary material

The Supplementary Material for this article can be found online at: https://www.frontiersin.org/articles/10.3389/fped.2023.1153124/full#supplementary-material

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Energy expenditure and weight-related behaviors in youth with Down syndrome: a protocol

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Background: The consequences of obesity are ominous, yet healthcare professionals are not adequately preventing or treating obesity in youth with Down syndrome (DS). Total daily energy expenditure (TDEE) is the energy expended in 24 h through physical activity and life-sustaining physiologic processes. An individual's TDEE is essential for determining the daily caloric intake needed to maintain or change body weight. Successful prevention and treatment of obesity in youth with DS is severely compromised by the lack of data on TDEE and information on weight-related behaviors for this high-risk population. This manuscript describes the protocol for the federally funded study that is in process to determine daily energy expenditure in a large cohort of children with DS.

Methods: This observational cross-sectional study will include a national sample of 230 youth with DS, stratified by age (5–11 and 12–18 years of age) and sex. Doubly Labeled Water analysis will provide the criterion body fat%, fat-free mass, and TDEE. To increase accessibility and decrease the burden on participants, the entire study, including obtaining consent and data collection, is conducted virtually within the participant's home environment on weekdays and weekends. The study team supervises all data collection via a video conferencing platform, e.g., Zoom. This study will (1) examine and determine average TDEE based on age and sex, (2) develop a prediction equation based on measured TDEE to predict energy requirements with a best-fit model based on fat-free mass, sex, age, and height and/or weight, and (3) use 24-hour dietary recalls, a nutrition and physical activity screener, wearable devices, and sleep questionnaire to describe the patterns and quality of dietary intake, sleep, and physical activity status in youth with DS.

Discussion: The lack of accurate information on energy expenditure and weight-related behaviors in youth with DS significantly impedes the successful prevention and treatment of obesity for this vulnerable population. The findings of this study will provide a further understanding of weight-related behaviors as obesity risk factors, currently not well understood for this population. This study will advance the science of weight management in individuals with disabilities and shift clinical practice paradigms.

KEYWORDS

Down syndrome, trisomy 21 (Down syndrome), nutrition, physical activity, energy expenditure, obesity, doubly labeled water (DLW), wearable devices

Introduction

The consequences of obesity are ominous, yet we are not adequately preventing or treating obesity in youth with Down syndrome (DS), who have a dramatically higher obesity prevalence (reported as high as 62.5%) (1) compared to their typically developing peers (18.5%) (2). Obesity is associated with life-long medical, economic, and psychological burdens which worsen with earlier age of onset (3–5). In children with disabilities, obesity limits independence, decreases the ability to self-manage health, increases the risk of social isolation, and is a barrier to caregivers' abilities to provide care (6, 7). In DS, obesity is linked to adverse health outcomes such as obstructive sleep apnea, dyslipidemia, hyperinsulinemia, impaired cardiorespiratory fitness, and orthopedic complications (1, 6–14). With dramatic increases in life expectancy for individuals with DS, it is imperative to ensure that they enter their adult years with optimal health (15). To address obesity in youth with disabilities, the National Institute of Child Health and Human Development (NICHD) expert panel's research agenda prioritized (1) addressing the need for accurate data on energy expenditure and (2) identifying and understanding weight-related behaviors as obesity determinants to inform potential interventions (16).

Obesity in youth often continues into adulthood impacting morbidity and mortality (17, 18). In the simplest terms, obesity is an outcome of an imbalance of excess energy intake as compared to energy expended (physical activity and physiologic processes) described for a 24-hour period as total daily energy expenditure (TDEE) (19). Characteristics inherent or related to DS (e.g., hypotonia, decreased fat-free mass, hypothyroidism, leptin resistance, less participation in physical activity) are associated with decreased TDEE (1, 12, 16, 20–24). These factors contribute to a lower level of energy expenditure resulting in a reduced caloric need and consequently increased risk of inadvertent overfeeding and subsequent weight gain (25). In addition, individuals and parents often overestimate the amount of energy expended through physical and sedentary activity further adding to unintentional excess intake (26–30). Growth retardation, decreased height velocity and muscle hypoplasia can further exacerbate the high percentage of body fat and can be accentuated with the youth's advancing age (1).

An individual's TDEE is essential for determining the energy intake required to maintain or change body weight (31) and is the foundation of anticipatory guidance provided by healthcare professionals to optimize growth and weight management. Specifically, the very limited data on the energy needs of youth with DS does not allow accurate recommendations for dietary intake (32). Successful prevention and treatment of obesity in youth with DS is severely compromised by the lack of data on TDEE and an understanding of weight-related behaviors.

Behaviors that contribute to obesity often begin in childhood or adolescent years (33). The onset of obesity in youth often continues into adulthood (17, 18, 34). Limitations in the current literature include a distinct void of inclusion of individuals with DS in weight-related research (23, 35). When individuals with disabilities are the focus of the study, limited studies have used "state-of-the-art measurement techniques" [i.e., doubly labeled water (DLW)] (24). While preliminary studies providing support for youth with developmental disabilities having poor quality diets, increased screen time, and needing less caloric intake per day are present, they are limited and recommend further study in larger samples (1, 16, 20, 23, 24, 36–38). Focusing on the prevention and treatment of obesity in youth with DS is a national priority (16, 39).

This study focuses on youth with DS and was a competitively reviewed supplement to our currently funded Body Composition and Energy Expenditure in Youth with Spina Bifida (R01HD096085). While the protocol is similar to the initial R01 aim addressing TDEE in children with spina bifida (SB), this protocol differs in the population of interest and specifics of the design, specifically the setting, recruitment, methods of data collection, and addition of DS-focused measures.

This protocol addresses gaps and weaknesses of prior research in this cohort as it pertains to establishing caloric need. This study will systematically investigate TDEE and develop an algorithm for use in youth with DS as stratified by age and sex to predict energy requirements. As a result, recommendations of daily caloric intake will be established. The second outcome will be information related to obesity determinants (i.e., dietary intake, sleep, and activity) in youth with DS.

The study aims are:

Aim 1. Using DLW, measure TDEE and develop a prediction equation for the energy requirements of youth with DS. We propose to: (a) Examine and describe average TDEE stratified by age and sex and (b) Develop a prediction equation based on actual TDEE to predict energy requirements with a best-fit model based on fat-free mass, sex, age, and height and/or weight.

TABLE 1 Sample stratification.

Sample stratification (*n*)		
N = 230	Male	Female
5–11 years	57	57
12–18 years	58	58

Aim 2. Using 24-hour dietary recalls, a nutrition and physical activity screener, accelerometers, activity trackers, and a sleep questionnaire, describe the patterns and quality of dietary intake and sleep, and duration and frequency of activity (physical and sedentary) in youth with DS.

Methods

Design and participants

This observational, cross-sectional study will include a national sample of 230 youth with DS, stratified by age group (5–11 and 12–18 years of age) and biological sex (**Table 1**). The study protocol is approved by the Western Copernicus Group (WCG) Institutional Review Board (IRB) (#20214186) and acknowledged by the local IRB of the Principal Investigator (PI).

Pilot study

This application was supported by our pilot study (P20NR015339 and UL1TR000055) that confirmed the feasibility of measurement of energy expenditure with DLW in youth with DS, SB, and without disabilities. In this small sample, TDEE was significantly lower in youth with disabilities. When matched for fat-free mass, TDEE in youth with DS averaged 500 fewer calories per day to balance their caloric intake compared to youth without disabilities (32).

Setting

The proposed study is conducted virtually with consent, data collection, and testing occurring within the participant's home environment via a HIPAA-compliant video conferencing platform. The decision to conduct the study virtually was done to minimize the study burden and to increase accessibility for participants to join from anywhere in the lower 48 United States. Hawaii and Alaska were excluded due to shipping costs.

Coordinating sites

This study is coordinated through the two agencies where the PI holds a joint appointment as the Joint Research Chair in the Nursing of Children, Children's Wisconsin, a free-standing Children's Hospital, and the University of Wisconsin—Milwaukee College of Nursing, both located in Milwaukee Wisconsin. The coordination center for assembling study kits, shipping, receiving, and sterilizing supplies, and processing and storing samples is through the Pediatric Translational Research Unit (PTRU) located within Children's Wisconsin. Accelerometer and activity tracker analysis is completed at the Department of Rehabilitation Science and Technology at the University of Pittsburgh and DLW is supplied and analyzed through the Isotope Ratio Mass Spectrometry (IRMS) lab of the University of Wisconsin—Madison.

Recruitment, screening, and consent

Primary recruitment strategies include the use of the National Institutes of Health (NIH) DS-Connect®, a national registry that connects individuals with DS and their families to research and healthcare providers. Once a study is reviewed and approved by the registry, the study description is shared with registry participants who meet inclusion and exclusion criteria (**Table 2**). In addition, the study is shared with family-focused DS organizations and their associated social media sites, specifically targeting organizations that have a diverse focus, and the use of snowball recruitment is incorporated. Through each of these recruitment methods, the interest in participating in the study is participant-driven to allow them to make an informed decision to participate.

Potential participants who are interested contact the study team through email or phone. A member of the study team meets with the potential participant via HIPAA-compliant video conferencing platform to review the study details, answer questions, screen for eligibility, and share additional study materials with them (e.g., a pictorial orientation booklet that provides a broad overview of the study protocol in an easy-to-read, child-friendly format). This allows the families to further consider and discuss as a family unit while making an informed decision to participate. If eligibility is confirmed and interest in the study remains, the team member performs the consenting/assenting (hereafter, consenting) process.

Consenting occurs via HIPAA-compliant video conferencing platform. This assists in ensuring the family's capabilities of using the virtual platform, and having sufficient Wi-Fi, and allows the consenting process to occur while seeing faces and/or body language to assist in confirmation of understanding and initiating the researcher-participant relationship that is helpful in the successful completion of the study. The study meets the requirements for a waiver of documentation of written consent under 45 CFR 46.117(c)(21)(ii). The consent forms are reviewed with the parent or legally authorized representative (LAR) by a Collaborative Institutional Training Initiative (CITI)-trained study team member. Due to the varying degrees of cognitive delays that may limit the ability to assent the IRB approved a waiver of assent. However, the study team member works with the parent/LAR to assess if the child is able to give verbal assent based on their maturity, psychological state, and cognitive ability on a case-by-case basis. While waiver of written documentation is present, all families are provided with a copy of the consent form for their records. All consents are professionally translated into Spanish. A data collector fluent in Spanish is employed for any families that primarily speak Spanish.

TABLE 2 Inclusion and exclusion criteria and rationale.

Inclusion criteria
Youth between the ages of 5–18 years old diagnosed with Down syndrome • Down syndrome is the focus of the study and ages 5–18 include youth during active growth and development when habits are being formed and there is a higher likelihood of being toilet trained and able to follow instructions with a parent or legally authorized representative (LAR) assistance.
Individuals who are English or Spanish speaking • Language study team has fluency in or access to a translator.
Access to Wi-Fi and basic capabilities with technology • Required for study completion.
Reside in the continental or lower 48 states of the United States • Hawaii and Alaska are excluded due to shipping costs associated with their geographical location.
Enrollment assures an equal split between males and females (115 in each group) • To analyze our data based on sex, as differences in energy expenditure are expected.
Live with a parent or LAR who is able to read/write/speak English or Spanish • Parent or LAR status and ability to read/write/speak English or Spanish are necessary for understanding the study materials and completion of the study protocol.
Exclusion criteria
Traveling >200 miles the week before or during the study protocol • Traveling >200 miles outside of the participant's primary residence during the protocol can impact the Doubly Labeled Water (DLW) results due to a shift in the natural abundances of the added isotopes (2H and 18O) in drinking water that varies per geographical region (40, 41).
Uses supplemental oxygen • The use of supplemental oxygen impacts the accuracy of one or more study measures.
Have medical restriction(s) to a 6-h fast • A minimum of a 6-h fast is recommended for the DLW test. For this reason, morning appointments will be recommended, and an approved snack will be offered to the participant early in the study protocol after baseline urine samples are completed.
Underwent a blood transfusion or IV infusion of >500 ml of IV fluids the week prior to the test date or are expecting to have during the study protocol • A blood or IV infusion >500 ml will negatively impact the accuracy of one or more study measures.
Are pregnant • Being pregnant will negatively impact the accuracy of one or more study measures.
Uses a g-tube for nutritional intake • The use of a g-tube for nutrition will provide atypical results for the dietary intake assessment.
Unable to stand independently or safely • The inability to stand independently or safely will interfere with the assessment of a standing height and performance of aspects of the study protocol.
Has an active viral or bacterial illness on the first day of testing • Having an active illness during data collection can impact the participant's hydration status, nutritional intake, and physical activity level.

Upon informed consent completion, the study visit is scheduled. To accommodate families' schedules, weekday and weekend visits are available, preferably close to when the child wakes up due to early fasting requirements. Drinking up to 8 ounces of water and using a spoonful of yogurt or food for medication intake is acceptable if needed.

Study procedures

The study includes an 8-day protocol that is conducted virtually within the family's home with a trained study team member working with the family via a HIPAA-compliant video conferencing platform, phone (call and text), and email communication. See Table 3 for a detailed study protocol and Figure 1 for a timeline of the study protocol. Once consenting has been completed, the parent/LAR is asked to provide an estimate of the child's weight (to dose DLW), share their home address to send supplies, and schedule their visit (Day 0). This initial data collection visit is estimated to last 4.5 h but it is recommended that 5 h be scheduled in case of unforeseen issues. Prior to the scheduled visit date, two boxes are shipped to the family home that includes the supplies needed to execute the study protocol. All materials are clearly marked, color-coded, and have an easy-to-read family-friendly procedure manual with them.

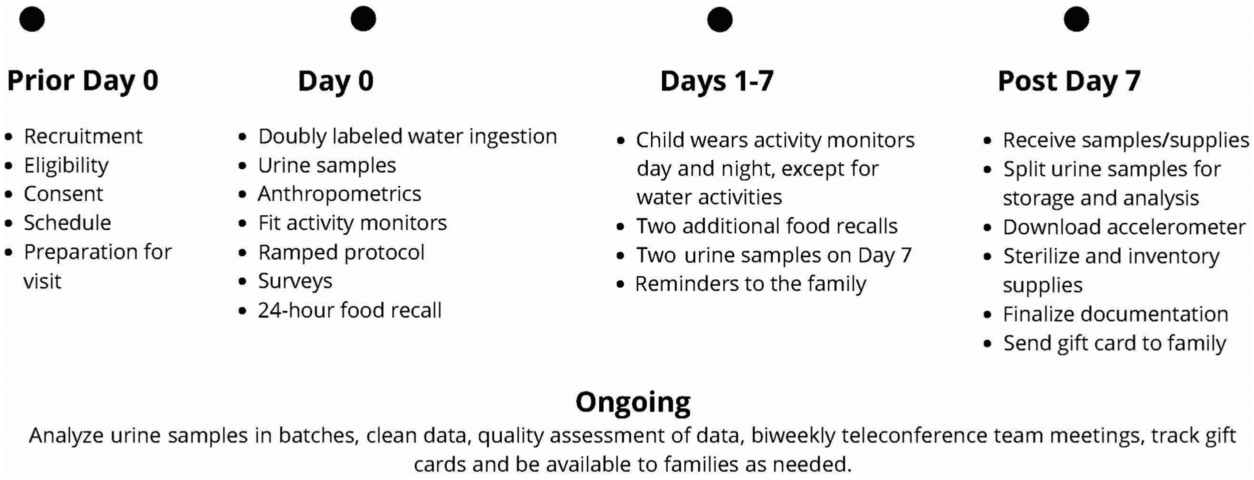
Box 1 includes supplies for measurement and assessment (portable scale for body weight, portable stadiometer, flexible tape measure, accelerometer, activity tracker, iPad for questionnaires, urine collection supplies (e.g., urine hats, urine cups, double bag, absorbent materials, preprinted labels, and parafilm), measuring cups, calorie-controlled snack, and paperwork. Box 2 is insulated and includes the DLW dose, shipping materials for returning urine samples and items used past Day 0 (accelerometer, activity tracker, ice packs). The week before the study visit, the family meets with a study team member to review fasting requirements, study kit materials, and the plan for the study visit including the collection of a baseline urine sample using the child's first-morning urine and refrigeration of DLW for taste purposes. In addition, written instructions, and materials for collecting urine samples as well as gloves and storage materials are provided. This allows the family to collect the baseline urine sample upon the child's waking but before the start of the virtual meeting depending on the start time of the visit.

TABLE 3 Study protocol overview.

<table>
<tr><th colspan="2">Prior to Day 0</th></tr>
<tr><td>Recruitment and consent</td><td>Recruit participants and consent/assent via virtual platform, e.g., Zoom. This will also confirm participants' Wi-Fi availability and ability to use computerized technology and address any concerns prior to data collection.</td></tr>
<tr><td>Preparation</td><td>Schedule study visit. Mail study supplies to the family. The week of the visit, meet with the family to confirm Day 0 virtual visit date and time, fasting requirements, no active illness, review supplies, and baseline urine collection.</td></tr>
<tr><th colspan="2">Day 0 (5-h virtual visit)</th></tr>
<tr><td colspan="2">DLW and urine collection
• Obtain body weight.
• Obtain pre-DLW baseline urine sample—timed and stored. This may be done with the first morning urine upon the child waking or during the start of the visit.
• Provide DLW based on body weight followed by 50 ml drinking water to ensure DLW dose is consumed.
• Obtain post-DLW consumption urine samples at hour 1 (discard), hour 3 (time and store), and hour 4 (time and store) after DLW is consumed.
Anthropometric measures (between urine collections)
• Standing height (with portable stadiometer).
• Waist, hip, and neck circumference with a flexible tape measure.
• Ramped protocol of perceived exertion while wearing an accelerometer.
Snack (between hour 1 urine and hour 3 urine)
• After hour 1 urine and before hour 3 urine sample, provide snack option (sent in study kit based on participant preference and caloric limitation).
Surveys (between urine collections)
• Parents/LAR to complete all instruments with child assistance as needed.
• All participants will complete Demographics, Block Food Screener, Child Habits Sleep Questionnaire, Autism Rating Scale, PEDI-CAT, PROMIS Peer Relations, Tanner stage, and a 24-hour dietary recall.
• Youth ages 8 and above: Block Kids Physical Activity Screener.
Prior to the end of the appointment
• Confirm correct labels and review storing the urine samples collected in the refrigerator.
• Review the sleep/monitor wear log to be completed for the 7 days.
• Instruct on continuously wearing the accelerometer and activity tracker for the 7-day study protocol except for water activities.
• Schedule the two additional 24-hour dietary recalls being performed over the 7-day study protocol.
After the end of the appointment
• Input study information in the REDCap database.</td></tr>
<tr><th colspan="2">Days 1–7</th></tr>
<tr><td colspan="2">• Complete the two additional virtual visit 24-hour dietary recalls for a total of 2 weekdays and 1 weekend day per dates chosen by participant/parent/LAR.
• Review and remind the family of the day 7 process of collecting two urine samples (1 h apart).
• Instruct families to ship back urine samples and wearable devices on Monday, Tuesday, or Wednesday.
• Provide reminders and periodic check-ins via phone and/or text and be available for family questions as needed.</td></tr>
<tr><th colspan="2">Post receipt of urine samples and supplies</th></tr>
<tr><td colspan="2">• Upon receipt of participant urine samples (Day 0 baseline, hour 3, hour 4, and day 7 hour 1 and hour 2), split all samples into two 5 ml cryotubes and freeze at −20°C. (One stays at PTRU for quality assurance, and one is mailed to IRMS Lab in Madison, Wisconsin in batches for analysis.).
• Download accelerometer data, reset activity tracker and charge the devices for the next participant.
• Sterilize and inventory all supplies.
• Finalize participant information in the REDCap database
• Email or mail gift cards to the family.</td></tr>
<tr><th colspan="2">Ongoing</th></tr>
<tr><td colspan="2">• Mail frozen urine samples (from each participant) to IRMS lab at UW-Madison.
• Store the backup frozen samples (5 ml tube) within the pediatric research unit at −20°C.
• Participate in biweekly and as-needed teleconference team meetings.
• Clean and perform quality checks of the REDCap database.
• Track gift cards.</td></tr>
</table>

On Day 0, a study team member connects via a video conferencing platform with the participant and a minimum of one parent/LAR. The child's fasting status and lack of any active illness are confirmed. If the family has not already collected a baseline urine sample, they are asked to collect this sample with the team member's guidance at the start of the visit. If they did collect the sample, confirmation of proper collection and timing of the sample is obtained. The parent/LAR is asked to obtain the child's body weight with excess clothing removed on the SECA 813 portable scale provided. The research assistant uses this weight to confirm that the dose of DLW is appropriate for the child's weight. If the DLW is spilled, the protocol would be stopped, the visit would be rescheduled with a new dose of DLW shipped and the baseline urine will be stored and analyzed. If the wrong dose was given and it is smaller than planned, the center staff calls the IRMS lab to discuss options.

The child drinks the DLW from the provided bottle and straw as spillage reduces accuracy. After the child drinks the DLW from the bottle that it was sent in, the parent/LAR is asked to add 50 ml of tap or bottled water to the now empty bottle with a provided measuring cup and a marked line identifying 50 ml on the DLW bottle. The child drinks the added water with the same straw used for the



Prior Day 0

- Recruitment
- Eligibility
- Consent
- Schedule
- Preparation for visit

Day 0

- Doubly labeled water ingestion
- Urine samples
- Anthropometrics
- Fit activity monitors
- Ramped protocol
- Surveys
- 24-hour food recall

Days 1-7

- Child wears activity monitors day and night, except for water activities
- Two additional food recalls
- Two urine samples on Day 7
- Reminders to the family

Post Day 7

- Receive samples/supplies
- Split urine samples for storage and analysis
- Download accelerometer
- Sterilize and inventory supplies
- Finalize documentation
- Send gift card to family

Ongoing

Analyze urine samples in batches, clean data, quality assessment of data, biweekly teleconference team meetings, track gift cards and be available to families as needed.

FIGURE 1
Timeline of study protocol.

DLW. This ensures that all DLW is consumed. Three additional urine samples beyond the baseline sample are obtained during the Day 0 visit. At 1 h after the child drinks the DLW, a second urine sample is obtained and discarded to flush the bladder. Two urine samples are collected and saved at 3- and 4 h post DLW consumption. These two samples are labeled with the child's coded identification number, date, and time and stored in the refrigerator. An example would be if the DLW was consumed at 08:15 a.m., the Hour 1 urine sample is obtained at 09:15 a.m. (discarded), the Hour 3 urine at 11:15 a.m., and the Hour 4 urine at 12:15 p.m. (both labeled and refrigerated). If the child is unable to void, the child is asked to try again in 15 min. If still unable to void, 60 ml of drinking water is provided, and the child is asked to try again in 15 min. This continues until the child is able to void. If a urine sample is delayed, the timing of the next urine collection is adjusted based on the actual time of the urine sample. In between the urine sample collection, ample time is available to complete survey instruments and other study measures and to provide the family with downtime to be off camera as needed.

Between the timed urine sample collection, families are guided on the completion of additional measurements including a standing height with the SECA 213 portable stadiometer. A flexible tape measure is used to obtain waist, hip, and neck circumferences. These measures are collected under the guidance of study staff to confirm landmarks and fidelity of the measures. All circumferences are measured three times and the average of the measures is calculated. If an extreme outlier (>3 cm) is obtained, the parent/LAR is asked to obtain an additional measure. The study team member documents all measures in the REDCap database. A study-provided calorie-controlled snack is included in the study box to be available after Hour 1 urine but before Hour 3 urine per DLW protocol. The snack is discussed during consenting to confirm no allergies and preferences of the child. If a family prefers their own snack, confirmation from the study team is needed to ensure that the snack is 250 kcal or less. During this snack time, the child is also offered 8 ounces of water. This supports the collection of the Hour 3 and Hour 4 urine samples. The snack (kcal) and drink (ounces) are documented in the amount and time consumed.

In addition to anthropometric measurements, the family is asked to complete questionnaires and is guided to set up data collection devices and place them on their child. All questionnaires, except the Block Nutrition Screener and Block Physical Activity Screener are provided via REDCap on the study iPad that is provided. The study team member, who is trained in conducting 24-hour dietary recalls, works with the parent/LAR and child if able to assist, to document the child's previous day's intake using a multiple-pass approach. Measuring cups, spoons, and visual aids are included in the supplies for the family to assist in quantification and portion sizes. The final item is conducting a ramped protocol to assess physical activity. This includes the child wearing the study-provided preprogrammed accelerometer (ActiGraph GT3X-BT, ActiGraph LLC, Pensacola, FL, USA) on their waist and the activity tracker (Fitbit Inspire 2, Fitbit, Inc, San Francisco, CA, USA) on their non-dominant wrist. With guidance from the study team, the parent fits each device to their child, activation is confirmed, and the device is time synced. The activity tracker is configured to minimize or remove notifications for the child/family to decrease the risk of altering the child's health habits for the week. The team members guide the child with the parent/LAR's assistance through a ramped protocol divided into five intervals that include the child moving at light, moderate and vigorous activity levels, with perceived exertion reported at each level. The five intervals include (1) obtaining a resting heart rate (3 min), (2) standing, and wiping surfaces for arm movement (3 min), (3) walking at a normal pace (3 min), (4) walking at a fast pace (6 min), and (5) dancing in place (2 min). Between intervals, the child's heart rate must return to baseline before doing the next activity. The child and parent/LAR discuss and provide the child's perceived exertion rate for that interval based on a pictorial perceived exertion chart (42), This allows the study team to individualize the analysis of the activity tracker and accelerometer raw data for the study protocol.

After the Hour 4 urine collection, it is expected that Day 0 study requirements are completed. The study team uses the end of the visit to review the remainder of the protocol including the continued wearing of the accelerometer on the child's waist and the activity tracker on their non-dominant wrist during wake and sleep times but removed during water activities (e.g., bathing, swimming). The benefit of the activity tracker worn with the accelerometer is the continuous recording of heart rate and physical activity information from both research-grade and commercially available wearable devices. The family is provided with a daily wear/sleep log sheet and asked to document when the child goes to bed, wakes up, and is not wearing the accelerometer or activity tracker over the following week. Guidance is also provided to assist the family in repackaging equipment and supplies. Appointment times for two additional 24-hour dietary recalls are set up based on the family's availability to include a total of 2 weekdays and 1 weekend day. The family is asked to continue with their normal daily routine during the protocol. The final action item of the study is the collection of two remaining urine samples a minimum of 1 h apart on Day 7, preferably close to the time of day that Day 0 samples are collected. The study team reviews this during the final food recall and is available to assist the family if needed.

After the study protocol is complete and the final two urine collections are obtained, the parent/LAR is guided to ship the boxes back using a prepaid shipping label. Specific instructions to schedule optional home pick up of the boxes are included to add convenience for the family. The refrigerated urine samples are shipped back using the insulated storage box and frozen gel bags that were provided. The prepaid shipping label for the insulated box that includes urine samples is for overnight shipment and the family is instructed to only ship this box on Monday, Tuesday, or Wednesday of each week to ensure that personnel will be available to accept the shipment. The other supplies in the second box use a prepaid shipping label for ground transportation. Upon receipt of the urine samples and supplies, the family is provided an e-gift card for $250.00 through email. If the family is uncomfortable with the electronic gift card, a physical gift card can be mailed via the United States Postal Service, but a signature will be needed to confirm receipt.

The two boxes are shipped back to the coordination center (i.e., PTRU Children's Wisconsin) where the urine samples are processed, documented, and split into two. One sample is frozen and remains at the PTRU for quality control purposes. The second sample is mailed in batches to the UW-Madison IRMS Lab for analysis. All samples are de-identified and labeled with the time and date of collection and participant study identification number. The remaining equipment and supplies are inventoried, sterilized, and confirmed to be in good working condition.

Measures

Anthropometric measures

To provide contextual support for body composition and risk factors for obesity-related comorbidities the participant's weight, height, waist, hip, and neck circumference are obtained. Circumference measures are repeated three times with the average used for analysis. All measures are obtained by the parent/LAR with direction and guidance provided by the study team during the virtual session. Pictorial directions for measurements are also provided in a family-friendly procedure manual. See **Table 4** for detailed measures and procedures.

DLW variables and calculations

DLW is a valid and reliable tool that provides a measure of body fat and TDEE (43). DLW uses drinking water mixed with two stable isotopes, deuterium (^{2}H) and oxygen-18 (^{18}O) which act as tracers when ingested. DLW is dosed based on the individual's body weight. The analysis is performed on the individual's body fluids (urine) by isotope ratio mass spectrometry to measure the elimination of the tracers over a specific time frame (43). The difference in the rate at which the tracers are eliminated from body water allows for the calculation of carbon dioxide production, a product of energy metabolism that is used to compute TDEE. The added tracers also can be used to calculate the individual's total body water. Based on total body water, fat-free mass and fat mass can be calculated. These equations are typically applied to DLW-derived total body water

TABLE 4 Anthropometric measures (weight, height, and body composition/circumferences).

Measures	Procedural operations
Weight (measured to the nearest 0.1 kg)	
Body weight	Participants remove shoes, extra clothing (jackets, heavy clothing, jewelry), and/or assistive devices and are weighed on a SECA 813 portable scale with an extra wide, non-skid platform.
Height (measured to the nearest 0.1 cm)	
Standing height	Participant removes shoes and/or assistive devices and stands erect with back and heels against a portable SECA 213 stadiometer. The Stadiometer arm is brought to the top of the child's head.
Body composition/circumferences (measured to the nearest 0.1 cm, unless otherwise indicated)	
Waist circumference	Measured with a flexible tape measure at two different landmarks: the umbilicus and immediately above the right iliac crest at the mid-axillary line.
Neck circumference	Measured with a flexible tape measure placed lightly around the neck at the height where a shirt collar would rest. Reminder to not crane the neck or move skin downward.
Hip circumference	Measured with a flexible tape measure at the widest part of the hips.
Doubly labeled water (DLW)	On Day 0, verify a minimum of 6 h of fasting/light fluid ingestion. Approximately 1–3 ounces of DLW (dosed on body weight) is consumed through a straw. After drinking the DLW, 50 ml of drinking water is added to the empty cup and consumed by the child. Urine specimens are collected at baseline (before DLW), hour 1-post-DLW (discarded), 3 (kept), and 4 (kept) and refrigerated. Day 7 parent/LAR collects two additional urine specimens 1 h apart with provided supplies and refrigerates until shipped back to the study team.

TABLE 5 Doubly labeled water variables, calculations, and energy expenditure.

Variables	Calculations and operational definitions
Fat-free mass (FFM)	FFM (kg) = total body water (kg)/Hydration factor of FFM based on child's age & sex (44) FFM is all body components except fat tissue (45). FFM contains 73.2% water in healthy adults, but in children the hydration of FFM is higher (46) and is based on age and sex and is listed in (47).
Fat%	Fat% = 100—[Weight-total body water/Hydration Factor of FFM based on child's age and sex (44)]/weight. The percentage of body weight that is fat. The equation uses the hydration factor of FFM for children (46)
Total body water (TBW)	TBW = [(N_O/1.007) + (N_D/1.043)]/2, where N_i = [(W × A/a) × (ΔDD/ΔBW)]/(1,000)—[cumulative fluid intake (kg)] (43) The water content of the body at birth is 70%–75% but decreases into adulthood. Water (intra and extracellular) is contained exclusively within the fat-free mass (43). The TBW was calculated from the dilution space of oxygen-18 (N_O) and deuterium (N_D) in the body water pool adjusted by the non-aqueous exchange values 1.007 and 1.043 for each isotope, respectively. In the calculation, N_i is the dilution space for each isotope, "W" is the amount of water used to prepare the diluted dose, and "a" is the amount of DLW used in this dilution. "A" is the dose of DLW consumed by the participant, ΔDD is the ^{2}H or ^{18}O enrichment measured in the diluted dose, and "ΔBW" is the plateau enrichment measured in body water on Day 0 (43).
Total energy expenditure (TEE) & TDEE	TEE (kcal/day) = rCO_2 × (1.106 + 3.94/RQ) (48) TEE is the total energy used by our body to maintain life (49) including basal metabolic rate, thermic effect of food, and physical activity (and growth in children) (19). In the TEE calculation, the rate of CO_2 production (rCO_2) is based on the body's elimination of isotopes (rCO_2 = 0.4554 × TBW × [(1.007 × k_O)—(1.043 × k_D)] × 22.26), on which the 22.26 is the gas constant for carbon dioxide in L/mol; and RQ = respiratory quotient estimated from typical diet (48). In our study, TEE is measured over 7 days and TDEE is the 1-day average.

to determine body fat%, an age-related adjustment for chemical maturation of fat-free mass.

While DLW is an objective reference measure of TDEE and valid for body fat%, it is not practical for clinical use due to its high cost, specialized equipment and expertise that is required (43). See **Table 5** for DLW variables and standard calculations.

Weight-related behaviors

Sleep and activity data are collected by an accelerometer and activity tracker that are worn day and evening but removed during water activities. See **Table 6** for physical activity assessment devices.

Instruments

Parent/LAR complete all instruments with child assistance as able. All instruments are available in Spanish and English. See **Table 7** for a detailed description of the instruments.

Retention

To ensure retention, we employ multiple strategies. Our initial strategy is to be clear and transparent as to what participation in the study involves. This allows the family to make an informed decision and be less likely to be surprised by the protocol which could lead to them to withdraw from the study. We also try to remain consistent with the study team member who is interacting with the family to support the building of a relationship and comfort with the study.

The next strategy is to support the family through the study. We provide information to guide the family verbally and in print with easy-to-follow instructions. We are flexible and available for their questions. Examples of being flexible include offering data collection visits on weekday and weekend mornings through early evening hours and accommodating the different time zones. We proactively consider potential concerns the family may have and provide reminders throughout the study. Our team is committed to reducing the study burden and supporting the completion of the protocol.

To accommodate unforeseen scheduling difficulties, we expect and accommodate appointment changes to the best of our ability. During the initial visit, we set up the additional two 24-hour dietary recalls (2 weekdays and 1 weekend day) per the family's schedule.

To support the families' participation in the study, each family is offered a $250 gift card for completing the study protocol. The gift card is not sent to the family until the Day 7 sample collections and supplies are returned and received by the study's coordinating center. The process and requirements for receipt of the gift card are discussed during the consenting process and reiterated during the Day 0 visit, so the family is aware of what to expect.

In summary, retaining study participants to complete the study protocol is enhanced by replicating strategies successfully used in our pilot study and current R01, including (1) the provision for a comprehensive explanation of what the study entails (aided by the pictorial study manual) so the family can make an informed choice to participate, (2) the provision of flexible scheduling options, (3) confirmation of understanding of the study protocol during the consenting process, (4) clear instructions provided verbally and in print, and (5) provision of all materials, clearly marked, that are needed for the collection and the return of the Day 7 urine samples, activity tracker and accelerometer with

TABLE 6 Physical activity monitors.

Monitor	Operational descriptions
ActiGraph GT3X-BT Accelerometer	The ActiGraph Accelerometer GT3X-BT is worn on the waist Days 0–7 during awake and sleep hours and removed during water activities (e.g., swimming, bathing) to measure activity and sleep. Parents/LAR will record the time when the child goes to bed and wakes (estimated) using a daily log sheet. Raw data at 30 Hz will be collected and converted to counts for analysis. During Day 0, participants will be guided by the study team to complete a ramped protocol based on the individual's self-reported perceived exertion at baseline, light, moderate and vigorous intensity levels aided by a validated pictorial perceived exertion chart (42).
Fitbit Inspire 2 Activity Tracker	The Inspire 2 Fitbit is worn on the non-dominant wrist on Days 0–7 to provide a second-level heart rate measurement and a second objective measure of sleep and sleep quality (e.g., total sleep time, sleep efficiency, wake after sleep onset, sleep onset, and sleep offset).

TABLE 7 Instruments.

Variable	Measure
Pubertal status	Parent report based on a pictorial and written definition of Tanner stages 1–5 (development of external genitalia for males and breast development for females). Tanner stage 1 = pre-pubertal and stages 2–5 = pubertal. The purpose of this study is not the specificity of the stage, but to discern pre-pubertal vs. pubertal. Parent report of youth was valid when compared to healthcare provider assessment [$r = .75$ to $r = .87$ ($p \le .001$, $k = .13–.55$)] (50).
Nutrition	Block Food Screeners for ages 2-17-2007 (51). This 41-item screening instrument assesses intake by food group by amount [3-point scale] and frequency [6—point scale] consumed in the last 7 days. When compared to 24-h dietary recalls, they were correlated between 0.526 for vegetables to 0.878 for potatoes. Bland-Altman plots indicated no systematic difference between the two based on food groups (52). Approximately 10–12 min to complete (51).
Function	PEDI-CAT (53). The Pediatric Evaluation of Disability Inventory Computer Adaptive Test measures abilities in ages 2–21 in four functional domains: daily activities, mobility, social/cognitive, and a responsibility domain. Uses Item Response Theory statistical model to estimate the ability from a minimal number of most relevant items. Positive reliability (ICC = 0.96–0.99) and discriminant validity between children with and without disabilities ($p < .0001$). Mean completion time of 12.66 min (SD = 4.47) (54).
Physical and sedentary activity	Block Kids Physical Activity Screener for ages 8-17-2003 (51). This 9-item tool assesses the frequency (6-point scale) and duration (4-point scale) of physical and sedentary activity in the last 7 days. When used to estimate kcals based on weight, age, intensity, frequency, and duration in 48 children against an accelerometer, partial correlations (controlling for age and weight) were significant ($r = 0.56$, $p < .0001$) (55). *Without a validated measure of physical activity for youth with disabilities, this instrument will provide additional context surrounding activity. Accelerometers will provide an objective measure of activity. Approximately 5 min to complete (51).
Child sleep habits questionnaire (CSHQ)	CSHQ (56) will be used with a sleep log and yields eight subscales, six of which are of interest in the current study: bedtime resistance, sleep onset delay, sleep duration, sleep anxiety, night awakenings, and daytime sleepiness. The retrospective questionnaire comprises 45 items; each is scored *usually* (1), *sometimes* (2), or *rarely* (3), and the parent indicates whether the sleep habit *is a problem (yes/no)*. The instrument has good internal consistency, reliability, and validity (57) and has been used successfully in children with developmental disabilities (58). We will calculate a global sleep problems score, and secondarily assess usual sleep latency and the number of awakenings. Approximately 10 min to complete (56).
Demographic form	Youth: age (month/year), ethnicity, sex, level of education, participation in an Individual Education Plan, and concurrent diagnoses. Parent/LAR: age, sex, marital status, relation to the child, family income, education, insurance, ethnicity, ZIP Code of residence, and work status. Approximately 5–10 min to complete.
Autism spectrum rating scale - ASRS (short form)	The ASRS (59) is a standardized, norm-referenced 15-item assessment that is available in English and Spanish and is a parent report measure designed to assess behaviors associated with autism spectrum disorder in children ages 2–18 years. The form includes a scale to assess behavioral rigidity, which we will use for the proposed study. Test-retest reliability ranges from .78 to .92 for the Total score and from .70 to .92 for the subscales. Internal consistency is high, ranging from .77 to .97; validity is also high. On average, the scales accurately predict group membership, with a mean overall correct classification rate of 92.1% (59). The ASRS subscale, behavioral rigidity, will be used to interpret patterns and quality of dietary intake. Approximately 5 min to complete.
24-hour dietary recall	A total of three (2 weekdays and 1 weekend day) multiple-pass 24-hour dietary recalls are conducted with the participant and parent/LAR during the study protocol. Days following an atypical event will be avoided. Recalls will be conducted via the virtual platform for the previous day's intake and adjunct supplies are provided to families (measuring spoons, cups, and a pictorial sheet on portions) to assist them in their accuracy of describing portion sizes. Estimated time per recall 30 min or less.
Parent-proxy peer relations	A validated PROMIS questionnaire that includes 7 questions related to the child's peer relationships answered by the parent/LAR with a five-point scale of never to almost always.

mailing supplies provided, and (6) touchpoints or interactions with the family during the study protocol to increase opportunities for questions, the reiteration of directions, and building of relationships with the family. To assist the family with the Day 7 urine collection, we call and/or text them on Day 5 and/or 6 to remind them of the final urine collection, review instructions, and answer questions.

While we do not anticipate challenges with retention based on the above strategies and our previous success, if we begin to have problems with retention, we will ask the families if they were willing to share what the challenges are and what led to their decision to not complete the study. Dealing with challenges early in the process allows us to make changes if able with our protocol and IRB amendments.

Statistical data analysis

Descriptive statistics, including mean, standard deviation, median, and range will be calculated for each variable/measurement. Descriptive analysis will be conducted to assess for missingness, describe sample characteristics, and estimate the reliability of scores for all instruments. For body mass index (kg/m^2), the average standing height measured will be used.

Missingness analysis

Univariate or regression analysis in both Aim 1 and Aim 2 will be performed using multiple imputation under the missing-at-random (MAR) assumption. Sensitivity analysis will be performed to check for potential violation of MAR assumption (60). Simulation under the MAR assumption will be performed to quantify the efficiency loss defined as $1-E\,[\hat{Y}\,(X^{*})-Y]^2/E[\hat{Y}\,(X)-Y]^2$ where X^{*} represent the observed data and the X is the data with missingness.

Analysis Aim 1, Bland-Altman plot analysis and concordance correlation will be used to evaluate the agreement between DLW body fat% and body mass index. We will predict TDEE by estimating basal metabolic rate and physical activity level and using these as our primary predictors. Several basal metabolic rate equations from cross-sectional studies with good model performance (i.e., R^2 0.7–0.8) have been reported[85] which mainly used age, fat-free mass, and fat mass weight as key predictors.

Thus, we will use those as our base model predictors and further consider height, race, sex, and pubertal status as potential predictors. Stepwise linear regression procedures in conjunction with Akaike information criterion (AIC) will be used for model selection and to develop prediction equations. Potential interactions between age/race and other variables will be examined. The resulting predicted TDEE is a weighted sum of a subset of potential predictors, where the weights are the parameter estimates associated with each predictor in the regression model. Predictive accuracy will be further evaluated by mean square error through a 10-fold cross-validation to test the predictive accuracy between the predicted and DLW TDEE.

Analysis Aim 2, The Block Food and Physical Activity Screeners, will be analyzed through Nutrition Quest, the child's function is scored through Pedi-Cat and the Autism Rating Scale is hand scored. The heart rate and sleep data obtained with the Fitbit activity tracker will be extracted and exported by Fitabase (Small Steps Labs LLC, San Diego, CA, USA.), a comprehensive data management platform. Descriptive analysis and univariate test (i.e., ANOVA or Chi-square test) on frequency and duration of physical activities, sleep, autism rating, sedentary activity, and youth's dietary intake by food groups and servings will be presented. Overall pattern by sex will be analyzed by principal component analysis or multiple correspondence analysis (61). Raw accelerometer signals at a sampling frequency of 30 Hz will be collected. Each data file will be manually cleaned to extract data collected and assessed for non-wear time using validated algorithms with ActiLife software (62). We plan to use the physical activity intensity thresholds based on counts per minute (CPM) that were validated in typically developing youth (63, 64); sedentary (<100 CPM), light (101–2,295 CPM), moderate (2,296–4,011 CPM), and vigorous intensity (>4,011 CPM). The CPM will be obtained based on a 10-second epoch to capture intermittent movement. We will also perform a 20-minute ramped protocol and collect participant perceived exertion and heart rate during Day 0 when parents can provide assistance as instructed. The ramped protocol will assist us in further validating the CPM thresholds with our participants with DS at individual levels and allow us to make any adjustments if needed based on raw data collected. The Physical Activity Screener will complement the objective accelerometer data. The 24-hour dietary recalls will be analyzed using Nutrition Data Systems for Research (65) (a nutrient analyses software) to identify energy intakes at the macronutrient levels and general Health Eating Index scores to compare with other youth groups and the Dietary Guidelines for Americans 2020–2025 (66).

Sex as a biological variable analysis

The proposed sample of 230 youth with DS will be stratified by sex with 115 males and 115 females being recruited. For Aim 1, sex as a biological variable will be used to describe the average TDEE and tested as a potential predictor in the equation described above (Statistical Data Analysis, Aim 1) to predict energy requirements for youth with DS. This is important as TDEE is expected to be different for males as compared to females. For Aim 2, sex as a biological variable will be used to describe and examine differences between the weight-related behaviors (dietary intake, sleep, and activity) by univariate analysis (i.e., ANOVA or Chi-Square test as appropriate) for the sample based on sex. This will inform if obesity risk factors are different based on sex and used in future interventions.

Power analysis

The power calculation is based on the increased coefficient of determination (R^2) from a baseline linear model to a multivariate model that regresses TDEE on potential predictors (i.e., height, race, age, sex, puberty status). Pilot studies from the literature suggest that the R^2 for a regression model of TDEE measured by DLW on basal metabolic rate and physical activity level is in the range of 0.7–0.8. As we will use 10-fold cross-validation to construct our predictive models for two sex groups and assume that 10% of subjects will not complete all measures based on Pilot One data, a sample size of 93 (230/2*0.9*0.9) achieves 90% power to detect an increase of $R^2 \geq 0.045$ attributed to additional four independent variables using an F-test with a significance level of 0.05. The variables tested are adjusted for two independent variables (basal metabolic rate and physical activity level) in the baseline linear model with an R^2 of 0.7.

Discussion

Individuals with DS are recognized to be at higher risk for obesity, yet there is insufficient evidence related to energy expenditure and weight-related behaviors that are integral to the prevention and treatment of obesity. This is critical as individuals with DS are living longer and the added burden of obesity can affect the individual's ability to self-manage their health and transition to independence. Furthermore, obesity is linked to multiple medical conditions. This lack of evidence-based information places added stress on the family and limits the ability of the healthcare provider to provide anticipatory guidance.

The study protocol was designed with the goal of obtaining clinically relevant information on TDEE and weight-related behaviors in youth with DS while reducing the burden on the child and their family. Specific burden-reducing attributes of this study include flexibility in scheduling and collecting data within the family's residence via a video conferencing platform along with the provision of family-centric, easy-to-understand study-related materials. This supports the family's ability to make an informed decision to participate, increases accessibility, supports recruitment efforts, aids in the collection of accurate data, and decreases the study burden on the participant. Post Covid-19, families have increased awareness and comfort with using virtual platforms such as Zoom which can be a benefit to conducting research studies and reduce the need to enter medical research facilities if not needed.

An added benefit of conducting the visit within the family's residence includes the ability to have the family be in a comfortable environment during data collection. This assists the child with comfort during the study and with obtaining data. A specific example of this is during the

24-hour dietary food recall, the family can go to their kitchen and show the study team actual serving sizes and brand names of food. The extended study visit allows the building of a relationship with the family and provides the ability to answer questions as they come up. The study is also designed to ensure that the family does not need to leave their house for participation by having all study-related equipment and supplies shipped to the family and picked up from the family's residence. The successful completion of this study with the use of virtual platforms, family-centric study materials, and a focus on reducing family burden during study participation may provide evidence for alternative study designs in the future.

The study outcomes will shift current research and clinical practice paradigms by providing an evidence-based prediction equation to support healthcare providers to provide accurate anticipatory guidance for youth with DS and their caregivers/families. Our protocol can serve as a template for research into other developmental disabilities and the virtual methodology can provide a model that supports study participation and potentially can increase the diversity of the sample. The Aim 1 evidence-based prediction equation for TDEE will be immediately useful and translatable into clinical practice. Our findings will also provide a requisite foundation for future intervention research, and when compared to our ongoing R01 findings, will generate knowledge about whether intervention components need to be tailored to specific disabilities (e.g., different TDEE in DS vs. SB) or if intervention components can be more broadly tested across populations. The findings from Aim 2 are foundational as the origin of obesity is multifactorial and can be influenced by behavioral modifications. The Aim 2 outcomes will inform both providers and future research on current weight-related behaviors as obesity risk factors in youth with DS. Evidence-based information on weight-related behaviors (nutrition, activity, sleep) can be used independently [e.g., recommendations for dietary modifications or opportunities to modify activity once we have a better understanding of the daily activities (physical and sedentary) of youth with DS] and with the TDEE information obtained in Aim 1 to developing interventions both from a clinical and research perspective.

The lack of accurate information on energy expenditure and weight-related behaviors (nutrition, activity and sleep) in youth with DS and the inability to provide daily caloric recommendations significantly impedes the successful prevention and treatment of obesity for this vulnerable population. The findings from this study will provide a foundational understanding of weight-related behaviors (energy expenditure, activity, nutrition, and sleep) as obesity risk factors, currently not well understood for this vulnerable population. This information will optimize clinical appointments and support and enhance the anticipatory guidance provided by healthcare providers. This innovative study will advance the science of weight management in individuals with disabilities, address national research priorities and shift clinical practice paradigms.

Ethics statement

The study protocol is approved by the Western Copernicus Group (WCG) Institutional Review Board (IRB) (#20214186).

Author contributions

Contributions to the study design include MP, LB, ZH, AM, DS, C-CH, DD, CB, and KS. Preparation of the database was completed by MR, ZH, AM, DS, and TS. The manuscript was drafted by MP and KS. Critical review and final approval were completed by all authors. All authors contributed to the article and approved the submitted version.

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Conflict of interest

LB is a guest associate editor for the special topic and a member of the editorial team.

The remaining authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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Associations between parenting strategies and BMI percentile among Latino children and youth with intellectual and developmental disabilities

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Introduction: Maintaining healthy weight is a challenge for all children, and particularly for children with IDD compared to nondisabled children and for Latino children compared to non-Latino White children. Parenting practices related to food intake and physical activity have been found to be important in maintaining children's weight. In this study, we describe the prevalence of overweight and obesity status among Latino children with IDD and their maternal caregivers and determine the relationship between food and physical activity parenting practices and childhood obesity among Latino children with IDD.

Methods: We interviewed 94 Latino parent/child dyads and collected information about parenting practices, home environment, and parent and child height and weight using standardized measures. Parent body mass index (BMI) and child BMI percentile were calculated from height and weight.

Results: The combined overweight/obesity status for children in our sample was high (60.3%) compared to national rates among nondisabled Latino children (56%) and non-Latino White children with autism (37%). Contrary to research on nondisabled children, we found that greater parental use of controlling dietary strategies was associated with lower BMI percentile in Latino children with IDD. These findings may be indicative of the fact that children with IDD tend to have unique dietary behaviors that warrant more disability and culturally sensitive strategies.

Discussion: Our findings suggest that overweight and obesity is especially prevalent for Latino children with IDD and that more research is needed on family factors that promote health in Latino families of children with IDD.

KEYWORDS

healthy weight, intellectual and developmental disabilities, Latino, obesity, parenting strategies

Introduction

One of the most common non-communicable health problems is overweight and obesity. The World Health Organization (WHO) defines overweight and obesity as conditions with excessive accumulation of body fat that presents a risk to health (1). Recent projections from the World Obesity Federation suggest that by 2060, approximately 91% of children and adults in the United States will be overweight or obese (2). The economic costs of overweight and obesity in the United States are projected to increase to $2.622 trillion by 2060 (2). Systematic reviews find that children and youth who are overweight or obese are more likely to develop and experience cardiovascular illness and diabetes, asthma, musculoskeletal discomforts, psychological distress, anxiety, and depressive symptoms (3–5), and that these effects can be long-lasting and persist into adulthood (6, 7). Furthermore, longitudinal studies find that children and youth who are overweight or obese face significant levels of stigma, achieve lower levels of education, and report lower quality of life than children and youth who are not overweight or obese (8).

Within the United States, Latino[1] children and youth (aged 2–19 years) are more likely to be overweight or obese than White children, with obesity rates reported as high as 26.2% among Latino children compared to 16.6% among White children (9–12). Moreover, children and youth with intellectual and developmental disabilities (IDD) have also been identified as more likely to be overweight or obese than children without IDD, ranging from 33.5% to 47.0% of children with IDD (13). These data are striking as Latino children and children with IDD experience significant obstacles in accessing a primary care provider, specialty health care services, and family-centered care (14, 15). Further disparities arise when we consider the intersectional identities of Latino children with IDD, as they may face substantial barriers to accessing health and education services and supports (14, 16).

Body fat composition is influenced by environmental factors affecting caloric surplus and deficit that result from food intake and caloric expenditure through physical activity (17). Family environment, particularly parenting practices related to food and physical activity, plays an important role in children's dietary and physical activity behaviors (18). Food parenting practices (FPP) are intentional or unintentional, food-specific actions or behaviors used by parents for child-rearing purposes that affect their child's eating-related attitudes, beliefs, or behaviors (19). Among non-disabled children, FPP are strongly associated with diet and weight. Parents who utilize factors that emphasize structure, warmth, and responsiveness (e.g., parent encouragement and modeling healthy behavior) and use family rules, limit-setting, and monitoring are more likely to have children who eat healthier foods (19–23). Conversely, parents who use more controlling FPP, such as feeding restrictions, overfeeding, using foods as rewards, and pressure to eat, have been linked to poorer diet and obesity development (24–27). Samples used in these studies were of predominantly White families and children. A study on food intake, FPP, and acculturation among Latino children and families found that immigrant mothers used more controlling and less indulgent feeding practices compared to Latina mothers born in the United States (28) and greater maternal acculturation to the United States was associated with higher unhealthy food consumption and higher rates of obesity among Latino children in a different study (29).

Parents may be particularly underprepared in FPP with their children and youth with IDD. Parents of children with IDD often face unexpected feeding issues as opposed to parents of nondisabled children (30, 31). Feeding issues are especially marked for children with autism spectrum disorder (ASD), who tend to have more restricted diets due to food selectivity, texture sensitivities, and specific mealtime expectations (32, 33). In addition, children with ASD may also be affected by medication side effects, sensory issues, specialized or focused behaviors, and gastrointestinal symptoms (34, 35). Therefore, parents of children with ASD are likely to be more involved in monitoring their child's diet and are more vigilant about their child's dietary behaviors to ensure that their child is getting sufficient nutrients (36, 37). Children with other types of IDD, such as intellectual disability or Down syndrome (DS), have different challenges with respect to feeding. For some children with DS, eating can be a challenge due to chewing and swallowing difficulties (38). One study found a notable tendency to overfill mouths and cheeks with food without swallowing in a sample children with DS (39). While children and youth with DS have a greater tolerance for various food textures than children with ASD, this same study found a preference for crispy and oily foods and a dislike for brittle and gooey foods leading to greater consumption of salty and cheesy products (39). Children with DS also demonstrate similar patterns of dietary behaviors to the general pediatric population with excessive consumption of protein and saturated fat, and preferred bread, pasta, fruit juices, meat, and cold cuts (38). In combination, these factors can lead to a less nutritious diet in this group. The challenges children with DS and IDD experience with eating may influence the types of strategies or practices parents use to impact their child's eating behaviors.

Research has demonstrated racial/ethnic differences in the influence of FPP on children's eating and weight. For instance, pressure to eat and restrictive feeding practices are more commonly observed among Latino, non-Latino Black, and Asian parents compared to non-Latino White parents (40–43). However, the results of studies conducted among Latino children have been mixed. Hughes et al. (44) found that Latino parents tend to be more indulgent of their children's diet (i.e., characterized by warmth and acceptance in combination with a lack of monitoring

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[1] We understand that terminology preferences often vary. Some prefer to be identified as Latino, while others prefer Latine or Latinx. Given the lack of consensus, we have chosen to honor the preferences of our research participants who expressed greater comfort and familiarity with being identified as "Latino". "Latina" will be used when referring to females.

of the child's behavior) and that such behavior was associated with higher child BMI. In contrast, a recent study using data from the Hispanic Community Children's Health Study/Study of Latino Youth (SOL Youth) found that children (ages 8–16 years) of parents who used controlling FPPs vs. indulgent FPPs were 1.75 times more likely to consume a diet that is high in calories (45). Although FPP are widely examined among typically developing children and youth, research on children and youth with IDD has been scant. There is even less research that has examined FPP and the intersection of race and disability.

Parenting practices can also influence children's engagement in physical activity. Research shows that when mothers exercise certain levels of control and enforce behavioral expectations, children are likely to spend more time engaging in physical activity and spend less time being sedentary (46, 47). For Latino children, it appears that parent involvement has a positive effect on the children's physical activity. One integrative review found that Latino children's engagement in physical activity was facilitated when parents monitored their child's behaviors, encouraged, or prompted their child to be more physically active, modeled active behaviors, offered logistic support for physical activity participation, and presented rewards and reinforcement for being physically active (48). However, Latino families of children with disabilities often mention barriers to engaging in physical activity (49, 50). These barriers include inclement weather, high cost, lack of time, neighborhood safety, and lack of space to exercise at home (50). Moreover, Latino families may be more likely to live in neighborhoods with limited access to affordable recreational facilities and healthy food options, which makes it difficult to maintain physical activity and a healthy diet routine (51–53).

Research on physical activity and parenting practices is very limited for children and youth with IDD. A systematic review of 30 studies demonstrated that children with IDD are less likely to engage in physical activity than children without disabilities (54). In an effort to promote physical activity, parents of children and youth with IDD may utilize a variety of parenting practices. A systematic review on children with disabilities, broadly speaking, identified three dimensions of parenting that were significantly and positively associated with physical activity behaviors in children with disabilities: participating in physical activity interventions, parental support (e.g., providing transportation, offering encouragement) and parents' perceived importance of their child engaging in physical activity (55). In addition to parent support, parents' perceived competence of their child's physical ability has also emerged as a key factor in promoting physical activity behaviors of children with disabilities (56). Some studies have identified barriers to engagement in organized physical activity for children and youth with disabilities. According to one study, these barriers include low socio-economic status, parents' and siblings' non-participation in physical activity, and being enrolled in special education vs. a mainstream school (57). Thus, families and children at the intersection of race and disability might face compounded barriers to physical activity engagement.

The physical home environment is an important determinant of child diet, physical activity, and obesity. Previous research indicates that children who live in households characterized by greater availability of unhealthy foods, fewer fruits, and vegetables, fewer sports/recreational equipment items, and more media equipment are at high risk for obesity. While high rates of childhood overweight/obesity in the Latino community are often attributed to cultural influences, attitudes, and beliefs (58), most Latino parents do recognize the importance of children eating healthy foods, fewer sweets, and being physically active (48). Yet, due to structural and economic barriers, they may struggle to provide healthy foods and find time and space to engage in physical activity with their children.

To date, there is limited research on Latino children with IDD related to weight and its associated factors. The influence of family context is understudied but is substantially important given this population's higher dependence on parents, siblings, and caregivers to accommodate their food intake and physical activity (59, 60). As the prevalence of obesity among Latino children with IDD continues to rise (61), examining the associations between food and physical activity parenting practices, the home food and physical activity environment, and obesity are warranted.

The aims of the current study are to (1) describe the prevalence of overweight and obesity status among Latino children with IDD and their maternal caregivers; and (2) determine the relationship between food and physical activity parenting practices, home food and physical activity environment, and childhood obesity among Latino children with IDD.

Methods

Study design and recruitment

The present study is based on data collected for a larger, cross-sectional study that investigated the health behaviors (e.g., diet, physical activity) and lifestyle factors (e.g., socioeconomic status, home environment) contributing to overweight and obesity among Latino children with intellectual and developmental disabilities (IDD) and their maternal caregivers. Mothers were selected for the study as they are typically the primary caregiver of children with IDD in Latino families (62). Research staff recruited caregiver-child dyads from two urban cities in the United States, both of which were characterized by large Latino populations (63). Institutional review boards of universities at both study sites approved the study. We formed a Community Advisory Board (CAB) at each site, consisting of researchers, representatives of local Latino-serving non-profit organizations, parents of a child with IDD, and disability self-advocates. The CABs provided ongoing input to the research team related to study design, recruitment, evaluation, and dissemination. Community agencies that serve the target population assisted with recruitment by sharing recruitment materials (i.e., a Spanish and English bilingual informational flyer) with Latino families through their websites, newsletters, email listservs, and social media (e.g., Facebook). To increase recruitment, research staff also delivered community outreach presentations at events such as local community fairs and parent support groups.

Participants

Families expressed interest in the study by filling out an online study interest form. After receiving the interest forms, research staff conducted eligibility screenings with families by phone. Eligibility criteria included: (1) the caregiver identified as a Latina mother (or other Latina female primary caregiver with custody of the child); (2) the caregiver had a child between 6 and 17 years of age; (3) the focal child had a diagnosis of autism spectrum disorder (ASD), Down syndrome (DS), and/or intellectual disability (ID); and (4) the focal child was able to walk since we also collected accelerometer data (accelerometers have not been well tested with children who are unable to walk without a device). Families with more than one child with IDD were encouraged to include all eligible children in the study.

For eligible families, trained bilingual research staff obtained verbal consent from the caregiver, parental consent for child participation, and child assent from each child. Between July 2020 and December 2022, we completed interviews with 94 Latino caregiver-child dyads via three, 60- to 75-minute phone or video calls over the course of 4–6 weeks. Seven families had more than one eligible child bringing the total number of enrolled children with IDD to 101. During the interviews, research staff administered survey questions in English or Spanish depending on preference, including demographics and caregiver-child health, health behaviors, quality of life, socioeconomic conditions, home environment, as well as height and weight data to calculate body mass index (BMI). Families could choose to complete assessments either in Spanish or English. Each family received a $25 gift card voucher as compensation for each interview completed, earning up to $75 for all three interviews.

Table 1 presents caregiver and child demographics of our study sample. Sixty-four families chose to complete the interviews in Spanish and the remaining 30 in English. On average, Latina caregivers were 42.9 (SD = 6.2) years old with a range from 30 to 58. Most of them were from lower socioeconomic backgrounds—about 60% had an annual household income of $35,000 or below; about half said they owned a house/apartment (45%), were uninsured (43%), and had high school or less education (48%); only 27% said they were employed/self-employed while others identified either as full-time caregivers (36%) or were unemployed/unable to work (37%). Most caregivers were married/partnered (82%) and born outside of the US (81%). For children with IDD, they were on average 10.8 (SD = 3.3) years old. Most of them were boys (71%), born in the US (95%), had insurance of any kind (96%), and had a primary diagnosis of autism (78%).

TABLE 1 Baseline demographic characteristics.

Characteristics	Mother ($N = 94$)	Characteristics	Child with IDD ($N = 101$)
Mean age (SD)^{a}	42.9 (6.2)	Mean age (SD)	10.8 (3.3)
	n (%)		*n* (%)
Annual household income^{a}		Male	72 (71.3)
≤$35,000 USD	52 (57.8)	Place of birth	
>$35,001 USD	38 (42.2)	US-born	96 (95.0)
Maternal education^{a}		Foreign-born	5 (5.0)
High school or less	40 (47.6)	Insurance status	
Some college or more	44 (52.4)	Uninsured	4 (4.0)
Employment status^{a}		Insured, any kind	97 (96.0)
Employed/self-employed	23 (27.4)	Primary diagnosis^{a}	
Full-time caregiver	30 (35.7)	ASD	79 (78.2)
Unemployed/unable to work	31 (36.9)	ID/DS	22 (21.8)
Married/partnered^{a}	68 (81.9)		
Foreign-born^{a}	68 (81.0)		
Insurance status^{a}			
Uninsured	36 (43.4)		
Insured, any kind	47 (56.6)		
Home ownership^{a}			
Own a house/apt	37 (44.6)		
Rent/other arrangement	46 (55.4)		
Language preference			
Spanish	64 (68.1)		
English	30 (31.9)		
BMI and weight status^{b}	**Mother ($N = 94$)**	**BMI and weight status^{b}**	**Child with IDD ($N = 93$)**
Mean BMI (SD)	30.2 (6.7)	Mean BMI percentile (SD)^{a}	75.2 (31.7)
Weight status	*n* (%)	Weight status^{a}	*n* (%)
Under weight	4 (4.3)	Underweight	9 (9.7)
Normal weight	16 (17.0)	Normal weight	28 (30.1)
Overweight	24 (25.5)	Overweight	22 (23.7)
Obese	50 (53.2)	Obese	34 (36.6)

SD, standard deviation; IDD, intellectual and developmental disabilities; ASD, autism spectrum disorder; ID, intellectual disability; DS, Down syndrome; BMI, body mass index.

[a] Sample sizes varied due to missing data. Data reported are for valid Ns and percentages.

[b] Adult weight status was categorized using raw caregiver BMI data: underweight (<18.5), normal weight (18.5–24.9), overweight (25.0–29.9), and obese (≥30.0). Child weight status was categorized using child BMI percentile data: underweight (<5.0), normal weight (5.0–84.9), overweight (85.0–94.9), and obese (≥95.0).

Dichotomous variables: caregiver—annual household income (0 ≤ $35,000, 1 > $35,000), education (0 = high school or less, 1 = some college or more), employment (0 = not employed/full-time caregiver, 1 = employed/self-employed), marital status (0 = not married, 1 = married/partnered), country of origin (0 = foreign-born, 1 = US-born), insurance status (0 = uninsured, 1 = insured, any kind), and home ownership (0 = rent/other arrangement, 1 = own a house/apartment). Child—gender (0 = female, 1 = male), place of birth (0 = foreign-born, 1 = US-born), insurance status (0 = uninsured, 1 = insured, any kind), and primary diagnosis (0 = ID/DS, 1 = ASD).

Measures

Demographics

Questions for caregivers included age, country of origin, education, employment, marital status, annual household income, insurance status, and home ownership. We also collected child demographics based on caregiver-reported data, including child age, gender, place of birth, insurance status, and IDD primary diagnosis.

Brief autism mealtime behaviors inventory (BAMBI)

To capture mealtime behaviors specific to children with IDD, we used the BAMBI, a 14-item questionnaire that asks parents to indicate how often their child exhibited negative (e.g., crying, screaming, and being disruptive during mealtimes) and positive (e.g., open to trying new foods and remained seated at the table while eating) behaviors (64). Responses are scored on a 5-point Likert-type scale ranging from 1 "never occurs" to 5 "always occurs". Positive behavior items are reverse-coded. A total frequency score was calculated by summing all 15 items, with higher scores reflecting more mealtime behavioral problems. As discussed earlier, children with ASD may have different mealtime behaviors when compared to those with DS or ID. We thus used the BAMBI scores as a covariate which we will discuss further in the analysis. The Cronbach's alpha is 0.79 for BAMBI for the current sample.

Home environment

We examined home food (HFE) and physical activity (HPAE) environment using items adapted from the Home Health Environment survey developed by Boles et al. (65). For home food environment, caregivers reported how often healthy (e.g., raw fruits, vegetables, and low-fat crackers) and unhealthy foods (e.g., chocolate candy, cookies, and regular sodas) were available to their children at home on a 5-point Likert-type scale from 1 "never" to 5 "always". For home physical activity environment, caregivers reported how often their children used certain physical activity equipment (e.g., bikes, jump rope, and active video games) available to them at home on a 5-point Likert-type scale from 1 "not available/don't use at all" to 5 "once a week or more". Items for healthy foods, unhealthy foods, and physical activity equipment were summed to calculate index scores. The Cronbach's alphas are 0.32 for the healthy food index, 0.75 for the unhealthy food index, and 0.65 for the physical activity equipment index for the current sample. Due to its low internal consistency, the healthy food index was excluded from the analysis.

Parenting strategies for eating and activity scale (PEAS)

To assess strategies that caregivers use to impact child diet and physical activity at home, we used the 26-item PEAS, developed to be culturally appropriate for Latino families (66). Based on 5-point Likert-type responses ranging from 0 "never" to 4 "very often", the PEAS measures five parenting strategies including three for diet (limit setting, monitoring, and control) and two for physical activity (monitoring and reinforcement). Items for each parenting strategy for diet (PEAS-diet) and physical activity (PEAS-PA) were summed to calculate index scores. The Cronbach's alphas are 0.81 for the PEAS-diet and 0.80 for the PEAS-PA for the current sample.

Body mass index (BMI)

Due to the COVID-19 restrictions, we relied on caregiver-report data. Caregiver and child heights (in inches) and weights (in pounds) were obtained. Specifically, mothers were first asked to report their own weight and height. They were then asked if they had a scale and tape measure available at home. If the response was "yes," they were asked to conduct the child measurements in real-time. Otherwise, mothers were asked to recall their child's weight and height data from their last pediatric visit. Caregiver BMI was calculated by dividing weight in pounds by height in inches squared and multiplying by a conversion factor of 703. A BMI of 25.0–29.9 in adults is considered overweight, and a BMI of 30.0 or higher is considered obese (67). For children, we used BMI age- and sex-adjusted growth charts, which are known to provide a reliable indicator of excess adiposity in children (68). Child BMI at the 85th percentile is considered overweight and 95th percentile is considered obese.

Data analysis

Data analyses were conducted using the Statistical Package for the Social Sciences (SPSS), version 27 (IBM Corp, Armonk, NY). Means, standard deviations, and frequencies for demographic characteristics of the caregiver-child dyads were calculated (see **Table 1**). Standardized measures were computed based on their respective scoring schemes. Distributional analysis was done to ensure that the data were normally distributed and free from errors. There were missing data throughout the raw dataset because of participant non-response (e.g., caregivers were concerned about providing certain personal information). Missing data ranged from 0 (child age) to 17% (marital status). Overall, missing data accounted for 7% of the overall dataset and diagnostics showed no patterns for the missing data. To address the missingness so that the full sample could be included in analyses, multiple imputation was conducted with the MI command in SPSS. Specifically, we used the default setting which ran five iterations using the automatic method assuming missing-at-random (MAR). Model constraints were set based on original data (e.g., child BMI percentile was limited to 0–100). SPSS generated pooled results through the iterative simulations in which missing values were replaced by plausible estimates (69). The pooled results thus represent the least-biased estimates for the study parameters and were used in the analysis.

Using caregiver BMI and child BMI percentile derived from caregiver-report weight and height data, we calculated the numbers and percentages of caregivers and children in our sample that were overweight or obese to compare with national prevalence rates of obesity among Latino children and adult women (Aim 1). To examine the relationships between home food and physical activity environment, parenting practices, and child BMI percentile (Aim 2), we conducted a series of hierarchical linear regression models with child mealtime behaviors (BAMBI) as a covariate throughout. Home environment (i.e., unhealthy food and physical activity equipment indices) and parenting strategies were entered as the first block in the hierarchical regression model to examine the crude relationships between these variables and child BMI percentile while accounting for child mealtime behaviors.

Caregiver-child factors were entered as the second block to examine the effects of home environment and parenting strategies net of socioeconomic and demographic variables. Four child variables were excluded in the second block—child age and gender were excluded because they were already adjusted when calculating child BMI percentile (see CDC, https://www.cdc.gov/healthyweight/bmi/calculator.html); child place of birth and insurance status were excluded due to a lack of variability. Subsequently, caregiver-child factors entered in the second block included caregiver age, BMI, country of origin, education, employment, marital status, annual household income, insurance status, home ownership, and child primary diagnosis. The model fit was examined using the proportions of the variance explained in the dependent variable (i.e., R^2 and R^2 change).

Results

Caregiver-report BMI, child BMI percentile, and weight statuses

On average, caregiver self-report BMI was 30.2 (SD = 6.7) with a range from 12.4 (severely underweight) to 52.9 (severely obese) in our study sample. More than half (53%) of the caregivers met criteria for adult obesity (BMI ≥30.0) and 26% were overweight but not obese for a combined 79% with overweight/obesity status. Caregiver-report child BMI percentile was on average 75.2 (SD = 31.7) and ranged from 0.1 (severely underweight) to 99.8 (severely obese). About 37% of the children with IDD met criteria for obesity (BMI percentile ≥95.0), and 24% were assessed to be overweight but not obese. Combined overweight and obesity status among the children was 60.3%. Caregiver-report BMI and child BMI percentile were significantly correlated (Pearson's $r = 0.22$, $p = 0.04$). Among the 50 caregivers who were reported to be obese, 21 reported their children were also obese.

Home environment and parenting strategies for eating and physical activity

Table 2 shows the characteristics of, and correlations between the home environment and parenting strategies subscales. On average, limit setting for diet ($M = 13.4$, SD = 5.6) and reinforcement for physical activity ($M = 12.0$, SD = 4.5) had higher scores indicating greater use by Latina caregivers. The correlation matrices show that physical activity monitoring was strongly correlated with all other parenting strategies. Additionally, limit setting and monitoring for diet were strongly correlated with each other. For home environment subscales, unhealthy food index was significantly correlated with physical activity monitoring, while physical activity equipment index was significantly correlated with physical activity reinforcement and unhealthy food index. No significant correlations were found among other parenting strategies subscales.

Hierarchical regression models

Table 3 shows the statistics of the two hierarchical regression models. In model 1, home environment and parenting strategies variables were entered as the first block while only child mealtime behaviors were accounted for. Results show that (1) controlling in parenting strategies for diet significantly predicted lower child BMI percentile ($t = -2.49$, $p = 0.01$), (2) monitoring in parenting strategies for physical activity significantly predicted higher child BMI percentile ($t = 2.31$, $p = 0.02$). The model fit statistics show that home environment and parenting strategies explained 15% of the variance ($R^2 = 0.15$ $p = 0.04$) in child BMI percentile.

In model 2, caregiver-child factors were further entered to examine the net effects of home environment and parenting strategies. Consistent with model 1, both controlling for diet ($t = -2.47$, $p = 0.02$) and monitoring for physical activity ($t = 2.34$, $p = 0.02$) remained significant predictors of child BMI percentile. Among all caregiver-child factors entered, only the child's primary diagnosis of ASD significantly predicted lower child BMI percentile ($t = -2.15$, $p = 0.04$). In model 2, 28% of the variance ($R^2 = 0.28$, $p = 0.02$) in child BMI percentile were explained which represents a 13% (R^2 change = 0.13) increase from model 1.

Discussion

In the present study, we examined prevalence of overweight and obesity status in a multisite sample of Latino children with IDD and correlates of the children's Body Mass Index (BMI) percentile with a focus on parenting strategies. Thirty-seven percent of the children in our study met criteria for obesity status, and 24% met criteria for

TABLE 2 Characteristics of and correlations between home environment and parenting strategies subscales.

Variables	*N*	Mean	SD	1	2	3	4	5	6	7
1. Diet—Limit setting	101	13.4	5.6	–						
2. Diet—Monitoring	101	10.7	6.1	0.54***	–					
3. Diet—Control	101	7.8	4.9	0.09	0.18	–				
4. PA—Monitoring	101	8.7	5.7	0.40***	0.57***	0.39***	–			
5. PA—Reinforcement	101	12.0	4.5	0.14	0.05	0.05	0.33**	–		
6. Unhealthy food index	94	19.4	5.3	−0.19	−0.16	−0.04	−0.22*	−0.17	–	
7. PA equipment index	94	19.6	6.9	0.03	0.07	0.05	0.11	0.22*	0.27**	–

SD, standard deviation; PA, physical activity.
*$p < 0.05$, **$p < 0.01$, ***$p < 0.001$.

TABLE 3 Results of hierarchical regression models for child BMI percentile.

Independent Variables	Model 1		Model 2	
	t	*p*-values	*t*	*p*-values
Home environment				
Unhealthy food index	−0.14	0.89	−0.37	0.71
PA equipment index	−0.73	0.47	−0.60	0.55
Parenting strategies				
Diet—Limit setting	1.61	0.11	1.58	0.11
Diet—Monitoring	−1.30	0.19	−1.32	0.19
Diet—Control	−2.49	0.01*	−2.47	0.02*
PA—Monitoring	2.31	0.02*	2.34	0.02*
PA—Reinforcement	−1.29	0.20	−0.59	0.56
Caregiver-child factors				
Caregiver age			−0.27	0.79
Caregiver BMI			1.17	0.25
Caregiver country of origin			−0.51	0.61
Caregiver education			−1.14	0.26
Caregiver employment			1.44	0.15
Caregiver marital status			1.50	0.14
Caregiver insurance status			0.70	0.49
Annual household income			−0.69	0.50
Home ownership			−0.23	0.82
Child IDD primary diagnosis			−2.15	0.04*
	R^2	*p*-value	R^2	*p*-value
	0.15	0.04*	0.28	0.02*

PA, physical activity; BMI, body mass index; IDD, intellectual and developmental disabilities.
Dichotomous variables: caregiver—country of origin (0 = foreign-born, 1 = US-born), education (0 = high school or less, 1 = some college or more), employment (0 = not employed/full-time caregiver, 1 = employed/self-employed), marital status (0 = not married, 1 = married/partnered), insurance status (0 = uninsured, 1 = insured, any kind), annual household income (0 ≤ \$35,000, 1 > \$35,000), and home ownership (0 = rent/other arrangement, 1 = own a house/apartment). Child—IDD primary diagnosis (0 = ID/DS, 1 = ASD).
*$p < 0.05$, **$p < 0.01$, ***$p < 0.001$.

overweight status (not obese). The combined overweight/obesity status for children in our sample was 60.3%. This is comparatively higher than overweight/obesity status among a representative sample of nondisabled Mexican American children who were reported to be 55.5% overweight/obese (70); and compared to a meta-analysis estimate of children with autism, which was reported to be 37% overweight/obese (71). Caregivers in our sample also had similarly high rates of overweight/obesity status (79%) compared to a representative sample of women assessed in 2016 at 68% (72). These findings are a call to action for more research into the determinants and consequences of obesity and overweight status in racial/ethnic minoritized children with IDD and their family caregivers.

To investigate further, we examined correlates and predictors of child BMI percentile with a focus on home food and physical activity environment and parenting strategies for eating and physical activity. Contrary to prior findings, there were no effects of the presence or absence of healthy foods (73, 74) or the presence of sports equipment (75) on child BMI percentile. This discrepant finding could be related to limitations with activities of daily living (ADL) independence among children with IDD. Studies show that children and youth with IDD experience significant difficulties with performing ADL, thereby restrict their participation in everyday activities that their age peers can perform independently (76, 77). Such activities might include serving themselves snacks available at home or initiating physical activities using available home equipment on their own. Covert changes in the home environment, such as purchasing healthy foods and making exercise equipment readily available, are contingent on the child's ability to notice these changes and initiate dietary and physical activity behaviors (78). For children with IDD, this type of covert control might be insufficient in isolation without active guidance and direction from caregivers.

With respect to parenting practices, we found that greater parent use of controlling strategies for child diet was associated with lower child BMI percentile. This finding is in contrast to what has been reported in previous research of non-disabled children, which finds that greater use of controlling behaviors is associated with higher BMI percentile (24–27). Research in the Latino community has similarly found an association between greater controlling strategies by the parents and higher caloric intake of the children (45). However, a study on immigrant parents finds that they use more controlling strategies with their children, which are not always associated with negative outcomes (28). Mothers in our study were primarily immigrant parents which may partially explain our findings with respect to use of controlling strategies (28, 29). Additionally, our findings suggest that parents of children with IDD may need to use different strategies than parents of nondisabled children. Children with IDD tend to have unique dietary behaviors related to oral-motor difficulties and food sensitivities and lesser autonomy in self-regulating dietary intake (32, 33). In such situations, parents might feel compelled to exercise greater control and vigilance of their child's dietary intake, which may lead to better outcomes for children with IDD. Consistent with theory, a recent study with 440 participants with IDD found that restricting access to unhealthy foods and sedentary behaviors was associated with children consuming less fried food and less sweetened drinks (79).

Whether parents used monitoring strategies for diet intake was not related to child BMI percentile. However, we found that greater monitoring for physical activity was related to a higher child BMI percentile. This finding contrasts with previous research on children with IDD who were more likely to be physically active when parents monitored and encouraged their child's physical activity engagement (55). Families of children with disabilities, especially from racial/ethnic minority backgrounds, face significant environmental barriers that restrict their ability to find opportunities for their children that are accessible and accommodating of their child's motor and sensory needs (51–53). Thus, environmental barriers might explain why parents' monitoring behaviors might have the opposite effect on their child's BMI in the absence of real and feasible opportunities for physical activity participation. Further research is needed to isolate the individual and combined effects of parenting strategies and neighborhood environments for Latino children with IDD.

We examined the relationships of demographic variables to BMI percentile in our second regression model to determine if they change or enhance the findings from model 1. We found that the findings regarding parenting practices were retained, and the final model was enhanced by identifying an additional relationship. We found that children with IDDs other than autism had higher BMI percentiles. This finding might be related to greater restrictive dietary habits among children with autism (32, 33) while children with IDD may be more prone to dietary excess as suggested by one study (38).

Limitations and future directions

There are a few important limitations to note. First, it is a cross-sectional study which does not allow us to determine the direction of effects. Future research should consider longitudinal designs. Secondly, this is a convenience sample from Illinois and Texas with predominantly Mexican American Latino populations, which may not represent all Latino families of children with IDD in the US. Another limitation is that this study only included maternal caregivers. Future research may examine the role and influence of fathers, grandparents, and/or siblings in shaping child health behaviors. One study found that Latino fathers are more likely to engage in male and female stereotyped activities (e.g., playing games, cooking, reading) than their White counterparts (80) demonstrating the importance of including fathers in future studies. In the present study, caregiver BMI and child BMI percentile were assessed based on caregiver-report due to the COVID-19 restrictions. Past literature has shown that the use of self-report weight and height data often lead to underestimated BMI (81). We also note that while BMI is widely used in public health, this measure does not capture variation in fat distribution, muscle, and bone density. Furthermore, BMI is not stratified by racial and sex differences in body composition (82). Particularly for children, the BMI does not reflect the onset of puberty, which can be impacted by race, nutrition, genetic and environmental factors (83). Thus, to better assess weight status, future studies should seek to include measures of different body composition metrics such as abdominal adiposity, waist circumference, and percent body fat. Lastly, it is important to acknowledge that all measures used in this study were based on self-report. Subjective measures of health are important in that they convey the experience of wellness among participants. However, future research may seek to corroborate findings by using different subjective measures of health combined with objective data.

Despite the limitations, the present study is significant and innovative in that it considers the family context and gathers information from both caregiver and child. Furthermore, it is among the first to examine the family context in Latino families with children with IDD. These families are particularly subject to cost, safety, and transportation barriers to community resources supporting nutrition and physical activity (51–53). Future research should examine more closely the relationship between parent controlling diet behaviors and healthy weight to determine how this practice should be supported in intervention development for Latino families of children with IDD. Future studies may also examine the mediating role of disability-sensitive attitudes and skills regarding engaging children with disabilities in physical activity on the effects of physical activity (as well as healthy food) environment on child outcomes. This is especially pressing for Latino families because their participation in health promotion programs is often limited by a lack of cultural sensitivity in program recruitment and content (80). Given that prior research has found that children with disabilities are less likely than their non-disabled peers to engage in physical activity (54) and their parents report more difficulties with feeding their children (30, 31), it is likely that this disparity of participation in health promoting programming is particularly pronounced for Latino families of children with disabilities. Our findings may have implications for future culturally tailored interventions for Latino families of children with IDD. There are some interventions that have been culturally tailored for Latino families and children (84, 85). However, future research will need to examine how to incorporate parenting strategies that may be unique to Latino parents of children with IDD into interventions and programs.

Conclusions

The present study examined the association between parenting strategies with body composition in a population that is often understudied—Latino children with IDD. Our findings establish that Latino children with IDD have worryingly high rates of obesity and add to the understanding of the associations between food and physical activity parenting practices, the home food and physical activity environment, and obesity in the Latino community. The present study is a significant and innovative exploratory work that prompts further examination of family factors that promote health in Latino families with children with intellectual and developmental disabilities.

Data availability statement

The raw data supporting the conclusions of this article will be made available by the authors, upon request.

Ethics statement

The studies involving human participants were reviewed and approved by the University of Texas at Austin and the University of Illinois Institutional Review Boards. Written informed consent from the participants' legal guardian/next of kin was not required to participate in this study in accordance with the national legislation and the institutional requirements.

Author contributions

SM conceptualized the study and contributed to the drafting of the manuscript as well as final revisions, VLE helped to conceptualize analysis, analyzed data and contributed to the draft, APY helped to draft and organize the introduction section, NH drafted the discussion section and provided revisions, WZ contributed to data analysis and drafting of methods and results sections and tables, MM, SV SB, DPM and YS-B drafted portions of the work. All authors contributed to the article and approved the submitted version.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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Priorities, barriers, and facilitators for nutrition-related care for autistic children: a qualitative study comparing interdisciplinary health professional and parent perspectives

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Introduction: Children with autism spectrum disorder often face nutrition-related challenges, such as food selectivity, gastrointestinal issues, overweight and obesity, and inadequate nutrient intake. However, the role of routine nutrition-related screening or care by interdisciplinary health professionals is not well understood. This study aimed to compare the beliefs of health professionals with those of parents of autistic children regarding high-priority nutrition-related challenges, barriers and facilitators to care, and desired education and resources related to nutrition for autistic children.

Participants: Interdisciplinary health professionals ($n = 25$) (i.e., pediatricians, occupational therapists, speech-language pathologists, board certified behavior analysts, registered dietitians) and parents of autistic children ($n = 22$).

Methods: The study used semi-structured phone interviews, which were recorded, transcribed, verified, and double-coded using the Framework Method.

Results: Thematic analysis of transcripts revealed that while health professionals and parents of autistic children shared some perspectives on nutrition-related challenges and care, they also had distinct viewpoints. Parents emphasized the importance of addressing food selectivity, behavioral eating challenges, sensory issues, and sleep disturbances affecting appetite. Both groups acknowledged the need for tailored support, access to an interdisciplinary care team, and reasonable expectations. Some health professionals perceived parents as lacking motivation or the ability to make changes. In contrast, many parents felt that health professionals lacked the knowledge and motivation to take nutrition or growth concerns seriously. Health professionals acknowledged that their lack of knowledge or capacity to provide nutrition education or referrals was a common barrier to care, particularly given limited community resources.

Discussion: Health professionals who serve autistic children are motivated to address nutrition-related challenges but lack resources related to nutrition. To promote better health outcomes for autistic children, professionals should identify and support parent motivations around nutrition-related care. Both groups expressed interest in accessing autism-specific resources for education, referral, and screening guidance. Future research could explore the development of healthcare training models that improve the competency of health professionals in providing nutrition care and referral for autistic children.

KEYWORDS

autism spectrum disorder, nutrition, obesity, selective eating, interdisciplinary education, pediatricians, registered dietitian nutritionists

1. Introduction

Autism spectrum disorder (ASD) is a complex neurodevelopmental disorder characterized by persistent behavioral, communication, and social interaction challenges (1). In the United States, 1 in 36 children is diagnosed with ASD (2). Research shows that 70%–80% of autistic children will experience eating or nutrition-related challenges, including food selectivity, behavioral difficulties with eating, inadequate nutrient intake, and gastrointestinal issues (3–5). The underlying reasons for feeding challenges are multi-faceted and complex, which can make addressing them difficult. For example, many autistic children will experience developmental delays that can impact swallowing, chewing, and the ability to feed themselves independently. Additionally, eating is a full-sensory experience, requiring acceptance of numerous tastes, textures, smells, and colors, all of which can be challenging for children with differences in sensory modulation (6). Finally, autistic children prefer sameness, which makes accepting new and fresh foods problematic as they vary in seasonality, preparation, and brand (5).

Since good nutrition status is essential for growth, learning, attention, and cognition, health professionals must prioritize assessment early and address nutrition-related problems upon identification (7). Research suggests that autistic children who exhibit food selectivity face an increased risk of inadequate nutrient intake for fiber, vitamins A, C, D, and E, calcium, zinc, and folic acid (8–10). Despite experiencing food selectivity, autistic children are significantly more likely to be overweight or obese than neurotypical peers. They are subsequently at higher risk for experiencing health disparities related to chronic diseases like diabetes and heart disease as they enter young adulthood (11, 12).

Providing comprehensive care for children with Autism Spectrum Disorder (ASD) involves the collaboration of various interdisciplinary medical professionals, including developmental-behavioral pediatricians, board-certified behavior analysts, occupational therapists, speech-language pathologists, and registered dietitian nutritionists. However, there is a limited understanding of how these medical professionals prioritize nutrition-related issues in their practice. Competence in addressing nutrition challenges in autism likely varies across disciplines.

For example, one study found that a majority of graduating medical students rated their nutrition knowledge as inadequate (13). Since nutrition education is often insufficiently incorporated into medical school curricula, a lack of familiarity with nutrition-related topics may impact pediatricians' confidence and effectiveness in providing evidence-based nutrition care to parents and patients (14). Similarly, other allied health professionals involved heavily in feeding therapies (i.e., occupational therapists, and behavioral analysts) also often lack specific nutrition-focused training. One study indicated gaps in nutrition training for speech-language pathologists and occupational therapists primarily due to a lack of implementation in educational settings. Consequently, there are limitations in their collaborative roles within nutrition competencies (15).

These findings highlight the need for improved nutrition education and training across medical and allied health disciplines involved in caring for children with ASD. Addressing these gaps can enhance the overall competence and effectiveness of medical professionals, ensuring the provision of holistic and evidence-based nutrition care to improve the health outcomes of children with ASD (12, 16). Examples of nutrition-related care could include any intervention (e.g., screening, education, referrals) for factors directly or distally related to dietary intake, growth, or nutrient absorption, including impacts on appetite (e.g., sleep, physical activity), gastrointestinal issues, medication, and anxiety around eating.

To address the existing gaps in the current body of literature, we conducted an exploratory qualitative study to better understand the views of interdisciplinary health professionals and parents of autistic children. Our three primary objectives were to: (1) describe perceived nutrition-related challenges that autistic children face, (2) identify barriers and facilitators to nutrition-related care, and (3) identify desired educational topics and resources for nutrition-related care for autistic children. Across all three objectives, we explored shared and differing perspectives between medical professionals and parent participants.

To ensure a systematic approach to our methods and analysis, we utilized the Theoretical Domains Framework. This evidence-based and theory-based framework enabled us to evaluate the practices of health professionals and their experiences with the healthcare system, identify potential areas for implementation, and enhance the quality of care. By considering cognitive, affective, social, and environmental influences on behavior, the Theoretical Domains Framework provided valuable guidance for our methods and analysis. Our research findings hold significant implications for developing future interventions aimed at improving nutrition and growth outcomes for children with ASD.

2. Methods

2.1. Participants

Our study aimed to recruit a minimum of 20 pediatric-focused health professionals who also treated patients with autism and 20 parents of autistic children. These sample sizes were deemed appropriate for a study using semi-structured interviews based on existing qualitative research best practices to achieve thematic saturation (17). By employing a combination of convenience purposive criterion sampling and nominated expert sampling, we selected a sample of interdisciplinary professionals involved in autism care across various professions and practice areas, focused on serving a pediatric population. We recruited no more than five health professional participants per profession across six distinct professions, which included general pediatricians, developmental-behavioral pediatricians, occupational therapists, speech-language pathologists, board-certified behavior analysts, and registered dietitian nutritionists.

Health professionals were recruited using internet searches, infographic flyers, and referrals from other interviewees to identify potential participants. We opted to use nominated expert sampling for pediatricians who were especially difficult to recruit during the COVID-19 pandemic (18). After voluntary acceptance, each health professional completed an interest screener survey to determine eligibility. Health professionals were eligible to participate if they had active status in their profession, had at least a year of experience working with children on the autism spectrum, and currently practiced in California.

Parents were recruited via flyers at local non-profit Regional Centers and on two Southern California Facebook autism parenting support groups. To address the lack of perspectives from people of color and fathers in the literature, we intentionally sought to achieve a racially and ethnically diverse group of parents, including both mothers and fathers (19, 20). Eligible parents were English-speaking, the primary caregiver of an autistic child between the ages of 3–18 years, and primarily responsible for feeding their child. If a parent had more than one autistic child, they were instructed to focus on their youngest child for this study.

After a brief screening process, eligible participants were contacted via phone or email to schedule an interview. They were then emailed confirming the interview appointment, an electronic consent form, and a brief pre-interview demographics questionnaire administered online via Qualtrics. All enrolled participants provided written informed consent and received a $25 Amazon gift card as compensation for participating in the study. The Institutional Review Board at California State University, Long Beach, reviewed and approved all aspects of this study.

2.2. Interview guides

Two separate semi-structured interview guides for health professionals and parents were developed as part of a broader study seeking to develop a nutrition-related assessment screening tool for children on the autism spectrum. Both guides consisted of open-ended questions and were developed based on previous research and informed by the Theoretical Domains Framework of behavior change (21). The guides can be found in **Supplementary Data Sheet S1**.

The Theoretical Domains Framework is a widely used behavior change framework that considers various factors influencing healthcare professionals' clinical behavior change (22). These factors include motivation, capability, and opportunity. We used this framework to guide the development of interview questions and to assess participants' views on nutrition-related risk factors for children with autism. To guide the development of our interview guide, we identified three content matter experts who were all experienced researchers and registered dietitians with extensive clinical practice experience with children with ASD. The experts reviewed multiple iterations of the two interview guides and provided feedback to promote face validity.

Before the interview, both groups of participants were given a list of nutrition-related challenges for children with autism and asked to review it. Nutrition-related challenges were defined as any health indicators or lifestyle factors directly or distally related to dietary intake, growth, or absorption, including impacts on appetite (e.g., sleep, physical activity), gastrointestinal issues, medication, and anxiety around eating. During the interview, they were asked to identify which items they felt were most important on that list (motivation), about their experiences with nutrition-related care/conversations (opportunity), and about other resources or support they felt would help address these challenges (capability). This list of challenges was also informed by our content matter experts.

2.3. Procedures

Interviews were conducted over the phone between October 2019 and June 2020, with each interview ranging from 15 to 30 min. Two graduate students (C.B., K.C.) and one undergraduate research assistant (A.L.) led the interview using the interview guides; each was trained in qualitative methods by R.B. before commencing the first interview. Afterward, interviewers completed field notes using a specific template to document environmental, methodological, and analytic observations and the overall quality grade of the interview data collected. All interviews were audio-recorded with two devices and stored securely.

2.4. Analytic approach

To analyze our qualitative data, we used the Framework Method, which is a combined inductive and deductive approach to thematic qualitative analysis (23). The deductive component uses an evidence-based theoretical framework to explore specific issues and thus begins with a coding scheme. However, the Framework Method also allows for inductive analysis through open, unrestricted coding and refinement of emergent themes. For Objective 1, describing perceived nutrition-related challenges that autistic children face, and Objective 3, identifying desired educational topics and resources, we used an inductive approach through open, unrestricted coding and refinement of emergent themes identified by both groups of participants.

For Objective 2, identifying barriers and facilitators to nutrition-related care, we used the Theoretical Domains Framework to organize the main themes of barriers and facilitators across pre-defined domains of motivation, capability, and opportunity that influence healthcare professionals' nutrition-related care and conversations with parents of children on the autism spectrum (22). We selected this deductive approach to allow for the organization of findings using a theory-based lens for understanding clinical behavior and behavior change with the hope that this organization would lead to clearer formative data to inform future interventions. Finally, we planned to explore shared and divergent perspectives between medical professionals and parents using coding matrices.

2.5. Data analysis

Following the completion of the interview, each recording was transcribed verbatim, de-identified, and verified for accuracy by the original interviewer and another researcher. An initial codebook was tested by three reviewers who coded ten randomly selected transcripts (CB, KC, RB), ensuring intercoder agreement through weekly meetings, discussion, revision, and consensus on newly identified emergent subthemes using constant comparative methods. Emergent themes were discussed, discrepancies reviewed, and finalized codes were synthesized into the next iteration of the codebook. When new emergent codes were added, the researchers re-coded the prior transcripts using the latest coding schema. Twelve additional transcripts were double coded with the revised codebook and with ongoing review and iterative revision. Finally, two researchers (CB, KC) reviewed all former and remaining transcripts using the finalized codebook and demonstrated good inter-rater reliability (κ coefficient between 0.75 and 0.8). The final codebook can be found in **Supplementary Data Sheet S2**. The team determined that data saturation had been reached when no new emergent codes were identified in the last five coded transcripts of both health professional and parent groups.

Finally, we ran two types of matrix queries based on participant characteristics to identify whether or not there were differences in the frequency of subthemes between groups. The first matrices compared subthemes between health professionals and parents. The second matrices examined subthemes between health professionals based on their self-reported frequency of exposure to clients with ASD. We identified the cutoff using a median split of high exposure (≥45% of patients with ASD) and low exposure (<45% of patients with ASD). All thematic analyses were performed using NVivo version 12. Demographic data were analyzed using Microsoft Excel to obtain frequencies, means, and standard deviations to describe the participant populations.

3. Results

Forty-seven participants completed in-depth interviews for this study. Health professional participants ($n = 25$) were predominantly female (76%) and identified as White (48%), Asian (28%), or Multiracial (16%). Their estimated years of experience working with children with ASD ranged from 3 to 34, with a mean of 10.7 years (SD = 8.7). Participants included pediatricians, developmental-behavioral pediatricians, occupational therapists, speech-language pathologists, board-certified behavior analysts, and registered dietitian nutritionists. They worked primarily in outpatient medical facilities (44%), private practice (24%), and school districts (20%). Only a minority (24%) were part of an interdisciplinary team that included a registered dietitian nutritionist. Additional health professional demographic details are presented in **Table 1**.

Parent participants ($n = 22$) were also primarily female (82%) and identified as Latino/Latinx/Hispanic (50%) or White (33%). Fewer than half were employed, and 41% were out of the workforce to care for a child or parent. The mean age of the children described was 6.8 years (range: 3–15 years), and the majority were male (82%). Additional parent demographic details are presented in **Table 2**.

3.1. Group-level differences

We did not observe differences in subtheme frequency between health professionals who worked more frequently with patients with ASD versus those less frequently across any of the coding domains. Therefore, our group-level findings will be based on the differences and similarities between groups of health professionals and parents of autistic children which were observed across all main themes and subthemes.

TABLE 1 Demographic characteristics of $n = 25$ health professionals with experience serving children diagnosed with autism spectrum disorder (ASD).

Demographic characteristics	*n*/mean	%/SD[a]
Total participants	25	
Gender identity		
Female	19	76
Male	5	19
Race and ethnicity[b]		
White	12	48
Multiracial	4	16
Asian	7	28
Black/African American	0	0
Other	2	8
Latino/Latinx/Hispanic	3	11
Profession		
Pediatrician (general)	4	16
Pediatrician (developmental-behavioral)	3	12
Occupational therapist	5	20
Speech-language pathologist	4	16
Board certified behavior analyst	5	20
Registered dietitian nutritionist	4	16
Work setting		
Outpatient medical facility	11	44
Private practice	6	24
School district	5	20
In-home	2	8
Other	1	4
Part of an interdisciplinary team with a registered dietitian	6	24
Years of experience as health professional (mean, SD)	11.4	10.6
Years of experience working with children with ASD (mean, SD)	10.7	8.7

[a]SD, standard deviation.

[b]Participants chose all that applied.

3.2. Nutrition-related challenges for autistic children

All health professionals interviewed reported encountering nutrition-related challenges while working with patients on the autism spectrum. Similarly, most parents (90%) voiced ongoing nutrition-related challenges for their children, with all having experienced challenges in the past. When asked to identify which nutrition-related challenges should be prioritized and addressed through referral or direct education, subthemes were organized by emergent among both groups, only health professionals, and only parents. **Table 3** summarizes key themes, subthemes, and illustrative quotes.

Both professionals and parents identified nutrition-related challenges for autistic children related to obesity, underweight, and gastrointestinal concerns. Additionally, medications were identified as a concern for contributing to both undernutrition and overnutrition.

TABLE 2 Demographic characteristics $n = 22$ parents and their child with a diagnosis of autism spectrum disorder (ASD).

Demographic characteristics	*n*/mean	%/SD[a]
Total participants	22	
Parent characteristics		
Gender identity		
Female	18	82
Male	4	18
Relationship to child		
Mother	18	82
Father	4	18
Race and ethnicity[b]		
White	8	33
Multiracial	1	4
Asian	1	4
Black/African American	1	4
Other	1	4
Latino/Latinx/Hispanic	11	50
Highest level of education		
High school graduate or GED[c]	1	5
Technical school	3	14
Some college	6	27
College graduate	6	27
Graduate or professional degree	6	27
Employment status		
Employed for wages	10	45
Out workforce to care for a child/parent	9	41
Full-time student	2	9
Self-employed	1	5
Age in years (mean, SD)	37	6.4
Number of children in household (mean, SD)	1.7	0.5
Reference child characteristics		
Gender		
Female	4	18
Male	18	82
Age in years (mean, SD)	6.8	3.4

[a] SD, standard deviation.
[b] Participants chose all that applied.
[c] GED, General education development.

> *I know it's the meds that make him not hungry. I hate that side effect. (Mother to 13-year-old boy, ID 135).*

> *Well, typically patients who are on atypical antipsychotics are gonna gain weight (Developmental Pediatrician, ID 233).*

Health professionals specifically identified four distinct nutrition-related challenges, including high-risk diagnoses (e.g., food allergies, epilepsy), poor dental hygiene, oral motor challenges, and parental lack of nutrition knowledge. Lack of knowledge was cited as contributing to poor diet quality and parenting strategies. There were no differences in subthemes between professionals who worked more versus less frequently with autistic children.

One distinct subtheme that emerged from the parent group was the importance of addressing poor diet quality, even among children with average growth. Many expressed anxiety and concern due to extreme food selectivity.

> *Look growing, he's fine. That's why I'm not worried about him getting fat right now or anything like that. But all he eats is, like I said, pancakes and waffles, chicken strips, won't eat anything else. I'd been worried about that with him not getting enough nutrition. (Father to 15-year-old boy, ID 143).*

> *I'm definitely concerned. There's always a fine line between, is his behavior a result of his atypical brain, or is it because he's lacking nutrition because of his picky eating? (Mother to 11-year-old boy, ID 100).*

Additionally, parents described the need to address behavioral feeding challenges that affect quality of life in addition to dietary intake, as well as sensory challenges impacting mealtime enjoyment. They expressed the need for behavioral feeding strategies to improve their children's overall quality of life, including sleep.

> *Meltdowns aren't mentioned [around eating] and can be severe. He hurts himself. (Mother to 13-year-old boy, ID 135).*

> *He will react very strongly to smells. For example, like the smell of fresh baked bread, like if we're walking by a bakery, he will start kinda like gagging. So, it's hard, you know, in the school setting, he also has to go to the cafeteria, or there's like a party. (Mother to 6-year-old boy, ID 109).*

> *On the days with difficult sleep there's more of a craving for carbs, you know, and he always wants carbs, but it's definitely more, "Can I have cake, can I have cookies?" (Mother to 6-year-old son, ID 110).*

> *Ask nine out of 10 parents, yes, our kids don't sleep. (Father to 9-year-old boy, ID 144).*

It is worth noting that physical activity was rarely identified as a nutrition-related priority by either group, despite its well-established role in improving quality of life, mental health outcomes, and weight balance (24, 25).

3.3. Barriers and facilitators to nutrition-related care

Barriers and facilitators to care for nutrition-related challenges for autistic children were categorized into three domains: motivation, capability, and opportunity, based on the Theoretical Domains Framework (22). A summary of key themes and subthemes, organized by domain, can be found in **Table 4**, with a complete table of subthemes and illustrative quotes in **Supplementary Table S1**.

TABLE 3 Themes with illustrative quotes regarding nutrition-related challenges to address for autistic children.

Theme: nutrition-related challenges to address for autistic children	
Shared subthemes: health professionals and parents	**Illustrative quotes**
Obesity	Well, he went up a size every 2 months for a year. So financially that was intense, and it was also really scary for me just when is he going to stop growing or slow down. (Mother to 6-year-old boy, ID 110)
	With obesity and prediabetes and diagnosis of diabetes, because that's huge in terms of impacting their mortality. (Board Certified Behavior Analyst, ID 219)
Underweight	If their growth is really significantly delayed or a big change from what they've been doing normally, that would be a big red flag for me to refer somebody to a dietitian. (Pediatrician, ID 227)
	If they're diagnosed with failure to thrive, I think that's high risk, just because failure to thrive is inability to put on weight and shows appetite issues. (Registered Dietitian Nutritionist, ID 213)
Gastrointestinal concerns	So, if a child is having water reflux issues, then I refer them back to the pediatrician to see if they should be medicated for that. (Occupational Therapist, ID 224)
	Every single family that I know with high-functioning kids on the spectrum have the gastrointestinal issues. (Mother to 9-year-old boy, ID 107)
	He has so much gas and his bowel movements were out of control. Mother to 3-year-old boy, ID 136)
Medication weight-related side effects	I know it's the meds that make him not hungry. I hate that side effect. (Mother to 13-year-old boy, ID 135)
	But I've definitely noticed with some clients, when parents do change their medication, it does affect the appetite. So, a lot of times, when they do put on more medication, they do tend to increase in weight. (Board Certified Behavior Analyst, ID 228)
	Well, typically patients who are on atypical antipsychotics are gonna gain weight (Developmental Pediatrician, ID 233)
Subthemes among health professionals	**Illustrative quotes**
Focus on specific high-risk diagnoses	I think if, say, this child has more complex issues or they have severe allergies to certain types of foods, that would need more attention. (Occupational Therapist, ID 223)
Dental hygiene	A lot of our kiddos don't like to brush their teeth. I think it's a huge concern. (Board Certified Behavior Analyst, ID 221)
Parent lack of knowledge	If I feel like the parent has a lack of knowledge around food and food groups and portions, then I'll refer. (Developmental Pediatrician, ID 233)
Oral motor challenges	If they're actually having ongoing problems with feeding, so like choking or gagging while feeding. (Developmental Pediatrician, ID 234)
	Children that have neuromotor issues—so, child with cerebral palsy that may have swallowing dysfunction as a result of that or, or issues with fine motor skills with feeding and chewing—they should get referral to a dietitian as well to address those concerns and screen for any particular problems. (Pediatrician, ID 235)
Subthemes among parents	**Illustrative quotes**
Poor diet quality	I'm definitely concerned. There's always a fine line between, is his behavior a result of his atypical brain, or is it because he's lacking nutrition because of his picky eating? (Mother to 11-year-old boy, ID 100)
	He's healthy for his height and weight and his age. But that's why they don't really see a concern. But, as a parent, I'm like, wait, he might not be getting in all the food groups in. (Mother to 3-year-old boy, ID 104)
	Look growing, he's fine. That's why I'm not worried about him getting fat right now or anything like that. All he eats is, like I said, pancakes and waffles, chicken strips, won't eat anything else. I'd been worried about that with him not getting enough nutrition (Father to 15-year-old boy, ID 143)
Behavioral feeding challenges	Meltdowns aren't mentioned [around eating] and can be severe. He hurts himself. (Mother to 13-year-old boy, ID 135)
	It's hard to get him to sit down and eat a meal. (Mother to 3-year-old boy, ID 105)
	It's a constant struggle to make sure he eats, and if he doesn't eat and gets in a bad mood, and then he gets in trouble at school. (Mother to 7-year-old boy, ID 118)
Sensory challenges	I would say the inability to sense fullness, that's kind of like the biggest issue here. (Mother to 8-year-old girl, ID 115)
	Gagging while eating is actually a very big one that I've spoken to a lot of parents lately, because the sensory input of when another child is seeing somebody else eat. Like my son, if he sees somebody chewing with his mouth open, he's done, has to get away, cannot be anywhere near those people. (Father to 9-year-old boy, ID 144)
	He will react very strongly to smells. For example, like the smell of fresh baked bread like if we're walking by a bakery, he will start kinda like gagging. So, it's hard, you know, in the school setting, he also has to go to the cafeteria or there's like a party. *(Mother to 6-year-old boy, ID 109)*
	I think a lot of her eating aversions have to do with sensory things. (Mother to 8-year-old girl, ID 116)
Sleep	On the days with difficult sleep there's more of a craving for carbs, you know, and he always wants carbs, but it's definitely more, "Can I have cake, can I have cookies?" (Mother to 6-year-old son, ID 110)
	Ask nine out of 10 parents, yes, our kids don't sleep. (Father to 9-year-old boy, ID 144)

3.3.1. Motivation-related barriers to care

In the Theoretical Domains Framework, motivation encompasses internal factors that impact behavior (e.g., beliefs, optimism, goals). A total of six subthemes emerged as motivation-related barriers to care for nutrition-related challenges for autistic children. Both healthcare professionals and parents shared one subtheme: *competing priorities for families,* identified by most participants in both groups. Examples of competing priorities included parents managing many appointments and medical therapies for their children and overall burnout when facing a child's more severe emotional or behavioral problems.

TABLE 4 Summary of themes regarding barriers and facilitators to care for nutrition-related challenges for autistic children.

Domain[a]	Shared subthemes: health professionals and parents	Subthemes among health professionals	Subthemes among parents
Theme: barriers to care for nutrition-related challenges			
Motivation *Beliefs, optimism, goals*	• Competing priorities for families	• Lack of parent compliance • Change may not be possible • Concerns that interventions worsen eating challenges	• Concerns not taken seriously • Judgment from providers
Capability *Knowledge, behavioral skills*	• Lack of autism-relevant information • Providers unsure how to help	–	• Child's growth in normal range
Opportunity *Environmental context and resources*	• Lack of access to nutrition services • Limited time during visits • Difficult doing nutrition education with child present • Family financial limitations	• Limited referral options	• Unaware of how to navigate services
Theme: facilitators to care for nutrition-related challenges			
Motivation *Beliefs, optimism, goals*	–	• Realistic expectations for setting goals	• Other parents of autistic children offer support
Capability *Knowledge, behavioral skills*	• Individualized support	• Embracing slow progress	• Mental health professionals offer support • ABA therapy helpful for feeding
Opportunity *Environmental context and resources*	• Access to an interdisciplinary team	• Nutrition-related screening part of practice	–

[a]Based on the theoretical domains framework of behavior change.

> *So what happens is a lot of the things can be lost in translation because the parents are tired. They have a lot going on. They work, they have the kids. (Registered dietitian nutritionist, ID 217).*

> *Honestly, we had other more behavioral concerns to address. It [his growth] just wasn't a priority to me. (Mother to 10-year-old boy, ID 119).*

Among health professionals, three subthemes emerged, centered on either parent or child motivation: (1) *lack of parent compliance*, (2) *change may not be possible*, and (3) *concern that intervention worsens eating challenges*. Many professionals expressed concerns that some children were simply too resistant to change and, thus might not successful.

> *If we were trying to increase activity or we were trying to change intake to foods that were lower in calories or healthier choices, it was one thing to recommend it, and it was another thing to actually have it take place. Mainly because the child would be unwilling to do it. (Pediatrician, ID 225).*

> *I also see kids that will very repetitively eat the same thing all the time, and I know that it's unhealthy for them instinctually, but it's hard to do anything about it because they're so entrenched in their schedule and their diet. (Occupational Therapist, ID 223).*

Some health professionals thought parents avoided addressing nutrition or diet issues because they were concerned that intervention would cause more harm than good.

> *I think the concern for a lot of parents, too, is like they're wary of working on it because they don't want their kiddo to like stop eating everything altogether. And they're eating really unhealthy foods, but at least they're eating you know. (Board Certified Behavior Analyst, ID 221).*

> *Parents are afraid that if they don't give the kids what they know that they'll eat, that the kids will not be gaining weight. That further restricts their diets or further narrows their diets. (Pediatrician, ID 222).*

The two main barrier subthemes among the parent group focused on medical professionals' motivation. Parents identified (1) *concerns not taken seriously* and (2) *provider judgment* as barriers to their child's care. Many parents reported that professionals were unmotivated to address nutrition-related concerns, despite parents expressing a desire to.

> *Because one, most doctors, and I hate to say it like this, but can be very condescending to a patient's requests or concerns. Yeah, they see the child for five minutes in the appointment, but we, as the parents, live with the child 24/7. The parent input is very important, and the concerns need to be addressed. (Father to 9-year-old boy, ID 144).*

Some discussed conversations with professionals that made them feel judged, leading parents to feel unsupported.

> *The general pediatrician has not been very receptive. He tends to brush these things off. Sometimes I feel that in discussions on picky eating, they tend to be kind of like judgmental, and it falls hard on the parent. (Mother to 6-year-old boy, ID 109).*

3.3.2. Motivation-related facilitators to care

While no shared subthemes for motivation-related facilitators to care emerged across both groups, two main subthemes emerged. The first, *having realistic expectations*, emerged from the health professional group, and centered around reasonable goal-setting with parents. Professionals described how too many or unrealistic goals could inhibit motivation and progress for their patients.

> *I think that trying to break it down for parents usually makes it less daunting and makes them more able to grasp and practice what it is we talk about in the office at home. (Pediatrician, ID 222).*

Among the parent group, a critical motivation-related facilitator was *support from other parents of autistic children* to offer motivation for nutrition care. When parents would get discouraged, they often cited other parents as being a source of inspiration and encouragement to continue addressing their children's challenges.

> *Nothing helps outside other than the mommy group talks that we ask each other like, "What works for your kid?" And that's been helpful. But it's super common among all our moms that our kids don't want to eat and have a hard time. (Mother to 3-year-old boy, ID 104).*

3.3.3. Capability-related barriers to care

Capability is defined as having the necessary knowledge and skills required to engage in a behavior. In this case, the behavior could be education or referral for nutrition-related challenges for autistic children. A total of three subthemes emerged as capability-related barriers to care.

The first subtheme centered around *a lack of available autism-relevant information*. Both groups described that many online resources, books, and handouts were geared toward neurotypical children and didn't always apply to the needs of autistic children.

> *I think it's difficult because even if we have nutrition classes or supplemental information for the parents to look into, very rarely are they specifically for autistic kids. (Pediatrician, ID 227.*

Additionally, both groups suggested that *providers are unsure how to help,* either because providers lack nutrition knowledge or awareness of referral options. Professionals acknowledged limitations in their knowledge and training about nutrition and autism, which was echoed by parents feeling that they, "*haven't gotten much help*" from their child's healthcare team (ID 118). One pediatrician explained (ID 225),

> *"Most of us didn't get much nutrition education in medical school or residency."*

A consistent theme from several parent interviews was that *their child's normal growth* was a barrier to care. Parents indicated that they felt providers lacked the knowledge about the impact and importance of a balanced diet despite a typical growth pattern. This theme repeatedly emerged among parents who expressed significant concerns about selective eating patterns.

> *His doctors, they don't seem too concerned because he's not losing weight. (Mother to 13-year-old boy, ID 135).*

> *But I haven't felt a lot of support from the nutrition part because they think he is good cause he's at a good weight. (Mother to 3-year-old boy, ID 104).*

3.3.4. Capability-related facilitators to care

Four subthemes emerged as capability-related facilitators to care. The first, *individualized support*, was identified across both groups as critical to promoting nutrition care for autistic children. Parents explained the importance of "customized" strategies to address challenges, and providers described the need to consider culture, income status, and the needs of each child/family.

> *I'm taking into account the family's culture, so what their daily routine is like, what their menu, what type of food that they're usually eating and then making sure that the interventions and strategies that I teach and educate the parents with can easily fit it to their everyday routine. (Occupational Therapist, ID 224).*

Health professionals specifically identified the need for *embracing slow progress* when making nutrition-related changes. This requires educating parents about progress expectations and avoiding overwhelming them with too much information.

> *Definitely flexibility, patience, the ability to go in at a slow pace and take baby steps and not have expectations that are out of line with what the parent feels they can do. (Speech-Language Pathologist, ID 214).*

Two subthemes that emerged only in the parent group were the specific capabilities of *mental health professionals* and *Applied Behavioral Analysts* in facilitating nutrition-related care. Parents explained that these providers spent more time monitoring lifestyle habits (e.g., eating, sleep, and activity) than others. Specifically, psychiatrists were identified as key facilitators of nutrition-related care among multiple parents, as they were more attentive to weight shifts due to medication management.

> *I've gotten the most feedback and understanding from a neuropsychologist. Somebody that has a little bit more understanding of the nervous system itself and sensory relation. And not just, "Oh, it's anxiety," or, "He'll outgrow it." or, "Keep trying." (Mother to 11-year-old boy, ID 100).*

> *One of the psychiatrists he was seeing actually recommended that because I was giving him like a Pedisure, and he's like,*

> *he's getting bigger. She says give him this because it has more carbs and more protein, and that's what he needs. (Mother to 13-year-old boy, ID 135).*

3.3.5. Opportunity-related barriers to care

Opportunity is defined as the presence of external factors that make a behavior possible, including environmental context and resources. The greatest number of barrier themes emerged within the Opportunity domain, with six emergent subthemes.

Both groups identified *a lack of access to nutrition services*, primarily related to feeding therapy or registered dietitian nutritionists understanding autism.

> *Even if parents are willing and wanting to put in the work, a lot of times, there's not the service available to guide them. (Pediatrician, ID 222).*

> *I can't actually have a dietitian on our team unless our doctor refers us because of our medical insurance. (Mother to 11-year-old boy, ID 100).*

Both groups also described two limitations during visits, which included *limited visit time* and *difficulty doing nutrition education with child present* at a visit.

> *A lot of us already have large scopes of practice, and it's like [nutrition care] that's such an important aspect, and yet we just don't have time. (Speech-Language Pathologist, ID 218).*

> *Having an autistic child with you at the pediatrician's office, I don't feel like you have the time to really focus on your answers. I'm not going to retain much because my brain has just been in fight or flight at that point!" (Mother to 4-year-old boy, ID 128).*

Finally, both groups discussed how *financial limitations* impacted access to healthcare services and healthy foods. A few providers explained that feeding therapy requires buying and trying multiple types of foods that can be wasted, which is not always feasible for their patients.

> *So, some of it is the resources of just having the money to buy the food or to maybe screen different foods, right? You know, we say, "Hey, why don't you go buy this, this, this, and this?" (Board Certified Behavior Analyst, ID 220).*

Parents echoed health professionals' concerns about being able to purchase affordable foods that their provider recommended and that their child would eat, and providers explained that food insecurity also could impact therapeutic sessions.

> *And there's just no good options. A working mom, working single mom to [be able to] give him unprocessed foods that have plenty of nutrition and protein. (Mother to 7-year-old boy, ID 118).*

> *A lot of my families too, who are very low income… in not having control or influence on what a kid eats and whether or not they're hungry. That can change the way an entire session with the child will go or an entire day a child will have. (Board Certified Behavior Analyst, ID 219).*

3.3.6. Opportunity-related facilitators to care

Two subthemes emerged as opportunity-related facilitators to care. The first appeared across both groups was *access to an interdisciplinary care team that included a nutrition professional* or therapist with expertise in nutrition. Parents who had access to these types of teams explained how their "team of therapists" gave them access to professionals who could answer their questions. Health professionals also felt access to others across disciplines, especially a registered dietitian, helped promote nutrition care.

> *Oh, the registered dietitians on our team, for sure. Yeah, I'm really lucky that we have RDs in-house cause I definitely feel very lost without them. (Occupational Therapist, ID 211).*

> *I think it's really a team approach. I think you have to have a nutritionist who understands what autism is, but you also need to have physicians or developmental-behavioral pediatricians who understand how to understand the child's unique characteristics. (Developmental Pediatrician, ID 233).*

Finally, a subtheme that emerged only among health professionals was how *nutrition-related screening* could facilitate care by stimulating discussions with families. Typically, this was described in the context of intake among only a few participants, namely pediatricians/developmental pediatricians, registered dietitians, and occupational therapists. Some examples of screening included the regular use of growth charts (i.e., height, weight, body mass index), adaptive skills history, intake forms related to diet or sensory challenges, and conversations with parents about eating issues.

3.4. Education opportunities and resource availability

When asked to identify potential educational topics and resources needed to address nutrition concerns for autistic children, participants discussed various topics of interest and delivery platforms. A summary of themes and subthemes can be found in **Table 5**. A complete table of themes and illustrative quotes can be found in **Supplementary Table S2**.

Overall, both groups were interested in learning more about dietary guidelines specific to autism, behavioral strategies to address food selectivity, dietary supplements (e.g., probiotics, fiber), and the efficacy of specialized diets such as gluten-free and casein-free diets, both of which are commonly sought alternative treatments parents turn to for children with ASD with limited evidence (26).

TABLE 5 Summary of themes regarding desired educational topics and resources related to nutrition-related challenges for autistic children.

Shared subthemes: health professionals and parents	Subthemes among health professionals	Subthemes among parents
Desired topics for education regarding nutrition-related challenges for autistic children		
• Dietary guidelines specific to autism • Behavioral strategies to address food selectivity • Dietary supplements • Efficacy of specialized diets for autism	• General autism education • Basic nutrition and feeding • Steps to take for providing support	• Meeting dietary needs within a restricted diet • Gut health • Pica
Desired resources to address nutrition-related challenges		
• List of local specialists or providers • Parent-friendly website	• Access to a registered dietitian nutritionist for professional advice • Evidence-based paper materials to supplement conversations	• Community groups

Health professionals—mainly pediatricians—identified interest in learning more about autism generally, while others emphasized learning basic nutrition and feeding recommendations. Professionals were also eager to understand the necessary steps for providing evidence-based nutrition-related support, particularly regarding referrals to other interdisciplinary team members.

> *I feel like oftentimes we can address it [nutrition concerns], but we would need access to a dietitian or knowing when we should go to them. (Occupational Therapist, ID 231).*

> *Because eating is a behavior, but it's also internal, and it's also psychological, and it's also oral motor. So, there needs to be like a really good cohesive, comprehensive team that's there to support the child in feeding. (Board Certified Behavior Analyst, ID 219)*

When asked about potential platforms for delivering nutrition education or resources, both groups identified the need for a clear list of relevant resources, including specialty providers with nutrition and feeding expertise.

> *A list of local professionals that we can refer people to, whether or not they take insurance, and what age groups they work with. (Speech-Language Pathologist, ID 214).*

> *Maybe if there is an actual website that they can direct us as parents of where to go. (Mother to 3-year-old boy, ID 136).*

Both also suggested the need for evidence-based parent-focused web resources that health professionals and parents could reference. While some health professionals discussed the benefits of having access to a dietitian on consult for professional advice, many expressed difficulties in referring patients to dietitians due to a lack of awareness of local availability, with some desiring more physical nutrition resources on hand (e.g., handouts, pamphlets) to provide to families when a referral to a dietitian is not possible. Moreover, parents suggested that more community-based offerings like feeding or food play groups, even informal ones, should be made available to support meaningful connections to other families facing similar struggles.

> *I do believe they should have eating groups and that there should be groups in my town of people like, you know, getting their kids together to try new foods and play with food. (Mother to 9-year-old boy, ID 107).*

4. Discussion

Our qualitative study revealed that while health professionals and parents of autistic children shared some perspectives on nutrition-related challenges and care for children with ASD, they also had distinct viewpoints. While both groups acknowledged the need for tailored support from an interdisciplinary care team, having reasonable expectations, and access to autism-specific educational resources and referrals, key themes arose which highlighted a mismatch in priorities between the two groups across several domains.

4.1. Addressing nutrition-related challenges

It was evident that both health professionals and parents of autistic children were motivated to address the numerous nutrition-related challenges faced by children on the spectrum. These findings are encouraging given that nutritional deficiencies, overweight, and obesity are a concern for children on the spectrum and can significantly negatively impact a child's physical, emotional, and cognitive well-being if left unaddressed (12). While health professionals tended to prioritize weight imbalances or complex medical nutrition issues, parents emphasized upstream challenges that impacted their child's quality of life, including food selectivity and sleep disturbances affecting appetite.

Selective feeding emerged as a key theme among parents, even if their child was experiencing typical growth. Selective eating can lead to meal-related anxiety, social isolation, and conflicts during family meals (27, 28). Parental attempts to manage selective eating may also lead to more obesogenic feeding practices, such as using screens to promote consumption, using food as bribes or rewards, and an increasingly limited diet of heavily processed foods (29, 30). Likewise, poor sleep is linked to overweight and obesity among children (31), but few professionals identified it as a concern to address, contrasting with nearly all parents who cited it as a priority concern. Even when a child is within a healthy weight range, lack of sleep over time can increase the long-term risk of overweight or obesity.

4.2. Barriers and facilitators to care

4.2.1. Motivation

While some health professionals perceived parents as lacking motivation or the ability to make changes, parents felt that health professionals themselves lackthe ed knowledge and expertise to take concerns seriously, thereby affecting their own motivation. In the newly released clinical practice guidelines for overweight obesity, the American Academy of Pediatrics recognizes that tailored advice is often deficient in healthcare for children with disabilities, which can widen health disparities (32). The guidelines recommend using motivational interviewing as a patient-centered approach to behavior change.

Motivational interviewing requires healthcare professionals to identify and reinforce the patient/parent's motivation to change when working with families (32). Suppose professionals are better aware of parent motivations. In that case, they may be able to facilitate more productive and collaborative strategies for addressing nutrition-related challenges when children are not yet ready to engage in decision-making. In our study, some parents expressed hesitance in discussing food-related issues because they felt that health professionals passed judgment when their children had selective diets or ate unhealthy foods. Motivational interviewing techniques, including non-judgmental, open-ended approaches and simple affirmations of challenges, may be positive and effective ways to engage in critical nutrition-related conversations with parents.

Another way to potentially address motivation-related challenges may be to educate providers about health disparities and practice limitations faced by autistic children. Research shows that using data to highlight practice deficiencies with providers can be one way to promote more family-centered care (33). A recent meta-synthesis of parent experiences with healthcare for their autistic children suggested that some medical providers are unaware of what they do not know about autism, which can lead to communication barriers and inadequate healthcare delivery (34). One concrete recommendation from the study was for providers to allow parents to be more active in contributing their expertise about their child during visits.

4.2.2. Capability

The lack of autism-specific nutrition-related knowledge was a clear barrier for professionals and parents. Parents often perceived health professionals' lack of addressing nutrition challenges or growth concerns as indifference, but the professionals shared that they felt ill-equipped to offer meaningful solutions for their autistic patients who faced unique behavioral and sensory challenges. In our study, most allied health professionals reported inadequate knowledge and training on nutrition needs for children with autism and felt uncertain about when to refer or provide care. Unfortunately, research shows that children with developmental disabilities such as autism often do not receive needed referrals for specialists (35).

In most cases, pediatricians are the primary medical contact for parents and are often perceived as the most authoritative and credible source for health-related information, including nutrition (36). However, not all general pediatricians are comfortable discussing ASD treatment options with parents due to a lack of knowledge about autism (37), even leading some pediatricians to discourage treatment or necessary therapies, which can lead to increased challenges for children as they transition into adulthood (38). In our study, multiple pediatricians acknowledged that their medical training did not emphasize nutrition. Therefore, pediatricians may benefit from additional autism-focused training, especially concerning nutrition care.

Our findings suggest that interdisciplinary healthcare professionals could also benefit from training on identifying nutrition-related risks, providing basic nutrition education, and making appropriate referrals as needed. The National Research Council Committee on Nutrition in Medical Education and the Institute of Medicine recommend a minimum of 25–30 h of nutrition education for medical professionals to understand nutrition concepts. Previous research has shown that medical professionals can increase their nutrition knowledge by participating in a 2-credit-hour elective course in clinical nutrition or a 1.5-credit-hour course on nutrition and lifestyle modifications during an academic year (39). Basic training on promoting healthy lifestyle habits, including physical activity, sleep, and screen use, could also be beneficial across disciplines.

4.2.3. Opportunity

Our study found that despite encountering nutrition-related challenges regularly, few health professionals reported using regular diet/lifestyle screening for their patients with autism. Recommendations published by the American Academy of Pediatrics in 2020 propose that autistic children receive regular assessment of both growth and nutrition/lifestyle factors, regardless of their weight status (40). The guidance also recommends assessing many of the nutrition-related challenges our participants identified, including sleep, gastrointestinal problems, and psychotropic medications.

Although screening is important, it is not enough to meet the needs of patients who require more guidance. According to a position paper published by the Academy of Nutrition and Dietetics, nutrition services conducted by registered dietitian nutritionists are an essential element for effective interdisciplinary care of children with developmental disabilities like autism (41). However, many professionals and parents in our study reported limited resources related to nutrition services. Several medical professionals expressed the need for a list of local specialists, such as registered dietitians, to whom they could refer patients for nutrition care assistance. Others indicated the need for a better understanding of how and when to trigger referrals and what red flags to look for that would warrant more support for a child. Further research could explore the impact of basic nutrition-related screening and intervention in interdisciplinary settings.

4.3. Education opportunities and resource availability

Healthcare professionals and parents of children with autism desire more autism-specific educational resources on websites and handouts related to dietary guidance, food selectivity, dietary supplements (such as probiotics and fiber), gut health, and pica. The availability of nutrition-related resources to the public may give parents access to knowledge, even when medical professionals cannot provide it. Consistent with other literature on parents of children with neurodevelopmental disabilities (16), parents in this study identified other parents of autistic children as an essential source of nutrition information when specialists were unavailable and desired more community resources and opportunities to connect with other parents using evidence-based materials. Notably, our participants rarely discussed physical activity despite its essential role in growth, mental health, and appetite (25). This could be due to a lack of awareness or lack of community resources. Inclusive opportunities for physical activity are often lacking for children with autism and other developmental disabilities (16), thus leading to increased levels of physical inactivity among this population (19).

4.4. Implications

This qualitative study is one of the first to compare attitudes toward nutrition care for autism between interdisciplinary professionals with diverse practice backgrounds and parents of children with ASD. One strength of the study was the ethnically diverse group of parent participants, including those with autistic girls who are less studied and fathers who are often excluded from feeding and parenting research (19, 42). However, the generalizability of our findings may be limited as our sample focused on health professionals and parents in California, and access to services may vary regionally. In addition, our data were collected between 2019 and 2020 and may not reflect changes in healthcare delivery and attitudes toward nutrition and dietary behaviors during the COVID-19 pandemic. Finally, the study was conducted only in English, limiting perspectives of non-English speaking families. Future studies could assess a broader range of parents and healthcare professionals across regions, races, and ethnicities, and levels of support needs for children with autism.

5. Conclusion

Our qualitative study found that while healthcare professionals and parents of autistic children shared some perspectives on nutrition-related challenges and care, there were also significant points of divergence that require further exploration. We found that while interdisciplinary health professionals who serve autistic children were motivated to provide care, many face challenges in accessing nutrition-related knowledge and resources. Parents often perceived providers to lack concern about nutrition-related challenges, which could be more due to a lack of resources than motivation. In these cases, nutrition-related challenges could be addressed by an interdisciplinary team or through referrals, though few professionals described referring out to registered dietitians. Both groups expressed interest in accessing autism-specific resources for education, referral, and screening guidance. Future research could explore developing healthcare training models that improve the competency of health professionals in providing nutrition care and promoting evidence-based guidance for children with ASD. These findings underscore the need for more integrated approaches to nutrition care for autistic children, which could ultimately improve their overall health and well-being.

Data availability statement

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

Ethics statement

The studies involving human participants were reviewed and approved by Institutional Review Board at California State University, Long Beach. The patients/participants provided their written informed consent to participate in this study.

Author contributions

RB led the study design in consultation with KB, RB, CB, KC, and AL contributed to data collection and cleaning. RB, KB, KC, and CB, contributed to data analysis, interpretation, and writing. All authors contributed to the article and approved the submitted version.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Publisher's note

Supplementary material

The Supplementary Material for this article can be found online at: https://www.frontiersin.org/articles/10.3389/fped.2023.1198177/full#supplementary-material

Footnote

How we talk about autism can reflect and reinforce ableist beliefs, as shown in the growing body of literature (43, 44). We recognize that there are differing opinions among the autistic community regarding preferred language and terminology (45, 46). Therefore, to show respect for these varying perspectives, both person-first (e.g., a child with ASD) and identity-first (e.g., an autistic child) language will be used.

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GamerFit-ASD beta test: adapting an evidence-based exergaming and telehealth coaching intervention for autistic youth

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Background: Health disparities faced by autistic youth are exacerbated by inadequate physical activity (PA) and sleep, whereas healthy PA and sleep may improve mood and function. Adaptive Game Squad (AGS) is an evidence-based telehealth coaching and exergaming intervention to improve PA and sleep for adolescents with diverse neurodevelopmental and psychiatric conditions. This study aimed to adapt AGS for autistic youth ages 10–15 years; beta-test the modified intervention for feasibility, accessibility, and engagement; and further refine the intervention for a larger planned demonstration pilot.

Methods: Interdisciplinary experts adapted AGS to create GamerFit-ASD, a 12-week intervention that included a progressive exergame schedule, Fitbit step-tracking, weekly health coaching, and health tip/exercise videos. For beta testing, the intervention was shortened to a 4-week trial with 5 parent/child dyads. Children completed exit surveys and parents and children were interviewed about intervention feasibility, accessibility, and engagement. Exit survey data were summarized with descriptive statistics. Qualitative data were analyzed using a modified grounded-theory approach.

Results: All participants (*n* = 5; ages 10–14 years) attended all 4 planned coaching sessions and completed an average of 9 of 12 planned exergame challenges for a weekly average of 50 min. All participants reported enjoying coaching sessions, 4 of 5 reported enjoying exergames, and 3 of 5 reported enjoying on-demand exercise videos. In interviews, children generally reported finding participation feasible, exergaming challenges active and fun, and coaches friendly and helpful. Parents reported high feasibility of supporting their children's involvement and valued child goal-setting and intervention flexibility; however, some found telehealth sessions overly scripted. Several adaptations to coaching scripts, coach training, and parent materials were made for the larger demonstration pilot, including changes to reduce scriptedness of coaching sessions, to provide parents with more information specific to autism, and to make video content more appropriate to children's needs/preferences.

Discussion: A telehealth coaching and exergaming intervention appears feasible, accessible, and engaging for autistic youth aged 10–15. Future studies with larger, more diverse samples, longer study durations and/or follow-up periods, and more rigorous study designs are needed to advance understanding of the appropriateness and effectiveness of this type of intervention for this population.

KEYWORDS

exergaming, exercise, telehealth, autism spectrum disorder, physical activity, health promotion

1. Introduction

Approximately 1 in 36 children in the United States has autism spectrum disorder (1), a developmental disability characterized by restricted interests, repetitive behaviors, and challenges with social communication (2). Autistic children and adolescents face considerable health disparities (3–5). For example, autistic youth have about twice the risk of obesity compared to youth without autism (6). Elevated chronic disease risk in this population is partially rooted in a variety of early and persistent behavioral patterns (7, 8), including lower physical activity (PA) levels (9), poor sleep quality (10, 11), and elevated screen time (6) compared to typically developing peers. Such behaviors not only confer increased health risks across the life course but also intensify the cognitive and behavioral challenges experienced by this population (10, 12, 13). By contrast, independent of the positive cardiometabolic effects of PA, over 25 studies in individuals with ASD (14, 15) have documented associations between increased PA and improvements in anxiety (16), executive functions such as the ability to focus and self-regulate (17), and meta-cognitive processes (15). Importantly, there is emerging evidence that engaging in low to moderate PA is associated with these improvements (18, 19), increasing the viability of PA as a potential therapeutic modality.

Increased PA can also support improved sleep in autistic youth (12). This combination may be powerful, given mounting evidence that interventions increasing PA and sleep quality can produce clinically meaningful improvements in daily function among individuals with autism (10, 12, 20). In the case of PA, our team's cybercycling intervention in youth with heterogenous psychiatric and neurodevelopment disorders, including autism, reduced the odds of poor self-regulation and disciplinary time out of class by 32%–51% (21). Likewise, for sleep, a randomized controlled PA trial conducted among autistic youth found that significant improvements in sleep predicted improved inhibitory control (12). Despite the potential benefits of increasing both PA and sleep in autistic youth, it is rare for behavior change interventions to address multiple needs by targeting both behaviors.

Autistic youth face significant barriers to PA and planned exercise engagement (9, 22). A recent systematic review by our team (23) found key structural, caregiver, and child barriers to participation in physical education classes (including adaptive classes) and in community-based PA programming and exercise interventions. Most exercise interventions are delivered face-to-face and target younger autistic children, rather than those in the pre-teen and teen years, when unhealthy habits tend to increase (24, 25). A common focus on high-intensity exercise in group environments, which are often loud and chaotic, discourages participation and retention among many autistic youth (26, 27). Moreover, focusing on in-person interventions is resource-intensive and depends on often depleted familial social capital (22).

Exergames are video games that require physical movement to play. They are relatively inexpensive, require little space to play, can be played alone or with a partner, and can be targeted for a variety of developmental levels. Because they explicitly meet the preferences of young people, exergames have been used effectively to improve moderate-to-vigorous PA (MVPA) in autistic teens (28). Additionally, telehealth coaching has also been used effectively to deliver behavioral health interventions to autistic youth and their families, lowering intervention resource intensity and reducing barriers to engagement (29). However, no prior interventions have integrated exergaming with telehealth coaching to promote PA engagement and improve sleep among autistic youth.

The present study aimed to fill this gap by modifying Adaptive GameSquad (AGS), an exergaming and telehealth coaching program, specifically for autistic children. Prior to the present study, the AGS intervention was developed by adapting GameSquad, a Social Cognitive Theory-based exergaming and telehealth coaching program that improved MVPA and BMI in racially diverse children ages 10–12 years with overweight and obesity (30). This adaptation was informed by the disability-health Empowerment Model (31), and AGS's feasibility was tested for use among older youth (12–17 years) with heterogeneous neurodevelopmental and psychiatric diagnoses, including autism (32). Although the feasibility trial indicated that AGS was appealing and engaging for younger autistic participants, it was not specifically developed for autistic youth. It was also not designed to be appropriate for those with a co-occurring intellectual disability, which affects about 38% of autistic children (1). In addition, the games were not tested for useability for participants who were younger than 12, and the AGS coaching scripts were originally developed for use with older teens. To our knowledge, no prior studies have modified a telehealth coaching and exergaming intervention specifically for autistic pre-teens and teens or tested such an intervention for feasibility, acceptability, and accessibility.

To address that knowledge gap, the current study aimed to (1) use an inclusion team science approach (33) to modify the original AGS intervention and materials specifically for youth ages 10–15 years with ASD; (2) beta-test the modified intervention for feasibility, accessibility, and engagement; and (3) use beta-testing results to further refine the intervention for feasibility and preliminary efficacy testing in a larger 12-week demonstration pilot.

2. Methods and materials

Figure 1 depicts the conceptual model of this study, including the initial adaptation of the AGS intervention, the aims of the beta test, and the beta test design, and the sections that follow describe how this model was operationalized.

All study procedures and materials were approved by the Tufts University Institutional Review Board (IRB).

2.1. Pre-beta test intervention adaptation

The original AGS intervention was a 10-week intervention featuring a paper-based challenge menu provided to participants along with necessary equipment (Xbox, three exergames, and Fitbit). The intervention is extensively described elsewhere in the literature (34), so only a summary overview relevant to the modifications undertaken is provided here.

In the original AGS, an Xbox was installed in each participant's home by study staff, and participants played a specific selection of exergames, presented on a challenge menu, three times per week, building from 10 min to 45 min daily over the span of the intervention. Participants were also challenged to meet incrementally increasing daily step goals tracked by a Fitbit that was wirelessly uploaded to their coach. In the original AGS, the participants and a parent/caregiver met with the coach via Skype on the Xbox each week for the first 2 weeks, and then every other week for the remainder of the intervention.

To further adapt the AGS intervention, we used an inclusion team science approach, whereby health researchers who work with the general population work collaboratively with disability researchers to adapt health-promotion programs (33). To that end, the research team included an autistic adult consultant, the parent of an autistic teen, a developmental psychologist, a pediatrician, a clinical psychologist, a clinical social worker, and behavioral scientists with expertise in adaptive PA, sleep, and nutrition interventions. Several of the disability researchers were also family members of individuals with autism and/or an intellectual disability. Components of AGS that might need to be modified for autistic youth aged 10–15, including those with an intellectual disability, were identified based on the expert opinion of the individuals on this team. These included: (1) telehealth coaching session scripts and session frequency; (2) challenge menu wording, step goals, and exergaming duration; and (3) exergame and gaming console accessibility to ensure that children of younger ages and those with mild to moderate intellectual disability could understand how to start, successfully play, and progress with the exergames.

Feedback from participants and parents in semi-structured interviews following the original AGS indicated that additional intervention components would be helpful to improve engagement, reduce parental burden, and facilitate the transition from screen-based PA (exergames) to non-screen-based PA. These additional components requiring development included: (1) an integrated delivery platform to simplify intervention access for parents; (2) enhanced technology support and troubleshooting materials; (3) motivational text messages to promote participant engagement between coaching sessions; (4) health tip videos to reinforce health literacy content introduced during coaching sessions; and (5) on-demand exercise videos to promote non-exergame-based PA and help participants meet step goals. The team attempted to address item #1 above by developing an integrated, web-based platform on which to host intervention materials, but this could not be achieved due to budget constraints and institutional restrictions regarding security. Instead, a hybrid system was developed using REDCap$^{\text{TM}}$ (35) to deliver electronic versions of study materials and tracking forms in addition to providing all materials to families as paper copies.

Prior to beta-testing, the research team undertook a comprehensive review of the original AGS materials and adapted them based on priority population needs and feedback from the original pilot. Adaptation also required evaluating nine different developmentally appropriate exergames on three gaming platforms (Xbox One$^{\text{TM}}$, PS4$^{\text{TM}}$, and Nintendo Switch$^{\text{TM}}$) and selecting both a platform and suite of games based on their suitability, accessibility, and affordability prior to beta testing. The Nintendo Switch was selected based on affordability and ease of set-up and use. Ring Fit Adventure and Just Dance 2021 were the games selected based on the variety of modalities and intensity of exercise elicited, accessibility, and perceptions of acceptability among experienced team members. Based on feedback from AGS, motivational text messages were also developed to reinforce messages from the coaching sessions (e.g., providing positive feedback for reaching goals). Finally, on-demand exercise and health tip videos were developed for beta-testing. These included four short on-demand exercise videos (two promoting aerobic activity, one promoting stretching, and one promoting simple strength exercises) and two health tip videos (one promoting healthy bedtime routines and the other promoting trying new healthy foods).

2.2. Beta test population

Beta-testers comprised five dyads of autistic youth ages 10–15 years and their parents. A sixth dyad, which included a child with an intellectual disability, was recruited and consented but had to withdraw before the beta test began due to unrelated medical issues. ASD and intellectual disability diagnoses were parent-reported, and dyads had to speak English or have a competent translator present for coaching sessions and interviews. Participants were recruited using clinician and social media networks, with purposive sampling to ensure representation across gender identity, age, and race/ethnicity.

2.3. Implementation of beta test intervention

The beta-test was a 4-week feasibility and engagement trial of the intervention with the five parent/child dyads. The original

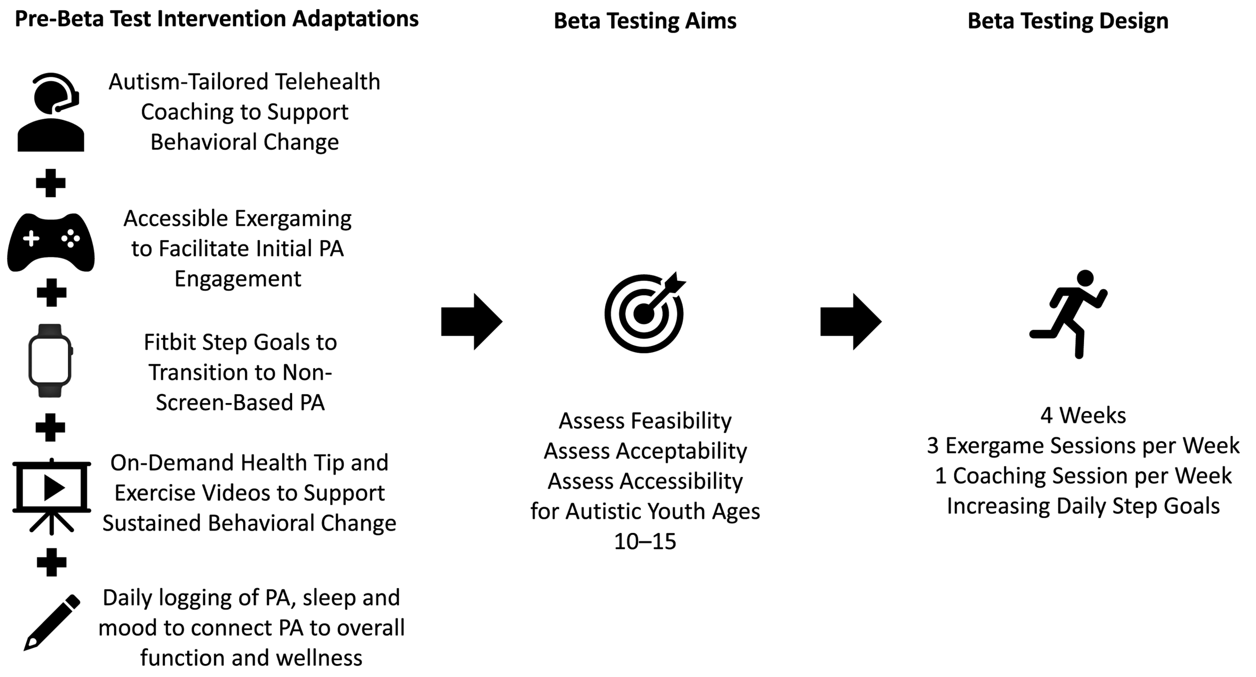

FIGURE 1
Conceptual framework for the GamerFit-ASD beta test.

AGS intervention included professional health coaches from Pennington Biomedical Research Center (PBRC) who led all telehealth coaching sessions. In contrast, to lower costs and increase potential for future replication, the beta test used a train-the-trainer model, with two non-professional coaches taking a lead role with support from PBRC coaches. The two coaches were a health sciences graduate student and a member of the research team, neither of whom had prior telehealth coaching experience. Prior to the intervention, the coaches completed a mix of asynchronous and live training sessions. Asynchronous sessions introduced the overall study design, the exergames used in the intervention, requirements for data management and reporting, and principles of effective coaching. The trainings on coaching strategies included two modules focused on considerations for working with autistic children, one led by a research expert and the other led by an autistic adult. The live training sessions included hands-on practice with the exergames and experiential role play activities to practice using coaching scripts. This combination was consistent with research showing that optimal train-the-trainer programs use a blend of experiential activities and didactic training (36, 37).

Weekly coaching sessions were delivered via HIPAA-compliant Zoom^{TM}. Following the standardized scripts, coaches reviewed exergaming and daily step goals for the prior, current, and upcoming weeks, provided encouragement and troubleshooting support as appropriate, and discussed other health tips (e.g., for trying new foods and reducing screen use before bed). The first two sessions were delivered jointly by newly trained coaches and professional PBRC coaches; the second two sessions were led independently by the new coaches. This approach gave the new coaches the opportunity to observe and learn from the experienced coaches before leading their own sessions, mirroring the approach that was planned for the full demonstration pilot.

Prior to the intervention, participants were provided wrist-worn Fitbits (Flex 2 model), a Nintendo Switch, and the two exergames (Ring Fit Adventure and Just Dance 2021). The intervention challenge menu included daily step goals, which started at 2,000 steps per day in week 1 and increased gradually to 2,750 steps in week 4. They also included three exergaming challenges per week, including a mix of Just Dance and Ring Fit Adventure games, with the target duration of each session increasing from 10 min per session in week 1 to 30 min per session in week 4. In Just Dance games, players mirror the movements of an avatar dancing to contemporary songs and earn points for accuracy. In Ring Fit Adventure games, players battle enemies and complete missions while engaging in active movement, like running and jumping. Participants had the option of tracking steps and exergaming using a paper version of the challenge menu. They were also asked to report their progress via a REDCap^{TM} survey at the end of each week; for each challenge they marked complete in the REDCap^{TM} survey, they would see a celebratory gif.

Motivational text messages were sent twice weekly to the parent's phone via Twilio, a web service that integrates with REDCap^{TM} and enables messages to be scheduled in advance for automatic delivery. Reminders to charge and sync the Fitbit and complete the challenge menu were also sent out via text twice weekly. Links to health tip videos and on-demand exercise videos, both hosted on YouTube, were sent via text in weeks 3 and 4.

2.4. Measures

Parents completed a demographic questionnaire after screening and consent/assent. Coaches recorded the completion of coaching sessions in REDCap^{TM}. Participants and parents reported the number of gaming sessions that were completed each week and the estimated duration of exergaming sessions via an electronic questionnaire delivered weekly via email from REDCap^{TM}. If they did not complete the weekly questionnaire, the missing information was collected during the next telehealth coaching session and entered in REDCap^{TM}. Each day parents also received a link, sent via REDCap^{TM}, for children to report their exercise behavior, sleep, and mood; these measures were used mainly for feasibility testing, not for outcome evaluation. In addition, children completed an exit survey (**Supplementary Material**) and children and parents completed a semi-structured interview (**Supplementary Material**) after the intervention concluded. The exit survey was adapted from the original AGS study and included items about whether the child enjoyed the exergames, coaching sessions, and on-demand exercise videos. The interview was aimed at understanding both participant and parent perceptions of feasibility, acceptability, and accessibility of the intervention. Interviews were approximately 45 min in duration and were conducted via Zoom^{TM}. Interviews were audio-recorded and then transcribed.

2.5. Data analysis

Descriptive statistics were aggregated to characterize participant demographic information. The total number of telehealth coaching sessions attended was tabulated for each participant. The number of participants indicating enjoyment of exergames, coaching sessions, and on-demand exercise videos was tabulated from the exit survey and from interview data. The Fitbit data were extracted from participants' accounts and mean steps per day calculated across the five participants for the 4-week intervention period. Interview recordings were transcribed and themes in the three domains (feasibility, acceptability, accessibility) were coded by a primary (WK) and secondary (DH) reviewer using a modified grounded-theory approach. In this approach, themes are inductively identified from interview responses, not deductively identified according to theory (38). The primary reviewer developed an initial codebook, which was used and added to by the secondary reviewer. Thematic coding results from the primary and secondary reviewers were then reviewed for discrepancies by a third, independent reviewer (AB) and any discrepancies reviewed by the team, with tie-breaking provided by the third reviewer.

2.6. Post-beta test intervention refinement

Based on findings from the beta test, including participant engagement data, exit survey data, and interview results, the full intervention was further refined for the full 12-week demonstration pilot.

3. Results

3.1. Participant demographics and program involvement

Table 1 describes participant demographic information and process data. The participants were mostly male and mostly White. One participant had an intellectual disability and four did not.

Overall engagement in the beta test was high, with all five participants attending all four planned coaching sessions. The average number of steps per day over the course of the intervention (8,009) exceeded the intervention step targets, which increased from 2,000 in week 1 to 2,750 in week 4. On average, participants completed three quarters of the planned exergame sessions, and they averaged a total of 200 exergaming minutes over the 4-week intervention. By comparison, the target exergaming times across the 4-week intervention totaled 225 min. The majority of participants reported enjoying the coaching sessions, the exergames, and the on-demand exercise videos.

3.2. Intervention feasibility, acceptability, and accessibility

A number of themes emerged through the child and parent interviews. These findings are presented in the following sections,

TABLE 1 Participant characteristics and process data ($n = 5$).

Participant characteristics	*N* or Mean (Range)
Age in years	11.6 (10–14)
Gender	
Male	3
Female	1
Non-binary	1
Race	
White	4
African-American/Latinx[a]	1
Parent-reported intellectual disability	
Yes	1
No	4
Process data	*N* or Mean (Range)
Number of coaching sessions attended (maximum: 4)	4 (4-4)
Fitbit steps per day	8,009 (1,951–14,582)
Exergame sessions completed (maximum: 12)	9 (7–12)
Mean exergame minutes per week	50 (31–63)
Reported enjoying coaching sessions	5
Reported enjoying exergames	4
Reported enjoying on-demand exercise videos	3

[a] The term Latinx is used here as a gender-neutral term to describe individuals of Latin American descent (39). Gender neutrality was determined to be of *a priori* importance when reporting demographics due to the high rates of gender-queer and non-binary identification among autistic youth (40).

organized into sub-sections for themes related to feasibility, acceptability, and accessibility of the GamerFit-ASD intervention.

3.2.1. Feasibility

Participating children generally reported being able to complete the weekly exergaming challenges, with some noting that they made changes to those challenges based on personal game preferences.

> "I beat every single thing. The last week, I didn't do the Just Dance, instead I did a ton of Ring Fit, half an hour to an hour of Ring Fit instead of half an hour of Just Dance." *(Participant 5)*

Notably, when participants were asked to reflect on what activities they would have done prior to the intervention during the time they spent exergaming, most reported that the exergames displaced sedentary activities.

> "Mostly probably just texting with my friends and writing music. That's pretty much it, probably." *(Participant 1)*

Although child participants generally recognized that the challenges became harder over the four weeks of the intervention, in terms of both the difficulty of the games and gaming duration, they generally found even the hardest weeks feasible to complete.

> "The final week was the hardest, but it wasn't actually too hard." *(Participant 5)*

However, participants did note factors that made it somewhat harder to complete the exergames, including mood and competing activities.

> "It was a little hard for the schedule because sometimes I might feel down, but for the most part it was okay." *(Participant 4)*

For child participants, feasibility of wearing the wrist-worn Fitbits was mixed compared to the exergaming. However, most participants reported wearing the device at least part of the time, though for some the amount of time was limited due to physical discomfort.

> "My parents would remind me, but it also just felt uncomfortable in my hands, so sometimes I would take it off." *(Participant 1)*

Parents likewise generally reported that it was easy overall to support their children's participation in the intervention.

> "It wasn't that hard. We had some challenges at times of him not wanting to do that, not wanting to work out, which is a challenge we have in general … but it really wasn't that difficult … Some days getting him to wear the Fitbit was a struggle, but for the most part he was a willing participant and it really wasn't that hard to support him." *(Parent 1)*

However, there were some exceptions, and one parent noted challenges with setting up the Fitbit and with managing the number of tasks required for study participants, particularly early in the intervention.

> "I mean it's like, 'Don't forget to put your Fitbit on. Don't forget to charge it overnight. Don't forget to do the form. Don't forget to fill out the form when you do the exercise.' I mean it was pretty intensive. But I would say by the end, it was much harder in the beginning and now I'm just like it's part of our routine." *(Parent 4)*

Participants' parents also reported challenges completing the daily logs about children's mood because the close-ended survey options often did not reflect the how the child was actually feeling.

> "I had some thoughts about the questions that were asked. I was like, 'where's tired in the descriptor of how I feel?'… I was like, 'what, how'd they pick these random words?'… It should be a write-in too." *(Parent 4)*

3.2.2. Acceptability

Participants generally reported enjoying the Ring Fit games. Some noted the particular appeal of the gamified elements of Ring Fit, like accumulating points.

> "I enjoyed Ring Fit … I enjoyed the fact that it made games, basically." *(Participant 1)*

However, one participant found the Ring Fit games excessively stimulating, both visually and auditorily.

> "Some of the [Ring Fit] games just did not work at all, the bright colored ones with flashing lights and visual noise all over the place, which was a lot of them." *(Participant 2)*

Compared with Ring Fit, children's enjoyment of Just Dance games was mixed. While some reported enjoying the games (or even preferring them to Ring Fit games), others did not, and lack of enjoyment was often related to disliking the songs:

> "I just dreaded doing it and I hated it while I was doing it. I don't know. I really don't know why… the ones I hated the most were the novelty songs, but we didn't always have to do those." *(Participant 1)*

Although participants generally enjoyed the games, some noted that they would value having additional options and variety in the games available.

> "I think adding one more to a bit of diversity, so you're not flipping, flipping, flipping, flipping between two games.

> Adding one or two more would just suffice … Variety is the spice of life." *(Participant 5)*

Notably, the one Latinx parent in the study spoke to the potential value in ensuring that games include culturally appropriate content, particularly in terms of music:

> "Maybe, because I'm a Spanish girl, maybe [include] more [culturally appropriate] music." *(Parent 3)*

Some participants indicated that even after the intervention's completion they intended to continue playing the exergames, particularly the ones that they preferred. Participants also reported high levels of engagement with monitoring their step counts through the Fitbit app. Similarly, parents reported that the aspects of the intervention that worked best for their children included having the opportunity to pursue challenges and to self-monitor progress toward goals, which kept them engaged and motivated.

> "Checking his steps motivated him, he's motivated by numbers, and just the whole thing really worked. I think having the Fitbit part of it really helped him because having that, how many steps did I get today? That was something he did like to know … Because he really enjoyed getting his average up." *(Parent 5)*

Participants also reported liking their telehealth coaches overall and enjoying the weekly coaching sessions, noting that the coaches were friendly, helpful, and easy to understand. Parents also generally had positive perceptions of coaches overall, including perceptions that the coaches were friendly, nice, and adaptable.

> "I think they both were very friendly and approachable, and [coach] asked some questions when he would notice that maybe [child] hadn't worn the Fitbit and would ask him, 'Can you tell me why? Is it uncomfortable?' So he would engage with him in that sense. So yeah, they were both friendly and nice and I think they worked well with him." *(Parent 1)*

On the other hand, the most common shortcoming parents reported about the coaching sessions was that at times it seemed apparent that the coaches were following a script, which may have made the sessions less engaging.

> "Definitely, it felt like they were following a script and a template mostly too." *(Parent 2)*

Parents also noted that they used both the paper log and the electronic log, accessed via a QR code, to track progress on the challenges. In some cases, those logs were used for different purposes; for example, some parents used the paper log to track activity throughout the week and then used the QR code to report overall results at the end of the week.

> "I did both. I would keep track of everything [on paper] and then I would go in, scan the QR code, and do it online." *(Parent 1)*

When asked if they would recommend participation in the intervention to other families, parents reported a positive disposition toward doing so, citing their overall positive impressions of the intervention. In particular, some parents noted that the program provided a valuable, enjoyable option for children who might typically resist PA.

> "I think especially for a kid like [child] though, he wanted to exercise, but he doesn't know how to bring himself to do it. He doesn't know how to get past some of his own anxieties. So this was great for him because it helped him get past his own fears." *(Parent 5)*

Some parents noted that their children demonstrated improvements in mood and/or in health behaviors other than PA, like improved sleep, which they attributed to participation in the intervention.

> "Mood improved … He slept better. He went to sleep easier. They noticed that at school, he was just a little bit calmer… Before he would have trouble going to sleep, and when he started this, he was tired finally for the first time in a while on a regular basis, which he used to be when he was swimming regularly." *(Parent 5)*

3.2.3. Accessibility

Overall, participants found both Ring Fit and Just Dance games relatively easy to learn. In some cases, prior experience or involvement of friends or siblings helped to increase their confidence in understanding how to play the games.

> "It [Ring Fit] was pretty easy. Yeah, it was really quick … I've already played Just Dance previously with some of my friends, so I already [knew how to play]"*(Participant 1)*

Despite the overall ease of learning to play the games, participants generally reported that both Ring Fit and Just Dance games did force make them to exert themselves physically, with most participants characterizing the games as eliciting at least moderate levels of exertion.

> "I think it [Ring Fit] was usually a moderate workout. It wasn't that hard, but it also wasn't easy. I was usually sweating and breathing relatively heavily." *(Participant 1)*

Participants generally reported that their gaming consoles were located in shared family spaces, like the living room, and some participants reported playing the games with siblings or parents in those spaces. Parents also noted the importance of customization and flexibility with both the Fitbit and exergaming goals. As the intervention progressed, participants tended to modify the exergaming challenges so they could play the games they liked best:

> "And then the coaches gave him the permission to deviate. So at the beginning he was like, 'Okay, I'm going to do exactly what it says.' But then he was getting tired of Just Dance because he didn't like it. So when they were like, 'Oh, if you want to do two Ring Fits and no Just Dance, that's okay.' And then he was like, 'Okay, this is great. I'm going to do that instead.'" *(Parent 5)*

Some parents also noted that it would have been useful to have even more flexibility in how children participated in the intervention, such as being more explicit about the option to swap out different exergames or providing a choice of both in-person and remote options for coaching sessions.

> "I would say having options for in-person or remote. That part was important … Something that might be cool is if … there were four video game options and you pick two?" *(Parent 4)*

In terms of the aspects of the intervention that worked best for them, parents reported that information was generally easy to access and that reminder messages helped them stay on top of study tasks.

> "The texts were good because that just pops up in my face and I just have to click on a thing and it goes right to that thing, and it doesn't require me finding the right device and getting the right … It doesn't require navigating a bunch of stuff. It just requires me to respond." *(Parent 2)*

Conversely, some parents noted that the text messages, health tip videos, and on-demand exercise videos sent to parents' mobile phones between sessions did not reach some children, and others noted that the videos were not entirely appropriate to their children's needs.

> "I see that one [on-demand video]. But when I say to him, he no pay attention a lot, because [it's] boring. That's for adult, but not for child." *(Parent 3)*

3.3. Program refinements

Given the generally positive feedback from both children and parents, most elements of the intervention were retained for delivery in a larger ($n = 23$ dyads), 12-week demonstration project. However, based on constructive feedback, several additional refinements were made to the participant orientation, videos, participant packet, coach training, coaching scripts, and evaluation forms. **Table 2** outlines these modifications and the underlying rationale for each. Broadly speaking, those modifications, together with the initial intervention adaptations, were developed to be consistent with principles from the Pediatric **P**hysical **A**ctivity Engagement for **I**nvisible Social, Emotional, and Behavioral **D**isabilities (PAID) Framework (41). PAID integrates disability-specific health behavior change theoretical constructs and implementation frameworks to inform the design and evaluation of interventions aiming to improve PA engagement and other health behaviors among youth with social, emotional and behavioral disabilities (41). **Table 2** additionally maps program modifications to specific constructs of the PAID Framework.

4. Discussion

Although telehealth coaching and exergaming have shown promise in typically developing youth (34, 42), the feasibility and acceptability of these strategies in autistic youth is less well understood. This study aimed to address this knowledge gap by further adapting a previously tested telehealth coaching and exergaming intervention (32) for youth aged 10–15 with autism and testing the intervention through a 4-week beta test. This test demonstrated good feasibility, with all child-parent pairs participating in all four telehealth coaching sessions and children completing three-quarters of the planned exergaming sessions on average. Findings from qualitative interviews also demonstrated high acceptability and accessibility of the intervention for participating children and parents. Overall, participating children, including the one child with parent-reported intellectual disability, reported finding the exergames easy to learn and the challenges feasible to complete, even as the games increased in intensity and duration over the four-week intervention period. They also reported that the games generally led to at least moderate-intensity exertion and most noted that the games displaced sedentary activities. These findings provide encouraging evidence that the intervention has the potential to contribute additively to daily MVPA, though additional evidence is needed to confirm this outcome.

The engagement levels observed in this study are slightly higher than those observed in the original AGS study (32), in which participants completed most coaching sessions (5 of 6 on average) and completed an average of 17 of the 30 planned exergaming sessions (57%). Anecdotally, our study team observed that children with ASD in that study ($n = 5$ of 11 total participants in the intervention group, all aged 12 or older, and without ID) demonstrated particularly high levels of engagement. The current study provides further evidence of the feasibility of this approach for autistic youth aged 10–15.

Parents' overall positive feedback regarding the intervention's feasibility and exergaming's possible impact on their children's behavior is encouraging given the importance of parental support for children's PA (43). Parents' perceptions that it was easy to support their children's participation is especially encouraging given the depleted reserve capacity that can result from the demands associated with managing a child's disability (22).

Some parents noted that the intervention was particularly acceptable and effective for children who might not typically be

TABLE 2 Adaptations made to GamerFit-ASD.

Program component	Description of modification	Rationale	Applicable PAID framework construct
Program orientation	Original approach: participants moved immediately into completing exergames and step challenges in week 1 of the intervention. Modified approach: week 1 was changed to an orientation week, focused on building rapport with the child and parent, explaining what participants could expect each week, and providing technical assistance on set-up and utilization of the Fitbit, Switch console, and exergames.	To strengthen coach-participant relationship building and alleviate early-intervention technical challenges that some families reported in the beta test.	Parent-level facilitator (ease of use)
Videos	Original approach: did not offer health tip videos or on-demand exercise videos. Modified approach: new health tip and on-demand exercise videos were created with detailed instructions and peer modeling.	To facilitate non-screen-based physical activity (PA) of different types (stretching, strength training, interval training) and to reinforce live health coaching with accessible health literacy videos.	Child-level self-efficacy (goal setting, action planning); reinforcement management and stimulus control (exploration of preferred PA, choice of PA modality and intensity); environmental facilitators (ease of participation, sensory aspects of programming setting)
Participant packet	Original approach: a participant packet provided to children and families included information about the intervention. Modified approach: the packet was updated to provide information on new topics including how GamerFit-ASD was tailored for autistic participants and specific considerations and tips related to PA, sleep, screentime reduction, and healthy eating for autistic youth.	To reinforce for parents the importance of healthy habits specifically for autistic youth and to clarify the rationale for the health tip and exercise videos, with the goal of encouraging parents to share them with their children.	Parent-level outcome expectations (explicitly connect PA to child symptom alleviation and overall wellness)
Coaching scripts	Original approach: scripts for weekly coaching sessions included word-for-word language that coaches could use to cover key topics. These scripts were originally developed for older teens with heterogeneous mental health and neurodevelopmental conditions. Modified approach: scripts were modified to describe topic areas in accessible terms but not to provide word-for-word scripting. Scripts were also expanded to include reviews of on-demand exercise videos and health tip videos, as well as to discuss participant PA, sleep, and mood logs.	To tailor coaching for younger autistic participants who may also have mild to moderate intellectual disabilities and to mitigate issues with scriptedness of coaching sessions noted by parents during the beta test.	Child-level outcome expectations (connect PA to symptom alleviation and overall wellness); self-efficacy (individualized goal setting, troubleshooting, and action planning)
Coach training	Original approach: the first two telehealth sessions were led jointly with professional Pennington Biomedical Research Center coaches. Modified approach: the number of sessions conducted jointly with PBRC coaches was extended to three.	To give coaches extra time to build confidence and comfort delivering the sessions in a non-scripted way.	Interventionist-level support and training
Forms for reporting mood	Original approach: no daily log was provided to connect PA, sleep, and mood. Modified approach: daily log was added. After beta testing, the mood item in the daily log was modified to include an "other" option with an open-ended write-in field.	To address parent-reported issues with the close-ended options not always including descriptors that represented their child's actual mood.	Child-level outcome expectations (connect PA to symptom alleviation and overall wellness); reinforcement management and stimulus control (participatory design)

drawn to other PA opportunities. This finding is consistent with prior studies that have found high acceptability of exergames like Just Dance for youth with autism (38). Finding non-traditional opportunities for PA may be particularly impactful for autistic youth, who often resist participation in traditional group PA programs, which tend to be loud, chaotic, and focused on high-intensity PA (26, 27).

One important success factor for the intervention was the telehealth coaches, whom both participants and parents characterized as fun, friendly, and easy to understand. Coaches played a particularly key role in helping the participants customize exergaming challenges and step goals to ensure they were appropriate to individual abilities and interests. In future exergaming interventions for autistic youth, this type of individual-level tailoring may likewise be important to participant engagement.

This study has several limitations that are important to note. The sample size of the beta test was small; however, it was appropriate to our study purpose and yielded useful insights about feasibility and engagement. A larger demonstration pilot is currently underway using the intervention refinements made from the beta test. In addition, while the intervention was adapted to be appropriate for autistic children with or without intellectual disabilities, only one participant in the study had an intellectual disability, making it difficult to evaluate the intervention's feasibility, acceptability, and accessibility for this subgroup. The full demonstration pilot will provide opportunities to explore these questions. Additionally, the beta test was also only 4 weeks in duration, and, although several participants noted plans to continue playing the exergames, it is unclear the extent to which engagement was maintained beyond the intervention period. Notably, in the 10-week AGS intervention, completion of the weekly exergaming sessions and total exergaming duration decreased among participants after weeks 7/8 of the program (32), so it is plausible that in this study engagement would have fallen off had the beta test been longer. Studies with longer intervention periods and post-intervention follow-up assessments are needed and, as previously noted, are currently underway. It is also possible that additional variety in gaming options may be necessary to sustain engagement over time, given that both children and parents noted the potential benefits of such variety. This will necessitate ongoing accessibility testing of new games that are always emerging on the market. Finally, future studies should also include larger, more diverse samples and more rigorous study designs (e.g., randomized controlled trials) to advance understanding of the effectiveness of this type of intervention for different communities and cultural contexts.

Overall, this study provides encouraging evidence that telehealth coaching and exergaming interventions, which have shown promise in typically developing children and older children with heterogeneous developmental and psychiatric disorders, may also be feasible and acceptable for autistic children aged 10–15. If shown to be effective in improving both PA and sleep in this population, approaches like GamerFit-ASD could be integrated into clinical treatment and school supports to improve both behavioral function and physical health in autistic youth.

Data availability statement

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

Ethics statement

This study involving humans was approved by the Tufts University Institutional Review Board (IRB). The study was conducted in accordance with local legislation and institutional requirements. Written informed consent for participation in this study was provided by participants' legal guardians/next of kin.

Author contributions

All authors contributed to the adaptation of the intervention and the development of research methods. RS and AB: tabulated descriptive statistics. AB and AM: conducted qualitative interviews, and DH, WK, and AB completed the qualitative analysis. DH and AB: drafted the manuscript. All authors contributed to the article and approved the submitted version.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Publisher's note

Supplementary material

The Supplementary Material for this article can be found online at: https://www.frontiersin.org/articles/10.3389/fped.2023.1198000/full#supplementary-material

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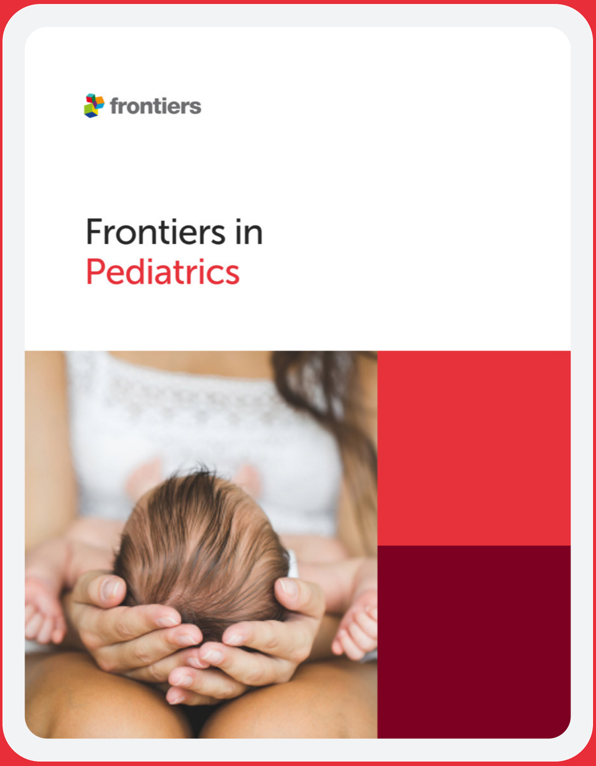

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