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UTILIZING THE ICF-CY AS A CONCEPTUAL FRAMEWORK TO EXAMINE PHYSICAL ACTIVITY AND DIETARY BEHAVIORS AMONG ADOLESCENTS WITH DOWN SYNDROME

by

ANNE O. ODUSANYA
(Under the Direction of Ashley Walker)

ABSTRACT

Introduction: Research has shown that obesity among children and adolescents is disconcerting in the Southeast United States. Additionally, children and adolescents with intellectual and developmental disabilities especially those with DS have an exacerbated risk of obesity. Despite the elevated risk of obesity for this population, very few studies have investigated factors that influence healthy eating and engagement in physical activity among children and adolescents with DS. The purpose of this study was to identify facilitators and barriers concerning healthy eating and physical activity for adolescents with DS. **Methods:** Adolescents with DS along with their parents were recruited from a local DS group of the National Down Syndrome Society and a county school system. Thirteen parents completed surveys pertaining to the dietary, physical activity and social behaviors of their adolescents with DS. The body fat of all thirteen adolescents was assessed using skinfold measurements, bioelectrical impedance analysis and Body Mass Index. Twenty-five interviews with parents and their adolescents with DS aged 10-17 years took place. The theoretical framework was the Social Ecological Model. The World Health Organization International Classification of Functioning, Disability and Health for Children and Youth served as the conceptual framework for this study and acted as the coding guide. **Results:** Facilitators were engagement in physical activity with family, sports such as dance or cheer, parental management of diet and fitness, close relationships with health professionals and being physically active with peers. Barriers were competitive sports, low motivation to be physically active, multitasking, pain, food aversions, weight maintenance issues and parents not promoting fruit and vegetable consumption. **Discussion:** The results of this study depict facilitators and barriers to healthy eating and physical activity for adolescents with DS. Although the results are not generalizable, the information from this study can

be used to develop and implement tailored programs to better assist adolescents with DS and their families in combatting obesity and meeting the special needs of this population.

INDEX WORDS: Down syndrome, Children with special healthcare needs, Intellectual disability, Developmental disability, ICF-CY, PROMIS, Food Behavior Checklist, Social Ecological Model, Healthy eating, Physical activity

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A Dissertation Submitted to the Graduate Faculty of Georgia Southern University
in Partial Fulfillment of the Requirements for the Degree

DOCTOR OF PUBLIC HEALTH

STATESBORO, GEORGIA

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by

ANNE O. ODUSANYA

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	John Dobson

Electronic Version Approved:
May 2018

DEDICATION

I would like to dedicate this dissertation to the person who inspired me to choose this topic for my dissertation and that is my younger brother Tosin who was born with Down syndrome. Tosin, although you passed away when I was too young due to your condition, I feel like we have grown closer through my dissertation research. I would also like to dedicate this dissertation to my parents, my sisters, and to my boyfriend Bernard who have supported me over the years throughout my journey in higher education.

ACKNOWLEDGMENTS

First, I would like to acknowledge my mom, dad, my sisters and my boyfriend. I would not be where I am today without their encouragement. Thank you to my parents for pursuing higher education and for prompting me to do the same and for being exemplary idols for me. Mom and Dad, you both reminded me to keep going when there were times during this dissertation process that I wanted to give up. Thank you both for always reminding me that God does not give me a challenge that I cannot handle.

To my sisters Martina and Mathilda, you two are the main reasons I strive to be a good role model and big sister. To my boyfriend Bernard, we met while I was studying for my comprehensive exams and you have supported me since then. Despite your busy schedule and working on your thesis, you drove me numerous times to and from the Coastal Health District over 45 minutes away for data collection when I was too exhausted to drive myself. You also attended the local Down syndrome society events with me to help me recruit families and more. I am truly lucky to have you in my life.

Another group of people who have always had my best interests at heart is my Nigerian community back at home and abroad. It really does take a village to raise a child and I am so thankful to be a product of this village where I have gained numerous mothers and fathers to encourage me every step of the way.

During my journey from one USF to another, I made some amazing lifelong friends. Although, we are miles apart, we have constantly stayed in touch proving that distance has gotten nothing on us.

To my friends Toyin and Tobi, we have been friends for several years and no one can put a price on our friendship. To my friends near and far that I met at the University of San Francisco, Awa and Allison, thank you for your support throughout the years, we have been friends since college, you two are my friends for life. The A Team will forever live on. To my friends that I met while I was at the University of South Florida, Yemisi, Ngozi, Makut and Onochie, thank you for being people that I look up to and for serving as successful examples of people who obtained their doctoral degrees. To my friends Gbemi, Nkem, Satchel, Lola, and Ivan, thank you for having my back since I met you all when I first started graduate school. My MPH degree was not the only blessing I received.

To my Georgia Southern squad in Eagle Nation, Kaila, we met as roommates and have been inseparable since then. Jarrett, Karmen and Dayna, as successful graduates from this doctoral program, thank you all for showing me that graduating from this doctoral program was a possibility. All of you were there for me whenever I needed advice or just wanted to vent. To my cohort members and my girls Daniella and Seme, I was so fortunate to meet you two and have you both by my side as we embarked on this journey. You two have definitely become close friends of mine. Looking forward to calling each other doctors. With respect to professors, thank you to Drs. Evans, Hansen, Ross and Telfair for providing me with guidance throughout this doctoral program.

I want to acknowledge my mentor Dr. Smallwood as well for taking me under his wing during this program. You taught me so many valuable and transferrable skills as your graduate assistant and you have stopped at nothing to boost my professional trajectory. Thank you for seeing me not just as a graduate assistant but as your colleague.

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CHAPTER 1

INTRODUCTION

Succinct Background of the Problem

Children and adolescents experience a disproportionate burden when it comes to obesity in the United States (Centers for Disease Control (CDC), 2017a; Hales, Carroll, Fryar, & Ogden, 2018). Among children and adolescents, adolescents are more likely to be obese or overweight (CDC, 2018a) due to unhealthy eating habits and engaging in little to no physical activity (CDC, 2017b, 2018b). With regard to rurality, obesity tends to have a higher prevalence among children and adolescents in rural communities than children and adolescents in urban communities (Johnson & Johnson, 2015).

Furthermore, within children and adolescents, children with special healthcare needs (CSHCN) are more susceptible to being obese or overweight than their non-disabled counterparts (Kim & Greaney, 2014). Among CSHCN, children and adolescents with Down syndrome (DS) have an exacerbated risk of obesity (Bertapelli, Pitetti, Agiovlasitis, & Guerra-Junior, 2016; CDC, 2013). This elevated risk results from factors pertaining to genetics (Bertapelli et al., 2016), reduced cardiovascular fitness levels, lower levels of motor development and muscle strength (National Center for Health, Physical Activity and Disability (NCHPAD), 2018a). In addition, weight management issues for individuals with DS stem from high caloric intake and low engagement in physical activity (National Down Syndrome Society (NDSS), 2018a). The community environment greatly influences the food choices and engagement in physical activity for children and adolescents including those with DS (CDC, 2016). Sectors of society such as families, peers, faith-based institutions, schools, neighborhoods, and homes can negatively impact the dietary and exercise behaviors of children and adolescents including children and adolescents with DS who are exposed to unsupportive environments (CDC, 2016).

Barriers specific to children and adolescents with DS that result in low engagement in physical activity are slower motor, behavioral and cognitive skills (Pitetti, Baynard, & Agiovlasitis, 2013). Additional barriers are very low aerobic fitness, low muscle tone, lack of accessible and inclusive

programs, negative community attitudes, having a low-income background, not having peers and more (Pitetti et al., 2013). In contrast, examples of facilitators for physical activity among children and adolescents with DS are accessible and inclusive programs, positive community attitudes, affordability of programs, having social support such as peers and more (Pitetti et al., 2013). When it comes to nutrition for children and adolescents with DS, there are barriers that lead to nutritional deficiencies such as Celiac disease, thyroid disease, hypothyroidism, congenital heart defects and other health-related conditions (NCHPAD, 2018b).

Despite the evidence that shows the susceptibility of obesity for children and adolescents with DS, there is a lack of research examining the effect of the community environment concerning the dietary, exercise and social behaviors of children and adolescents with DS. Moreover, the influence of the individual characteristics of children and adolescents with DS that impact engagement in both physical activity and nutrition have yet to be explored. It is imperative to examine the facilitators and barriers that impact healthy eating and engagement in physical activity relative to the community environment and the individual characteristics of children and adolescents with DS. Knowledge of these facilitators and barriers can lead to the development of tailored programs to reduce the risk of obesity for children and adolescents with DS.

Summary of the Literature

Since the 1970s, the percentage of children and adolescents with obesity has tripled (CDC, 2018a). Obesity has affected millions of children and adolescents and continues to progress due to low levels of nutrition and physical activity (CDC, 2017b, 2018b). When it comes to children and adolescents, the prevalence and rate of obesity for adolescents is more problematic than that of children (CDC, 2017a). This may be attributable to physical activity and proper nutrition declining as children age (CDC, 2017b; United States Department of Health and Human Services (DHHS), 2018).

Among children and adolescents in the United States, CSHCN experience more of an obesity burden than children and adolescents without special healthcare needs especially in the Southeastern

United States (Data Resource Center for Child & Adolescent Health, 2007a; Ghandour et al., 2013; Kim & Greaney, 2014). Within CSHCN, adolescents with DS have an exacerbated risk for obesity resulting from genetic predisposition which impacts nutritional status and participation in physical activity (Bertapelli et al., 2016). Additional factors concerning the nutrition of adolescents with DS include Celiac Disease (gluten sensitivity), gastroesophageal reflux disease (NCHPAD, 2018b), delayed oral-motor skills, narrow food preferences and texture selectivity (Field, Garland, & Williams, 2003). With respect to physical activity, short stature, low muscle tone, poor balance and low cardiovascular fitness negatively impact engagement in physical activity for adolescents with DS (NCHPAD, 2018a). All of these modifications hinder maintenance of adequate nutrition and engagement in physical activity to reduce the risk of obesity and being overweight for this population (Academy of Nutrition and Dietetics, 2015; Bertapelli et al., 2016; Crook & Hakkak, 2013).

Impairments, activity limitations, and participation restrictions associated with CSHCN including those with DS can result in challenges with consuming a healthy diet and being physically active (CDC, 2017c). An impairment is defined as a problem regarding body functions or body structures (WHO, 2007) such as delayed oral-motor skills, low muscle tone or small hands and feet relative to adolescents with DS. An activity limitation concerns an individual experiencing difficulty executing tasks (WHO, 2007). For example, adolescents with DS may have trouble participating in competitive sports, running or walking for long periods of time because of delayed motor skills (2018a). Participation restrictions comprise adolescents with DS having issues engaging socially and recreationally in addition to obtaining health care and preventive services (WHO, 2007).

Statement of the Research Problem

Although research has shown that adolescents with DS have an increased risk for obesity due to genetic predisposition, very few research studies have examined this health issue from a community environmental lens while taking into account the individual characteristics for adolescents with DS pertaining to nutrition and physical activity for adolescents with DS in the Southeastern United States.

Additionally, literature concerning obesity among adolescents with DS is scarce (Bertapelli et al., 2016; Murray & Ryan-Krause, 2010). Therefore, obesity risk factors in relation to adolescents with DS in the Southeastern United States warrants further investigation.

Study Purpose

The purpose of this study was to assess the community environment factors and individual characteristics for adolescents with DS that influence healthy eating and engagement in physical activity in Southeast Georgia.

Research Questions

1. How do perceived facilitators and perceived barriers mediate the risk factors associated with obese/overweight and non-obese/overweight adolescents with DS?

    a. What are the perceived facilitators and barriers regarding physical activity identified by adolescents with DS?

    b. What are the perceived facilitators and barriers regarding physical activity identified by parents of adolescents with DS?

    c. What are the perceived facilitators and barriers regarding healthy eating identified by adolescents with DS?

    d. What are the perceived facilitators and barriers regarding health eating as identified by parents of adolescents with DS?

Conceptual Framework

The Social Ecological Model (SEM) has been used to depict the multifaceted nature of obesity among children and adolescents (Institute of Medicine (IOM), 2005; Patrick, Baynard, & Agiovlasitis, 2013). The five levels of influence of the SEM are intrapersonal, interpersonal, organizational, community and public policy levels (Glanz, Rimmer, & Viswanath, 2008). The intrapersonal level

pertains to the individual characteristics of the child. The interpersonal level centers on the social network of the child. The organizational level concerns institutions and organizations impacting the child. The community level is related to the built environment of the child and community norms (IOM, 2005). The public policy level consists of laws at the national, state and local levels (Hammond, 2009; Huang & Glass, 2008; Patrick et al., 2013). The International Classification of Functioning, Disability and Health (ICF-CY) is similar to the SEM with a focus on CSHCN. The SEM and the ICF-CY were the theoretical and conceptual frameworks for this study, respectively.

The ICF-CY was established in 2001 by the WHO (WHO, 2007). The ICF-CY was developed to meet the specific needs of assessing disability and health-related conditions pertaining to CSHCN due to the differences in conditions regarding nature, impact and intensity in comparison to adults with special healthcare needs. The ICF-CY consists of categories and identifiers pertaining to the functioning and health status of CSHCN. These categories are Body Structures, Body Functions, Activities and Participation, Environmental Factors and Personal Factors. The ICF-CY makes use of an alphanumeric code to develop a public health framework relative to CSHCN (WHO, 2007).

The purpose of the ICF-CY is to document the severity of Body Structures, Body Functions, Activities and Participation, Environmental Factors and Personal Factors in connection to the development of CSHCN (WHO, 2007). Additionally, the ICF-CY asserts that the environment of CSHCN comprising psychosocial and physical elements is key in enhancing the health status and functioning among CSHCN. Furthermore, the ICF-CY highlights activity limitations, participation restrictions and impairments concerning CSHCN relative to their daily lives. The ICF-CY has been used for clinical, statistical, policy, educational and research purposes. With respect to these disciplines, the ICF-CY proved to be effective to record data, measure quality of life outcomes, the environment, perform needs assessments, design and implement policy, develop curricula and raise awareness (WHO, 2007).

Methodology

The methodology for this research proposal embodied a sequential mixed methods design. Inclusion criteria encompassed adolescents with DS aged 10-21 and their parents residing in the Southeast Health and Coastal Health districts in Southeast Georgia. Thirteen families participated in this study totaling 26 participants. The quantitative arm was executed first in the form of questionnaires consisting of the United States Department of Agriculture (USDA) Food Behavior Checklist (FBC), the World Health Organization Disability Assessment Schedule 2.0 (WHODAS) and the Patient-Reported Outcome Measures Information System (PROMIS) Physical Activity Short Form evaluated by the National Institutes of Health (NIH). The quantitative arm entailed bioelectrical impedance analysis (BIA), Body Mass Index (BMI) and skinfold thickness measurements. Families were classified as obese/overweight and non-obese/overweight based on the body fat values of the adolescents with DS. Travel vouchers for parents and mini Hoberman spheres for the adolescents with DS were used as incentives to recruit study participants.

The qualitative arm consisted of interviews with all participants to identify ICF-CY categories and identifiers in relation to facilitators and barriers to healthy eating and engagement in physical activity for the adolescents with DS. The semi-structured interviews created opportunities to provide opinions, thoughts and depth from both parents of adolescents with DS and adolescents with DS themselves (most studies interview solely parents and caregivers). Following data collection, data was coded and analyzed using SPSS Version 23 and NVivo Version 11 for the quantitative and qualitative arms, respectively. Additionally, the interviews and interview codebook were reviewed by two disability experts to verify consistency. Themes pertaining to the interviews were concluded regarding perceptions of the adolescents with DS and their parents. The FBC, the PROMIS Physical Activity Form, and WHODAS 2.0 data were analyzed to generate descriptive statistics relative to the body fat groups: obese/overweight and non-obese/overweight.

Assumptions

Assumptions pertinent to this study were that study participants answered the questionnaires and interview questions truthfully and fully comprehended the questions being asked of them.

Limitations

Limitations concerning the sample were the small sample size due to the rarity of DS, and not having a representative sample of adolescents with DS and parents. This was due to the study setting being limited to the Southeast Health and Coastal Health Districts in Southeast Georgia. A further limitation is that the study centered on a convenience sample.

Delimitations

Delimitations for this study were selecting adolescents with DS aged 10-21 instead of adults with DS. The reason for this was that adolescents in general including those with DS have lower rates of physical activity and healthy eating than children.

Definition of Terms

ASD- Autism spectrum disorder

Barrier- Anything that hinders or impeded healthy eating or physical activity

BIA- Bioelectrical Impedance Analysis

BMI- Body Mass Index

Categories- ICF-CY classifications comprising Body Structures, Body Functions, Activities and Participation, Environmental Factors and Personal Factors

CP- Cerebral palsy

CSHCN- Children with special health care needs

DS- Down syndrome

Facilitator- Anything that promotes or encourages healthy eating or physical activity

FBC- Food Behavior Checklist

ICF-CY- The International Classification of Functioning, Health and Disability for Children and Youth

IDD- Intellectual and Developmental Disabilities

Identifiers- Specific components of the ICF-CY categories

PROMIS- Patient-Reported Outcome Measurements Information System

WHODAS 2.0- World Health Organization Disability Assessment Schedule 2.0

CHAPTER 2

LITERATURE REVIEW

Obesity among Children and Adolescents

Obesity among children and adolescents serves as one of the most disconcerting public health challenges of the 21st century (WHO, 2018a). During 2011 to 2014, approximately 12.7 million children and adolescents were determined to be obese (CDC, 2017a). Scientific evidence shows that obesity is more prominent regarding adolescents than that of children (Ogden, Carroll, Fryar, & Flegal, 2015). According to the National Center for Health Statistics, from 2011 to 2014, the prevalence of obesity among children aged 2-5 years was 8.9%. For children aged 6-11 years and youth aged 12-19 years, the prevalence of obesity was 17.5% and 20.5%, respectively (Ogden et al., 2015).

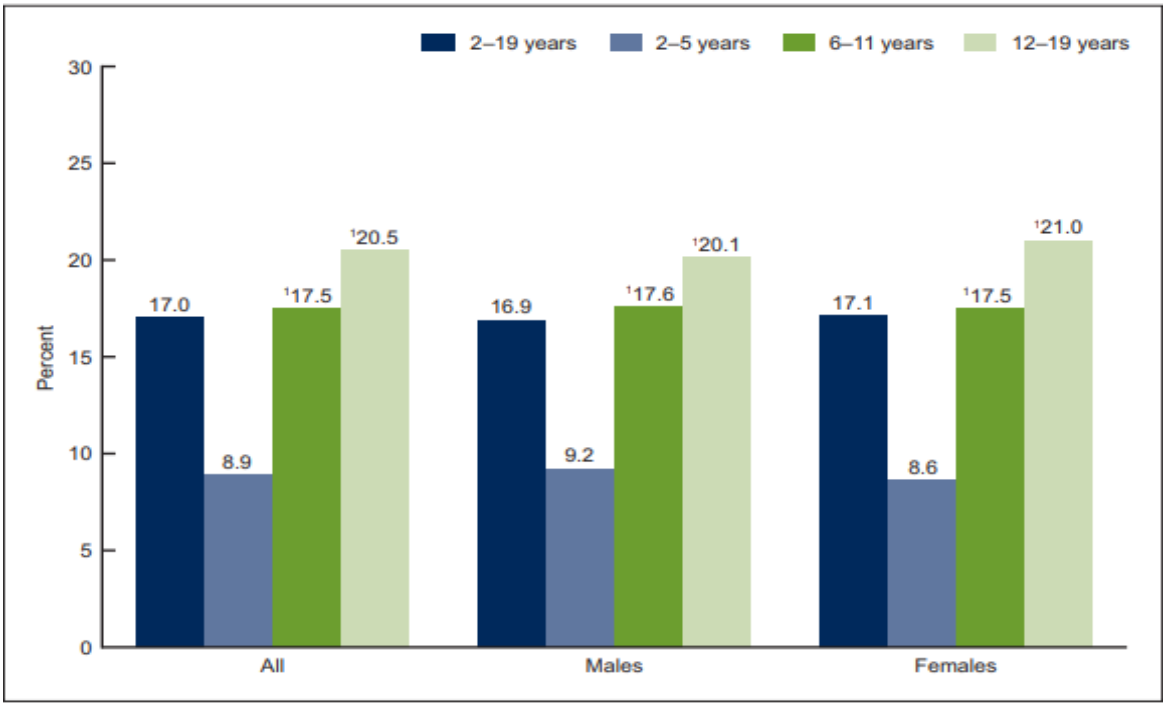

Figure 2.1 Prevalence of obesity among youth aged 2-19 years, by sex and age: United States, 2011-2014

At the regional level, there was a higher prevalence of obesity pertaining to children and adolescents in the Southeastern United States than the Midwestern, Northeastern, and Western states (Singh, Kogan & van Dyck, 2010; Tudor-Locke, Kronenfield, Kim, Benin, & Kuby, 2007; Wang & Beydoun, 2007). Singh et al (2010) found that Georgia had 162% higher odds of obesity and 89% higher odds of obesity compared to Oregon which had the lowest prevalence. In 2007, Georgia ranked 49 concerning overall prevalence with 37.3% of children and adolescents deemed to be obese or overweight exceeding the national prevalence of 31.6% (Data Resource Center for Child and Adolescent Health, 2007b).

Obesity among adolescents is a significant health problem in Georgia (Georgia Department of Public Health, 2011). In 2010, 15% (43,000) and 12% (55,000) of middle school and high school students were obese, respectively. Georgia's performance was worse than the Healthy People 2010 national target of obesity among adolescents. Georgia's prevalence of obesity for adolescents was alarming across demographics including all ages, both males and females, and every race and ethnic group (Georgia Department of Public Health, 2011). Moreover, in 2013, 17.1% of adolescents in Georgia were classified as overweight exceeding the national level of 16.6% (CDC, 2017d).

Children and adolescents who are obese or overweight are defined as having excess body fat and body weight for a given height due to genetic, behavioral and environmental factors (CDC, 2016). Being obese or overweight results from a caloric imbalance with consumption exceeding expenditure (CDC, 2016). BMI is used to screen individuals regarding body fat to assess the risk for health issues. BMI is the equivalent to an individual's weight in kilograms divided by square of the height in meters: weight (kg)/height $(m)^2$ (CDC, 2015a). For children and adolescents, BMI is specific for age and sex since weight and age change throughout growth and development. A high BMI indicates high body fat. BMI is not a direct indicator of body fat. But BMI has been known to be associated with direct measures of body fat encompassing skinfold thickness measurements, BIA, underwater weighing, Dual-energy X-ray Absorptiometry (DEXA) and more (CDC, 2015b).

Following the BMI calculation for children and adolescents, a percentile is generated and is depicted on growth charts that are commonly used to measure the growth and development of children and adolescents in the United States (CDC, 2015b). Four weight status categories based on the BMI percentiles were established by field experts: underweight, normal or healthy weight, overweight and obese. A child or adolescent is underweight when their BMI percentile is less than the 5th percentile. Normal or healthy weight constitutes having a BMI percentile between the 5th and 85th percentiles. Overweight means that the child or adolescent has a BMI percentile between the 85th and 95th percentiles. Lastly, obese is the equivalent to or higher than the 95th percentile (CDC, 2015b).

Table 2.1 BMI Weight Status Categories and Percentile Ranges

Weight Status Category	**Percentile Range**
Underweight	Less than the 5th percentile
Normal or Healthy Weight	5th percentile to less than 85th percentile
Overweight	85th percentile to less than 95th percentile
Obese	Equal to or greater than 95th percentile

(CDC, 2015B)

An obesogenic environment plays a major role among children and adolescents (Poston & Foreyt, 1999; Swinburn, Egga, & Raza, 1999). Individuals may struggle with maintaining a healthy weight due to the community environment encouraging high caloric intake and sedentary behaviors. In other words, an obesogenic environment influences low energy expenditure and high caloric intake (Poston & Foreyt, 1999; Swinburn et al., 1999). As a result of the obesogenic environment, adolescents develop obesogenic behaviors comprising low participation in physical activity, high consumption of unhealthy food and frequent screen time (Patrick et al., 2013). An obesogenic environment contributes to low engagement in physical activity and poor nutrition promoting obesity (Poston & Foreyt, 1999; Swinburn et al., 1999).

The NIH (1998) defines nutrition as the "science of food, the nutrients and other substances therein, their action, interaction and balance in relation to health and disease, and the process by which the organism ingests, absorbs, transports, utilizes and excretes food substances" (1). The WHO (2018b) reports that physical activity entails the skeletal muscles producing movement of the body requiring energy expenditure. Examples of physical activity are recreation, sports, playing, traveling, doing household chores and more (WHO, 2018b).

Rurality is another factor that impacts obesity among children and adolescents (Johnson & Johnson, 2015). Children and adolescents who reside in rural locations have a higher prevalence or increased odds of obesity than their urban counterparts (Davis, Bennett, Befort, & Nollen, 2011; Johnson & Johnson, 2015). According to the National Center for Health Statistics, rural areas comprise nonmetropolitan or micropolitan counties (Ingram & Franco, 2012). Children and adolescents residing in rural areas are about 25% more likely to be overweight or obese than children and adolescents living in urban or metropolitan areas (Lutfiyya, Lipsky, Wisdom-Behounnek, & Inpanbutr-Martinkus, 2007).

There are numerous aspects of the built environment that influence the physical activity levels, eating behaviors and quality of life of individuals (Southwest Rural Health Research Center, 2015). In addition, these environmental features such as pedestrian orientation, natural outdoor settings, and safety are severely lacking in rural communities (Southwest Rural Health Research Center, 2015). Pedestrian orientation (benches, sidewalks, lighting, crosswalks) has been known to foster sense of community (Leyden, 2003) and intention to walk leisurely (Wood, Frank, & Giles-Corti, 2010). Pedestrian-oriented neighborhoods encourage social capital consisting of relationships with neighbors, civic engagement, trust and social interaction (Leyden, 2003).

Furthermore, residences with natural outdoor settings (parkland or greenery) enhance quality of life and positive health status (De Vries, Verheij, Groenewegen, & Spreeuwenberg, 2003; Frumkin, 2001). Neighborhoods with natural outdoor settings endorse mental health well-being and intentions to be physically active (Thompson et al., 2011). Participation in physical activity in natural outdoor settings can result in reduced anxiety, anger, fatigue and sadness (Bowler, Buyung-Ali, Knight, & Pullin, 2010).

Safety is another element that is connected to the built environment. Residences consisting of stressors such as traffic, noise, toxins and safety hazards impede intentions to engage in physical activity (Southwest Rural Health Center, 2015).

The built environment not only affects physical activity and quality of life, but it also impacts the eating behaviors of individuals (Walker, Keane, & Burke, 2010). Rural and low-income urban communities have low accessibility to supermarkets and high availability of convenience stores and fast food establishments (Walker et al., 2010). This lack of access to healthy eating options constitutes a food dessert and increases exposure to high caloric food options (Drenowski & Specter, 2004). These high caloric foods contain vast amounts of sodium, sugar, and fats producing poor health outcomes such as obesity, diabetes, cardiovascular disease and more (Swinburn, Caterson, Seidell, & James, 2004). Additionally, residents in rural or low-income urban areas without cars or adequate transportation are more susceptible to these poor health outcomes (Lake & Townshend, 2006).

With regard to Georgia, there are 18 public health districts statewide with each comprising one or more of Georgia's 159 counties and health departments (Georgia Department of Public Health, 2017). Among these districts are the Southeast Health District and Coastal Health District. The Southeast Health District houses the following counties: Appling, Atkinson, Bacon, Brantley, Bulloch, Candler, Charlton, Clinch, Coffee, Evans, Jeff Davis, Pierce, Tattnall, Toombs, Ware and Wayne (Georgia Department of Public Health, 2012). The Coastal Health District consists of Bryan, Camden, Chatham, Effingham, Glynn, Liberty, Long, and McIntosh counties (Georgia Department of Public Health, n.d.). The Southeast Health District encompasses rural communities while the Coastal Health District houses both rural and urban communities.

When it comes to childhood obesity, the SEM has been used to illustrate the multiple levels that influence the obesogenic behaviors of youth (Patrick et al., 2013). The IOM (2005) issued a report *Preventing Childhood Obesity: Health in the Balance* maintaining that the SEM depicts the etiology of childhood obesity and provides the foundation for assessment and interventions regarding childhood obesity.

The ICF-CY categories include Body Structures, Body Functions, Activities and Participation, Environmental Factors and Personal Factors corresponding to the levels of the SEM centering on CSHCN. There are five levels of the SEM: intrapersonal, interpersonal, organizational, community and public policy (Glanz et al., 2008).

Figure 2.2 The Social Ecological Model

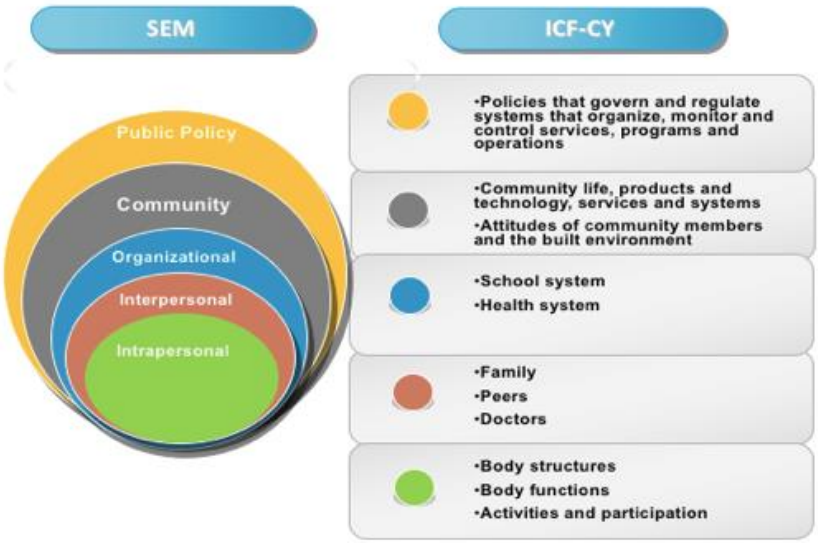

Figure 2.3 Interactions between the Components of the SEM and ICF-CY

Intrapersonal Level

The intrapersonal level refers to the individual characteristics of the child or adolescent consisting of weight status, race, ethnicity, genetics, attitudes, values and obesogenic behaviors. The prevalence of obesity is significantly higher for children and adolescents of racial or ethnic minorities (Isong et al., 2017). Genetic factors can also contribute to obesity and are difficult to modify (CDC, 2016). Attitudes and values can vastly influence engagement in physical activity and healthy eating for children and adolescents (Buchanan, 2000; Gao, Podlog, & Huang, 2013). Negative attitudes and values toward physical activity and healthy eating can result in low physical activity levels and a lack of intention to eat healthy food (Buchanan, 2000; Gao et al., 2013). Obesogenic behaviors concerning eating habits comprise high consumption of food in restaurants and fast food establishments, frequent snacking, high caloric intake, and eating less than five servings of fruits and vegetables daily (French et al., 2001; Jahns, Siega-Riz, & Popkin, 2001; Rolls, Roe & Meengs, 2004). With regard to physical activity, behaviors that contribute to obesity risk for children and adolescents entails little to no leisure time, spending a large amount of time in the household, and being physically inactive (IOM, 2005).

Interpersonal Level

The interpersonal level pertains to the social network of the child or adolescent including their family, teachers and peers. The eating and physical activity behaviors of children and adolescents are strongly impacted by their families (IOM, 2005). The home is instrumental for families to foster behaviors such as healthy eating and a physically active lifestyle (IOM, 2005). Parents that do not model or reinforce these behaviors are likely to contribute to the obesity risk for their children and adolescents (IOM, 2005). In addition, parents who have long workdays lack time to be physically active with and prepare home cooked meals for their children and adolescents (Sturm, 2004). For these reasons, parents are likely to purchase food outside of the home that is readily available and inexpensive (Sloan, 2003).

Increasing time demands prompt reduced grocery shopping, food preparation and meal planning (Crepinsek & Burstein, 2004). This results in children and adolescents developing food preferences for

sweetened beverages and other high caloric foods as opposed to consuming nutritious foods such as fruits and vegetables (IOM, 2005). Additionally, excessive food portion sizes and watching television during family dinners can negatively affect fruit and vegetable intake for children and adolescents (Diliberti, Bordi, Conkin, Roe & Rolls, 2004; IOM, 2005). With regard to physical activity for children and adolescents, parental support is crucial for encouraging participation in a new activity, driving to an activity class, and purchasing sports equipment (IOM, 2005). However, if parents have low socioeconomic status or lack adequate transportation, then providing support for children and adolescents to be physically active may prove to be difficult (Drenowatz et al., 2010).

With respect to role modeling, when parents do not model healthy eating and physical activity behaviors, the obesity risk for the child or adolescent increases (Draxten, Fulkerson, Friend, Flattum, & Schow, 2014; Scaglioni, Salvioni & Galimberti, 2008). Furthermore, the values and attitudes of families toward health outcomes influence the obesity risk for children and adolescents (Scaglioni et al., 2008; Whitaker, 2004). For instance, some families may not place importance on health outcomes associated with obesity which can result in drawbacks of changing the eating and physical activity behaviors of the child or adolescent (Scaglioni et al., 2008; Whitaker, 2004). Moreover, families may not perceive that the weight status of the child or adolescent is an issue delaying early intervention (Lovejoy, 2011; Scaglioni, et al., 2008; Whitaker, 2004). Likewise, families may avoid bringing up weight-related issues during conversation in fear that the child or adolescent will develop low self-esteem or eating disorders (Borra, Kelly, Shirreffs, Neville, & Geiger, 2003).

For teachers and educators, there is lack of nutrition education for children and adolescents in schools (IOM, 2013). This is alarming because children and adolescents spend more than half of each week day in school where teachers can use the school setting to promote healthy eating and physical activity behaviors (IOM, 2005). In addition, teachers that administer free time or recess are recommended to provide 30 minutes of physical activity for leisure during each school day to minimize the risk of obesity for children and adolescents (IOM, 2005). Peers or friends impact the food and physical activity choices of children and adolescents as well (IOM, 2005). Peers directly influence the food preferences of

due to children and adolescents gravitating toward food options highly valued by peers which tend to be high in calories (IOM, 2005). Research has also shown that peer support encourages positive change in physical activity over time lowering chances of obesity for children and adolescents (Neumark-Sztainer, Wall, Story, & Perry, 2003).

Organizational Level

The organizational level pertains to institutions and organizations such as the school and health care settings (IOM, 2005). With respect to schools, it is imperative to promote consistent messages and opportunities for healthy eating and physical activity for children in the classroom, gymnasium and cafeteria. This can facilitate children adopting healthy eating and physical activity behaviors increasing their self-efficacy to practice these behaviors. The National School Lunch Program and the School Breakfast Program have been encouraging healthy eating for 28 million and 8 million children and adolescents, respectively. The nutritional guidelines for these programs are periodically revised to ensure distribution of nutritionally balanced meals (IOM, 2005; USDA, 2018a). Furthermore, minimizing competitive foods consisting of food and beverage options outside of the federal school meal programs can endorse healthy eating for children. Examples of competitive foods include food sold by the school services, vending machines, and fundraisers or bake sales. These foods are of low nutritional value comprising chips, candy and other salty or fatty snack foods (IOM, 2005).

As for physical activity, schools are recommended to provide daily physical education classes for children and adolescents (IOM, 2005; Society of Health and Physical Educators, 2016). Additional recommendations for schools are to offer time for unstructured physical activity outside of physical education, and to supply time and space for intramural sport clubs and interscholastic sports (IOM, 2005; Society of Health and Physical Educators, 2016).

Within the health care setting, physicians have a profound impact in preventing obesity for children and adolescents. The American Academy of Pediatrics (2003) reports that physicians can curb the obesity epidemic by assessing BMI, recognizing families at risk, assessing eating and physical activity

behaviors, and educating families about tactics to maintain a healthy weight for children and adolescents. However, not having health insurance coverage can hinder prevention and treatment of obesity for children and adolescents (Lovejoy, 2011). In addition, lack of reimbursement for behavioral treatments and antiobesity drugs, seeing a nutritionist, medication prescriptions and surgeries present challenges to address obesity among children and adolescents (Lovejoy, 2011).

Community Level

The community level centers on the child's neighborhood and aforementioned built environment relative to the food systems, parks and recreational facilities. Inaccessibility to recreational spaces and lack of pedestrian orientation hinder physical activity levels for children and adolescents (IOM, 2005; Wood et al., 2010). With regard to the food environment, low affordability of healthy food options within walking distance and high availability of high caloric foods impede the healthy eating behaviors of families including children and adolescents (IOM, 2005).

Additionally, the social and cultural norms of the community influence the physical activity levels and eating habits of children and adolescents (IOM, 2005). The norms of the community impact the perception of body image for children and adolescents. For instance, if a child or adolescent's BMI indicates that the child or adolescent is overweight, and the community does not perceive the child or adolescent as having a health issue, the child or adolescent will not feel compelled to eat healthy and to regularly engage in physical activity to mitigate their obesity risk (IOM, 2005).

Public Policy Level

Lastly, the public policy level consists of national, state and local laws (Hammond, 2009; Huang & Glass, 2008; Patrick et al., 2013). There have only been two policies relative to involvement of children and adolescents in physical activity (DHHS, 2012). Physical activity in schools for children and adolescents has been mandated in the United States since the 19th century. Currently most states require students to take physical education classes. Only 84% of elementary, 80% of middle school and 86% of

high school students have participated in physical education classes. Although the quality and quantity of physical education do not meet standards, state policies mandating physical education support providing opportunities for children and adolescents to be physically active. Moreover, Congress and President Nixon passed the *Title IX of the Education Amendments of 1972.* Title IX has prohibited exclusion of girls and women from activities and educational programs. In the past 40 years, this legislation has fostered participation in sports for girls and women in high school and college (DHHS, 2012).

However, there are challenges concerning regulation and implementation of state policies resulting in policies at the local level being open to various interpretations (Society of Health and Physical Educators, 2016). Only the District of Columbia and Oregon are meeting the national recommendations for daily physical activity for elementary and middle school students. In addition, very few states have executed a minimum amount of time for students to participate in physical education classes and have additional funding for physical education programs. Furthermore, most states allow waivers or substitutions for physical education classes and some states withhold or utilize physical activity as a form of punishment. All of these policy factors can lead to the reduction of physical activity for children and adolescents (Society of Health and Physical Educators, 2016).

To address nutrition for children and adolescents, there are no policies in place. But there are national guidelines supporting consumption of nutritious foods for children and adolescents relative to the aforementioned National School Lunch Program and School Breakfast Program (USDA, 2018a). Despite these national guidelines, there is still a need for policies to be developed and implemented to facilitate healthy eating habits for children and adolescents.

Implications of Risk Factors and Effects on the Quality Of Life and Mortality

Engagement in physical activity and healthy eating for children and adolescents is disconcerting due to environments and multiple levels of influence not supporting healthy habits (CDC, 2016). Low participation in physical activity and consuming unhealthy foods increases the risk of obesity for children and adolescents. Obesity poses numerous threats to the health, quality of life and mortality for children

and adolescents into adulthood. Children and adolescents with obesity have an increased susceptibility to high blood pressure and cholesterol, diabetes, breathing issues, musculoskeletal issues, joint problems and more. Obesity for children and adolescents results in social issues including stigmatization and being bullied. Moreover, psychological problems associated with obesity comprise depression, anxiety, and low self-esteem. The risk factors for obesity have a profound negative effect on the quality of life for children and adolescents (CDC, 2016).

Obesity among Children and Adolescents with Disabilities

CSHCN are defined as "those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally" (McPherson et al., 1998). CSHCN consists of children and adolescents with conditions such as anxiety, depression, asthma, diabetes and other chronic illnesses (DHHS, Health Resources and Services Administration (HRSA), & Maternal and Child Health Bureau (MCHB), 2013). CSHCN also comprise children and adolescents with disabilities (DHHS, HRSA, &, MCHB, 2013) which will be the priority population for this paper. Disabilities can influence an array of features including mobility, vision, recall, thinking, learning, communication, hearing, mental health and social relationships (CDC, 2017c). Children and adolescents with disabilities consists of diverse populations with various needs (CDC, 2017c).

Within children and adolescents, CSHCN have a higher obesity risk than children and adolescents without special health care needs (Kim & Greaney, 2014; Rimmer, Rowland, & Yamaki, 2007). Rimmer et al. (2007) assert that children and adolescents with conditions encompassing spina bifida, cerebral palsy (CP), DS, Prader-Willi syndrome, brain injury and muscular dystrophy have a higher prevalence of being obese and overweight among CSHCN. Brain injury (Jourdan et al., 2012), learning disabilities (Grondhuis & Aman, 2014), Attention-Deficit/Hyperactivity Disorder (Law, Sideridis, Prock, & Sheridan, 2014), and Autism Spectrum Disorder (ASD) (Curtin, Jojic, & Bandini, 2014) are additional conditions that increase the risk of being obese and overweight for CSHCN. Individuals with intellectual

and developmental disabilities (IDD) have the greatest risk for obesity among individuals with special health care needs (Bandini, Curtin, Hamad, Tybor & Must, 2005). Furthermore, higher costs are associated with obesity chronic-related conditions concerning individuals with intellectual disabilities as life expectancy increases (Fisher & Kettl, 2005). In a study conducted by Rimmer et al. (2011), CSHCN with IDD had higher obesity rates than children and adolescents with physical disabilities.

Developmental disabilities serve as an umbrella term that is inclusive of intellectual disabilities (American Association on Intellectual and Developmental Disabilities (AAIDD), 2018). Developmental and intellectual disabilities often co-occur (AAIDD), 2018). Although developmental and intellectual disabilities overlap, it is important to note that developmental and intellectual disabilities are distinct (AAIDD, 2018). Developmental disabilities pertain to chronic diseases that affect cognitive or physical features (AAIDD, 2018). The prevalence of children and adolescents with developmental disabilities in the United States is increasing (Boyle et al., 2011). Between 1997 and 2008, the rate for children and adolescents with developmental disabilities increased over 17%. Close to 14% of children and adolescents are living with a developmental disability (Boyle et al., 2011). Developmental disabilities emerge before the age of 22 and are lifelong (AAIDD, 2018; Academy of Nutrition and Dietetics, 2015). Examples of developmental disabilities are CP, epilepsy, DS, fetal alcohol syndrome and more (AAIDD, 2018).

In contrast to developmental disabilities, intellectual disabilities consist of only thought processes and does not affect physical features (AAIDD, 2018). An intellectual disability refers to having limitations related to learning and functioning at an expected level in daily life (Academy of Nutrition and Dietetics, 2015). Intellectual functioning concerns learning, reasoning, problem solving and other mental functions (AAIDD, 2018). The degree of an intellectual disability varies among children and adolescents ranging from very slight to very severe (CDC, n.d.). Children and adolescents with an intellectual disability may experience difficulty communicating their wants and needs with others and maintaining self-care (CDC, n.d.).

Children and adolescents with an intellectual disability may also have trouble sitting upright, crawling, talking or walking than children without intellectual disabilities (CDC, n.d.). Additionally,

children and adolescents with an intellectual disability have difficulty recalling information, comprehending social norms, and understanding the effects of their actions. Causes of an intellectual disability are attributable to problems that arise before age 18 or even prior to birth. An intellectual disability can be caused by injuries, illnesses, an issue concerning the brain or can be unknown. The most common causes of an intellectual disability encompass DS, fragile X syndrome, fetal alcohol syndrome, birth defects, genetic disorders, and infections before birth (CDC, n.d.). Researchers have acknowledged individuals with IDD are highly susceptible to obesity (Emerson, 2005; Rimmer & Yamaki, 2006). Population-level prevalence data has shown that obesity levels for adults with IDD are higher than their counterparts without IDD (Emerson, 2005).

With regard to data, little is known about the prevalence of CSHCN and the obesity prevalence for this population. According to the 2009-2010 National Survey of Children's Health, 15.1% of children nationwide constituting 11.2 million had special health care needs (Data Resource Center for Child and Adolescent Health, n.d.). In 2009 to 2010, 23% of households in the United States contained a minimum of one child with special health care needs (Data Resource Center for Child and Adolescent Health, n.d.). The obesity and overweight prevalence relative to CSHCN contribute to the childhood obesity epidemic in the general population of children and adolescents (Minihan, Must, Anderson, Popper, & Dworetzky, 2011). In the National Survey for Children with Special Health Care Needs (NS-CSHCN), CSHCN were 31.3% and 26.7% more likely to be classified as obese compared to children and adolescents without special health care needs in 2003 and 2007, respectively (Ghandour et al., 2013).

The 2007 NS-CSHCN results maintained that the overall prevalence of obesity among adolescents in the United States (aged 10-17 years) was 31.6%. The prevalence of obesity for adolescents without special health care needs was 30.2% and 36.3% for adolescents with special health care needs (Data Resource Center for Child and Adolescent Health, n.d.). Based on the evidence provided, adolescents with special health care needs have an increased risk for being obese and overweight (Rimmer et al., 2007). At the regional level, there are 10 Health Services and Resources Administration (HRSA) regions (Data Resource Center for Child and Adolescent Health, n.d.). They are as follows:

- HRSA Region I: Maine, New Hampshire, Vermont, Massachusetts, Rhode Island, and Connecticut
- HRSA Region II: New York and New Jersey
- HRSA Region III: Pennsylvania, Maryland, Delaware, Virginia, and West Virginia
- HRSA Region IV: Kentucky, Tennessee, North Carolina, South Carolina, Georgia, Florida, Alabama, and Mississippi
- HRSA Region V: Minnesota, Wisconsin, Illinois, Indiana, Michigan, and Ohio
- HRSA Region VI: New Mexico, Texas, Oklahoma, Arkansas, and Louisiana
- HRSA Region VII: Nebraska, Kansas, Iowa, and Missouri
- HRSA Region VIII: Montana, North Dakota, South Dakota, Wyoming, Colorado, and Utah
- HRSA Region IX: Nevada, California, Arizona, and Hawaii
- HRSA Region X: Washington, Oregon, Idaho, and Alaska

Table 2.2 illustrates the disconcerting difference between CSHCN and children and adolescents without special health care needs in 2007 based on HRSA regions illustrated by the Data Resource Center for Child and Adolescent Health, n.d.).

Table 2.2 2007 HRSA Region Prevalence of Children and Adolescents who were Overweight or Obese

HRSA Region	Overall (%)	CSHCN (%)	Non-CSHCN (%)
I	28.6	31.8	27.4
II	32.3	38.2	30.6
III	30.4	39.1	27.3
IV	35.4	38.1	34.6
V	31.1	38.5	28.7
VI	32.8	32.4	33.0
VII	30.1	34.6	28.4
VIII	25.8	24.5	26.2
IX	30.7	38.1	28.7
X	28.0	30.4	27.3

(DATA RESOURCE CENTER FOR CHILD AND ADOLESCENT HEALTH, N.D.)

HRSA Region IV depicting the Southeastern United States comprising Kentucky, Tennessee, North Carolina, South Carolina, Georgia, Florida, Alabama and Mississippi has the highest overall prevalence (35.4%) of children and adolescents classified as obese or overweight (Data Resource Center for Child and Adolescents Health, 2007a). In addition, HRSA Region IV falls into the top 5 HRSA regions with the highest prevalence of CSHCN categorized as obese or overweight with 38.1%. Furthermore, HRSA Region IV has the highest prevalence of children and adolescents without special health care needs determined to be obese or overweight (Data Resource Center for Child and Adolescents Health, 2007a). The obesity and overweight disparity between CSHCN and their counterparts without special health care needs is more prominent in Georgia . The overall prevalence of children and adolescents who were obese or overweight in 2007 was 37.3% for Georgia (Data Resource Center for Child & Adolescent Health, 2007b). Additionally, the obesity and overweight prevalence was 43.4% and 35.9% for CSHCN and children and adolescents without special health care needs in Georgia, respectively (Data Resource Center for Child & Adolescent Health, 2007b).

Obesity threatens the physical status of CSHCN by reversing or delaying health gains (Janssen, Craig, Boyce, & Pickett, 2004). Obesity for CSHCN serves as another stigmatizing factor on top of special health care needs (Janssen et al., 2004). Obesity-related secondary conditions for CSHCN encompass pain, fatigue, social isolation, deconditioning, and difficulty performing daily living activities (NCHPAD, 2018c). Secondary conditions can adversely influence nutrition and participation in physical activity among CSHCN especially those with IDD (Collins & Staples, 2017; NCHPAD, 2018c). There are several factors that hinder healthy eating and physical activity behaviors for CSHCN relative to the SEM.

Intrapersonal Level

At the intrapersonal level, race, ethnicity, medical conditions, eating patterns, physical activity behaviors and more affect whether or not CSHCN partake in physical activity and healthy eating. CSHCN who represent racial and ethnic minorities have an increased risk for obesity (Minihan et al., 2011).

Moreover, CSHCN are likely to have unhealthy eating and physical activity behaviors due to their medical conditions (Minihan et al., 2011). For instance, children and adolescents with CP, a disorder involving lack of muscle control resulting from brain injury, are susceptible to poor nutrition increasing chances of obesity (Van Riper & Wallace, 2010). CSHCN experience more adversity controlling weight and consuming a healthy diet (CDC, 2017e). Lack of healthy eating habits along with little engagement in physical activity are also growing concerns among individuals with intellectual disabilities (Emerson, 2005; Rimmer & Yamaki, 2006). This results in CSHCN eating unhealthy food and beverage options such as soda, fast food, finger foods, candy and more (Minihan, Fitch, & Must, 2007).

Nutritional issues among CSHCN also stem from multiple problems including physical and neurological limitations disrupting caloric needs. (Minihan et al., 2007). Additional problems are taste or texture selectivity and medications contributing to both weight gain and altering appetite (Academy of Nutrition and Dietetics, 2015; Van Riper & Wallace, 2010). For children and adolescents with developmental disabilities, there is an increased risk for poor nutrition elevating the likelihood of obesity (Crook & Hakkak, 2013). Furthermore, medicinal side effects of vitamin and mineral deficiencies along with feeding tubes negatively impact nutritional efficiency for CSHCN (Academy of Nutrition and Dietetics, 2015; West Virginia Center for Excellence in Disabilities, 2018). For instance, medications entailing antidepressants, anticonvulsants, mood stabilizers and more can result in weight gain (Minihan et al., 2007).

With respect to behavior, little engagement in physical activity along with an unhealthy diet due to high frequency of television viewing with media advertisements can lead to consumption of high caloric foods and beverage options (Minihan et al., 2007). Issues concerning swallowing, increased body adiposity, avoidance of food, and mealtime resistance contribute to the likelihood of CSHCN becoming obese (Van Riper & Wallace, 2010). Nutritional challenges comprising gastrointestinal disorders, difficulty sucking, swallowing, and chewing increase the risk of obesity for CSHCN (Academy of Nutrition and Dietetics, 2015). For children and adolescents with IDD, lack of ability to self-feed, food textural problems, pica (eating substances such as dirt and paint) and food aversions are heightened

(Academy of Nutrition and Dietetics, 2015; Crook & Hakkak, 2013). The severity of barriers relative to nutrition for CSHCN with IDD depends on numerous factors (Van Riper & Wallace, 2010). Factors pertaining to functioning level, disability severity, general health status, comorbidities, education as well as environmental conditions affect nutrition for CSHCN with IDD (Bertapelli et al., 2016; Van Riper & Wallace, 2010).

When it comes to mealtime support, assistance regarding cutting food, or feeding may be necessary for CSHCN with IDD (Academy of Nutrition and Dietetics, 2015). Ball et al. (2012) found that as individuals with intellectual disabilities aged, levels of support for mealtime assistance from caregivers increased with 82% of the study participants. For children and adolescents with ASD, a disorder associated with delayed speech and language development, repetitive behaviors and impairments during social interactions, there are several elements that influence the nutritional value of their diet (Academy of Nutrition and Dietetics, 2015; Van Riper & Wallace, 2010). Restricted food choices, high intake of foods with low nutritional value, food interaction with medicine for, and avoidance of food groups associated with nourishment or recommended guidelines can increase the risk for obesity for children and adolescents with ASD (Academy of Nutrition and Dietetics, 2015; Van Riper & Wallace, 2010).

Personal barriers regarding lack of energy and self-efficacy, pain, fatigue, being self-conscious about engaging in physical activity and perceiving physical activity as being very difficult can impede engagement in physical activity for CSHCN (Rimmer & Marques, 2012). Additional barriers to engagement in physical activity for CSHCN reported by parents are numerous behavioral problems (NCHPAD, 2018c). For instance, children and adolescents with physical disabilities such as spina bifida or CP experience pain in the joints and muscles from spasticity or overuse of muscles due to pushing a wheelchair or utilizing crutches for mobility (NCHPAD, 2018c). Furthermore, adolescents with disabilities have a higher likelihood of engaging in sedentary behavior and encounter more obstacles participating in physical activity in comparison to adolescents without disabilities (NCHPAD, 2016c; Rimmer & Marques, 2012).

Interpersonal Level

It is imperative to note that parental influence plays a major role in the dietary habits of CSHCN (Minihan et al., 2007; Yazdani, Yee, & Chung, 2013). Parents who do not model healthy eating behaviors may enhance the risk for obesity for their CSHCN (Minihan et al., 2007). CSHCN abide by the rules of the household including parental behaviors (Minihan et al., 2007; Yazdani et al., 2013). Evidence shows that both types of parental modeling including overly restrictive and overly permissive have been linked to the food intake of their CSHCN (Minihan et al., 2007). Reasons contributing to an unhealthy diet for CSHCN relative to parents are out of pocket expenses to manage medical conditions of CSHCN, and employment issues such as cut hours or leaving work to care for their CSHCN (Minihan et al., 2007; NCHPAD, 2018c; Yazdani et al., 2013). This can create difficulty with setting aside time to prepare healthy meals, and to reduce sedentary behavior of CSHCN (Minihan et al., 2007; Van Riper & Wallace, 2010).

Parents may find it disheartening to limit high caloric foods for their CSHCN due to feeling guilty about the limitations placed upon their CSHCN (Minihan et al., 2007; Zimmer et al., 2012). In addition, parents may purchase soft drinks or food advertised on television to put in their children's lunchbox for their CSHCN to be accepted among their peers or to prevent social isolation (Minihan et al., 2007; Zimmer et al., 2012). Unhealthy food options are used as incentives for behavioral control among CSHCN (Minihan et al., 2007; Zimmer et al., 2012). With regard to the built environment, the proximity of supermarkets and convenience stores in relation to the family home can have an effect (Minihan et al., 2007). Residing near convenience stores and further away from farmers' markets or supermarkets can lead to poor nutrition for CSHCN (Minihan et al., 2007). Additionally, lack of adequate transportation can hinder access to healthier food options for CSHCN and their families (Minihan et al., 2007).

Physical inactivity or low engagement in physical activity, low motivation and negative attitudes toward physical activity exacerbate the poor levels of physical activity for CSHCN (Yazdani et al., 2013). CSHCN are likely to practice sedentary behaviors such as watching television or videos, and playing computer games (NCHPAD, 2018c). These sedentary behaviors are linked to CSHCN with

disabilities not wanting to engage in physical activity due to their cognitive, sensory and physical impairments. The aforementioned impairments create difficulty for CSHCN to participate in competitive sports and recreational activities with their peers who exude higher fitness levels and more developed motor skills (NCHPAD, 2018c; Rimmer & Marques, 2012). Peer involvement can promote physical activity for CSHCN to address obesity (Shields & Synnot, 2016). CSHCN who lack involvement of peers for physical activity have an increased risk for obesity (Shields & Synnot, 2016). In addition, negative societal attitudes and exclusion from peers can lead to a lack of motivation for CSHCN to be physically active (Shields & Synnot, 2016).

Organizational Level

When it comes to the school setting, federal school meal programs administered by the USDA have set guidelines to accommodate CSHCN (USDA, 2017). The guidelines assert that the process of providing modified meals for CSHCN should be as inclusive as possible. School Food Authorities (SFA) are required to collaborate with parents and caregivers to ensure safe or modified meals and equal opportunities for CSHCN to participate in the federal school meal programs. The Food Nutrition Service (FNS) of the USDA also utilizes the Individual Education Program (IEP) (USDA, 2017). An IEP is a developed, reviewed and revised document for CSHCN to cater to the specific needs of each child (United States Department of Education, 2007). The FNS and SFA refer to the IEP to work with parents and caregivers to meet each child's nutritional needs (USDA, 2017). However, there is a lack of specific nutrition education to prevent obesity for CSHCN (Meresman & Drake, 2016).

With regard to schools and physical activity, physical education courses may not accommodate CSHCN and may lack adapted physical education (NCHPAD, 2018c; Rimmer & Marques, 2012; Rimmer, Riley, Wang, Rauworth, & Jurkowski, 2004). Adapted physical education is an individualized program to enhance physical and motor fitness for CSHCN (Winnick, 2000). Physical activities such as aquatics, dance, individual and group games along with sports, Special Olympics and more tailored to CSHCN are components of adapted physical education (NCHPAD, 2018c). Adapted physical education

is supervised by a physical education teacher or a full-time adapted physical education teacher (NCHPAD, 2018c). In the health care setting, not having a physician assess the weight status of CSHCN can result in CSHCN becoming obese (Yazdani et al., 2013). In a study conducted by Yazdani et al. (2013), the majority of parents acknowledged that their child's physician had recommended more participation in physical activity to protect CSHCN from obesity.

Community Level

At the community level, the social and physical environment play a role in whether CSHCN engage in adequate physical activity and proper nutrition (Yazdani et al., 2013). Labeling, and adverse language toward CSHCN by community members serve as social factors that limit participation for CSHCN in community-based programs (Rimmer et al., 2007). Additionally, there is a lack of culturally appropriate programs for CSHCN. Moreover, negative public attitudes from community members can lead to CSHCN feeling socially isolated (Rimmer et al., 2007).

The built environment has an effect on the engagement in physical activity for CSHCN. Some CSHCN experience difficulty in maneuvering recreational settings such as gyms, pools and playgrounds impeding physical activity (NCHPAD, 2018c; Shields & Synnot, 2016; Yazdani et al., 2013). Poor physical access also contributes to CSHCN not getting an adequate amount of physical activity (NCHPAD, 2018c). Lack of sufficient parking, accommodations without van lifts, easy-to-open doors, elevators and ramps in buildings may hinder CSHCN using recreational facilities or participating in physical activity (NCHPAD, 2018c; Rimmer & Marques, 2012). Performing a simple activity such as walking around the community may prove to be difficult for CSHCN (Rimmer & Yamaki, 2006). For example, an individual with an intellectual disability will most likely need supervision when walking around the community making the environment more complex for the individual (Rimmer & Yamaki, 2006).

Inadequate accommodations for play equipment, parks and playgrounds (low drinking fountains, accessible restrooms, picnic tables) for CSHCN in wheelchairs contribute to physical inactivity as well

(NCHPAD, 2018c). Transportation is also essential for CSHCN engaging in physical activity (NCHPAD, 2018c; Rimmer & Marques, 2012). The NCHPAD (2018c) acknowledges that CSHCN may not have access to accommodative transportation or recreational spaces especially those in rural communities due to the scarcity of public transportation or transportation options existing in faraway communities. The need for assistance can also serve as another obstacle for CSHCN to partake in daily physical activity or meet physical activity guidelines (NCHPAD, 2018c).

Parents of CSHCN may experience frustration due to inaccessibility to adaptive recreational equipment encompassing roll-in swim chairs, a pool lift, flotation devices and personnel including personal care assistants and inclusion aides (NCHPAD, 2018c). In addition, recreational facilities may not have adequate technology pertinent to CSHCN with IDD to enable communication to effectively participate in physical activity (NCHPAD, 2018c). Furthermore, some programs may combine CSHCN with various disabilities without tailoring physical education to specific disabilities facilitating a "one size fits all" approach (NCHPAD, 2018c). This impedes the participation of CSHCN in recreational activities corresponding to their appropriate level (NCHPAD, 2018c; Verschuren, Wiart, Hermans, & Ketelaar, 2012).

Public Policy Level

There are no current public policies regarding physical activity for CSHCN. But with regard to nutrition, the USDA guidelines accommodate the special dietary needs for CSHCN for federal school meal programs. In the educational setting, there are three public policies concerning CSHCN: the Individuals with Disabilities Education Act (IDEA), the Rehabilitation Act of 1973 and the Americans with Disabilities Act (ADA) (Lipkin & Okamoto, 2015). The IDEA authorizes allocation of funding to states for early intervention services for infants and toddlers with IDD (Apling & Jones, 2008; Lipkin & Okamato, 2015). In addition, the IDEA requires schools to provide special education and related services for CSHCN aged 3 to 21 years (Apling & Jones, 2008; Lipkin & Okamato, 2015). The IDEA maintains

that states and school districts must identify and evaluate CSHCN to confirm needs for special education and services and work with parents to establish an IEP (Apling & Jones, 2008; Lipkin & Okamato, 2015).

The IDEA requires educators to maintain a least restrictive environment. In other words, CSHCN must be educated with their counterparts to the maximum extent possible (Apling & Jones, 2008). The Rehabilitation Act of 1973 and the ADA forbid discrimination directed toward individuals with disabilities in any federally funded activity or program (Apling & Jones, 2008). The ADA also bans discrimination against individuals with disabilities of all ages and in all public areas of life comprising public accommodations, public services, and employment (Apling & Jones, 2008).

Implications of Risk Factors on Quality of Life and Mortality

It is evident that lifestyle factors consisting of unhealthy eating and low levels of physical activity contribute to obesity among CSHCN especially CSHCN with IDD (Rimmer & Yamaki, 2007). Furthermore, obesity is associated with higher morbidity and mortality rates for CSHCN with IDD. In addition, obesity relative to CSHCN with IDD is strongly correlated with conditions including diabetes, heart disease, hypertension, arthritis and more reducing the quality of life (Rimmer & Yamaki, 2007).

Obesity among Children and Adolescents with Down Syndrome

When it comes to subgroups of individuals with IDD, obesity is disconcerting among women and those with DS (Rimmer & Yamaki, 2006). Within individuals with intellectual disabilities, analysis of clinical data has found that adolescents with DS have a higher prevalence of obesity (Luke, Mowbray, Klump, Herman, & Bootsmiller, 1996; Rimmer, Yamaki, Lowry, Wang, & Vogel, 2010). Children and adolescents with DS have a higher obesity risk than that of children and adolescents in the general population attributable to the genetic predisposition (Bertapelli et al., 2016; NCHPAD, 2018a; Van Riper & Wallace, 2010).

The CDC maintains that 1 in every 700 babies in the United States is born with DS resulting in DS being the most common chromosomal condition (NDSS, 2018b). Close to 6,000 babies in the United

States are born with DS every year (CDC, 2018c; NDSS, 2018b). DS is a lifelong condition and genetic disorder resulting from having a full or extra chromosome copy of chromosome 21 (CDC, 2018c). The extra chromosome copy results in an alteration of brain and body development producing physical and mental health challenges for children and adolescents into adulthood (CDC, 2018c). According to the NDSS (2018b) and CDC (2018c), there are three classifications of DS: translocation, mosaic, and Trisomy 21.

Translocation DS consists of part of the extra chromosome 21 copy or the entire extra chromosome 21 copy attaching to a different chromosome (CDC, 2018c; NDSS, 2018b). Translocation DS affects close to 3% of individuals with DS. Those with Mosaic DS have a mixture encompassing some body cells having 3 copies of the chromosome while others have the usual 2 copies of chromosome 21. Mosaic DS has an effect on 2% of individuals with DS. Individuals with Mosaic DS may have fewer physical features as others with DS due to the presence of some body cells having the usual 2 copies of chromosome 21. Trisomy 21 concerns each cell in the body having 3 copies of chromosome 21 as opposed to the usual 2 copies. Trisomy 21 is the most common type of DS affecting 95% of individuals with DS (CDC, 2018c; NDSS, 2018b).

Not including birth, close to 50% of children with DS are hospitalized before the age of 3 (So, Urbano, & Hodapp, 2007). These hospitalizations are a result of medical conditions comprising respiratory illnesses and congenital heart disease (So et al., 2007). Respiratory illnesses and congenital heart disease for children with DS can lead to a high demand on the health system that can be as much as 13 times higher than children without DS (Boulet, Molinari, Grosse, Honein, & Correa-Villasenor, 2008). Despite the increase in medical costs associated with respiratory illnesses and congenital heart disease, life expectancy has improved in the past few decades nearing 60 years for individuals with DS (Day, Strauss, Shavelle, & Reynolds, 2005). However, the mortality rates of individuals with DS remain higher than those without DS (Pitetti et al., 2013).

The leading causes contributing to the mortality rates for individuals with DS are congenital heart defects and respiratory illnesses such as asthma, pneumonia, and bronchitis (Pitetti et al., 2013).

Additional leading causes driving the mortality rates are leukemia, circulatory diseases (e.g., cerebrovascular disease, ischemic heart disease) and Alzheimer's disease. There is a significant increase pertaining to death rates for individuals with DS after the age 40. This upsurge is due to the decline of functional status and rise in behavioral problems from Alzheimer's disease (Pitetti et al., 2013).

With regard to communication, children and adolescents with DS tend to speak slowly to others and have intelligent quotients within the mild to moderate low range (CDC, 2018c). Children and adolescents with DS experience trouble expressing themselves through speaking, gesturing, and interacting with others making it difficult to form social relationships (Smith, Næss, & Jarrold, 2017). When it comes to physical traits, there are numerous physical features that children and adolescents with DS possess (CDC, 2018c). Some of these features are a flattened face, slanted almond-shaped eyes, a short neck and small ears (CDC, 2018c). The influences concerning physical activity and eating behaviors relative to children and adolescents with DS can be examined through a social ecological lens.

Intrapersonal Level

With respect to nutrition, children and adolescents with DS require more mealtime assistance among CSHCN (Academy of Nutrition and Dietetics, 2015). Moreover, micronutrient deficiencies are common in this population (Bertapelli et al., 2016). Additionally, children and adolescents with DS will continue to eat if food is constantly given and have little sense of knowing when they are full (Down's Syndrome Association, 2018). Furthermore, children and adolescents with DS have slower metabolism compared to that of the general population of children and adolescents (Braaten, 2018). In other words, their bodies burn fewer calories (Vanderbilt Kennedy Center for Excellence in Developmental Disabilities, 2015). There are certain conditions relative to children and adolescents with DS that can impede proper nutrition (NCHPAD, 2018c). These conditions encompassing Celiac Disease, constipation, a reduced immune system, hypothyroidism and gastroesophageal reflux disease are associated with poor nutrition for children and adolescents with DS (NCHPAD, 2018b).

Celiac Disease is an autoimmune disorder that involves sensitivity to gluten which can be found in rye, barley and wheat (NCHPAD, 2018b). Once gluten is ingested, the lining of the small intestine becomes damaged (NCHPAD, 2018b). Constipation occurs due to low consumption of water, and sources of fiber such as raw fruits and vegetables, and cereal (NCHPAD, 2018b). Children and adolescents with DS are highly susceptible to constipation because of low muscle tone and practicing sedentary behavior (NCHPAD, 2018b). With regard to the immune system, abnormalities associated with mild to moderate B and T cell lymphocytes, low count of new lymphocytes, and reduced specific antibody responses to immunizations have been known to present in children and adolescents with DS (Kusters, Gemen, Vestergen, Wever, & deVries, 2010; Ram & Chinen, 2011).

Congenital hypothyroidism has been associated with children and adolescents with DS (Fort et al., 1984; Coleman, 1994). Children and adolescents with DS are 28 times more likely to have congenital hypothyroidism than children and adolescents in the general population (Fort et al., 1984). Hyperthyroidism can lead to hyperactivity, weight loss, nervousness, diarrhea, and goiter (enlargement of neck due to swelling of thyroid gland) (Coleman, 1994). Gastroesophageal reflux disease is a condition regarding the occurrence of contents in the stomach refluxing back to the esophagus resulting in a sore throat, heartburn, chest pain and issues with swallowing hindering nutritional intake (NCHPAD, 2018b). When it comes to personal characteristics concerning diet, children and adolescents with DS have a tendency to consume unhealthy food due to delayed oral-motor skills, texture selectivity, narrow food preferences and food refusal (Field et al., 2003; Lazenby, 2008).

Physical features such as short stature, small hands and feet, inadequate muscle tone and loose joints can make it difficult for children and adolescents with DS to engage in physical activity (CDC, 2018c; NCHPAD, 2018a). Research has shown that children and adolescents with DS have reduced levels of muscle strength, motor development, and cardiovascular fitness that can impede participation in physical activity or team sports (NCHPAD, 2018a). Pertaining to age, adolescents with DS have been found to practice sedentary behavior more than their younger counterparts with DS (NCHPAD, 2018a). Additionally, the acute medical conditions (e.g. congenital heart defect, low muscle tone) of children and

adolescents with DS act as barriers regarding energy and endurance to be physically active (Barr & Shields, 2011; Pitetti et al., 2013). Individuals with DS may execute movement at a slower and safer pace to ensure accurate movement patterns (Latash, 2007). These slower movements are due to the interplay of time constraints of completing tasks, cognitive impairment and the environment (Latash, 2007).

Interpersonal Level

For parents, ensuring their children and adolescents with DS maintain a healthy diet may prove to be difficult (NDSS, 2018a). Children and adolescents with DS have a propensity to eat junk food and usually take a long periods of time to eat their meals. In addition, parents often praise their children and adolescents with DS for cleaning their plate or finishing their meals. However, this may foster overeating by sending the wrong message to their children and adolescents with DS to eat everything when food is offered to them. Furthermore, because of food preferences for unhealthy food, at the dinner table, parents may have to prepare or serve different meals for their children and adolescents with DS to ensure that they eat (NDSS, 2018a).

Additional barriers to healthy eating for children and adolescents with DS are parents not preparing meals with their children and parents not encouraging the exploration of new foods (NDSS, 2018a). Moreover, relative to parents, high portion sizes, promoting unhealthy ingredients, frequent snacking, using food as a reward, and not preparing lunch at home can impede the nutrition of their children and adolescents with DS. With respect to peer involvement, there is a lack of literature concerning the attitudes of peers affecting the eating behaviors of children and adolescents with DS. However, it would be reasonable to assume that children and adolescents with DS tend to favor unhealthy food options admired by their peers which is common practice among CSHCN with IDD (NDSS, 2018a).

Pertaining to physical activity, parents and siblings are significant determinants for physical activity regarding children and adolescents with DS (Barr & Shields, 2011). Children and adolescents with DS are less likely to participate in physical activity without encouragement from their siblings (Barr & Shields, 2011). The lack of endorsement to be physically active with their brothers or sisters with DS

result in children and adolescents with DS practicing sedentary behaviors (Barr & Shields, 2011). Additionally, due to time constraints, parents may not provide opportunities for their children with DS to engage in physical activity (Barr & Shields, 2011; Buckley, 2007). Likewise, without the help of other caregivers or authority figures to create physical activity opportunities for children and adolescents with DS, the likelihood of physical inactivity is high (Barr & Shields, 2011).

Children and adolescents with DS also require supervision because of behavioral issues and safety concerns (Barr & Shields, 2011). Parents with busy schedules are unable to supervise their children and adolescents with DS impeding physical activity. Furthermore, expensive medical services associated with children and adolescents with DS may take priority with home and work tasks over physical activity for the children and adolescents with DS. Peer involvement is crucial for promoting physical activity for children and adolescents with DS as well. Children and adolescents with DS often imitate their peers. Lack of involvement and encouragement from peers hinder physical activity for children and adolescents with DS (Barr & Shields, 2011).

Organizational Level

The school setting can serve as a protective factor against low engagement in physical activity for children and adolescents with DS if barriers are addressed (MacDonald, Leichtman, Esposito, Cook, & Ulrich, 2016). Little is known about the participation patterns of children and adolescents with DS relative to physical activity for educators to meet the program needs of children and adolescents with DS (MacDonald et al., 2016). Children and adolescents with DS tend to experience trouble participating in formal, physical, and skill-based activities (MacDonald et al., 2016). In addition, lack of encouragement for children with DS to consume healthy food may lead to improper nutrition. As for nutrition education in schools, children and adolescents with DS are exposed to the same messages as the general population. However, the scarcity of nutrition education tailored for children and adolescents with DS in school may be acting as an obstacle for healthy eating to prevent obesity.

With respect to the health system, Bull and the Committee on Genetics of the American Academy of Pediatrics (2011) established the *Clinical Report—Health Supervision for Children with Down Syndrome*. This report discusses conditions associated with DS that should evaluated, life stage transitions, shared decision-making with families, and providing recommendations for families to promote physical activity and a healthy diet for children and adolescents with DS (Bull & Committee on Genetics of the American Academy of Pediatrics, 2011). However, families who lack access to care are likely to have greater unmet needs including dietary and physical activity recommendations to manage weight of children and adolescents with DS (McGrath, Stransky, Cooley, & Moeschler, 2011).

Community Level

There is a scarcity of literature pertaining to the community's influence on the nutritional status of children and adolescents with DS. But it can be assumed that the community impacts the eating behaviors of CSHCN with IDD (Rimmer & Yamaki, 2007). Understanding community environmental factors that impact caloric intake such as access to healthy foods and grocery stores soliciting fruits and vegetables is needed to determine reasons for obesity for children and adolescents with DS (Rimmer & Yamaki, 2007). With regard to physical activity, lack of accessible and culturally appropriate programs can contribute to low physical activity or physical inactivity for children and adolescents with DS (Barr & Shields, 2011; Buckley, 2007; Rimmer & Yamaki, 2007). Parents may experience difficulty enrolling their children with DS into mainstream programs (Barr & Shields, 2011). In a study conducted by Barr and Shields (2011), parents reported lack of time and poor adaptive physical education of program staff prevented inclusion for their children and adolescents with DS. Furthermore, parents did not feel compelled to attend unadvertised programs in fear that the programs would not be inclusive of their children and adolescents with DS (Barr & Shields, 2011).

Community norms perpetuating negative attitudes toward children and adolescents with DS impede physical activity for children and adolescents with DS as well (Barr & Shields, 2011). Barr and Shields (2011) found that parents reported being frustrated due to stereotypes, preconceived notions, and

others utilizing the word “disability” to describe their children with DS. Parents maintained that as soon as their children and adolescents with DS were labeled as having a disability, community members exuded exclusionary behaviors and negative attitudes hindering participation for their children and adolescents with DS (Barr & Shields, 2011). Moreover, parents wanted advice from program staff regarding home and community-based activities to help teach their children and adolescents with DS how to play sports and to be physically active (Buckley, 2007).

Public Policy Level

Children and adolescents with DS have the opportunity to participate in the federal school meal programs similar to the general population. However, public policies concerning nutrition for children and adolescents with DS are not in existence despite their elevated risk for obesity. It is imperative to conduct more research to accumulate evidence to implement such policies. With regard to physical activity, there are no public policies specific to children and adolescents with DS even though physical activity is problematic among this population.

Implications of Risk Factors on Quality of Life and Mortality

Children and adolescents with DS have a higher risk of obesity compared than their counterparts without DS due to psychological mechanisms, an unfavorable diet and little to no engagement in physical activity (Bertapelli et al., 2016; Murray & Ryan-Krause, 2011). Individuals with DS have a 4 to 16-fold increased risk of mortality because of medical conditions comprising congenital heart disease, respiratory illnesses, cerebrovascular disease and more (Hill et al., 2003). The obesity risk for children and adolescents with DS increases after the age of 2 (Bertapelli et al., 2016). Children and adolescents with DS with obesity have an elevated risk for diabetes and other chronic conditions (Bertapelli et al., 2016). Children and adolescents with DS with obesity are susceptible to exclusion from peers and bullying lowering self-esteem and quality of life (Barr & Shields, 2011; Rimmer et al., 2010).

Conceptual Framework

According to the WHO (2007), the International Classification of Functioning, Disability and Health for Children and Youth also known as the ICF-CY serves as the best framework for assessing health concerns and implementing health programs and services for CSHCN. The ICF-CY is a derivation of the International Classification of Functioning, Disability and Health established in 2001 comprising CSHCN and adults with special healthcare needs. The ICF-CY centers on CSHCN and was developed to meet the specific needs of recording disability and health conditions for CSHCN since these conditions differ in nature, impact and intensity in comparison to adults (WHO, 2007).

The ICF-CY specifically aims to assess and record traits pertinent to the development of CSHCN in addition to environmental characteristics surrounding CSHCN in infancy, childhood and adolescence (WHO, 2007). The ICF-CY can be used across numerous disciplines including but not limited to educators, researchers, policy makers, administrators, providers, consumers and additional disciplines to promote the well-being of CSHCN. Furthermore, the ICF-CY supplies a common language or terminology to facilitate research in clinical, public health and other scientific settings to document and measure disability and health among CSHCN. Health professionals are able to utilize the ICF-CY to document and assess problems regarding functioning, body structures, limitations associated with activities, and participation restrictions relative to CSHCN and their environment (WHO, 2007).

The ICF-CY is one of many international classifications that originated from the WHO for application purposes regarding health assessment (WHO, 2007). Moreover, the ICF-CY provides a conceptual framework and classification system that can promote access to education, healthcare, habilitation and social services to respect and affirm the rights of CSHCN. The ICF-CY accounts for features pertaining to functioning and health to endorse a public health framework. The ICF-CY encourages health promotion and functioning for CSHCN (WHO, 2007).

There were 4 issues for CSHCN that resulted in the development of the ICF-CY: the child in the context of the family, developmental delay, participation and environments (WHO, 2007). The child in

the context of the family asserts that development is a multifaceted process that entails the child progressing from social, physical, and psychological dependency on others to independence during adolescence. In this multifaceted process of development, the functioning and health of the child heavily depends on the continuous family or caregiver interactions comprising the social environment. Therefore, it is imperative to take into account the context of the family system because it has a major impact on the functioning of the child and serves as the source for the life skills acquired by the child in the first two decades of life (WHO, 2007).

With respect to developmental delay, the formulation of body structures, body functions, and skills vary to a certain degree based on individual differences regarding growth and development (WHO, 2007). These variations act as a foundation to identify CSHCN with an elevated risk of disabilities. Additionally, delays affecting the emergence of body structures, body functions, and acquisition of skills may not be permanent but may be due to the developmental delay of the child. Functions of developmental delay entailing cognitive ability, speech, mobility and communication are significantly influenced by physiological and physical factors in the child's environment (WHO, 2007).

Within the ICF-CY, there are 5 categories: Body Structures, Body Functions, Activities and Participation, Environmental Factors and Personal Factors (WHO, 2007). Each of these components are classified by an alphanumeric code associated with the ICF-CY. The letter 'b' is assigned to Body Functions, the letter 's' for Body Structures, the letter 'd' for Activities and Participation and the letter 'e' for Environmental Factors. Personal Factors are not classified in the ICF-CY. However, they are included in the framework due to their contributions to and impact on interventions (WHO, 2007).

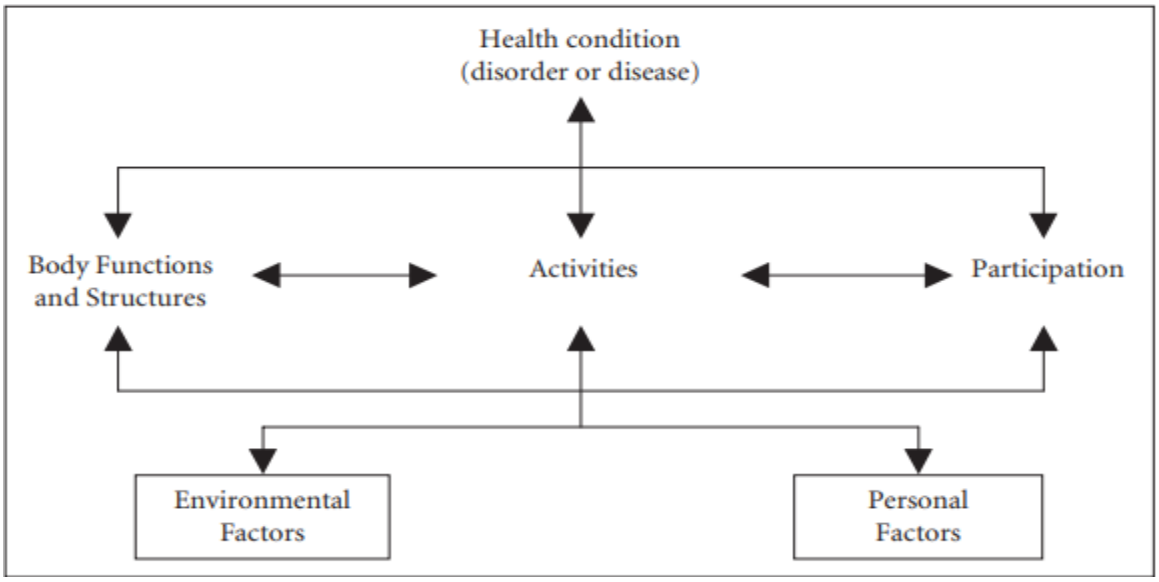

Figure 2.4 Interactions between the Categories of the ICF-CY

The ICF-CY is used to document the severity of a condition associated with Body Structures, Body Functions, and Activities and Participation concerning lags in development regarding the child (WHO, 2007). Severity encompasses five levels ranging from no impairment, difficulty or barrier (0) to complete impairment, difficulty or barrier (4). Body Structures refers to the anatomical parts of the body comprising organs, limbs and other parts of the body while Body Functions centers on the physiological and psychological functions of the body. With respect to disability, an impairment is defined as a defect or loss in Body Structures or Body Functions. An activity involves executing a task or action and participation is defined as engagement in a life situation (WHO, 2007).

In contrast, activity limitations are difficulties experienced when executing tasks or actions while participation restrictions are issues concerning involvement in life situations (WHO, 2007). Moreover, Activities and Participation can be classified according to capacity and performance. Performance describes what a person does in their current environment while capacity is the ability to execute tasks or actions to determine the highest probable level of functioning in a standard or uniform environment. Furthermore, with respect to participation, life situations are subject to change depending on the degree of

complexity of multiple relationships with primary caregivers, solitary play of the child, peer relationships and the school setting (WHO, 2007).

The younger the child, the more the child's participation is defined by role models including parents, caregivers and providers (WHO, 2007). Lastly, the environment does not only consist of the physical factors of the child's environment but also includes the social and attitudinal aspects of the child's environment as well. A tenet of the ICF-CY is that a child's environment is modified due to transitions from infancy to childhood to adolescence while establishing a sense of independence. For example, products for the child's use (e.g. play objects) must correspond to the developmental level of the child (WHO, 2007).

It is important to note that Environmental Factors can be categorized as facilitators or barriers (WHO, 2007). Examples of environmental barriers are low-nutritional food options and a lack of opportunities for physical activity for the child. These barriers that serve as contributors to diseases such as obesity, diabetes and other chronic diseases adversely affect the health, functioning, and learning ability of CSHCN. Factors related to the physical, social and psychological environments play a significant role in a child's development as well. An example of a facilitator relative to the physical environment that can be altered is the substitution of healthy food options for the child in the home while social and psychological factors include aspects such as social support for families and education delivered to caregivers. Therefore, modifying the environment for CSHCN regarding physical, social and psychological factors is crucial to enhance functioning and health status among CSHCN (WHO, 2007).

The ICF-CY consists of several aspects associated with the well-being of a child: memory, perception, mental functions of attention, and activities centering on play, family life, learning and education within two components (WHO, 2007). The two components are functioning and disability in addition to contextual factors. Functioning and disability comprise Body Structures and Body Functions, and Activities and Participation. Functioning entails the Body Structures, Body Functions, and Activities and Participation while disability encompasses impairments, activity limitations and participation restrictions. Contextual factors consist of Environmental Factors and Personal Factors (WHO, 2007).

Environmental Factors are classified as barriers (0=no barrier to 4=complete barrier) or facilitators (0=no facilitator to 4=complete facilitator) pertinent to health and functioning (WHO, 2007). Environmental Factors can be individual or societal. Environmental Factors concerning the child are settings such as the family home, work and school along with interactions with individuals in each setting. Societal factors include systems in the community or society consisting of organizations and services. Examples of organizations and services are government agencies, transportation services, laws, the workplace and more. The social norms and attitudes associated with these services and organizations impact the health and functioning of CSHCN as well. Personal Factors comprise sociodemographic factors, cultural beliefs, other health conditions, lifestyle habits, upbringing, and events regarding the past and present, personal preferences and more. Personal Factors are not classified under the ICF-CY due to social and cultural variance associated with each child (WHO, 2007).

The ICF-CY serves as an adapted form of the SEM tailored to CSHCN. The Body Functions, Body Structures, Activities and Participation and Personal Factors correspond to the intrapersonal level of the SEM by taking into account the specific individual characteristics of CSHCN. Examples are low muscle tone, slower movements, behavioral issues, individual preferences and more for children and adolescents with DS. With respect to the Environmental Factors of the ICF-CY, the interpersonal, organizational, community and public policy levels of the SEM are addressed.

Similar to the interpersonal level of the SEM, the ICF-CY investigates the relationships of CSHCN with their families, peers, and health professionals. For the organizational level of the SEM, the school, and health system are examined regarding effects on the child's functioning and health status. Furthermore, the ICF-CY looks at the community, social and physical life, products and technology, services and systems, the attitudes of community members and the built environment equating to the community level of the SEM. Lastly, at the public policy level of the SEM, the ICF-CY considers the policies that influence the well-being of CSHCN.

CHAPTER 3

METHODOLOGY

Study Description

This study utilized a sequential mixed methods approach to identify barriers and facilitators to healthy eating and physical activity for adolescents with DS. The quantitative arm was executed first followed by the qualitative arm. For the quantitative arm, parents were asked to complete three questionnaires: the FBC, the PROMIS Physical Activity Short Form and the WHODAS 2.0. The questionnaires measured the eating, physical activity, and social behaviors of the adolescents with DS, respectively. Additionally, the body fat of the adolescents with DS was assessed through BIA, skinfold thickness measures and BMI.

The body fat values were used to categorize the adolescents with DS and their parents into two groups: obese/overweight and non-obese/overweight. For the qualitative arm, the perspectives of the parents and the adolescents with DS were gathered. The interviews provided insight regarding the items from the questionnaires to determine facilitators and barriers for healthy eating and physical activity relative to the ICF-CY. The Georgia Southern University Institutional Review Board granted ethical approval to conduct this study. The primary researcher received grant funding to provide travel vouchers and mini Hoberman spheres as incentives for the families.

Participants

Participants who were eligible for this study were parents of adolescents with DS aged 10-21 and adolescents with DS aged 10-21 years (μ=12.92, SD=1.89). The adolescents with DS and their parents resided in the Southeast Health and Coastal Health Districts in Southeast Georgia. Participants were recruited through schools in the Southeast Health District and the Lowcountry Down Syndrome Society (a local affiliate of the NDSS) located in the Coastal Health District. The study sample contained 13 families (13 adolescents with DS and 13 parents).

Data Collection

Parents were asked to provide parental consent in addition to informed consent. The adolescents with DS provided minor assent by signing their names after their parents discussed the study with them. Cognitive difficulties concerning problem-solving, memory and trouble conveying viewpoints may be present pertaining to the adolescents with DS (Dunn, Kroese, Thomas, McGarry, & Drew, 2006; Nind, 2008). To compensate for this, some researchers apply novel methods such as visual images and simplifying interview or survey questions based on readability and intelligent quotients of participants (Dunn et al., 2006). Because of challenges presented in previous research related to individuals with IDD, the primary researcher utilized the method of simplifying interview questions for the adolescents with DS.

Cameron & Murphy (2007) acknowledged the importance of including probing questions regarding interviewing individuals with IDD. For this study, probing questions were administered to the adolescents with DS. Examples of these questions are ‘Do you like fruits?’ ‘Do you like to exercise?’ ‘What is your favorite sport?’ ‘Does your school have recess?’ In addition, Cameron and Murphy (2007) emphasized that when interviewing individuals with IDD, repeated explanations along with time to process the information being asked can promote comprehension for respondents. The primary researcher repeated questions and explanations and allowed time for the adolescents with DS to retrieve and process information.

Confidentiality was upheld by informing all participants that the FBC, the PROMIS Physical Activity Short Form, the WHODAS 2.0 and interview answers would not be disseminated in a manner than can identify them. For example, Non-Obese/Overweight Parent Participant 1 represented the first parent who was interviewed in the entire sample. Non-obese/overweight was used to classify Parent Participant 1 because their adolescent with DS was concluded to be non-obese/overweight based on the body fat assessment. The information was preserved on a server that was password-protected with only the research team having access to the computer files. Per the Georgia Board of Regents retention policy,

data collected will be retained for 7 years following completion of this study. Data gathered for this study will be used for future publications and presentations.

Quantitative Arm

The body fat of the adolescents with DS was measured and the parents completed the FBC, the PROMIS Physical Activity Short Form, and the WHODAS 2.0. Activity Short (refer to Appendices B to D). Body fat was measured for all of the adolescents with DS. The body fat assessment was used to categorize the families into two groups: non-obese/overweight and obese/overweight.

Qualitative Arm

After families were assigned to their respective groups, the interview portion commenced for all participants entailing ICF-CY questions relative to healthy eating and physical activity for the adolescents with DS. All of the interviews took place separately. Although there were 26 participants, only 25 interviews were conducted. This was because one of the adolescents with DS was nonverbal and unable to answer interview questions. A semi-structured interview guide consisting of a list of topics and questions was generated. The interviews were audio-recorded and transcribed verbatim to determine underlying themes that emerged, and participants were informed that the interviews were being recorded according to the guidelines of the Center for Community Health and Development (2018).

Instrumentation

Quantitative arm

Body fat assessment

The body fat values pertaining to the adolescents with DS were measured through BMI, BIA and skinfold thickness measures. BMI was computed using the equation constituting weight in kilograms/ square of height in meters. (CDC, 2015b). Those who fell into the 5th to 84th percentile range were categorized as non-obese/overweight while those in the 85th to the 100th percentile range were categorized as obese/overweight (CDC, 2015b). BMI is an easy method to perform and serves as a screener to detect

weight categories at risk for chronic diseases or health issues (CDC, 2015b). However, since BMI is not a direct measure of body fat, the CDC suggests that other methods that serve as direct measures of body fat such as skinfold thickness, BIA, underwater weighing, dual-energy X-ray absorptiometry and more should be utilized in conjunction with BMI (CDC, 2015b). The American Academy of Pediatrics (2016) recommends using the CDC BMI charts regarding adolescents aged 10 and above with DS.

BIA served as another method to assess body fat to group the adolescents with DS and parents into obese/overweight and non-obese/overweight classifications. In addition, using two common methods to determine body fat lessens the chances of error. The BIA device known as the BodyStat 1500 Body Composition Analyzer uses frequencies ranging from 5KHz-200KHz to enable an electrical current to permeate cells. Participants lie in a supine position for close to 5 to 10 minutes. Demographics including gender, weight and height were entered into the BIA BodyStat 1500 Body Composition Analyzer. Furthermore, electrodes were placed on the wrist and ankle. Prior to electrode placement, each participant's skin for the electrode sites (wrist and ankle) were cleaned with alcohol for hygienic purposes and to obtain accurate measurements (CDC, 2000).

BIA has been used to accurately determine adiposity among adolescents with DS (Loveday, Thompson, & Mitchell, 2012). For the skinfold thickness measurements, the subscapular and triceps skinfolds were measured by taking a double fold of skin under the soft tissue on the right side of the body using the Lange skinfold calipers following standard body measurement procedures outlined by the National Health and Nutrition Examination Survey (NHANES) (CDC, 2000). The body fat percentage of the participants was estimated by inserting the subscapular and triceps skinfold values into the body fat standard equation for children and adolescents with DS established by González-Agüero, Vicente-Rodríguez, Ara, Moreno and Casajus (2011). The triceps and subscapular skinfolds were each measured three times to compute average values for both skinfolds.

Food Behavior Checklist

The FBC was established by the University of California Cooperative Extension, the California Nutrition Network, and the University of California Davis (USDA, 2018b). Furthermore, the FBC serves as the primary tool to record behavior change for the Supplemental Nutrition Assistance Program-Education (USDA, 2018b). Baseline data from a 1997 study conducted by Townsend, Kaiser, Allen, Joy and Murphy (2003) served as the foundation of the FBC (Blackburn et al., 2006; Townsend et al., 2003). This study was used to establish validity relative to nutrition education concerning the fruit and vegetable questions on the FBC for 100 low-income women. Three validation methods were used: correlation of the fruit and vegetable questions with biomarkers, comparing fruit and vegetable intake to 24-hour dietary recalls, and comparing nutrient intakes indicated by the FBC to 24- hour dietary recalls (Blackburn et al., 2006; Townsend et al., 2003).

With regard to internal consistency and reliability, the Cronbach alpha was 0.80 while the reliability coefficients ranged from 0.35 ($P>0.05$) to 0.65 ($P<0.0001$) (Blackburn et al., 2006; Townsend et al., 2003). The FBC is both a valid and reliable assessment of fruit and vegetable consumption (Blackburn et al., 2006). In contrast to a 24-hour dietary recall, the FBC is less time-intensive to administer, code, analyze and can reduce respondent burden than a 24-hour dietary recall (Blackburn et al., 2006). Although the FBC has not been validated for parents of adolescents with DS, the FBC was revised by experts in the field resulting in an adapted version entailing 30 items to quantify dietary behaviors. Majority of the FBC questions asked for how many days the adolescents with DS consumed food and beverages in the past week. Answer options for these questions were 1-3 days, 4-6 days or every day (refer to Appendix B).

Patient Reported Outcomes Measurement Information System Physical Activity Short Form

Following the completion of the FBC, parents filled out the 8-question PROMIS Physical Activity Short Form. The PROMIS Physical Activity Short Form was developed and evaluated with NIH funding (Northwestern University, 2018a). The 8 questions came from the parent proxy version of the

PROMIS Physical Activity Short Form pertaining to the frequency of physical activity in the past week (Northwestern University, 2017). Each question was answered on a scale of 1-5 regarding how many days the adolescents with DS were physically active: 1 (no days), 1 (1 day), 2 (2-3 days), 4 (4-5 days) and 5 (6-7 days) (Northwestern University, 2017). A score was computed for each participant based on the answers that were provided with a minimum score of 8 to a maximum score of 40 (Northwestern University, 2017). Higher scores indicated more frequency of physical activity (Northwestern University, 2017). There were several strategies utilized to preserve the validity and reliability of the PROMIS Physical Activity Short Form (Northwestern University, 2017).

Comprehensive literature review searches of potential items and existing measures were performed to ensure content validity (Northwestern University, 2018b). In addition, focus groups and analyses of themes were carried out to eliminate items deemed to be repetitive, confusing or poorly conveyed. Furthermore, cognitive interviews were conducted so that each item had multiple reviewers from diverse backgrounds including both males and females, minority groups and moderate reading levels to obtain feedback on clarity, language and relevance of items. Validity studies were also executed to confirm the degree to which items measured what they aimed to measure (Northwestern University, 2018b). The PROMIS Physical Activity Short Form can be found in Appendix C.

World Health Organization Disability Assessment Schedule 2.0

Lastly, parents completed the WHODAS 2.0. The WHODAS 2.0 is unique because it has a direct link to the ICF-CY (WHO, 2018c). The WHODAS 2.0 comprises 36 items asking for information pertaining to understanding and communicating, getting around, self-care, getting along with people, life activities, and participation in society. The WHODAS 2.0 was adapted for this study resulting in 35 items by excluding sexual activities thus lowering the number of items from 36 to 35. Additionally, the answer options for the WHODAS 2.0 ranged from 0 to 4: 0 (no difficulty), 1 (mild difficulty), 2 (moderate difficulty), 3 (severe difficulty), 4 (extreme difficulty or cannot do). A score was calculated based on the answers provided for each question. The WHODAS 2.0 has been administered in 19 countries across the

globe and possesses exceptional psychometric properties. Test-retest studies have deemed the WHODAS 2.0 to be highly reliable with item-response theory being utilized to select the items to be included in the WHODAS 2.0 (WHO, 2018c). The WHODAS 2.0 can be located in Appendix D.

Qualitative Arm

The AAIDD (2009) acknowledges that there are several benefits associated with interviewing individuals with IDD including those with DS. Individuals with IDD have unique perceptions and lived experiences that might not be noted by others and can yield valuable insights for research and the planning and delivery of health promotion efforts. Additionally, interviewing individuals with IDD such as adolescents with DS enables them to be viewed as self-advocates. Furthermore, the interviewing process conveys respect and value concerning the personal opinions and perceptions of those with IDD. Nonverbal cues such as shifting body, posture, smiles, eyes gazes, frowning and more can yield valuable information pertaining to research. The interview process can serve as an empowering outlet to discuss issues and resources regarding the health status of individuals with IDD and can help them learn about themselves in relation to activities, support and other aspects that were not previously considered (AAIDD, 2009).

The primary researcher utilized questions from Schiariti et al. (2014) to create an interview guide for both parent and adolescent with DS participants regarding healthy eating and physical activity relative to the adolescents with DS. The interview guides can be found in the Appendix F. These interview questions addressed categories and identifiers pertaining to the ICF-CY. The ICF-CY categories were Body Structures, Body Functions, Activities and Participation, Environmental Factors and Personal Factors (Schiariti et al., 2014). The interview guide comprised questions assessing facilitators and barriers to engagement in physical activity and healthy eating for the adolescents with DS.

Data Analysis

Following data collection, data from both the quantitative and qualitative items were coded and analyzed using SPSS Version 23 and NVivo Version 11, respectively. Data was used to identify themes and statistics to generate a situational analysis pertaining to the adolescents with DS in the sample concerning physical activity and healthy eating. With respect to the FBC, the PROMIS Physical Activity Short Form and the WHODAS 2.0, the composite and partial scores and answer options of participants underwent analysis to yield any relationships between the obese/overweight and non-obese/overweight groups. The interview themes were highlighted using the ICF-CY alphanumeric code. In addition, the codebook used for the interviews were reviewed by disability experts.

Data analysis consisted of line by line coding using the ICF-CY as a framework and coding guide. The themes in the transcripts were pinpointed based on the ICF-CY categories encompassing Body Structures, Body Functions, Activities and Participation, Environmental Factors and Personal Factors (WHO, 2007). Each ICF-CY category was classified by their designated letters per instructions of the ICF-CY framework. The letter 'b' was assigned to Body Functions while 's','d', and 'e' corresponded to Body Structures, Activities and Participation and Environmental Factors, respectively. Personal Factors were not categorized by a letter as the ICF-CY maintains. A numerical code was associated with the four levels of the ICF-CY beginning with the chapter number of first level (one-digit) followed by the subsequent levels including second (two-digits), third (three-digits) and fourth (four-digits) depending on the specificity pertaining to the ICF-CY categories (WHO, 2007).

For example, in the case of *e1521 adapted products and technology for play*, 'e' stands for Environmental Factors (WHO, 2007). Similar to the other ICF-CY categories, there are numerous chapters within Environmental Factors. At the first chapter level, the number 1 in e1521 symbolizes that the identifier is for the first chapter of Environmental Factors: Products and Technology. The second chapter level is products and technology for personal use in daily living (e15). The third chapter level is products and technology used for play (e152) and the fourth chapter level is adapted products and

technology for play (e1521). In other words, identifiers become more specific when moving from the first chapter level to the fourth chapter level (WHO, 2007).

Quantitative and qualitative data were triangulated (Merriam, 2009) and experts from the disability health field were performed a peer review of the data to assess whether the findings were plausible (Merriam, 2009). Furthermore, the specific outcome measures of data instruments were assessed to determine particular barriers and facilitators relative to healthy eating and physical activity among adolescents with DS. A final report of the themes that emerged from analysis was generated and distributed to participants.

Summary

Parents of adolescents with DS and adolescents with DS aged 10-21 were recruited for this study. The body fat of the adolescents with DS was assessed and used to categorize families into two groups: non-obese/overweight and obese/overweight. Parents completed the FBC, PROMIS Physical Activity Short Form and the WHODAS 2.0. Parents and the adolescents with DS answered interview questions relative to healthy eating and physical activity regarding the adolescents with DS. Confidentiality of the questionnaire and interview responses for all participants was preserved. Parents provided informed consent and parental consent while the adolescents with DS provided minor assent. Descriptive statistics and frequencies were generated for the questionnaire items and interview questions. SPSS Version 23 was used to code data for the questionnaires and NVivo Version 11 was used to code and analyze the interview responses. Interview themes associated with the ICF-CY were highlighted.

CHAPTER 4

RESULTS

Demographics

The sample consisted of 26 participants comprising thirteen families. Each family included one adolescent with DS and one parent. With respect to adolescent with DS weight status or body fat classification, 8 adolescents with DS were deemed obese/overweight while five adolescents with DS were categorized as non-obese/overweight. Similar to the adolescents with DS, there were eight parents of obese/overweight adolescents with DS and five parents of non-obese/overweight adolescents with DS. These categorizations were determined by the body fat measurements of the adolescents with DS.

The demographics of the sample can be found in Table 4.1. The majority of the participants (69.23%) were recruited from the Coastal Health District. The average age of the adolescents with DS was 12.92 years. Most of the adolescents with DS in the sample constituting 61.54% were in grades 6 and 7. For race and ethnicity, based on parental responses, 84.61% of the adolescents with DS were White or Caucasian. With respect to gender, 69.23% of the adolescents with DS were female.

Table 4.1 Characteristics of the Sample

	N	*%*
Location of Families		
Southeast Health District	8	30.77
Coastal Health District	18	69.23
Race and Ethnicity of Child		
White or Caucasian	11	84.62
Hispanic	2	15.38
Age of Child		
10 years	1	7.69
11 years	3	23.08
12 years	1	7.69
13 years	2	15.4
14 years	5	38.46
17 years	1	7.69
Grade Level of Child		
Grade 3	1	7.69
Grade 5	2	15.4
Grade 6	4	30.77

Table 4.1 (Continued)

Grade 7	4	30.77
Grade 8	1	7.69
Grade 11	1	7.69

Quantitative Arm

Body Fat Assessment

The body fat assessment of the adolescents with DS resulted in errors. The three methods used to assess body fat were BMI, BIA, and skinfold thickness measurements of the subscapular and triceps skinfolds. However, the skinfold equations concerning children and adolescents with DS was not applicable for this sample due to different parameters relative to the participants. The skinfold equations computing body fat percentage for children and adolescents with Down syndrome were %BF = $0.546(\text{triceps} + \text{subscapular})^2 + 9.7$ for females and %BF = $0.783(\text{triceps} + \text{subscapular})^2 + 1.7$ for males established by González-Agüero et al. (2011). The aforementioned equations are applicable when the total of the triceps and subscapular skinfold measurements is greater than 35 millimeters. These equations were not used to depict the body fat percentage of the adolescents with DS because the total of the subscapular and triceps skinfold for the adolescents with DS was less than 35 millimeters.

In addition, the BMI values from the weight/height^2 equation and BIA values for BMI conflicted with one another classifying some of the adolescents with DS as obese/overweight in one method and non-obese/overweight in the other method. For example, the same adolescent with DS was determined to be obese/overweight by BMI and non-obese/overweight with BIA or vice versa. The BMI and BIA values for the adolescents with DS are displayed in Table 4.2. As a result, the CDC age and sex specific BMI percentile ranges served as the basis for the obese/overweight (μ=30.50, SD=10.36) and non-obese/overweight (μ=18.33, SD=2.38) classifications. Adolescents with DS who fell into the 5th to 85th percentile range were characterized as non-obese/overweight while those within the 85th to 100th percentile range were characterized as obese/overweight. It is well known that children and adolescents with DS have different body fat distribution than that of the general population of children and

adolescents. There is still a lot of work that needs to be done to accurately assess the body fat of children and adolescents with DS.

Table 4.2 Body Fat Values for Adolescents with DS (N=13)

Child	**Classification**	BMI	BIA
DS Participant 1	Non-Obese/Overweight	17.39	17.5
DS Participant 2	Obese/Overweight	23.46	298
DS Participant 3	Obese/Overweight	26.75	23.4
DS Participant 4	Non-Obese/Overweight	21.56	18.3
DS Participant 5	Non-Obese/Overweight	14.86	40.9
DS Participant 6	Obese/Overweight	24.2	21.5
DS Participant 7	Non-Obese/Overweight	17.45	44.5
DS Participant 8	Non-Obese/Overweight	20.40	20.6
DS Participant 9	Obese/Overweight	28.51	19.4
DS Participant 10	Obese/Overweight	25.8	29.8
DS Participant 11	Obese/Overweight	32.06	22.6
DS Participant 12	Obese/Overweight	55.26	43.4
DS Participant 13	Obese/Overweight	28.0	29.8

Food Behavior Checklist

The percentages of parents of obese/overweight and non-obese/overweight adolescents with DS in relation to the FBC items are provided in Table 4.3. The percentages of parents of non-obese/overweight adolescents with DS was higher than parents of obese/overweight adolescents with DS for items *child ate vegetables as snacks, drank sports drinks, child ate more than one kind of fruit each day,* and *child ate 2 or more vegetables at their main meal*. Additionally, parents of non-obese/overweight adolescents with DS had less percentages than parents of obese/overweight adolescents with DS for *child drank punch, child drank soda* and *child ate fried foods*. With respect to food security,

the parents of non-obese/overweight adolescents with DS had higher percentages for *read nutrition labels when food shopping* and *had nutritious food at home to last a month* than parents of obese/overweight adolescents with DS. Furthermore, parents of non-obese/overweight adolescents had higher scores for *average score for the quality of child's eating habits*.

Table 4.3 Food Behavior Checklist Percentages

Items	Non-Obese /Overweight Adolescents with DS	Obese /Overweight Adolescents with DS
Child ate fruits as snacks	60	100
Child ate vegetables as snacks	40	14.3
Child drank 100% pure juice	40	75
Child drank sports drinks	60	0
Child drank punch	40	87.5
Child drank citrus juice or ate citrus fruit	20	50
Child drank soda	40	75
Child drank milk	60	87.5
Child ate more than one kind of fruit each day	80	37.5
Child ate 2 or more vegetables at their main meal	60	37.5
Child ate chicken	100	100
Child ate fried foods	50	75
Read nutrition labels when food shopping	100	60
Had nutritious food at home to last a whole month	100	62.5
Average score for quality of child's eating habits from 1 (poor) to 10 (excellent)	5.6	4.6

PROMIS Physical Activity Short Form

The average score for relative to all of the items for the non-obese/overweight adolescents with DS was 22.6 while the average score was 21.5 for obese/overweight adolescents with DS. The average scores for each item can be found in Table 4.4. Parents of non-obese/overweight adolescents with DS provided higher scores for the number of *days child exercised or played so hard that his/her body got tired, child exercised really hard for 10 minutes*, and *child exercised or played so hard that his/her muscles burned*. Parents of non-obese/overweight adolescents also had higher scores for the number of

days *child exercised or played so hard that he/she felt tired, child was physically active for 10 minutes or more* and *child ran 10 minutes or more*.

Table 4.4 PROMIS Physical Activity Short Form Average Scores

Items	Non-Obese /Overweight Adolescents with DS	Obese /Overweight Adolescents with DS
Days child exercised or played so hard that his/her body got tired	3.2	3.13
Days child exercised really hard for 10 minutes or more	3	2.75
Days child exercised so much that he/she breathed hard	2.6	3.13
Days child was so physically active that he/she sweated	2.6	2.38
Days child exercised or played so hard that his/her muscles burned	1.8	1.63
Days child exercised or played so hard that he/she felt tired	3.8	2.63
Days child was physically active for 10 minutes of more	3.6	3.38
Days child ran for 10 minutes or more	2	2.38

World Health Organization Disability Assessment Schedule 2.0

On a scale of 0 (no difficulty) to 4 (extreme difficulty or cannot do), parents of obese/overweight adolescents with DS reported more difficulty for their children concerning *understanding and communicating* and *getting around* subscales than parents of non-obese/overweight adolescents with DS. Additionally, parents of non-obese/overweight adolescents with DS provided higher scores for their children regarding *self-care, getting along with people, participation in society, life activities* and *number of days in the past month that there were difficulties due to their children's health conditions*.

Table 4.5 World Health Disability Assessment Schedule 2.0 Scores for All Adolescents with DS

Subscale	Parents of Obese/Overweight Adolescents with DS			Parents of Non-Obese/Overweight Adolescents with DS		
	Score	Frequency	%	Score	Frequency	%
Understanding and Communicating	6	4	57.14	7	1	20
	9	1	14.28	18	1	20
	10	1	14.28	13	1	20
	8	1	14.28	10	1	20
				11	1	20
Getting Around	5	2	28.57	1	2	40
	2	2	28.57	3	1	20
	4	2	28.57	5	1	20
	3	1	14.28	2	1	20
Self-Care	5	2	28.57	4	1	20
	7	1	14.28	1	1	20
	4	2	28.57	6	2	40
	0	2	28.57	7	1	20
Getting Along with People	3	2	28.57	1	1	20
	1	1	14.28	0	1	20
	0	3	42.85	2	1	20
	2	1	14.28	3	1	20
				4	1	20
Life Activities	9	3	42.85	8	1	20
	11	1	14.28	17	1	20
	15	1	14.28	9	1	20
	10	1	14.28	20	1	20
	7	1	14.28	21	1	20
Participation in Society	11	1	14.28	5	1	20
	0	1	14.28	4	1	20
	7	1	14.28	8	1	20
	2	2	28.57	11	1	20
	5	1	14.28	7	1	20
	10	1	14.28			
Number of Days in the Past Month with Difficulties Due to Health Conditions	0	4	57.14	0	3	60
	2	2	28.57	2	1	20
	15	1	14.28	18	1	20

Qualitative Arm

Perspectives of Obese/Overweight and Non-Obese/Overweight Adolescents with DS

With respect to the adolescents with DS, both groups of obese/overweight and non-obese/overweight adolescents with DS had the same ranking of ICF-CY categories. Both groups referenced Activities and Participation the most followed by Environmental Factors and Body Functions as the third common ICF-CY category. Environmental Factors were depicted in Figure 4.1 (Obese/Overweight Adolescents with DS) and Figure 4.2 (Non-Obese/Overweight Adolescents with DS) as (+) for perceived facilitators and (-) for perceived barriers. Additionally, obese/overweight and non-obese/overweight adolescents with DS had the highest number of references for the most frequent identifiers within Activities and Participation, Environmental Factors and Body Functions. The common identifiers were the same for Activities and Participation, Environmental Factors and Body Functions for both non-obese/overweight and obese/overweight adolescents with DS.

The frequencies of ICF-CY categories for obese/overweight adolescents with DS are shown in Table 4.6 for obese/overweight adolescents with DS and Table 4.8 for non-obese/overweight adolescents with DS. The frequency of the ICF-CY classification and levels for obese/overweight and non-obese/overweight adolescents with DS are displayed in Table 4.7 and Table 4.9, respectively. The definitions of the ICF-CY categories and identifiers can be found in Table A1 in Appendix A.

Obese/Overweight adolescents with DS.

Table 4.6 Frequency of ICF-CY Categories for Obese/Overweight DS Participants

DS Participants	Body Structures	Body Functions	Activities and Participation	Environmental Factors	Personal Factors
Obese/Overweight DS Participant 2	3	11	55	41	9
Obese/Overweight DS Participant 3	2	17	43	28	12
Obese/Overweight DS Participant 6	3	8	34	29	6

Table 4.6 (Continued)

Obese/Overweight DS Participant 10	2	11	26	24	9
Obese/Overweight DS Participant 11	2	5	22	12	4
Obese/Overweight DS Participant 12	3	6	26	17	5
Obese/Overweight DS Participant 13	1	5	25	8	5

Table 4.7 Frequency of ICF-CY Levels by Classification for Obese/Overweight Adolescents with DS

ICF-CY Classification and Levels	Obese /Overweight Adolescents with DS
Activities and Participation	
d 9201 Sports	23
d 571 Managing diet and fitness	14
d 4401 Grasping	12
Environmental Factors	
e 585 Education and training services	17
e 320 Friends	20
e 310 Immediate family	22
Body Functions	
b 2800 Generalized pain	14
b 1471 Quality of psychomotor functions	13
b 1400 Sustaining attention	11

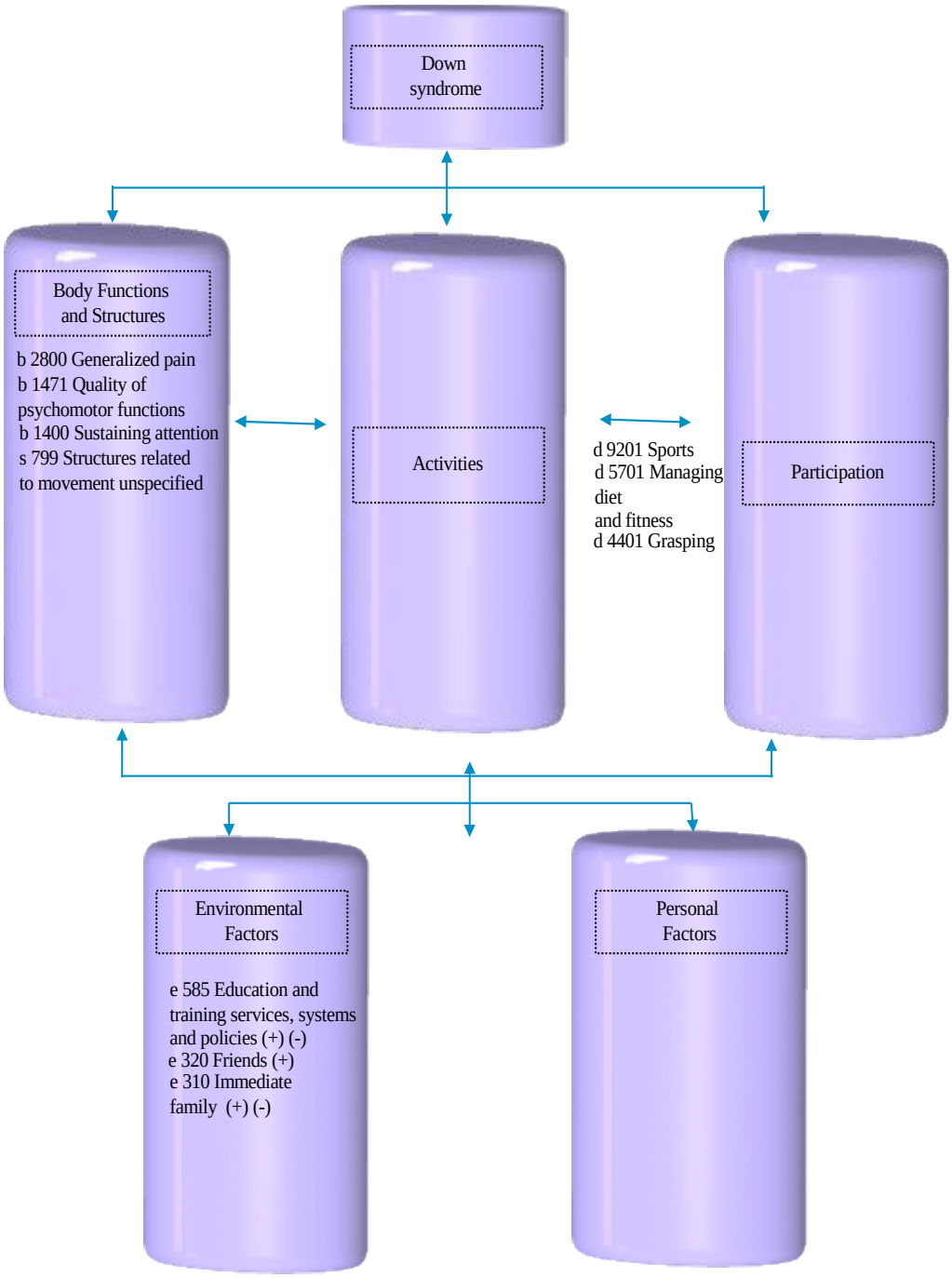

Figure 4.1 Interaction between ICF-CY Categories and Identifiers for Obese/Overweight Adolescents with DS

For obese/overweight adolescents with DS, the common identifiers among Body Functions were *b 2800 generalized pain*, *b 1471 quality of psychomotor functions*, and *b 1400 sustaining attention*. Within Body Structures, *s 799 structures related to movement unspecified* was the only common identifier. Activities and Participation consisted of *d 9201 sports*, *d 5701 managing diet and fitness* and *d*

4401 grasping. Environmental Factors comprised of facilitators (+) and barriers (-) for *e 585 education and training services, systems and policies* and *e 310 immediate family*. Identifier *e 320 friends* contained facilitators (+). Identifiers *e 310 immediate family* influenced *d 5701 managing diet and fitness* while *e 585 education and training services, systems and policies* impacted *d 5701 managing diet and fitness* and *d 9201 sports*. Lastly, *e 320 friends* was connected to *d 9201 sports*.

Activities and participation.

Identifier *d 9201 sports* was referenced the most among all of the obese/overweight adolescents with DS. All of the obese/overweight adolescents with DS relayed that they enjoyed playing sports including kickball, baseball, basketball, volleyball, tennis, dance, cheer and gymnastics. One obese/overweight adolescent with DS described her enjoyment regarding basketball when asked if she played sports. DS Participant 6 said "Basketball…because I get to do drills."

For identifier *d 5701 managing diet and fitness*, all of the obese/overweight adolescents with DS stated that their parents regulated their diet or engagement in physical activity. An obese/overweight adolescent with DS discussed how she had to ask to her mom whenever she wanted to go outside to be physically active. DS Participant 3 said "Yeah, I have to ask my mom and she says [child's name], let's get your bike [laughter]."

For identifier *d 4401 grasping*, all of the obese/overweight adolescents with DS referred to identifier *d 4401 grasping*. The obese/overweight adolescents with DS maintained that they were able to grab and pick up the ball when they played competitive sports such as kickball, basketball, dodgeball and more.

Environmental factors.

For Environmental Factors, the most common identifier for the obese/overweight adolescents with DS was *e 310 immediate family*. Identifiers *e 320 friends* and *e 585 education and training services* were the second and third most common, respectively.

With respect to identifier *e 310 immediate family* for nutrition, 60% of obese/overweight adolescents with DS who recognized this identifier stated that their parents served them fruits and vegetables at home acting as a facilitator. In contrast, 40% of the obese/overweight adolescents with DS who referred to this identifier maintained that their parents did not give them fruits and vegetables at home. This resulted in identifier *e 310 immediate family* being coded as a barrier concerning nutrition for 40% of the obese/overweight adolescents with DS. For physical activity, identifier *e 310 immediate family* was recorded as a facilitator for all of the obese/overweight adolescents with DS who referenced this category because they reported exercising with their families. One obese/overweight adolescent with DS relayed how she and her family engaged in physical activity. DS Participant 2 said "I go to the gym…just me and my family." One of the obese/overweight adolescents with DS discussed his reservations when asked whether his family prompted him to exercise. DS Participant 12 said "Yes, but they kind of get on my nerves."

For identifier *e 320 friends*, all of the obese/overweight adolescents with DS who acknowledged this identifier relative to physical activity acknowledged that they engaged in physical activity with their friends or peers. For this reason, *e 320 friends* was coded as a facilitator. One of the obese/overweight adolescents with DS talked about how she was physically active with her friends when asked if she plays at her friends' houses. DS Participant 2 said "I play basketball."

With regard to identifier *e 585 education and training services, systems and policies*, all of the obese/overweight adolescents with DS who referred to this identifier affirmed that their school offered fruits serving as a facilitator for nutrition. One of the obese/overweight adolescents with DS talked about fruits and vegetables her school provided in the cafeteria. DS Participant 2 said "Apples, bananas, carrots, and broccoli." For physical activity, 87.5% of the obese/overweight adolescents with DS maintained that they had opportunities for physical activity during physical education and recess acting as a facilitator. DS Participant 10 said "I play basketball, kickball, and with the swings" when asked if she played at school. In contrary to the 87.5% of obese/overweight adolescents with DS who recognized *e 585 education and training services, systems and policies* as a facilitator, 25% of the obese/overweight adolescents with DS

stated that they did not have recess at school resulting in coding identifier *e 585 education and training services, systems and policies* as a barrier for them. When asked if she had recess at her school, DS Participant said "Well no, I do middle school now."

Body functions.

The three most common identifiers for the obese/overweight adolescents with DS were *b 2800 generalized pain, b 1471 quality of psychomotor functions* and *b 1400 sustaining attention*. Identifier *b 2800 generalized pain* contained the most references while *b 1471 quality of psychomotor functions* and *b 1400 sustaining attention* were the second and third most common identifiers, respectively.

Relative to identifier *b 2800 generalized pain,* half of the obese/overweight adolescents with DS stated that they did not experience any pain when they engaged in physical activity. However, half of the obese/overweight adolescents with DS acknowledged *b 2800 generalized pain* reporting that there were certain parts of their bodies (feet, stomach, abdominal sides, arms) that caused pain when they were physically active. An obese/overweight adolescent with DS discussed how his arms were affected when he participated in physical activity. DS Participant 12 said "Um my um arms swelling up."

For identifier *b 1471 quality of psychomotor functions,* all of the obese/overweight with DS who referred to this identifier stated that they were able to do two things at once when playing sports. In other words, the obese/overweight adolescents with DS claimed that they had good hand-eye coordination. Identifier *b 1400 sustaining attention* comprised four of the obese/overweight adolescents with DS expressing that they were able to pay attention when they were physically active. One of the obese/overweight adolescents with DS referred to identifier *b 1400 sustaining attention* regarding physical activity by stating that they did not pay attention when they were playing kickball.

Non-Obese/Overweight adolescents with DS.

Table 4.8 Frequency of ICF-CY Categories for Non-Obese/Overweight DS Participants

DS Participants	Body Structures	Body Functions	Activities and Participation	Environmental Factors	Personal Factors

Table 4.8 (Continued)

Non-Obese/Overweight DS Participant 1	4	14	35	56	15
Non-Obese/Overweight DS Participant 4	1	11	23	22	6
Non-Obese/Overweight DS Participant 5	2	7	42	35	6
Non-Obese/Overweight DS Participant 7	1	4	31	15	4
Non-Obese/Overweight DS Participant 8	2	6	26	22	4

Table 4.9 Frequency of ICF-CY Levels by Classification for Non-Obese/Overweight Adolescents with DS

ICF-CY Classification and Levels	Non-Obese /Overweight Adolescents with DS
Activities and Participation	
d 9201 Sports	18
d 5701 Managing diet and fitness	12
d 4401 Grasping	10
Environmental Factors	
e 585 Education and training services	21
e 320 Friends	32
e 310 Immediate family	19
Body Functions	
b 2800 Generalized pain	12
b 1471 Quality of psychomotor functions	7
b 1400 Sustaining attention	9

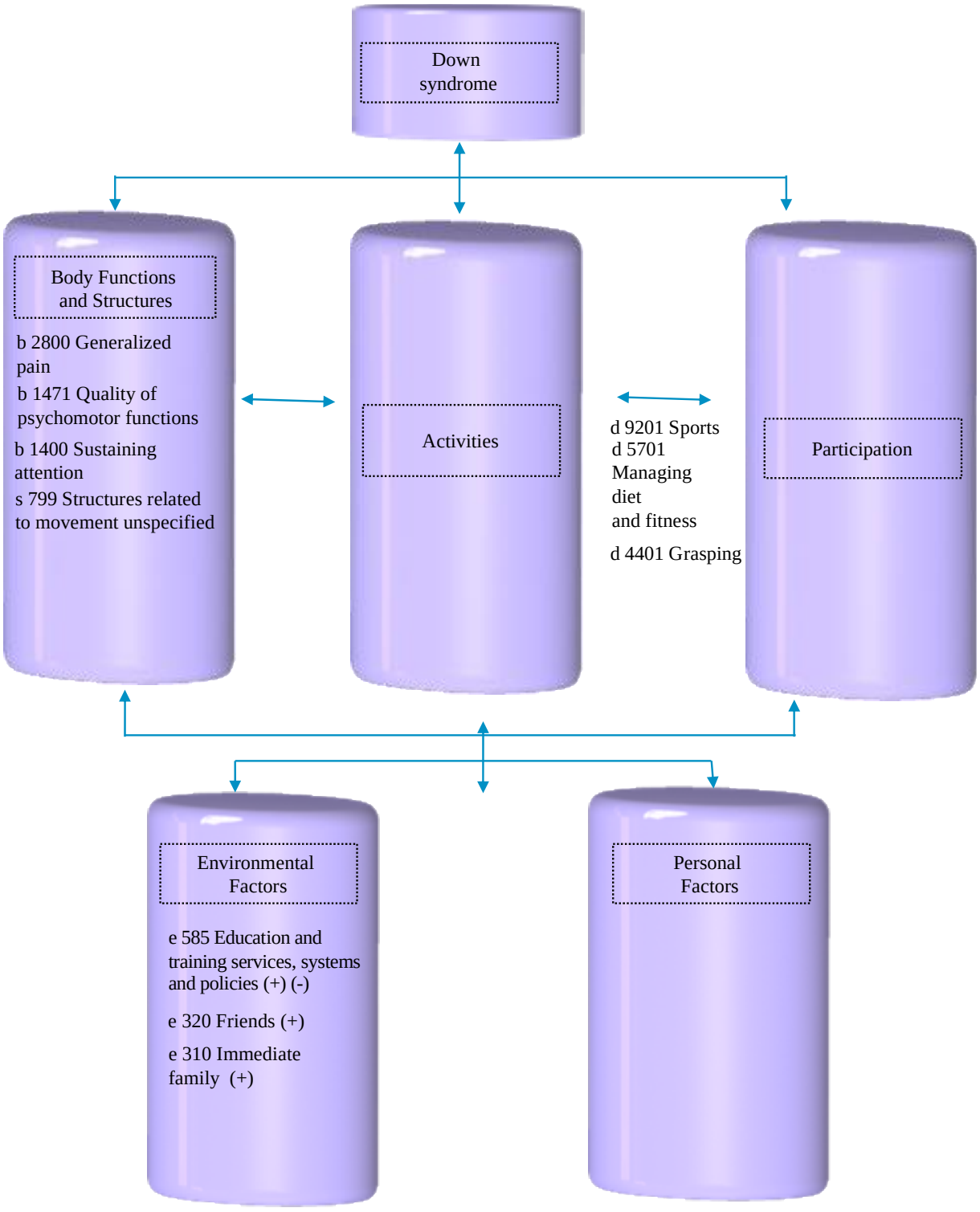

Figure 4.2 Interaction between ICF-CY Categories and Identifiers for Non-Obese/Overweight Adolescents with DS

For non-obese/overweight adolescents with DS, the common identifiers for Body Functions were *b 2800 generalized pain, b 1471 quality of psychomotor functions*, and *b 1400 sustaining attention*. Body Structures consisted of *s 799 structures related to movement unspecified*. The common identifiers for Activities and Participation were *d 9201 sports, d 5701 managing diet and fitness*, and *d 4401 grasping*. Environmental Factors contained facilitators (+) and barriers (-) for *e 585 education and training services, systems and policies*. Identifiers *e 320 friends* and *e 310 immediate family* comprised facilitators (+). Both *e 585 education and training services, systems and policies* and *e 310 immediate family* affected *d 5701 managing diet and fitness* while *e 320 friends* was tied to *d 9201 sports*.

Activities and participation.

Identifier *d 9201 sports* was the identifier most frequently coded for Activities and Participation. All of the non-obese/overweight adolescents with DS reported that they enjoyed playing sports including kickball, basketball, swimming, soccer, dance, cheer and dodgeball. When asked what her favorite sport was, DS Participant 3 said "I love basketball!" Additionally, DS Participant 3 said "It's fun, I shoot hoops" to explain why she loved basketball.

Identifier *d 5701 managing diet and fitness* entailed all of the non-obese/overweight adolescents with DS claiming that their parents regulated their diet or engagement in physical activity. DS Participant 6 said "Well, I need to ask mom" when asked if she was able to get food from the fridge when she is hungry. For identifier *d 4401 grasping*, none of the non-obese/overweight adolescents with DS reported that they had issues grasping a ball when they engaged in physical activity. A non-obese/overweight adolescent with DS talked about her ability to play basketball when asked if she can grab the ball. DS Participant 4 said "Yeah, dribble and I shoot. I made a basket."

Environmental factors.

Identifier *e 320 friends* was the most referenced identifier for non-obese/overweight adolescents with DS followed by *e 585 education and training services* and *e 310 immediate family*. For identifier *e*

320 friends, only 2 of the non-obese/overweight adolescents with DS recognized this identifier relative to physical activity. Both of the non-obese/overweight adolescents with DS maintained that they engaged in physical activity with their friends. One non-obese/overweight adolescent with DS discussed how she engaged in physical activity with help from her friends. DS Participant 1 said:

> I always play at my friend's house, I run around…and I play volleyball, soccer and stuff. I always play basketball with my friend [friend's name] and she's LDSS (Lowcountry Down Syndrome Society) too and she has Down syndrome.

With regard to identifier *e 585 education and training services, systems and policies*, all 5 of the non-obese/overweight adolescents with DS stated that their school offered them fruits and vegetables acting as a facilitator. When asked if the school provides fruits and vegetables, DS Participant 4 said "We have salad there…no we have fruits too…yeah in the cafeteria."

For identifier, *e 585 education and training services, systems and policies*, three out of the five non-obese/overweight adolescents with DS maintained that their school did not provide recess presenting a barrier. One of the non-obese/overweight adolescents with DS described her experience when asked if there is recess at her school. DS Participant 4 said "Free time, no recess…you can play on the computers, games inside."

With respect to identifier *e 310 immediate family*. All of the non-obese/overweight adolescents with DS expressed *e 310 immediate family* as a facilitator due to their families encouraging them to eat healthy. One of the non-obese/overweight adolescents with DS stated what type of food she ate when asked how her family helps her to eat healthy. DS Participant 1 said:

> They cook food. For example, I usually eat like broccoli or zucchini. Sometimes squash. I always eat some healthy food…yes like always.

For physical activity, only two of the non-obese/overweight adolescents with DS referenced *e 310 immediate family* with both non-obese/overweight adolescents with DS acknowledging that they engaged in physical activity with their families.

Body functions.

For non-obese/overweight adolescents with DS, the identifier with the highest number of references was *b 2800 generalized pain* followed by *b 1400 sustaining attention.* The third most common identifier was *b 1471 quality of psychomotor functions*.

Relative to identifier *b 2800 generalized pain,* four out of the five non-obese/overweight adolescents with DS maintained that they did not feel any pain when they engaged in physical activity. Two of the non-obese/overweight adolescents with DS expressed that they felt pain in their arms and legs when they were physically active. When she asked if she felt pain when she exercised, DS Participant 4 said "It really hurts…I'm so tired."

For identifier b *1471 quality of psychomotor functions*, only three of the non-obese/overweight adolescents recognized this identifier. All three of them reported that they were able to multitask or had good hand-eye coordination when they participated in sports. One non-obese /overweight adolescent with DS talked about how she was able to perform multiple actions during cheer when asked if she can do two things at once when she exercises. DS Participant 1 said "Yes, but I do tumbling and cheer same thing together. When I do my dance, I do tumbling…yes!"

In relation to identifier *b 1400 sustaining attention*, all five of the non-obese/overweight recognized this identifier pertaining to physical activity. Four of the non-obese/overweight adolescents with DS reported that they were able to pay attention when they engaged in physical activity. In contrast, one non-obese/overweight adolescent with DS expressed that they had trouble paying attention when they were physically active. DS Participant 1 said:

> Sometimes, it is hard…cause I don't know, I don't know any people, I don't know them and know people that much. Sometimes, I'm shy…because I get I work so hard I forget.

Perspectives of Parents of Obese/Overweight and Non-Obese/Overweight Adolescents with DS

With regard to both groups of parents of obese/overweight and non-obese/overweight adolescents with DS, the ICF-CY category with the highest number of references was Activities and Participation.

Environmental Factors was the second most common category followed by Body Functions serving as the third most frequent ICF-CY category. The frequencies of the ICF-CY classifications and levels for the parents of obese/overweight adolescents with DS can be seen in Table 4.11 and in Table 4.13 for parents of non-obese/overweight adolescents with DS.

For Activities and Participation, the common identifiers for parents of obese/overweight and non-obese/overweight adolescents with DS were *d 9201 sports, d 5701 managing diet and fitness,* and *d 4401 grasping*. For parents of obese/overweight adolescents with DS, the common identifiers were the same as the parents of non-obese/overweight adolescents with DS with an additional identifier: *d 7602 sibling relationships*. For Environmental Factors, the common identifiers were the same for parents of obese/overweight and non-obese/overweight adolescents with DS. These identifiers were *e 585 education and training services, systems and policies, e 320 friends, e 310 immediate family* and *e 355 health professionals***.** Table 4.10 and Table 4.12 contain the frequencies of the ICF-CY categories for parents obese/overweight and non-obese/overweight adolescents with DS, respectively. Additionally, the interaction of the ICF-CY categories is portrayed in Figure 4.3 for parents of obese/overweight adolescents with DS and Figure 4.4 for parents of non-obese/overweight adolescents with DS.

But, the identifiers were ranked differently based on the number of references. Within Body Functions, three of the four common identifiers were the same for both groups of parents. Personal Factors also had an influence on healthy eating and physical activity according to parents of both obese/overweight and non-obese/overweight adolescents with DS. It is important to note that Personal Factors is the only ICF-CY category that does not have an alphanumeric code.

Parents of obese/overweight adolescents with DS.

Table 4.10 Frequency of ICF-CY Categories for Obese/Overweight Parent Participants

Parent Participants	Body Structures	Body Functions	Activities and Participation	Environmental Factors	Personal Factors
Obese/Overweight Parent Participant 2	2	6	45	26	16
Obese/Overweight Parent Participant 3	2	29	45	20	21
Obese/Overweight Parent Participant 6	1	34	84	39	44
Obese/Overweight Parent Participant 9	3	24	42	43	16
Obese/Overweight Parent Participant 10	3	11	40	25	24
Obese/Overweight Parent Participant 11	0	14	29	18	30
Obese/Overweight Parent Participant 12	1	14	41	24	19
Obese/Overweight Parent Participant 13	3	17	55	24	34

Table 4.11 Frequency of ICF-CY Levels by Classification for Parents of Obese/Overweight Adolescents with DS

ICF-CY Classification and Levels	Parents of Obese /Overweight Adolescents with DS
Activities and Participation	
d 9201 Sports	21
d 5701 Managing diet and fitness	21
d 7602 Sibling relationships	5
d 4401 Grasping	14

Table 4.11 (Continued)

Environmental Factors	
e 585 Education and training services	27
e 320 Friends	14
e 310 Immediate family	21
e 355 Health professionals	19
Body Functions	
b 2800 Generalized pain	15
b 1471 Quality of psychomotor functions	23
b 1442 Retrieval and processing of memory	18
b 1400 Sustaining attention	7
b 530 Weight maintenance functions	10

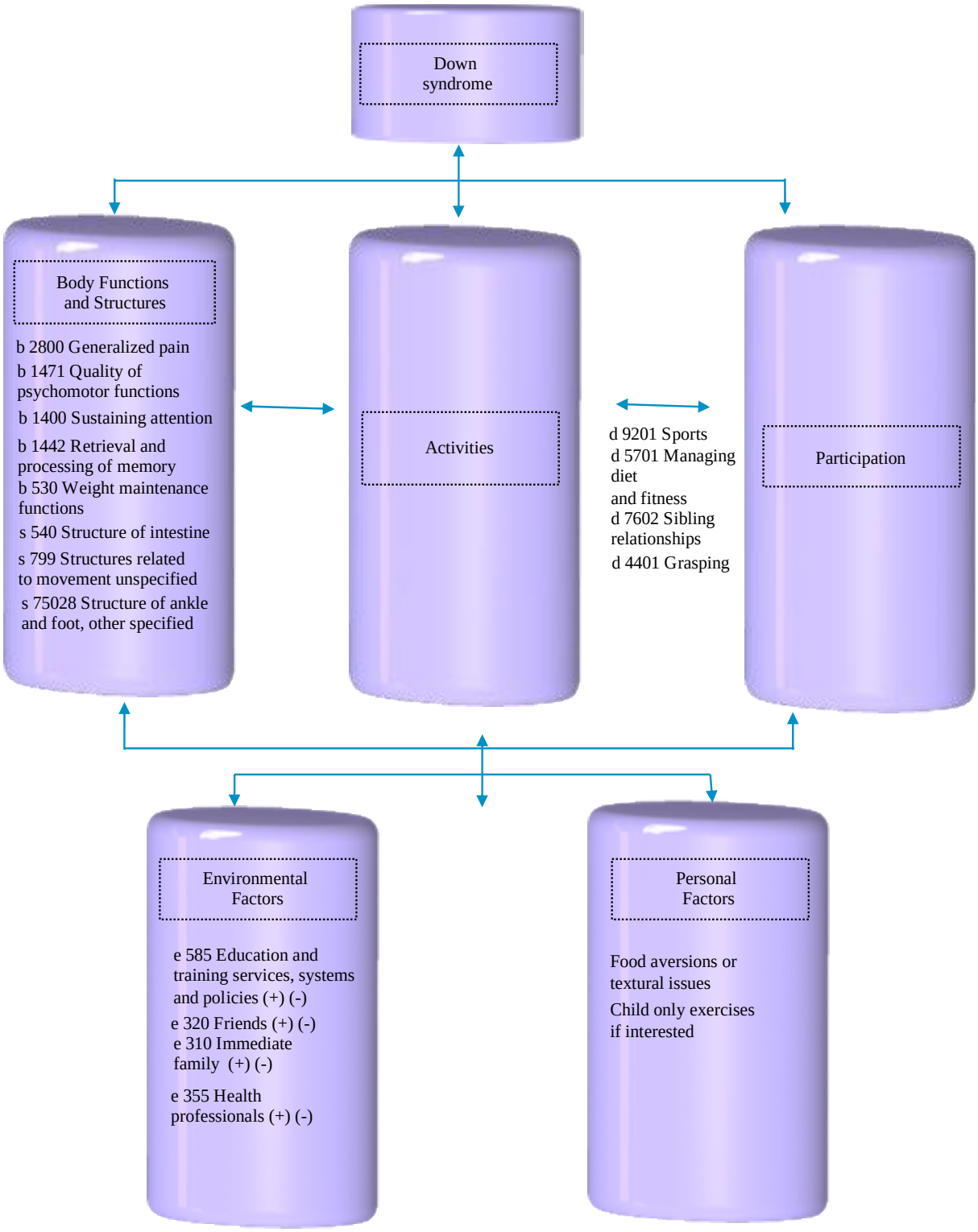

Figure 4.3 Interaction between ICF-CY Categories and Identifiers for Obese/Overweight Adolescents with DS

The common identifiers within Body Functions for parents of obese/overweight adolescents with DS were *b 2800 generalized pain, b 1471 quality of psychomotor functions, b 1400 sustaining attention* and *b 530 weight maintenance functions*. Body Structures highlighted *s 540 structure of intestine, s 799 structures related to movement unspecified* and *s 75028 structure of ankle and foot, other specified*. Activities and Participation comprised *d 9201 sports, d 5701 managing diet and fitness, d 7602 sibling relationships* and *d 4401 grasping*. Environmental Factors consisted of facilitators (+) and barriers (-) for *e 585 education and training services, systems and policies, e 320 friends, e 310 immediate family*, and *e 355 health professionals*. For Personal Factors, *food aversions or textural issues* and *child only exercises if interested* were the common identifiers. Identifiers *e 585 education and training services, systems and policies* and *e 310 immediate family* had an effect on *d 5701 managing diet and fitness*. In addition, *e 310 immediate family* was connected to *d 7602 sibling relationships* influencing *d 5701 managing diet and fitness*. Furthermore, identifier *e 320 friends* was linked to *d 9201 sports*.

Activities and participation.

Identifier *d 9201 sports* was the most common for all of the parents of obese/overweight adolescents with DS. Seven out of the eight parents of obese/overweight adolescents stated that their children were involved in sports including basketball, tennis, baseball, swimming, frisbee, and dodgeball. Parents of obese/overweight adolescents with DS discussed negative aspects of competitive sports for their children. Two of the seven parents of obese/overweight adolescents with DS expressed how difficult it was for their children to participate in competitive sports with their peers. A parent of an obese/overweight adolescent with DS narrated her child's involvement in competitive sports. Parent Participant 6 said the following:

> She played typical tee ball, you know typical um even until she was maybe 8. You know just playing typical tee ball and whatever but then it starts to get faster and whatever and you know she can't keep up. So it's always like she's a little bit too athletic and active for

> the majority of children with special needs. But she's not fast enough for the typical kids. She's kind of to me in a place in the middle.

Identifier *d5701 managing diet and fitness* was the second most common identifier for all of the parents of obese/overweight with DS. All eight of the parents of obese/overweight highlighted that they managed their children's diet and fitness. Two parents of obese/overweight adolescents with DS emphasized that without parental management, their child would not eat healthy foods. Parent Participant 3 said "Um, no. She wouldn't pick the right options [laughter]. No [laughter]. Like I said, she would not be able to do anything if it was up to her" when asked if she managed her child's diet.

For identifier *d 4401 grasping,* six of the eight parents of obese/overweight adolescents with DS recognized *d 4401 grasping* relative to physical activity for their children. All six parents reported that their children were able to pick up and grab a ball when they engaged in competitive sports. When asked if her child was able to grab the ball when playing competitive sports, Parent Participant 10 said "No, she would be able to pick up, grasp, throw and catch a ball."

For parents of obese/overweight adolescents with DS, the third most common identifier was *d 7602 sibling relationships* among the six parents of obese/overweight adolescents with DS who acknowledged this identifier. Of the six parents of obese/overweight adolescents with DS, five parents stated that their children engaged in physical activity with their siblings. A parent of an obese/overweight adolescent with DS expressed how her child's sibling promoted physical activity for her child. Parent Participant 3 said "Yeah, her brothers especially, they are real physical so they are always trying to get her to go out and play, they are good about it." However, two parents of obese/overweight adolescents with DS expressed that their children's siblings did not engage in physical activity with their children because their children's siblings did not want to exercise or that they were not at home with the children. Parent Participant 6 said "She wants to go out and play and she would do that every day but she wants someone to play with and…my other children are gone."

With respect to healthy eating, one parent of an obese/overweight adolescent with DS reported that her child's older sibling encouraged healthy eating for her child. Parent Participant 3 said:

> …My oldest son, he is a vegan so he really…gets on to me about you know cause she drinks milk every day 'oh you need to get her off that dairy, it's terrible. They (her two sons) will get her (adolescent with DS) to drink almond milk and they will tell her it's ice cream milk so I'm like 'I don't like almond milk, so we will just keep drinking skim milk [laughter].

Environmental factors.

Identifier *e 585 education and training services, systems and policies* was the most common for parents of obese/overweight adolescents with DS. Six of the eight parents of obese/overweight adolescents with DS recognized *e 585 education and training services, systems and policies* regarding physical activity. All six of these parents of obese/overweight adolescents with DS stated that their children's schools provided opportunities for physical activity including recess, physical education and competitive sports acting as a facilitator. When asked if the school helps her child to exercise, Parent Participant 6 said:

> But I do think because she's the basketball team manager, the coach lets her do some drills and stuff and she will do a few things. I had to tell the coach you know don't let her use the lazy card and I had to tell the PE coach too because she is in a typical PE class every day. And that's a good thing because she gets some exercise every single day. But I had to tell the coach because she's a soft-hearted lady, don't let her play you. She (adolescent with DS) can do what everybody can do, she just might do it a little bit slower.

With regard to the food items at their children's schools, six of the parents of obese/overweight adolescents with DS affirmed that the schools provided healthy food options serving as a facilitator. In contrast, two parents of obese/overweight adolescents with DS discussed their dislike of the food options at the schools resulting in coding *e 585 education and training services, systems and policies* as a barrier

for nutrition. When asked to provide their thoughts about their child's food options at school. Parent Participant 3 said:

> They are terrible [laughter]…the school menu, every day it's…chicken nuggets and the next day is chicken fingers then fried chicken then chicken sandwich...yeah and waffle fries: French fries potatoes [laughter]. String potatoes…French fries…in different form.

Identifier e *355 health professionals* was the third most frequent category for parents of obese/overweight adolescents with DS. Seven of the eight parents of obese/overweight adolescents with DS confirmed that their children were close with their health professionals. Health professionals for obese/overweight adolescents with DS comprised of an endocrinologist, ear/nose/throat doctors, neurologists, occupational therapists, optometrists, pediatricians and speech therapists. Furthermore, most of the parents of the obese/overweight adolescents with DS reported that their children were somewhat close with their health professionals. Parent Participant 6 said:

> [Sigh] I mean she's comfortable with them, she's not afraid of them. She's happy to go see them generally as long as she doesn't think she will get the shot.

In contrast, one parent of an obese/overweight adolescent with DS discussed her child's behavioral issues relative to one of their health professionals. Parent Participant 9 said:

> He was supposed to have a physical therapist, but they gave him a physical therapist that he pushed to a window. She can't give him physical therapy no more until his behavior has changed. And they can't give him no speech therapy because they say they worry about the therapist's health. [Child's name] is very aggressive and he's seen a psychologist and they will send him another one in the New Year for his medicine and for his behavior.

Identifier *e 310 immediate family* was the second common identifier for parents of obese/overweight adolescents with DS. Five of the parents of obese/overweight adolescents with DS referred to *e 310 immediate family* concerning physical activity. All five of these parents reported that

their children engaged in physical activity with them or their siblings acting as facilitators. For example, Parent Participant 12 said:

> And you know when we get to talking you know or lose weight which we do a lot, we tell him he needs to be more active. And he might go outside and run around the yard for a minute and his brother tried to get him to exercise walk every day.

Additionally, six of the eight parents of obese/overweight adolescents with DS acknowledged *e 310 immediate family* for nutrition. Of the six parents of obese/overweight adolescents with DS, four parents stated that they took action to promote healthy eating for their children. When asked if the family helps her child to eat healthy, Parent Participant 10 said:

> Yes, just by helping her make good choices and limiting what she eats. You know we don't let her snack all day long and you know you can have a snack between mealtimes, but you can't have 2 snacks between mealtimes.

However, the remaining two parents acknowledged that they did not promote healthy eating or fruit and vegetable consumption for their children because of time constraints and not modeling healthy eating for their children. One parent of an obese/overweight adolescent with DS described why it was difficult to endorse healthy eating for her child regarding lack of time. Parent Participants 6 said

> I do focus…everything on [child's name] but it's more of like the activities that we are doing and…eating is the last thing that we are worried about because she has an activity every single day...

Identifier *e 320 friends* was the third most frequent category for parents of obese/overweight adolescents with DS. With respect to physical activity, only two parents recognized this identifier. Both parents affirmed that their children were physically active with their friends. When asked if her child engages in physical activity with her friends, Parent Participant 13 said "One of her friends I think is in gymnastics."

On the other hand, one parent of an obese/overweight adolescent with DS let it be known that her child experienced trouble communicating with peers or maintaining relationships. Parent Participant 9 said:

> …But…he doesn't have any friends that he plays with around here or that he just like goes to their house and stuff...He doesn't have that kind of relationship with anyone. He…kind of separates himself from people he doesn't know.

Body functions.

Identifier *b 1471 quality of psychomotor functions* was the most frequent identifier referenced by parents of obese/overweight adolescents with DS. Five parents referred to this identifier. All five of the parents of obese/overweight adolescents with DS stated that their children were able to multi task and had good hand-eye coordination when they were physically active. When asked if her child had good hand-eye coordination when they engaged in physical activity, Parent Participant 10 said "But she, she's pretty good with hand-eye coordination. I mean she can catch a ball, she can throw a Frisbee, you know stuff like that."

However, five parents mentioned that their children experienced difficulty with hand-eye coordination and multitasking when they engaged in physical activity as well. One parent of an obese/overweight adolescent with DS discussed her child's engagement in physical activity. Parent Participant 13 said:

> She…doesn't know how…to coordinate…kicking the ball…they were playing soccer…we asked the coach for participation…But the ball comes to her and…it's too late or too early…not really good coordination. The reaction time is slow, and she gets frustrated…wants to quit...

The third common identifier for parents of obese/overweight adolescents with DS *was b 2800 generalized pain* consisting of seven parents in relation to physical activity for their children. Six of the seven parents of obese/overweight adolescents with DS expressed that their children did not complain of

any pain when engaging in physical activity. In contrast, one parent of an obese/overweight adolescent with DS stated that her child felt pain in her knees when dancing due to jumping really hard.

Identifier *b 1442 retrieval and processing of memory* was the third most common identifier for parents of obese/overweight adolescents with DS. With regard to physical activity, four of the parents of obese/overweight adolescents with DS emphasized that their children were able to remember the rules of physical activity games. Parent Participant 10 said "When it comes to rules of games, she catches on pretty quickly. So she has no trouble remembering or paying attention." In contrast, six parents of obese/overweight adolescents with DS confirmed that their children had trouble remembering or adhering to the rules in physical activity games. For example, Parent Participant 3 said:

> Like she doesn't remember like how to play certain sports. Yeah, like you know we will play baseball and you know after she has run the bases you know she's mad 'I didn't run the bases.' The next time she's up to bat, she forgets that you have to run to first then run to second. So, the rules of sporting events, you know she has forgotten, she forgets how to play.

For identifier b *1400 sustaining attention*, only two of the parents of the obese/overweight adolescents with DS acknowledged this identifier concerning physical activity for their children. Both parents of the obese/overweight adolescents with DS stated that their children had no difficulty concentrating when they engaged in physical activity. Parent Participant 12 said "Not really, he does pretty well" when asked if her child was able to concentrate during physical activity.

Identifier b *530 weight maintenance functions* was the fourth most frequent identifier for parents of obese/overweight adolescents with DS. Five of the eight parents of obese/overweight adolescents with DS referred to this identifier. All five of these parents of obese/overweight adolescents with DS claimed that their children experienced issues regarding physical activity due to their children being overweight. Additionally, some of the parents of obese/overweight adolescents with DS stated that their children's low muscle tone burdened their children's weight issues. A parent of an obese/overweight adolescent with

DS described how her child's weight negatively impacted her child's engagement in physical activity. Parent Participant 6 said:

> Yeah, so you know her, the low muscle tone and being heavier and shorter legs, you know; everything. You know she's not the same body shape as a typical 14-year-old, so you know. So, she wouldn't be able to compete with typical 14-year-old girls in soccer.

Personal factors.

For food aversions and textural issues, six parents of obese/overweight adolescents with DS recognized this identifier. All six of the parents reported that their children would avoid certain fruits and vegetables due to their children not liking the texture of the foods. With regard to her child eating fruits, Parent Participant 13 said:

> She eats her applesauce, she eats peaches in the little peach cups, mandarin oranges, what is it…tangerines, she will eat a little bit of an apple which she doesn't like the texture. She will just chew off of the white part and leave the skin.

As for eating vegetables, Parent Participant 2 said:

> But she doesn't like uh, we will eat a sandwich, but she doesn't still like feeling the lettuce or kale, I don't like kale either [laughter]. But the lettuce or something like that, she doesn't like to feel the leafy greens in her mouth.

Furthermore, with respect to their children's engagement in physical activity, five parents of obese/overweight adolescents with DS stated that their children would only exercise if they were interested in the activity. A parent of an obese/overweight adolescent with DS discussed the circumstances when her child liked to exercise. Parent Participant 3 said

> If it's something she likes to do, and she just so happens to be getting exercise at the same time, then that's good. So, she has to know that she's not exercising [laughter].

Parents of non-obese/overweight adolescents with DS.

Table 4.12 Frequency of ICF-CY Categories for Non-Obese/Overweight Parent Participants

Parent Participants	Body Structures	Body Functions	Activities and Participation	Environmental Factors	Personal Factors
Non-Obese/Overweight Parent Participant 1	0	17	23	34	27
Non-Obese/Overweight Parent Participant 4	2	37	55	62	38
Non-Obese/Overweight Parent Participant 5	3	12	65	53	51
Non-Obese/Overweight Parent Participant 7	1	16	36	39	16
Non-Obese/Overweight Parent Participant 8	0	26	23	32	21

Table 4.13 Frequency of ICF-CY Levels by Classification for Parents of Non-Obese/Overweight Adolescents with DS

ICF-CY Classification and Levels	Parents of Non-Obese/Overweight Adolescents with DS
Activities and Participation	
d 9201 Sports	46
d 5701 Managing diet and fitness	15
d 7602 Sibling relationships	16
d 4401 Grasping	10
Environmental Factors	
e 585 Education and training services	22
e 320 Friends	22
e 310 Immediate family	22
E 355 Health professionals	28

Table 4.13 (Continued)

Body Functions	
b 2800 Generalized pain	11
b 1471 Quality of psychomotor functions	12
b 1442 Retrieval and processing of memory	8
b 1400 Sustaining attention	13
b 530 Weight maintenance functions	1

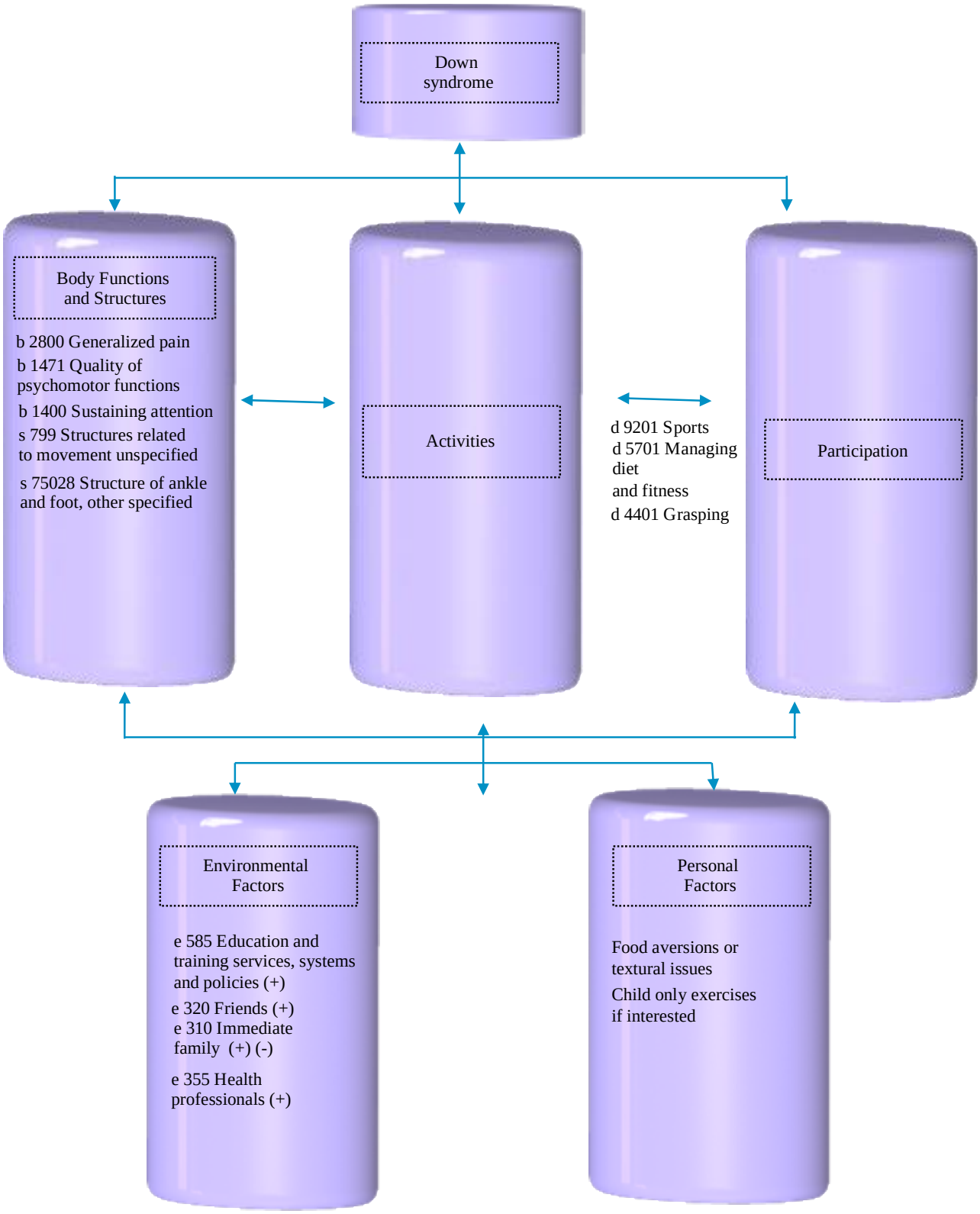

Figure 4.4 Interaction between ICF-CY Categories and Identifiers for Parents of Non-Obese/Overweight Adolescents with DS

For parents of non-obese/overweight adolescents with DS, *b 2800 generalized pain*, *b 1471 quality of psychomotor functions*, and *b 1400 sustaining attention* were common identifiers for Body Functions. The common identifiers within Body Structures were *s 799 structures related to movement unspecified* and *s 75028 structures related to ankle and foot, other specified*. Common identifiers for Activities and Participation with regard to parents of non-obese/overweight adolescents with DS were *d 9201 sports*, *d 5701 managing diet and fitness* and *d 4401 grasping*. With respect to Environmental Factors, *e 310 immediate family* entailed facilitators (+). Facilitators (+) and barriers (-) were present for *e 585 education and training services, systems and policies*, *e 320 friends*, and *e 355 health professionals*. Identifiers *e 585 education and training services, systems and policies* and *e 310 immediate family* impacted *d 5701 managing diet and fitness* while *e 320 friends* influenced *d 9201 sports*.

Activities and participation.

Identifier *d 9201 sports* was the most common category for all of the parents of non-obese/overweight adolescents with DS. All of the parents of the non-obese/overweight adolescents with DS affirmed that their children participated in sports encompassing Frisbee, capture the flag, kickball, swimming, tennis, dance, football, soccer, basketball, dance and cheer. When asked about sports her child played, Parent Participant 4 said:

> She played a brief year of basketball with a league that we do here through the church. And then she's also part of our youth group and they are pretty active um. I mean they do games and stuff very physical games, I mean not just like physical games like capture the flag, ultimate Frisbee, kickball, those types of things where they all together on teams.

Identifier *d 5701 managing diet and fitness* was also common among parents of non-obese/overweight adolescents with DS in addition to being the second most frequent category. All of the parents of the non-obese/overweight adolescents with DS reported that they managed their children's diet and fitness. A parent of a non-obese/overweight adolescent with DS described regulating fitness for her child. Parent Participant 1 said:

> She would do very little...she would…tinker around the house. It has to be…a slight breeze…overcast…to want to be outside. It's either too hot, too cold, too [sigh] muggy, too rainy…I spend a lot of time going…you're going out.

Furthermore, one parent of a non-obese/overweight adolescent with DS emphasized that her child's diet consisted mainly of PediaSure because her child ate very little due to having trouble chewing and avoiding certain foods. Parent Participant 5 said

> ... Her diet…is mostly…PediaSure. And she'll…like chicken nuggets, mac n cheese um mashed potatoes…mostly like soft foods…her speech therapist told me…her jaws so weak that…she gets tired chewing, maybe that's why she doesn't like to eat...she doesn't like fruit…

Identifier *d 4401 grasping* was the third common category for parents of non-obese/overweight adolescents with DS. All five parents of non-obese/overweight adolescents with DS recognized *d 4401 grasping* relative to physical activity for their children with their children having no difficulty grabbing or picking up a ball when they were physically active. A parent of a non-obese/overweight adolescent with DS relayed her child's experience with grasping objects during physical activity. Parent Participant 1 said

> Um, she I uh think you know her fine motor and like her ability to you know pick things up and all are fine. She always surprises me because you know typically they have low muscle tone.

For parents of non-obese/overweight adolescents with DS, in contrast to parents of obese/overweight adolescents with DS, *d 7602 sibling relationships* was not a common identifier. Only three out of the parents of non-obese/overweight adolescents with DS acknowledged this identifier concerning physical activity for their children. All three parents stated that their children were physically active with their siblings. When asked if her child engages in physical activity with his siblings, Parent Participant 7 said:

> …I will say 'come ride your bike while I walk the dog' but he is very active um having 3 brothers helps [laughter].

With respect to healthy eating, none of the parents of the non-obese/overweight adolescents with DS acknowledged that their children's siblings promoted healthy eating for their child.

Environmental factors.

Identifier *e 585 education and training services, systems and policies* was the second most common identifier for parents of non-obese/overweight adolescents with DS. Only four of the five parents of non-obese/overweight adolescents with DS referenced this category in relation to physical activity. All four of the parents affirmed that their children's school encouraged physical activity for their children. For instance, Parent Participant 1 said:

> …We were fortunate because they you know they didn't let [child's name] the coach that she had all these years you know, um PE uh coach you she didn't just cause maybe [child's name] couldn't do, she wouldn't just modify whatever it was so that [child's name] could participate. She didn't let her sit over there…So then she's (adolescent with DS) like 'Okay.' You know again, we've been fortunate because we've had people understand how we want her involved and want to treat her like everybody else. She wouldn't let another child sit over there you know a typical child you know. So anyway, we've been fortunate with that.

With regard to diet, *e 585 education and training services, systems and policies* comprised four of the five parents of non-obese/overweight recognizing *e 585 education and training services, systems and policies* as a facilitator. All four of the parents of the non-obese/overweight adolescents with DS acknowledged that there were healthy food options at their children's schools. One of the parents expressed that although her child's school provided healthy food options, her child did not like eating the cafeteria food. Parent Participant 4 said:

> They (child and siblings) just don't they don't like it. And you know a couple of times they have had some experiences where they were going to get what was on the menu and by the time they get there they didn't have it. She takes her lunch every day and that way

> she is happy with that and she likes to eat the same thing and she doesn't have to wait in line and she's ready to go and she knows what she is having. For her, there is no surprise and there's no chance that she won't have any gravy on her potatoes. You know it takes all the guesswork out.

Contrary to parents of obese/overweight adolescents with DS, *e 355 health professionals* was the most frequent category for parents of non-obese/overweight with DS. Health professionals reported by parents of non-obese/overweight adolescents with DS included cardiologists, dentists, endocrinologist, ear/nose/throat doctors, gynecologists, neurologists, optometrists, pediatricians, pulmonologists, and speech therapists. Furthermore, all of the parents of the obese/overweight adolescents with DS reported that their children were very close with their health professionals. A parent of a non-obese/overweight adolescent with DS emphasized the extent to how close her child was with her health professionals. Parent Participant 1 said:

> Oh Lord [laughter]. She loves [doctor's name] as like one of her favorite people in the whole world. They have their own little love relationship cause he carries on about her and I mean sometimes it like the appointment lasts like 2 or 3 times longer than it should…We go into the office and you know he obviously looks at his patient list for the day…but she'll go [whistles] and he'll go wherever he is [whistles]. And they go back and forth whether he is in a room and he can't hear us then she always knows he's out with the door ajar, I mean they don't close it the whole way, they leave it ajar.

Identifier *e 310 immediate family* was the third most common for parents of non-obese/overweight adolescents with DS. Only four of the five parents of non-obese/overweight adolescents recognized this category pertaining to physical activity. All four parents emphasized that they engaged in physical activity with their children. When asked if the family helps her child to exercise, Parent Participant 5 said "There's parks, sometimes we go and walk in the park. Um, I mean I guess I try to take her places like you know when we go to the gym (referring to CrossFit) or yeah." However, one parent of

a non-obese/overweight adolescent with DS claimed that her family did not engage in physical activity frequently. Parent Participant 1 said:

> But as far as you know doing like a real like none of us are real big walkers or runners or anything you know. So [child's name] doesn't um [pause], [child's name] doesn't get a whole lot of exposure to that when we go to things.

With regard to nutrition, only two parents referenced identifier *e 310 immediate family*. Both parents reported that they promoted healthy eating for their children. When asked if her family helps her child to eat healthy, Parent Participant 8 said:

> Uh, yeah, I think so. Um, we I guess we just offer it (healthy food) to her you know. We are not the healthiest, I mean. Some people I know, they are eating fast food like 3 times a week. We don't do that [laughter].

Identifier *e 320 friends* was the fourth most common category for parents of non-obese/overweight adolescents with DS. Only four of the five parents of non-obese/overweight adolescents with DS identified *e 320 friends* for physical activity. All four stated that their children were physically active with their friends or peers. When asked how her daughter's friend helps her child to be physically active. Parent Participant 8 said:

> …Her best friend will come over, she's the one that brings the soccer ball, she's…into sports…very athletic…runs track and plays soccer for…school…will bring her soccer ball and…will make all my girls play because they all need it especially [child's name] [laughter].

Body functions.

Identifier *b 1471 quality of psychomotor functions* was the second most frequent category recognized by parents of non-obese/overweight adolescents with DS. All five of the parents of non-obese/overweight adolescents with DS recognized *b 1471 quality of psychomotor functions* for physical activity. Two of the five parents maintained that their children were able to multi task or had good hand-

eye coordination when they were physically active. Parent Participant 7 said "No, it is not difficult for him to move and think at the same time when he is being active" when asked if her child was able to multitask during physical activity. In contrast, four of the five parents of obese/overweight adolescents with DS acknowledged that their children struggled with hand-eye coordination when they engaged in physical activity. When asked about hand-eye coordination, Parent Participant 5 said:

> Oh yeah, it's really hard like when she plays tennis, um it's a lot of you know hand-eye coordination. So, uh yeah, she's troubled, it is hard for her. The same with dance, you know she sometimes focuses on one movement instead of two or if you talk to her, she will like look at you and stop what she's doing. So, it's hard for her to multitask.

The third common identifier for both parents of non-obese/overweight adolescents with DS was *b 2800 generalized pain*. All five of the parents of the non-obese/overweight adolescents with DS asserted that their children did not complain of any pain when eating healthy or engaging in physical activity. Parent Participant said "She doesn't complain of pain and has a very high pain tolerance."

Identifier *b 1442 retrieval and processing of memory* was the fourth most frequent category for parents of non-obese/overweight adolescents with DS. In relation to physical activity, only five parents affirmed this identifier. All four parents referred to *b 1442 retrieval and processing of memory* as having a negative influence on their children's physical activity. For example, Parent Participant 8 said "I don't think she can really follow the rules. So, it does affect how long she plays and I guess how engaged she is." However, 1 parent discussed that her child had no issues remembering the rules regarding physical activity. Parent Participant 7 said "As far as the rules, he does pretty well."

For parents of non-obese/overweight adolescents with DS, *b 1400 sustaining attention* was the most frequent identifier. Three of the five parents of the non-obese/overweight adolescents with DS mentioned this identifier concerning physical activity. Three parents maintained that their children were able to concentrate during physical activity. One parent of a non-obese/overweight adolescent with DS explained why her child's interest was connected to her child's ability to concentrate. For instance, when

asked if her child had trouble concentrating during physical activity, Parent Participant 8 said "Um, I don't think so. She enjoys what she's doing, she can do it for long periods of time."

In contrast, three parents of obese/overweight adolescents with DS stated that their children would lose focus during physical activity. Parent Participant 7 said "You know if it was baseball where you are standing in the outfield for a long time, he loses interest."

For parents of non-obese/overweight adolescents with DS, *b 530 weight maintenance functions* was not a common identifier that was acknowledged. Only one parent of an obese/overweight adolescent with DS referenced *b 530 weight maintenance functions.* Parent Participant 4 said:

> "Um that this is when you see more weight gain you know and all the puberty stuff has kicked in and she doesn't need to eat 6 desserts a day.

Personal factors.

Three of the five parents of non-obese/overweight adolescents with DS acknowledged food aversions or textural issues for their children. A parent of a non-obese/overweight adolescent with DS explained how her child's diet had been affected due to textural issues. Parent Participant 8 said:

> And she likes the fruits that are easier to eat like if she has to bite into an apple, like strawberries, it's real soft and easy to eat, loves it. Grapes, easy to eat. If I peel a orange and take it off of the segments, she will eat it. But if it requires her to you know peel it and take it apart herself, you know she's not going to. Bananas, soft, easy to eat, she loves them. Apples she will not eat, it's just hard.

In contrast, one parent of an obese/overweight adolescent with DS reported no food aversions or textural issues for her child. Parent Participant 1 said:

> …I mean she has no food aversions as far as no textural really. A lot of kids with Down syndrome have textural aversions whatever. Um, she really doesn't. Um, she has pretty good oral motor strength. Um, you know we have found she can chew the chewiest you

> know whatever or um bite down hard enough and chews things up. I mean you know there are no issues health wise going on with her.

For engagement in physical activity of the adolescents with DS, four of the five parents of non-obese/overweight adolescents with DS reported that their children would only exercise if the physical activity was appealing to them. A parent of a non-obese/overweight adolescent with DS discussed the circumstances when her child liked to exercise. Parent Participant 4 said:

> Um I would say that she does not like to exercise if she knows she is exercising like if her father is going to walk around the neighborhood. So, like he is going to walk around the neighborhood, I'm not going to say that she would make it around the whole neighborhood because she would be tired before she got around the neighborhood. But to her that's a walk with dad, even though that would be exercise.

Summary

In summary, both the obese/overweight adolescents with DS and the non-obese/overweight adolescents with DS had the same order of ICF-CY categories. Both groups frequently recognized Activities and Participation followed by Environmental Factors and Body Functions. The common identifiers for Activities and Participation were the same for both groups. In contrast, the Environmental Factors and Body Functions identifiers differed between obese/overweight and non-obese/overweight adolescents with DS. For obese/overweight adolescents with DS, Environmental Factors comprised of facilitators (+) and barriers (-) for *e 585 education and training services, systems and policies* and *e 310 immediate family*. Identifier *e 320 friends* contained facilitators (+). With regard to non-obese/overweight adolescents with DS, Environmental Factors contained facilitators (+) and barriers (-) for *e 585 education and training services, systems and policies*. Identifiers *e 320 friends* and *e 310 immediate family* comprised facilitators (+).

The common identifiers for both parent groups for Activities and Participation were the same with parents of obese/overweight adolescents with DS having an additional identifier: *d 7602 sibling*

relationships. Parents of obese/overweight and non-obese/overweight adolescents with DS had identical identifiers for Body Functions with the exception of *b 530 weight maintenance functions*. Identifier *b 530 weight maintenance functions* was only common among parents of obese/overweight adolescents with DS. With respect to parents of obese/overweight adolescents with DS, Environmental Factors included *e 310 immediate family* entailing facilitators (+). Additionally, facilitators (+) and barriers (-) were present for *e 585 education and training services, systems and policies*, *e 320 friends*, and *e 355 health professionals*. Environmental Factors consisted of facilitators (+) and barriers (-) for *e 585 education and training services, systems and policies*, *e 320 friends*, *e 310 immediate family*, and *e 355 health professionals* for parents of obese/overweight adolescents with DS.

CHAPTER 5

DISCUSSION

Quantitative Arm

Food Behavior Checklist

Parents of non-obese/overweight adolescents with DS reported that their children ate vegetables as snacks, drank sports drinks, drank less punch and soda compared to that of parents of obese/overweight adolescents with DS. These findings are consistent with the Academy of Nutrition and Dietetics (2015) and Must et al. (2014) acknowledging that the risk of obesity for children and adolescents with IDD can be mediated by limiting the consumption of sugar-sweetened beverages. Additionally, these study results support the CDC (2017) that asserting that obesity among CSHCN can be addressed by increasing the intake of fruits and vegetables.

Additionally, parents of non-obese/overweight adolescents with DS recorded that their children ate more than one kind of fruit each day, 2 or more vegetables at their main meal and less fried foods than parents of obese/overweight adolescents with DS. These results endorse the Academy of Nutrition and Dietetics (2015) maintaining that CSHCN with IDD can reduce their risk of obesity through reducing the consumption of fried foods. Moreover, Must et al. (2014) report that fruit and vegetable consumption can help to prevent obesity among CSHCN with IDD.

Furthermore, all parents of the non-obese/overweight adolescents with DS indicated that they read nutrition labels when food shopping, had more nutritious food to last a whole month and higher average scores to rate the quality of their children's eating habits than parents of obese/overweight adolescents with DS. This aligns with the NDSS (2018) asserting that children and adolescents with DS are heavily influenced by the eating habits of their parents emphasizing the need for parents to model healthy eating behaviors to lower their children's risk for obesity.

PROMIS Physical Activity Short Form

With regard to physical activity, the average score for the non-obese/overweight adolescents with DS was 22.6 while the average score was 21.5 for the obese/overweight adolescents with DS. These scores indicate that the non-obese/overweight adolescents with DS engaged in more physical activity than their obese/overweight counterparts. *Days child exercised or played so hard that his/her body got tired*, *child exercised really hard for 10 minutes*, and *child exercised or played so hard that his/her muscles burned* were associated with higher scores for parents of non-obese/overweight adolescents with DS. In addition, parents of non-obese/overweight adolescents had higher scores for the number of days *child exercised or played so hard that he/she felt tired*, *child was physically active for 10 minutes or more* and *child ran 10 minutes or more*. This aligns with Whitt-Glover, O'Neill and Stettler (2009) who suggest that increasing engagement in physical activity may be appropriate to prevent obesity among children and adolescents with DS.

World Health Disability Assessment Schedule 2.0

For the subscales comprising *understanding and communicating* and *getting around*, parents of obese/overweight adolescents with DS reported more difficulty for their children than parents of non-obese/overweight adolescents with DS. Furthermore, the scores for parents of non-obese/overweight adolescents with DS indicated more difficulty for their children pertaining to *self-care*, *getting along with people*, *participation in society*, *life activities* and *number of days in the past month that there were difficulties due to their children's health conditions* than parents of obese/overweight adolescents with DS. Although there were no observable differences based on the weight status of the adolescents with DS, the results illustrate that adolescents with DS experience trouble with communicating with others, forming relationships, participating in social and recreational activities. These findings are consistent with Smith, Næss, and Jarrold (2017) and Barr and Shields (2011).

Qualitative Arm

There were four research questions that aimed to determine the perceived facilitators and perceived barriers to healthy eating and physical activity for obese/overweight and non-obese/overweight adolescents with DS. The four research questions were:

a. What are the perceived facilitators and barriers regarding physical activity identified by adolescents with DS?

b. What are the perceived facilitators and barriers regarding physical activity identified by parents of adolescents with DS?

c. What are the perceived facilitators and barriers regarding healthy eating identified by adolescents with DS?

d. What are the perceived facilitators and barriers regarding health eating as identified by parents of adolescents with DS?

Research Question 1: What are the perceived facilitators and barriers regarding physical activity identified by adolescents with DS?

Obese/Overweight adolescents with DS

All of the obese/overweight adolescents with DS who referenced *e 310 immediate family* for physical activity stated that they engaged in physical activity with their family. For this reason, *e 310 immediate family* was coded as a facilitator. Again, *e 310 immediate family* impacted *d 5701 managing diet and fitness* due to parents prompting their children to exercise. Children and adolescents with DS who exercise with their parents can lower their risk for obesity (American Academy of Pediatrics Committee on Genetics, 2001; Shields and Blee, 2012).

Similar to *e 310 immediate family* for physical activity, all of the obese/overweight adolescents with DS who referenced *e 320 friends* claimed that they engaged in physical activity with their friends or peers. As a result, *e 320 friends* was determined to be a facilitator. These obese/overweight adolescents

with DS mentioned sports when they when they discussed being physically active with their peers. In other words, *e 320 friends* was connected to *d 9201 sports*. Having friends or peers to play with has been known to promote physical activity among children and adolescents reducing chances of obesity (IOM, 2005). Additionally, it may be possible that the obese/overweight adolescents with DS played sports instead of individual activities with their friends to fit in with their non-disabled peers.

With regard to physical activity, *e 585 education and training services, systems and policies* was concluded to be a facilitator for 87.5% of the obese/overweight adolescent with DS who referred to this identifier. The obese/overweight adolescents with DS affirmed that schools provided opportunities for physical activity during recess and physical education.

Physical activities sponsored by schools have been proven to be effective to prevent or mediate obesity among children and adolescents (Wechsler et al., 2004). In contrast, 25% of the obese/overweight adolescents with DS regarding *e 585 education and training services, systems and policies* reported that their schools did not have recess. This was because the obese/overweight adolescents with DS were in middle school when recess is no longer offered. Although, the absence of recess was attributable to grade level, *e 585 education and training services, systems and policies* was recognized as barrier for these obese/overweight adolescents with DS because the nonexistence of recess resulted in a missed opportunity for physical activity for the obese/overweight adolescents with DS.

Non-Obese/Overweight adolescents with DS

For non-obese/overweight adolescents with DS who referenced identifier *e 320 friends,* majority of the non-obese/overweight adolescents with DS stated that they participated in physical activity with their friends or peers by playing sports. For this reason, *e 320 friends* was determined to be a facilitator and connected to *d 9201 sports*. One of the non-obese/overweight adolescents with DS expressed that they were physically active with their friend who also had DS. This shows that the non-obese/overweight adolescent with DS was able to maintain an informal relationship with their friend who was similar to them while reaping the benefits of physical activity. Barr and Shields (2011) suggest that children and

adolescents with DS who lack peers or friends to engage with in physical activity are susceptible to obesity.

With respect to physical activity, identifier *e 585 education and training services, systems and policies*, all of the non-obese/overweight adolescents with DS who mentioned this identifier stated that their schools did not provide recess, did not have a playground or substituted free indoor time for recess. This resulted in *e 585 education and training services, systems and policies* being coded as a barrier. Although these non-obese/overweight adolescents with DS were in middle school where they no longer have recess, staying indoors for screen time to play on computers or play games for leisure should have been replaced with opportunities for physical activity. The American Academy of Pediatrics (2006) recommends that schools should provide recess or nonstructured physical activity before, during, and after school hours to prevent obesity among children and adolescents.

Research Question 2: What are the perceived facilitators and barriers regarding physical activity identified by parents of adolescents with DS?

Parents of Obese/Overweight Adolescents with DS

Parents of the obese/overweight adolescents with DS were most likely engaging in physical activity with their children to help their children reach a healthy weight. For identifier *e 585 education and training services, systems and policies*, six of the eight parents of obese/overweight adolescents with DS acknowledged physical activity for their children. All six parents affirmed that their children's schools provided opportunities for their children to engage in physical activity. These opportunities entailed recess, physical education and competitive sports. As a result, *e 585 education and training services, systems and policies* was coded as a facilitator for parents of obese/overweight adolescents with DS. Among these six parents, one parent mentioned that her child was the basketball team manager for her school and participated in drills and practice. Although the parent's child did not play for the basketball team, the school was inclusive of the child enabling her to play basketball with her non-disabled peers.

Participation in physical activity with peers has been recommended to decrease the likelihood of obesity for children and adolescents with DS (Barr & Shields, 2011). Since teachers and authority figures serve as role models for children in school where children frequently engage in physical activity, it is imperative for them to promote physical activity for all children specifically those with DS who have an elevated risk of obesity. Identifier *e 310 immediate family* comprised of five parents acknowledging *e 310 immediate family* regarding physical activity. All five parents stated that the family engaged in physical activity with their children. Identifier *e 310 immediate family* was coded as a facilitator for parents of obese/overweight adolescents with DS since they exercised with their children to help them reach a healthy weight to mitigate obesity.

Lastly, *e 320 friends* was referenced by two parents of obese/overweight adolescents with DS. Both parents mentioned that their children engaged in physical activity with their friends or peers resulting in *e 320 friends* being coded as a facilitator in relation to *d 9201 sports*. Engagement in physical activity with friends or peers can prevent obesity among children and adolescents with DS (Barr & Shields, 2011). However, one parent reported that their child experienced trouble communicating with and forming relationships with peers. Lack of communication skills can impede social interactions with peers resulting in low engagement in physical activity with peers heightening the chances of obesity (Barr & Shields, 2011). Furthermore, e *320 friends* was connected to b *530 weight maintenance functions* and *d 9201 sports*. All five of the parents who recognized *b 530 weight maintenance functions* mentioned that their children's weight status impeded engagement in physical activity with their peers. Physical activity had been associated with adiposity of adolescents with DS (Pitchford, Adkins, Hasson, Hornyak, & Ulrich, 2018). In other words, the higher the BMI, the lower the frequency of physical activity relative to adolescents with DS (Pitchford et al., 2018).

Parents of Non-Obese/Overweight Adolescents with DS

For identifier *e 585 education and training services, systems and policies*, four parents expressed that their children's schools encouraged physical activity for their children serving as facilitators. Of these four parents, one parent mentioned that the school was very inclusive of their child regarding physical activity supporting the family's goals of promoting physical activity for their child. The parent highlighted that the physical education teacher did not let their child "skate by" and treated their child as they would any other child. With respect to *e 355 health professionals*, parents of non-obese/overweight adolescents with DS reported their children and families were very close with their health professionals. One parent discussed their child's appointments lasting two or three times longer because of their child's close-knit relationship with their doctor. For this reason, *e 355 health professionals* was coded as a facilitator. It can be assumed that because of the close relationship between the families and their children's physicians, families participated in shared-decision making regarding treatment options with the physicians. The MCHB's System of Care for CSHCN Core Outcomes been encourages shared-decision making between families and physicians (Lipstein, Lindly, Anixt, Britto, & Zuckerman, 2016). Identifier *e 310 immediate family* was connected to *d 5701 managing diet and fitness*. For identifier *e 310 immediate family*, five parents recognized this identifier for physical activity. Four of the five parents stated that they engaged in physical activity with their children resulting in coding *e 310 immediate family* as a facilitator due to encouragement of physical activity for the children. One of the four parents mentioned that they walked in the parks with their child. This shows the importance of having access to recreational spaces such as parks, walking trails and more to promote physical activity for children with DS and their families. In contrast, one parent expressed that their family did not exercise with the child since the family did not frequently engage in physical activity which was coded as a barrier.

Research Question 3: What are the perceived facilitators and barriers regarding healthy eating identified by adolescents with DS?

Obese/Overweight Adolescents with DS

For *e 310 immediate family* concerning nutrition, 60% of the obese/overweight adolescents with DS acknowledged that their parents offered them fruits and vegetables acting as a facilitator. Identifier *e 310 immediate family* had an effect on *d 5701 managing diet and fitness.* Parents were promoting healthy eating for their children by encouraging fruit and vegetable consumption which has been shown to lower the risk of obesity among children with DS. Contrary to the 60% of obese/overweight adolescents with DS, 40% of the obese/overweight adolescents with DS reported that their parents did not serve them fruits and vegetables which in turn can be a barrier for *d 5701 managing diet and fitness*. Low fruit and vegetable consumption has been associated with increased obesity risk for adolescents and adults with DS (Nordstrøm, Paus, Andersen, & Kolset, 2014).

Identifier *e 585 education and training services, systems and policies* was recognized as a facilitator for all of the obese/overweight adolescents with DS who mentioned this identifier related to nutrition. The obese/overweight adolescents with DS stated that their schools offered fruits and vegetables in the cafeteria. Schools that endorse healthy eating can reduce the likelihood of obesity for children and adolescents. Addressing nutrition services by promote healthy eating through a Coordinated School Health Program can curb the obesity epidemic among children and adolescents (Wechsler, McKenna, Lee, & Dietz, 2004).

Non-Obese/Overweight Adolescents with DS

For identifier *e 585 education and training services, systems and policies*, all of the non-obese/adolescents confirmed that their schools offered fruits and vegetables acting as a facilitator by promoting healthy eating. For nutrition, all of the five non-obese/overweight adolescents with DS reported that their schools provided fruits and vegetables endorsing healthy eating. Identifier *e 310*

immediate family comprised all of the non-obese/overweight adolescents with DS acknowledging that their parents served them fruits and vegetables at home which positively influenced *d 5701 managing diet and fitness*.

Research Question 4: What are the perceived facilitators and barriers regarding healthy eating identified by parents of adolescents with DS?

Parents of Obese/Overweight Adolescents with DS

Identifier *e 585 education and training services, systems and policies* was also recognized for nutrition by all 8 parents of obese/overweight adolescents with DS. Six out of the eight parents stated that their children's schools offered fruits and vegetables regarding healthy eating for their children acting as a facilitator. However, the remaining two parents expressed their displeasure of the food options at their children's schools. Both parents reported that their children's schools offered unhealthy options consisting of various forms of chicken and potatoes, and very limited menus including pizza or the main menu item.

For this reason, *e 585 education and training services, systems and policies* was coded as a barrier for these two parents. Identifier e *355 health professionals* was another common identifier within Environmental Factors. All eight of the parents of obese/overweight adolescents with DS recognized *e 355 health professionals*. It is important to note that *e 355 health professionals* was not a frequent identifier for parents of obese/overweight adolescents with DS.

Seven out of the eight parents confirmed that their children were close with their health professionals resulting in e *355 health professionals* being coded as a facilitator. Access to health professionals, medical homes or care coordination have been associated with better health status for CSHCN including children and adolescents with DS (Romley et al., 2016). One parent, however, reported that their child was not close to one of their health professionals because of the child's aggressive behavioral problems. For this reason, e *355 health professionals* was recognized as a barrier because the

child's behavioral problems negatively affected the individual attitudes of the health professionals (Environmental Factors) obstructing access to quality health care for the child's needs. Identifier *e 310 immediate family* also influenced *d 5701 manage diet and fitness* concerning fitness of the children.

With regard to nutrition, four parents confirmed that they provided fruits and vegetables for their children and took additional steps such as limiting snacking and unhealthy food options for their children acting as a facilitator. This shows that these parents were aware of the weight status of their children and took action to address the obese/overweight status of their children. In contrast, two parents affirmed that they did not encourage healthy eating for their children because of time constraints and not modeling healthy eating behaviors. For one parent, time constraints resulted from the child's busy schedule of activities taking precedence over healthy eating. In other words, competing tasks such as the numerous activities concerning the child hindered prioritizing healthy eating for the child. The other parent who did not model healthy eating behaviors stated that they were guilty of not encouraging healthy eating for the child. This could have been due to the parent being overly permissive of the child's food options allowing the child to consume unhealthy food due to the child's narrow food preferences. This agrees with Phillips, Conners and Curtner-Smith (2017) who found that mothers of children and adolescents with DS have a permissive parenting style and ignored misbehavior more than parents of children and adolescents without DS. For both of these parents, *e 310 immediate family* was coded as a barrier for nutrition.

Parents of Non-Obese/Overweight Adolescents with DS

For nutrition, *e 310 immediate family* was referenced by two parents who specified that they provided healthy food options for their children including fruits and vegetables. Identifier *e 310 immediate family* was coded as a facilitator because healthy eating has been correlated with a reduced risk of obesity for adolescents with DS (Curtin et al., 2013). Identifier *e 320 friends* comprised of 4 parents reporting that their children were physically active with their friends via competitive sports overlapping with identifier *d 9201 sports*. Identifier *e 320 friends* was coded as a facilitator because of engagement in physical activity with peers or friends.

Comparison of Parents and Adolescents with DS

Activities and Participation

Among all of the adolescents with DS in this sample, *d 9201 sports* was referenced more by non-obese/overweight adolescents with DS. Many of the adolescents with DS in both groups stated that they were involved in sports that they enjoyed including dance, cheer, gymnastics, basketball, baseball, soccer, kickball, dodgeball, swimming and more. This finding was very similar to findings of their parents. In contrast to their parents, none of the adolescents with DS in both groups referenced *d 9201 sports* negatively regarding competitive sports. A reason for this are that the adolescents with DS did not perceive that having DS hindered their involvement in competitive sports.

With respect to *d 9201 sports*, the majority of parents of obese adolescents with DS and non-obese adolescents with DS asserted that their children were involved in sports with most of them participating in dance or cheer followed by gymnastics. This is consistent with literature that maintains that the best opportunities for physical activity encompass sports such as dancing, gymnastics, horseback riding, swimming and more (Buckley, 2007; Cunningham, 2006; Naumovich, 2007). Additionally, dance, cheer and gymnastics serve as suitable alternatives to competitive sports for children and adolescents with DS due to the fitness benefit that these activities offer (Jobling, 1984; Naumovich, 2007). The majority of

all parents of the adolescents with DS in this sample asserted that their children could not participate in competitive sport settings especially those who were parents of obese/overweight adolescents with DS.

It is well known that children and adolescents with DS have less developed motor skills compared to their counterparts without DS. Therefore, a tailored approach for physical activity is required for children and adolescents with DS. Dance and cheer enable children and adolescents with DS to be taught skills at their own pace, improve their motor skills, express themselves, and learn to follow directions while enjoying the activity (Naumovich, 2007). With regard to this study, all of the parents whose children were involved with dance or cheer stated their children would only want to be physically active if there was dancing involved or that they would get tired from dancing all day. This is consistent with the findings of Naumovich (2007) who maintained that children and adolescents with DS who participated in dance always looked forward to dancing.

Similar to their parents, for *d 5701 managing diet and fitness*, all of the adolescents with DS maintained that their parents regulated their diet and involvement in physical activity. Obese/overweight adolescents with DS referenced *d 5701 managing diet and fitness* more than their non-obese/overweight counterparts. These findings are consistent with the NDSS (2018) that has asserted that parents highly influence the diet and physical activity of children and adolescents with DS.

For *d 5701 managing diet and fitness*, all of the parents managed the diet and physical activity for their children with emphasis on those of non-obese/overweight adolescents with DS. The parents stated that they managed diet and fitness for their children because without management, their children would not be physically active and eat healthy. One can assume that these results were expected since the adolescents with DS were non-obese/overweight. One parent of a non-obese/overweight adolescent with DS acknowledged that their child ate very little due to having difficulty chewing and the jaw hurting. In addition, the parent of the non-obese/overweight adolescent with DS emphasized that their child avoided certain foods or had food aversions (Personal Factors) because of chewing (Body Functions) and the jaw (Body Structures) hurting as well. This agrees with literature claiming that children and adolescents with

DS tend to avoid certain foods due to texture making it difficult to eat healthy (Field, Garland, & Williams, 2003; Lazenby, 2008).

For *d 4401 grasping*, all of the adolescents in DS in the obese/overweight and non-obese/overweight groups recognized that grasping objects such as balls during physical activity was not an obstacle for them. These results resembled all of the parents in the sample who reported that their children did not experience issues grasping objects when being physically active. Both parents and adolescents with DS findings contradict with the literature such as the CDC (2018c) and NCHPAD (2018a) suggesting that children and adolescents with DS have trouble grasping items due to low muscle tone. For *d 7602 sibling relationships*, most of the parents of obese/overweight adolescents with DS maintained that their children engaged in physical activity with their siblings encouraging physical activity for their children than parents of non-obese/overweight adolescents with DS. Having more obese/overweight adolescents with DS than non-obese/overweight adolescents with DS in the sample may have had an effect regarding this identifier.

Environmental Factors

For *e 585 education and training services, systems and policies,* all of the adolescents with DS reported that their schools offered healthy food items such as fruits and vegetables acting as a facilitator. This conflicts with the parents of non-obese/overweight adolescents with DS who pointed out that their children's school did not offer healthy food items. Underlying reasons for this contrast may be due to the adolescents with DS being asked if there were fruits and vegetables in their schools while parents were able to provide more context. With respect to physical activity, majority of both groups of adolescents with DS in both groups noted that there were opportunities for physical activity at their schools regarding free time and physical education.

However, non-obese/overweight adolescents with DS referenced *e 585 education and training services, systems and policies* more as a barrier than obese/overweight adolescents with DS because of indoor free time, their schools not having a playground and not playing outside during school breaks. The

aforementioned barriers may not have been perceived as obstacles due to most of the adolescents with DS being enrolled in middle school where there is no recess and only just physical education classes. The majority of the adolescents with DS stated that because they were in middle school, there was no more recess or playing outside. This provided more context regarding physical activity in their schools since most of the parents in the entire sample stated that they could not provide information about their children's school concerning physical activity since they are working at the time while their children were in school.

Identifier *e 355 health professionals* comprised of the majority of parents in both groups reporting that their children saw various health professionals to maintain their health status. Parents of non-obese/overweight adolescents with DS referenced this category more than parents of obese/overweight adolescents with DS. In addition, parents of non-obese/overweight adolescents with DS maintained that their children were very close with their health professionals. Most of the families of the obese/overweight adolescents with DS were members of the local DS support group. This supports the findings of Skotko, Levine, and Goldstein (2011) who conducted a study involving parents of children with DS. Parents recommended that expectant parents of children with DS should search for a good physician who is knowledgeable about DS, seek resources and join DS support groups (Skotko et al., 2011).

For *e 310 immediate family*, close to all of the adolescents with DS asserted that their parents endorsed healthy eating with more references from non-obese/overweight adolescents with DS. This was consistent with findings of the parents where majority of parents in both groups stated that they encouraged healthy eating for their children. It is expected that non-obese/overweight adolescents with DS would have healthier eating behaviors. However, some of the non-obese/overweight adolescents with DS maintained that their parents did not promote fruit and vegetables consumption at home.

This could have been a result of various interpretation of what constitutes healthy food for both groups of adolescents with DS and their parents. These findings illustrated the influence of the family on the diet of children and adolescents with DS. With regard to physical activity, all of the adolescents in

both groups reported that they engaged in physical activity with their families. However, one parent of an obese/overweight adolescent with DS stated that her family rarely engaged in physical activity because their child would get tired easily which relates to general physical endurance (Body Functions) and walking long distances (Activities and Participation). This finding agrees with the NCHPAD (2018a) that suggests that children and adolescents with DS have low aerobic fitness.

Identifier e *320 friends* entailed several of the adolescents with DS in the entire sample expressing that they engaged in physical activity with their friends or peers which acted as a facilitator. Non-obese/overweight adolescents with DS had more references pertaining to adolescents with DS being physically active with their friends. This is consistent with Barr & Shields (2011) asserting that children and adolescents with DS who have peers to be physically active have a lower risk for obesity. Additionally, one non-obese/overweight adolescent with DS stated that they did not engage in physical activity with their friends during recess which supports the findings of Venuti, de Falco, Esposito and Bornstein (2009) that children and adolescents with DS value solitary play (Activities and Participation). With regard to all of the parents in the sample, one parent from each group maintained that their children did not have friends to play with for physical activity purposes which clashed with the findings of the adolescents with DS who failed to mention this.

Moreover, one parent of an obese/overweight adolescent with DS confirmed that their child had trouble communicating with peers which agrees with research asserting that children and adolescents with DS have trouble communicating with peers. Lack of friends has been shown to negatively impact physical activity for children and adolescents with DS according to Barr and Shields (2011).

Body Functions

With respect to *b 1471 quality of psychomotor functions*, close to all of the adolescents with DS asserted that they were able to do two things at once regarding hand-eye coordination when being physically active. These results clashed with the findings of most of the parents in the sample who reported that their children had poor hand-eye coordination. The differences between parents and

adolescents with DS may be explained by the adolescents with DS not perceiving themselves as having difficulty performing multiple tasks during physical activity.

The majority of parents in both groups frequently referred to *b 1471 quality of psychomotor functions* negatively pertaining to physical activity for their child with more references for parents of obese/overweight adolescents with DS. The negative aspects were due to lack of hand-eye coordination. The findings of the parents are consistent with Latash (2007) maintaining that children and adolescents with DS have slow motor skills relative to cognitive skills.

For *b 2800 generalized pain*, non-obese/overweight adolescents with DS were more likely than obese/overweight adolescents with DS to state that parts of their body did not hurt when they engaged in physical activity. These findings support literature by Pitetti et al. (2013) and Mendonca, Pereira, and Fernhall (2010) that maintain that individuals with DS feel fatigue and pain while exercising. In contrast, close to all of the parents in both groups reported that their children did not feel any pain while exercising. This could be due to the parents not truly knowing if their child felt pain when exercising.

Lastly, b *1442 retrieval and processing of memory* consisted of more references from parents of obese/overweight adolescents with DS than those of non-obese/overweight adolescents with DS because of the difficulty for their children to retrieve and process memory when being physically active. This supports current literature such as Latash (2007) highlighting that children and adolescents with DS have a cognitive delay which is more evident during physical activity especially for those at risk for obesity. In contrast, close to all of the adolescents with DS in the sample asserted that they were able to remember or abide by the rules when they engaged in physical activity such as the sports that they were involved in. The reason for this finding may be that the adolescents with DS felt that they were self-sufficient concerning this identifier.

For identifier *b 1400 sustaining attention*, the majority of adolescents of both groups of adolescents with DS acknowledged that they were able to pay attention while they engaged in physical activity. Parents of non-obese/overweight adolescents with DS referenced *b 1400 sustaining attention* negatively concerning their children while none of the parents of the obese/overweight adolescents with

DS reported that their children had difficulty retaining concentration while they engaged in physical activity. This may have been a result of the makeup of the sample. The NDSS (2018c) acknowledges that individuals with DS may have problems concerning attention.

Most of the parents of obese/overweight adolescents with DS reported that their children experienced issues engaging in physical activity due to their unhealthy weight and low muscle tone. Parents of non-obese/overweight adolescents with DS did not mention *b 530 weight maintenance functions* at all. These findings are consistent with Pepi and Alesi (2005) who found that parents of children and adolescents with DS reported their concerns about their children's weight acting as a barrier for their children's engagement in physical activity.

Personal Factors

For food aversions and textural issues, both parents of obese/overweight and non-obese/overweight adolescents with DS mentioned their children's dislike of certain fruits and vegetables (e.g. apples, leafy greens, meat) because of texture selectivity. These findings agree with current literature by Field et al. (2003) and Lazenby (2008) emphasizing that children and adolescents with DS are particularly selective of food option because of issues with texture. With respect to their children's engagement in physical activity, most of the parents of both obese/overweight and non-obese/overweight adolescents with DS reported that their children only engaged in activity if they were interested in the activity due to low motivation. This finding is consistent with Menear (2007).

Overlap of ICF-CY Categories

Identifier *d 9201 sports* (Activities and Participation) overlaps with *d 4401 grasping* (Activities and Participation) concerning playing in competitive sports such as basketball, soccer, baseball, and more. When playing competitive sports, part of the game is grabbing, dribbling, kicking, catching, or shooting the ball. Performing these tasks may be difficult for adolescents with DS due to their low muscle tone (Body Functions). Identifier *b 1471 quality of psychomotor functions* (Body Functions), *b 1400 sustaining*

attention (Body Functions) and *b 1442 retrieval and processing memory* was also connected to *d 9201 sports*. Parents reported that their children experienced difficulty with hand-eye coordination, concentrating for a period of time and remembering the rules when they engaged in sports for physical activity, respectively. With regard to *d 5701 managing diet and fitness* (Activities and Participation), all of the parents managed the diet and fitness of their children to prevent their children from practicing obesogenic or sedentary behaviors.

Some of the parents of both obese/overweight and non-obese/overweight adolescents with DS noted that due to low muscle tone (Body Functions), their children were not able to consume fruits such as an apple because of issues with chewing (Body Functions) and a weak jaw (Body Structures). As a result, the low muscle tone (Body Functions) adversely affected the diet of some of the adolescents with DS. Additionally, *d 5701 managing diet and fitness* (Activities and Participation) was connected to food aversions or textural issues (Personal Factors). Parents acknowledged that their children avoided specific fruits and vegetables because they disliked their texture. Identifier *e 310 immediate family* (Environmental Factors) and *e 585 education and training services* (Environmental Factors) were linked to *d 5701 managing diet and fitness* (Activities and Participation) as well. Parents of the non-obese/overweight adolescents with DS expressed their dislike of the unhealthy food options provided at their children's school due to the negative impact on their children's diet.

Identifier *e 585 education and training services, systems and policies* (Environmental Factors) was intertwined with *d 5701 managing diet and fitness* (Activities and Participation) too. Most of the adolescents with DS claimed that they had indoor free time or did not have recess since they were in middle school. Although the adolescents with DS participated in physical education, providing opportunities for physical activity outdoors would have been beneficial to engage the adolescents with DS in more physical activity. For *d 7602 sibling relationships* (Activities and Participation), *e 310 immediate family* (Environmental Factors) was tied to this identifier. The majority of the parents of both groups of adolescents with DS asserted that their children engaged in physical activity with their siblings and that their children exercised with their parents.

Parents of both obese/overweight and non-obese/overweight adolescents with DS reported that getting their children to exercise with the family was problematic because their children did not like walking long distances (Activities and Participation) and struggled with general physical endurance (Body Functions). Lastly for *b 2800 generalized pain* (Body Functions), in relation to physical activity, the adolescents with DS in both groups stated that they felt pain in their arms, stomach, legs and feet (Body Structures) when they exercised. For *b 530 weight maintenance functions*, parents of the obese/overweight adolescents with DS expressed concern about their children's weight status in connection to low physical activity and low muscle tone (Body Functions).

Summary of ICF-CY Categories

In conclusion, regardless of weight status, all of the adolescents with DS and parents reported that the adolescents with DS were involved in sports or activities promoting physical activity. Additionally, most of the parents in both groups maintained that their children experienced trouble participating in competitive sports with their peers. Furthermore, the majority of obese/overweight and non-obese/overweight adolescents with DS were members of a dance or cheer team to accommodate their special needs pertaining to physical activity. With respect to diet, all of the adolescents with DS and their parents emphasized that the parents managed the diet and physical activity of their children. Moreover, most of the parents in both groups pointed out that their children would select sedentary activities and consume unhealthy foods without parental management. Moreover, the majority of parents of both obese/overweight and non-obese/overweight adolescents with DS stated that their children experienced difficult multi-tasking while being physically active. As for generalized pain, mostly obese/overweight adolescents with DS reported that they felt pain or that parts of their bodies would hurt when they engaged in physical activity.

Retrieval and processing memory was a common hinderance concerning physical activity identified by parents of both obese/overweight and non-obese/overweight adolescents with DS. For weight maintenance, most of the parents of obese/overweight adolescents with DS expressed concern

about their children's weight status and low muscle tone negatively affecting their engagement in physical activity. With respect to the community environment of the adolescents with DS, parents asserted that their children were physically active with their peers. For diet, some parents of obese/overweight adolescents with DS stated that they did not promote fruit and vegetable consumption and did not model healthy eating behaviors due activities of their children taking priority. Another notable finding was that parents of non-obese/overweight adolescents with DS were more likely to acknowledge that their children had very close relationships with their doctors. Furthermore, parents reported that their children were selective food due to texture and that their children would not engage in physical activity if the activity did not appeal to them. Although, no significant differences based on weight status were concluded due to the difficulty assessing the body fat of the adolescents with DS, prominent themes presented in the literature were highlighted in this study.

Connections between the ICF-CY Categories and the SEM

Parents of obese/overweight adolescents and non-obese/overweight adolescents with DS reported that their children had difficulty engaging in physical activity with their friends or peers when playing competitive sports. Friends and peers align with the interpersonal level of while competitive sports correspond to the community level. To promote physical activity for their children outside of competitive sports, parents in both groups of adolescents with DS enrolled their children in dance or cheer teams in the community. With regard to the interpersonal level, it was evident that parents influenced the diet and engagement in physical activity relative to their children. Additionally, majority of the parents of obese/overweight and non-obese/overweight adolescents with DS emphasized that if they did not manage their children's diet and participation in physical activity, their children would practice sedentary behaviors and make unhealthy food choices.

At the intrapersonal level, mainly obese/overweight adolescents with DS acknowledged that they felt pain when they were physically active. Furthermore, pertaining to the intrapersonal level, parents of obese/overweight and non-obese/overweight adolescents with DS mentioned that memory processing and

recall was delayed while their children engaged in physical activity. In addition, the majority of parents of obese/overweight adolescents with DS maintained that the weight status and low muscle tone of their children impeded engagement in physical activity. Moreover, parents in both groups reported that their children engaged in physical activity with their peers or friends at the interpersonal level. In contrast, for diet, some parents of obese/overweight adolescents with DS stated that they did not promote fruit and vegetable consumption and did not model healthy eating behaviors for their children. These actions have a vast impact at the interpersonal level concerning their children's weight status.

Parents of non-obese/overweight adolescents with DS discussed in detail the close relationships between their children and their children's doctors aligning with the organizational level. The children's schools played a major role concerning the diet and physical activity for the children at the organizational level. Lastly, pertaining to the intrapersonal level, most of the parents in both groups mentioned that their children were selective regarding food due to issues with texture and that their children would engage in physical activity only if the activity was desirable to them.

Strengths and Limitations

There were numerous strengths relative to this study. This exploratory study is the first to assess facilitators and barriers concerning both healthy eating and physical activity for adolescents with DS in the Southeast let alone the state of Georgia. Additionally, no study has been conducted involving interviews with adolescents with DS. Furthermore, utilizing a sequential mixed methods design established a comprehensive lens to identify concrete barriers and facilitators for this population. Moreover, experts in the disability health field served as reviewers for this study. The primary researcher attended monthly meetings of the local DS support group establishing a long lasting relationship with the community. The use of the SEM as the theoretical framework and the ICF-CY as the conceptual framework provided more understanding of the characteristics specific to adolescents with DS association resulting in a convenience sample in two health districts. In addition, this study, to the best of our

knowledge is the first exploratory study to use the ICF-CY to identify facilitators and barriers to both healthy eating and physical activity for adolescents with DS.

This is study is not without its limitations. First and foremost, the sample size was 26 which is too small to generalize results or to conclude external validity. Second, the principal investigator recruited participants through one county school system and a local DS association resulting in a convenience sample. Thirdly, adolescents with DS were interviewed for this study and may have provided inaccurate information. Fourthly, due to the conflict concerning body fat values of the three methods used for this study, the weight status of the adolescents with DS may not be precise. Lastly, recall bias was introduced into the study due to participants being asked to complete questionnaires and answer interview questions.

Practical Implications

There is a lack of research examining facilitators and barriers concerning healthy eating and physical activity adolescents with DS in the Southeastern United States, specifically in Georgia. This study, relative to Southeast Georgia, contributed to the literature by including the perspectives of parents and the adolescents with DS contrary to previous studies that only ask for the perspectives of the parents. The adolescents with DS were able to articulate their opinions and thoughts regarding the ICF-CY categories and identifiers. Additionally, the study shed light on facilitators and barriers to healthy eating and physical activity for the adolescents with DS to mediate their risk for being obese and overweight. Obesity is very problematic for children and adolescents with DS due to genetic factors, body functions, personal factors, activity limitations, participation restrictions and impairment.

The results from this study can be used to inform the development and implementation of tailored programs to reduce the risk of obesity for children and adolescents with DS and better meet the needs of families. Due to the body fat distribution and adiposity for children and adolescents with DS differing from the general population, future studies should aim to develop standard methods to accurately measure body fat for children and adolescents with DS to assess their risk for obesity. Recommendations to prevent or address obesity for children and adolescents with DS are parental support for physical activity

and healthy eating. In addition, teachers and educators are advised to provide time for recess and nonstructured physical activity (Wechsler et al., 2004).

Furthermore, the IEP for children and adolescents with DS should be taken into account regarding nutrition. The IEP should highlight weight management of children and adolescents with DS if necessary and include texture modifications authorized by a licensed physician (National Food Service Management Institute, 2006). With respect to the community, individuals should avoid stereotypes and labeling of children and adolescents with DS to allow for participation in recreational activities (Barr & Shields, 2011; Rimmer et al., 2007).

Community program staff are recommended to tailor program activities by endorsing activities desirable for children and adolescents with DS such as dance, cheer, or gymnastics. Program staff can also encourage activities where all of the children and adolescents with DS take a turn playing or touching a ball when engaging in physical activity. With regard to health professionals, shared-decision making is encouraged to include families when considering prevention and treatment options regarding obesity to promote the health outcomes of children and adolescents with DS. Lastly, for researchers, the ICF-CY can be a useful framework for investigating factors affecting health outcomes and quality of life to establish a care-coordinated plan to address obesity for children and adolescents with DS.

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APPENDICES

Appendix A

Table A1 Definitions of ICF-CY Categories and Identifiers

Activities and Participation	Activity is the execution of a task or action by an individual. Participation is involvement in a life situation. Activity limitations are difficulties an individual may have in executing activities. Participation restrictions are problems an individual may experience in involvement in life situations.
d 9201 Sports	Engaging in competitive and informal or formally organized games or athletic events, performed alone or in a group, such as bowling, gymnastics or soccer.
d 5701 Managing diet and fitness	Caring for oneself by being aware of the need and by selecting and consuming nutritious foods and maintaining physical fitness.
d 4401 Grasping	Using one or both hands to seize and hold something, such as when grasping a tool or a door knob.
d 7602 Sibling relationships	Creating and maintaining a brotherly or sisterly relationship with a person who shares one or both parents by birth, adoption or marriage.
Environmental Factors	
e 585 Education and training services	Administrative control and monitoring mechanisms that govern the delivery of education programs, such as systems for the implementation of policies and standards that determine eligibility for public or private education and special needs-based programs; local, regional or national boards of education or other authoritative bodies that govern features of the education systems, including curricula, size of classes, numbers of schools in a region, fees and subsidies, special meal programs and after-school care services.
e 320 Friends	Individuals who are close and ongoing participants in relationships characterized by trust and mutual support.
e 310 Immediate family	Individuals related by birth, marriage or other relationship recognized by the culture as immediate family, such as spouses, partners, parents, siblings, children, foster parents, adoptive parents and grandparents.
e 355 Health professionals	All service providers working within the context of the health system, such as doctors, nurses, physiotherapists, occupational therapists, speech therapists, audiologists, orthotist-prosthetists, medical social workers.
Body Functions	
b 2800 Generalized pain	Sensation of unpleasant feeling indicating potential or actual damage to some body structure felt all over, or throughout the body.
b 1471 Quality of psychomotor functions	Mental functions that produce nonverbal behavior in the proper sequence and character of its subcomponents, such as hand and eye coordination, or gait.

b 1400 Sustaining attention	Mental functions that produce concentration for the period of time required.
b 1442 Retrieval and processing of memory	Specific mental functions of recalling information stored in long-term memory and bringing it into awareness.
b 530 Weight maintenance functions	Functions of maintaining appropriate body weight, including weight gain during the developmental period. Inclusions: functions of maintenance of acceptable Body Mass Index (BMI); and impairments such as underweight, cachexia, wasting, overweight, emaciation and such as in primary and secondary obesity.
Personal Factors	
Food aversions or textural issues	Child avoids certain foods due to texture or just being a picky eater.
Only exercises if interested	Child will engage in physical activity only if the activity is desirable to them.

Appendix B

Food Behavior Checklist

ID: _____ Date: _____ BF Classification: _____

Q1. During the past week, did your child eat fruits as snacks?
- Yes
- No

Q1A. If yes, how many days per week?
- 1-3 days
- 4-6 days
- Every day

Q2. During the past week, did your child eat vegetables as snacks?
- Yes
- No

Q2A. If yes, how many days per week?
- 1-3 days
- 4-6 days
- Every day

Q3. During the past week, did your child drink 100% pure juice?
- Yes
- No

Q3A. If yes, how many days per week?
- 1-3 days
- 4-6 days
- Every day

Q4. During the past week, did your child drink sport drinks?
- Yes
- No

Q4A. If yes, how many days per week?
- 1-3 days
- 4-6 days
- Every day

Q5. During the past week, did your child drink punch (e.g. Hi-C, Tang, Caprisun, etc)?
- Yes
- No

Q5A. If yes, how many days per week?
- 1-3 days
- 4-6 days
- Every day

Q6. During the past week, did your child have citrus fruit or citrus juice (grapefruit, orange juice, lemon juice, etc)?
- Yes
- No

Q6A. If yes, how many days per week?
- 1-3 days
- 4-6 days
- Every day

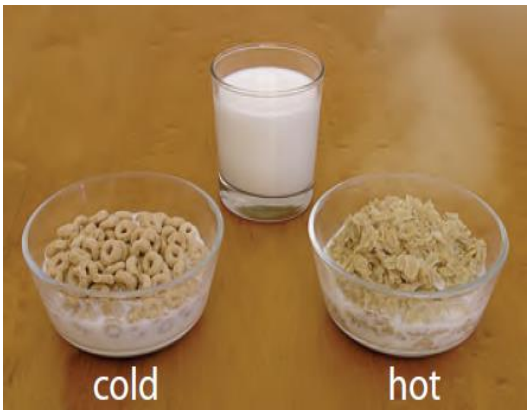
Q7. During the past week, did your child drink carbonated drinks or soda?
- Yes
- No

Q7A. If yes, how many days per week?
- 1-3 days
- 4-6 days
- Every day

Q8. During the past week, did your child drink milk or use milk on cereal during the past week?
- Yes
- No

Q8A. If yes, what kind of milk?
- Whole milk
- 2% milk
- Skim milk
- Other _____

Q8B. If yes, how many days per week?
- 1-3 days
- 4-6 days
- Every day



Q9. During the past week, did your child eat more than one kind of fruit each day?
- Yes
- No, does not eat fruit
- No, only eats one kind of fruit each day

Q9A. If yes, how many days per week?
- 1-3 days
- 4-6 days
- Every day

Q10. Fruit: During the past week, how much did your child eat each day?
None
½ cup
1 cup
1 ½ cup
2 cups
2 ½ cups
3 cups or more

Q11. Vegetables: During the past week, how much did your child eat each day?
None
½ cup
1 cup
1 ½ cup
2 cups
2 ½ cups
3 cups or more

○ none ○ 1/2 cup ○ 1 cup ○ 1 1/2 cups ○ 2 cups ○ 2 1/2 cups ○ 3 cups or more

Q12. During the past week, did your child eat 2 or more vegetables at their main meal?
- Yes
- No

Q12A. If yes, how many days per week?
- 1-3 days
- 4-6 days
- Every day

Q13. During the past week, did your child eat chicken?
- Yes
- No

Q13A. If yes, was it skinless?
- Yes
- No

Q14. During the past week, did your child eat fried foods?
- Yes
- No

Q14A. If yes, how many days per week?
- 1-3 days
- 4-6 days
- Every day

Q15. Do you read nutritional labels when food shopping?
- No
- Yes, sometimes
- Yes, always

Q16. Do you have sufficient nutritious food to last a whole month?

- No
- Yes, sometimes
- Yes, always

Q17. On a scale of 1-10, with 1 (poor) to 10 (excellent):

	1	2	3	4	5	6	7	8	9	10
How would you rate the quality of your child's eating habits?										

Appendix C

Patient-Reported Outcome Measures Information System Physical Activity Short Form

PROMIS Parent Proxy Item Bank v1.0 - Physical Activity – Short Form 8a

Physical Activity – Short Form 8a

Please respond to each question or statement by marking one box per row.

	In the past 7 days…	**No days**	**1 day**	**2-3 days**	**4-5 days**	**6-7 days**
PAC_M_009_PXR1	How many days did your child exercise or play so hard that his/her body got tired?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
PAC_M_105_PXR1	How many days did your child exercise really hard for 10 minutes or more?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
PAC_M_002_PXR1	How many days did your child exercise so much that he/she breathed hard?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
PAC_M_008_PXR1	How many days was your child so physically active that he/she sweated?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
PAC_M_010_PXR1	How many days did your child exercise or play so hard that his/her muscles burned?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
PAC_M_011_PXR1	How many days did your child exercise or play so hard that he/she felt tired?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
PAC_M_114_PXR1	How many days was your child physically active for 10 minutes or more?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
PAC_M_134_PXR1	How many days did your child run for 10 minutes or more?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

5 May 2016

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Appendix D

World Health Organization Disability Assessment Schedule 2.0

ID: _____ Date: _____ BF Classification: _____

Please score the following items from 0 to 4 concerning your child:

0= No Difficulty

1= Mild Difficulty

2= Moderate Difficulty

3= Severe Difficulty

4= Extreme Difficulty or Cannot Do

Understanding and Communicating: **Score:**

D1.1 Concentrating on doing something for ten minutes?

D1.2 Remembering to do important things?

D1.3 Analyzing and finding solutions to problems in day-to-day life?

D1.4 Learning a new task, for example, learning how to get to a new place?

D1.5 Generally understanding what people say?

D1.6 Starting and maintaining a conversation?

Getting Around: **Score:**

D2.1 Standing for long periods such as 30 minutes?

D2.2 Standing up from sitting down?

D2.3 Moving around inside your home?

D2.4 Getting out of your home?

D2.5 Walking a long distance such as a kilometer [or equivalent]?

Self-care: **Score:**

D3.1 Washing their whole body?

D3.2 Getting dressed?

D3.3 Eating?

D3.4 Staying by his/her self for a few days?

Getting Along with People: **Score:**

D4.1 Dealing with people they do not know?

D4. 2 Maintaining a friendship?

D4.3 Getting along with people who are close to them?

D4.4 Making new friends?

Life Activities: **Score:**

D5.1 Taking care of household responsibilities?

D5.2 Doing most important household tasks well?

D5.3 Getting all the household work done that they needed to do?

D5.4 Getting their household work done as quickly as they needed?

D5.5 Their day-to-day work/school?

D5.6 Doing their most important work/school tasks well?

D5.7 Getting all the work done that they need to do?

D5.8 Getting their work done as quickly as needed?

Participation in Society: **Score:**

D6.1 How much of a problem did they have in joining in community activities (for example, festivities, religious or other activities) in the same way as anyone else can?

D6.2 How much of a problem did they have because of barriers or hindrances

in the world around them?

D6.3 How much of a problem did they have living with dignity because of the attitudes and actions of others?

D6.4 How much time did they spend on their health condition, or its consequences?

D6.5 How much have they been emotionally affected by their health condition?

D6.6 How much has their health been a drain on financial resources of you and your family?

D6.7 How much of a problem did your family have because of their health problems?

D6.8 How much of a problem did they have in doing things by his/her self for relaxation or pleasure?

Number of Days:

H1. Overall, in the past 30 days, how many days were these difficulties present?

H2. In the past 30 days, for how many days were they totally unable to carry out their usual activities or work because of any health condition?

H3. In the past 30 days, not counting the days that they were totally unable, for how many days did they cut back or reduce their usual activities or work because of any health condition?

Appendix E

ICF-CY Semi-Structured Interview Guide for Parent Participants

ID: _____ Date: _____ BF Classification: _____

SOCIODEMOGRAPHIC FACTORS:

1. What race does your child identify with?
    a) White or Caucasian
    b) Black or African American
    c) American Indian or Alaska Native
    d) Asian
    e) Native Hawaiian or Other Pacific Islander
    f) Multiracial
    g) Other _____
2. How old is your child?
3. What county does your family reside in?
4. What grade in school is your child in?

BODY FUNCTIONS:

- *Attention, memory*
    - Physical activity
        - Do you think how your child can pay attention or remember things helps or makes it hard for your child to be physically active? If so, how?
    - Nutrition
        - Do you think how your child can pay attention or remember things helps or makes it hard for your child to eat healthy? If so, how?

- *Psychomotor functions*

    - Physical activity
        - Do you think when your child moves and thinks at the same time, it helps or makes it hard for your child to be active? If so, how?

- *Emotional functions*
    - Physical activity
        - How does your child feel when they exercise? Does this feeling help or make it hard for your child to exercise? If so, how?
    - Nutrition
        - How does your child feel when they eat healthy? Does this feeling help or make it hard for your child to eat healthy? If so, how?
- *Sensation of pain*
    - Physical activity
        - Does your child feel pain when exercising? If so, where on their body does your child feel the pain when exercising?
    - Nutrition
        - Does your child feel pain when trying to eat healthy? If so, how?

BODY STRUCTURES:

- *Structures related to movement*
    - Physical activity
        - Are there any parts of your child's body that make it hard for your child to be physically active? If so, what are they?
    - Nutrition
        - Are there any parts of your child's body that make it hard for your child to eat healthy? If so, what are they?

ACTIVITIES AND PARTICIPATION:

- *Mobility*
    - Physical activity
        - Does picking up or grasping things help or make it hard for your child to be physically active? If so, how?
    - Nutrition
        - Does picking up or grasping things help or make it hard for your child to eat healthy? If so, how?

- *Self-care*
    - Is your child able to dress his/herself? If so, how?
    - Can your child eat or drink by his/herself? If so, how?
    - Is your child able to manage his/her own diet? If so, how?
    - Is your child able to manage his/her own fitness? If so, how?

- *Domestic life*
    - Is your child able to prepare meals for his/herself? If so, how?
    - Can your child do housework or chores by his/herself? If so, how?

- *Interpersonal interactions and relationships*
    - Who are the people who are important to your child?
    - Do these people help or make it hard for your child to be physically active? If so, how?
    - Do these people help or make it hard for your child to eat healthy? If so, how?

- *Major life areas*

  Education

  - Physical activity
    - Does school help or make it hard for your child to be physically active? If so, how?
  - Nutrition
    - Does school help or make it hard for your child to eat healthy? If so, how?

- *Community, social and civic life*

  Community

  - Physical activity
    - Does your community help or make it hard for your child to be physically active? If so, how?
  - Nutrition
    - Does your community help or make it hard for your child to eat healthy? If so, how?

ENVIRONMENTAL FACTORS:

- *Products and technology*
  - Does your child use equipment to help get around? If so, how?
- *Support and relationships*
  - Is your child close with his/her friends? If so, how?
  - Is your child close with your family? If so, how?
  - Is your child close with your doctors? If so, how?

ICF-CY Semi-Structured Interview Guide for DS Participants

ID: _____ Date: _____ BF Classification: _____

WARM UP QUESTIONS:

- Tell me about your hobbies or things you like to do.
    - What do you like to do for fun?
- What is your favorite sport? Why?

BODY FUNCTIONS:

- *Attention, memory*
    - Physical activity
        - Is it easy for you to pay attention when you exercise or play?
        - Can you remember the rules when you exercise or play?
    - Nutrition
        - Can you sit still when you eat?
- *Psychomotor functions*
    - Physical activity
        - When you exercise or play, can you do two things at once?
        - If yes, what two things can you do when you are playing (state activity that child plays)?
- *Emotional functions*
    - Physical activity
        - Do you like to exercise?
        - Does exercising make you happy?
        - How do you feel when you exercise?
    - Nutrition
        - Do you like to eat healthy foods?

        - What are healthy foods?

- *Sensation of pain*
    - Physical activity
        - Do you feel pain when you exercise?
        - Does your body hurt when you exercise?
        - If so, where on your body?
    - Nutrition
        - Do you feel pain when you eat healthy foods?
        - If so, how?

BODY STRUCTURES:

- *Structures related to movement*
    - Physical activity
        - Is there any part of your body that make it hard to exercise?
        - Height, legs, arms, stomach, etc?
    - Nutrition
        - Are there any parts of your body that make it hard to eat healthy?
        - Stomach, mouth, throat, etc?

ACTIVITIES AND PARTICIPATION:

- *Mobility*
    - Physical activity
        - Do you play (name a sport with a ball that child plays)?
        - If so, can you catch the ball?
        - Can you throw the ball?
- *Self-care*

  - Are you able to dress yourself? If so, how?
  - Can you eat or drink by yourself? If so, how?
  - When you are hungry, do you have to ask your parents what to eat? If so, how?
  - When you want to exercise or go outside, do you ask your parents first? If so, how?

- *Domestic life*
  - Can you cook meals by yourself? If so, how?
  - Can you do housework or chores by yourself? If so, how?

- *Interpersonal interactions and relationships*
  - Who are the people who are important to you? Who are the people you love the most?
  - Do these people exercise with you? If so, how?
  - Do these people help you to eat healthy? If so, how?

- *Major life areas*

  Education

  - Physical activity
    - Do you get exercise at school?
    - Is there PE?
    - Is there recess?
  - Nutrition
    - Does school give you fruits and vegetables?

- *Community, social and civic life*

  Community

  - Physical activity
    - Do you exercise in the neighborhood?
    - Do you go to the gym? If so, how?
    - If yes, what do you do?
  - Nutrition

- Are there grocery stores near home?

ENVIRONMENTAL FACTORS:

- *Support and relationships*
    - Are you close with your friends? If so, how?
    - Are you close with your family? If so, how?
    - Are you close with your doctors? If so, how?

Appendix F

Parental Informed Consent

Study Title: Comparing Obesity Risk Factors for Youth with Down Syndrome

Dear Parent or Guardian:

I am Anne Odusanya and a graduate student at Georgia Southern University and I am conducting a study examining factors that make it difficult or easy for youth with Down syndrome to eat healthy and be physically active. If you agree to be part of the project, we will ask you to complete 3 questionnaires and sit down for an interview. It will take 1 hour for you to do this project. In particular, I will be asking you to complete 3 questionnaires: the Food Behavior Checklist (FBC), the Patient-Reported Outcomes Measurement Information System (PROMIS) Physical Activity Short Form and the World Health Organization Disability Assessment Schedule 2.0 (WHODAS 2.0). The FBC contains questions asking for your child's food and drink intake in the past week. The PROMIS Physical Activity Short Form contains 8 questions regarding the frequency of your child's physical activity for in the past week. The WHODAS 2.0 developed by the World Health Organization assesses social traits such as understanding and communicating, getting around, self-care, getting along with people, life activities and participation in society via 35 items relative to your child. The interview questions ask for details about how body structures, body functions, activities and participation, environmental factors and personal factors promote or impede healthy eating and physical activity relative to your child.

Your participation in this study is completely voluntary. The risks from participating in this study are no more than would be encountered in everyday life. However, you may stop participating at any time without any penalty. You may choose to not answer any question(s) if you do not wish to for any reason.

There are benefits associated with this study. The identification of these environmental factors can assist you with reducing your child's risk for obesity by modifying their surroundings to lessen barriers while increasing facilitators for healthy eating and engagement in physical activity in the future.

After completion of **all** portions of the study (questionnaires, interviews, body fat measurements), your family will receive one $20 Walmart gift card in total for participation. Furthermore, the study will further the line of inquiry for health programs for young people with DS.

Again, you do not have to participate in this research and may end your participation at any time by telling the individual collecting the data. However, participants who drop out of at any stage of the study cannot reenter the study at any time. You do not have to answer any questions you do not want to answer. There is no penalty for you deciding not to participate in the study.

Again, your confidentiality will be protected. In order to protect the confidentiality of your information, a code number will be assigned to the transcripts from the interviews, and completed surveys. All data will be collected without revealing any personally identifiable information.

You will answer the survey and interview questions at your family home. No one will see your information or know how you answered the questions. Audio-recordings of interviews will be stored on my password protected computer until transcripts are obtained. At that point, audio-recordings will be permanently deleted from my computer. Transcripts will be stored on investigators and my password

protected computers for a period of seven years. At which time, assuming data are no longer needed for grant writing and publication efforts; transcripts will be deleted permanently from both computers.

If you have any questions or concerns regarding this study at any time, please feel free to contact Anne Odusanya, Doctor of Public Health Candidate in Community Health Behavior and Education and principal investigator or her Research Faculty Advisor Dr. Ashley Walker.

To contact the Office of Research Services and Sponsored Programs for answers to questions about the rights of research participants please email IRB@georgiasouthern.edu or call (912) 478-5465.

You will be given a copy of this consent form to keep for your records. This project has been reviewed and approved by the GSU Institutional Review Board under tracking number H17356.

If you are giving permission for you to participate in the experiment, please sign the form below and return it to the principal investigator as soon as possible. I am asking your permission for you to participate in this study. Thank you very much for your time.

Anne Odusanya, MPH, CPH
Doctor of Public Health Candidate
College of Public Health
Community Heath Behavior and Education
Email: ao01531@georgiasouthern.edu
Phone: 925-323-2987

Ashley Walker, PhD, CHES
Associate Professor
Research Faculty Advisor
Community Health Behavior and Education
Email: awalker@georgiasouthern.edu
Phone: 912-478-2477

_____ _____
Participant Signature Date

I, the undersigned, verify that the above informed consent procedure has been followed.

_____ _____
Investigator Signature Date

Parental Consent- DS Participants Under 18

Study Title: Comparing Obesity Risk Factors Among Youth with Down Syndrome

Dear Parent or Guardian:

I am Anne Odusanya and a graduate student at Georgia Southern University and I am conducting a study examining factors that make it difficult or easy for youth with Down syndrome to eat healthy and be physically active. If you agree to allow your child to be a part of the project, we will take some measurements in our lab and then ask your child some questions. The measurements will see how much muscle and how much body fat your child has. These measurements will involve a machine where we will tape some wires to your child's wrist and ankle and measure the thickness of their skin. After taping the wires to your child, your child will have their body fat measured by the skinfold thickness method. The calf skinfold and triceps skinfold (skin underneath the arm) will be measured using calipers to hold the skinfolds. We will then ask your child some questions about things that make it easy or hard for them to exercise and eat healthy. It will take 1 hour for your child to do this project. There will be two phases for this project. The first phase includes measuring your child's body fat while the second phase consists of interviewing your child at Georgia Southern or a convenient location. The second phase will take place on another day at a convenient location (Georgia Southern campus, the library, your home, etc) based on your child's availability.

The interview questions ask for details about how body structures, body functions, activities and participation, environmental factors and personal factors promote or impede healthy eating and physical activity relative to your child. If you provide permission, your child will have the opportunity to participate in this study.

This study will take approximately 1 hour for your child to participate. Your child's participation in this study is completely voluntary. The risks from participating in this study are no more than would be encountered in everyday life; however, your child will be told that he or she may stop participating at any time without any penalty. Your child may choose to not answer any question(s) he/she does not wish to for any reason. Your child may refuse to participate even if you agree to her/his participation.

There are benefits associated with this study. The identification of these environmental factors can assist you and your child with reducing your child's risk for obesity by modifying their surroundings to lessen barriers while increasing facilitators for healthy eating and engagement in physical activity in the future.

After you and your child complete **all** parts of the study (questionnaires, interviews, body fat measurements), your family will receive one $20 Walmart gift card in total. Furthermore, the study will further the line of inquiry for health programs for young people with DS.

Again, your child does not have to participate in this research and may end their participation at any time by telling the individual collecting the data. However, participants who drop out of at any stage of the study cannot reenter the study at any time. You do not have to answer any questions you do not want to answer. There is no penalty for you deciding not to participate in the study.

Again, your confidentiality will be protected. In order to protect the confidentiality of your information, a code number will be assigned to the transcripts from the interviews, and completed surveys. All data will be collected without revealing any personally identifiable information.

Your child will answer the questions at a convenient location (Georgia Southern campus, the library, your home, etc) based on your child's availability. Your child will also be asked to complete the lab tests at Georgia Southern or a convenient location. No one will see their information or know how they answered the questions. Lab measurements will be stored on investigators and my password protected computers for a period of seven years. Audio-recordings of interviews will be stored on my password protected

computer until transcripts are obtained. At that point, audio-recordings will be permanently deleted from my computer. Transcripts will be stored on investigators and my password protected computers for a period of seven years. At which time, assuming data are no longer needed for grant writing and publication efforts; transcripts will be deleted permanently from both computers.

If you have any questions or concerns regarding this study at any time, please feel free to contact Anne Odusanya, Doctor of Public Health Candidate in Community Health Behavior and Education and principal investigator or her Research Faculty Advisor Dr. Ashley Walker.

To contact the Office of Research Services and Sponsored Programs for answers to questions about the . rights of research participants please email IRB@georgiasouthern.edu or call (912) 478-5465.

You will be given a copy of this consent form to keep for your records. This project has been reviewed and approved by the GSU Institutional Review Board under tracking number H17356.

If you are giving permission for your child to participate in the experiment, please sign the form below and return it to the principal investigator as soon as possible. I am asking your permission for your child to participate in this study, and will provide your child with an informed consent letter/verbal description before enrolling them in this study. Thank you very much for your time.

Anne Odusanya, MPH, CPH
Doctor of Public Health Candidate
College of Public Health
Community Heath Behavior and Education
Email: ao01531@georgiasouthern.edu
Phone: 925-323-2987

Ashley Walker, PhD, CHES
Associate Professor
Research Faculty Advisor
Community Health Behavior and Education
Email: awalker@georgiasouthern.edu
Phone: 912-478-2477

Investigator's Signature_____

Child's Name: _____

Parent or Guardian's Signature: _____

Date: _____

Minor Assent- DS Participants Under 18

Hello,

I am Anne Odusanya and I am a graduate student at Georgia Southern University and I am conducting a study called looking at things that affect the health of young people with Down Syndrome.

If you agree to be part of the project, we will take some measurements in our lab and then ask you some questions. The measurements will see how much muscle and how much body fat you have. These measurements will involve a machine where we will tape some wires to your wrist and ankle and measuring the thickness of your skin. We will then as you some questions about things that make it easy or hard for you to exercise and eat healthy. It will take 1 hour for you to do this project. There will be two parts for this project. The first part is the measurements while the second part is the questions. The second part will be on another day at a convenient location (Georgia Southern campus, the library, your home, etc).

You do not have to do this project. You can stop whenever you want. If you do not want to get your body fat measured or answer any questions, you can stop. It is ok, nothing bad will happen. You can refuse to do the project even if your parents say you can.

No one will see the answers to the questions that I ask you. All of the answers that you give me will be kept in a safe location, and only I or others working on the project will see your answers. We are not going to put your name on your answers, so no one will know which answers were yours.

When answering the questions, you will be asked questions about your health. If for some reason the questions make you feel uncomfortable, you may stop answering them. If for some reason you feel that you need to talk to someone about this further, you may contact a low-cost community based counseling service: Pineland at 912-764-6906.

If you choose to participate, you will answer the questions and we will take the measurements at Georgia Southern or a convenient location. No one will see your information or know how you answered the questions. In order to be sure no one sees your information, a number and not a name will appear on records. All of the interviews will be audio recorded and downloaded to safe place and only the researchers will see them. All of your answers will be collected without revealing anyone's names. All the information will be stored a password-protected computer at Georgia Southern University for a period of seven years. After seven years, all the information will be deleted permanently from the computers. The study will help in making health programs for young people with DS.

After you and your parent finish **all** parts of the study (papers, questions, measurements), your family will receive one gift card in total.

If you or your parent/guardian has any questions about this form or the project, please call or email on of us below.

By signing on the line below, you are saying that you understand what you just read or what was read and explained to you.

You will be given a copy of this form to keep for your records. This project has been reviewed and approved by the GSU Institutional Review Board under tracking number H17356.

Thank you!

Anne Odusanya, MPH, CPH
Doctor of Public Health Candidate
College of Public Health
Community Heath Behavior and Education
Email: ao01531@georgiasouthern.edu
Phone: 925-323-2987

Ashley Walker, PhD, CHES
Associate Professor
Research Faculty Advisor
Community Health Behavior and Education
Email: awalker@georgiasouthern.edu
Phone: 912-478-2477

If you understand the information above and want to do the project, please sign your name on the line below:

_____ _____
Minor Signature Date

I, the undersigned, verify that the above informed consent procedure has been followed.

_____ _____
Investigator Signature Date

Informed Consent – DS Adults

Study Title: Comparing Obesity Risk Factors for Youth with Down Syndrome

Hello,

I am Anne Odusanya and I am a student at Georgia Southern University.

If you want to be part of the project, we will take measure how thick your skin is in our lab and ask you some questions. The measures I take will see how much muscle and how much body fat you have. These measures will involve a machine where we will tape some wires to your wrist and ankle and measure how thick your skin is. We will then ask you some questions about things that make it easy or hard for you to exercise and eat healthy. It will take 1 hour for you to do all of this. The measures will be on the first day and the questions will be on another day at an easy location for you (Georgia Southern campus, the library, your home, etc) based on your convenience.

You do not have to be a part of this project. You can stop if you want to. If you do want to stop, it is ok, nothing bad will happen. You can say you do not want to do the project even if your parents say you can.

No one will see the answers to the questions that I ask you. All of the answers that you give me will be kept in a safe, and only I or others working on the project will see your answers. We are not going to put your name on your answers, so no one will know which answers were yours.

When you answer the questions, you will be asked questions about your health. If you feel the questions make you feel uncomfortable, you can stop answering them. If you feel that you need to talk to someone about this, you can call Pineland at 912-764-6906. The study will help young people with DS.

After you and your parent finish **all** parts of the study (papers, questions, measures), your family will get one $20 Walmart gift card in total.

Again, you do not have to be a part of this project and you can stop being part of the project at any time by telling me. If you want to stop being a part of this project, then you can't be a part of the project again. You do not have to answer any questions you do not want to answer. Nothing bad will happen if you want to stop being part of the project.

Again, your answers and measures will be safe. To keep your answers and measures safe, number will be written on your answers and measures.

You will answer the questions and have your measures taken in the lab at Georgia Southern or a convenient location. No one will see your answers and measures. Your answers and measures will be kept safe on safe computers for 7 years. The taping of your answers will be kept on my safe computer until I type your answers. At that point, I will cancel the typed answers from my safe computer. The typed answers will be safe on my computer for 7 years. If your answers and measures are no longer needed for project papers; your answers and measures will be cancelled.

If you have any questions about this project at any time, please feel free to reach Anne Odusanya or Dr. Ashley Walker.

To reach the project office for answers to questions about your rights for being part of the project, please email IRB@georgiasouthern.edu or call (912) 478-5465.

You will be given a copy of this form for you to keep. This project has been studied and accepted by the GSU Institutional Review Board under tracking number H17356.

If you are agreeing to be a part of this project, please sign the form below and return it to me as soon as you can. I am asking your permission for you to be a part of this project. Thank you very much for your time.

Anne Odusanya, MPH, CPH
Doctor of Public Health Candidate
College of Public Health
Community Heath Behavior and Education
Email: ao01531@georgiasouthern.edu
Phone: 925-323-2987

Ashley Walker, PhD, CHES
Associate Professor
Research Faculty Advisor
Community Health Behavior and Education
Email: awalker@georgiasouthern.edu
Phone: 912-478-2477

Investigator's Signature_____

Your signature: _____

Date: _____

Appendix G

Institutional Review Board Approval Letter

Georgia Southern University
Office of Research Services & Sponsored Programs

Institutional Review Board (IRB)

Phone: 912-478-5465
Fax: 912-478-0719
IRB@GeorgiaSouthern.edu
Veazey Hall 3000
PO Box 8005
Statesboro, GA 30460

To: Odusanay, Anne; Walker, Ashley; Colquitt, Gavin; Dobson, John; Vogel, Robert

From: Office of Research Services and Sponsored Programs

Initial Approval Date: 6/22/2017

Expiration Date: 5/31/2018

Subject: Status of Application for Approval to Utilize Human Subjects in Research – **Full Board Process**

After a review of your proposed research project numbered **H17356** and titled **"Comparing Obesity Risk Factors Among Youth with Down Syndrome"** it appears that (1) the research subjects are at minimal risk, (2) appropriate safeguards are planned, and (3) the research activities involve only procedures which are allowable. You are authorized to enroll up to a maximum of 60 subjects.

Therefore, as authorized in the Federal Policy for the Protection of Human Subjects, I am pleased to notify you that the Institutional Review Board has approved your proposed research. **Description: The purpose of this study is to assess the environmental factors that influence healthy eating and physical activity among adolescents with Down syndrome in Southeast Georgia to identify aspects of the environment that can be modified to reduce the risk of obesity for this population.**

If at the end of this approval period there have been no changes to the research protocol; you may request an extension of the approval period. In the interim, please provide the IRB with any information concerning any significant adverse event, **whether or not it is believed to be related to the study**, within five working days of the event. In addition, if a change or modification of the approved methodology becomes necessary, you must notify the IRB Coordinator **prior** to initiating any such changes or modifications. At that time, an amended application for IRB approval may be submitted. Upon completion of your data collection, you are required to complete a *Research Study Termination* form to notify the IRB Coordinator, so your file may be closed.

Sincerely,

Eleanor Haynes
Compliance Officer