

MOTHERS' PERCEPTIONS OF PHYSICAL ACTIVITY HABITS AND FEEDING
PATTERNS BETWEEN SIBLINGS WITH AND WITHOUT
DOWN SYNDROME

A DISSERTATION

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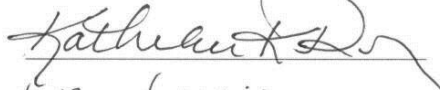
To the Dean of the Graduate School:

I am submitting herewith a dissertation written by Kelly Allums Featherston entitled "Mothers' Perceptions of Physical Activity Habits and Feeding Patterns between Siblings with and without Down Syndrome." I have examined this dissertation for form and content and recommend that it be accepted in partial fulfillment of the requirement for the degree of Doctor of Philosophy with a major in Kinesiology.



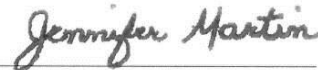
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We have read this dissertation and recommend its acceptance:



Department Chair

Accepted:



Dean of the Graduate School

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ABSTRACT

KELLY ALLUMS FEATHERSTON

MOTHERS' PERCEPTIONS OF PHYSICAL ACTIVITY HABITS AND FEEDING PATTERNS BETWEEN SIBLINGS WITH AND WITHOUT DOWN SYNDROME

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Children with Down syndrome are disproportionately obese compared to the general population and their siblings; however, a clear understanding of the familial aggregation of influential factors (i.e., physical activity habits, weight concerns, child feeding patterns, and mothers' eating behaviors) have yet to be investigated between siblings with and without Down syndrome. The purpose of this study was twofold. First, to investigate the relationship between mothers' physical activity levels, past eating behaviors, and child feeding practices on the physical activity levels and weight concerns among their children with and without Down syndrome. Second, to further explore these practices between siblings and investigate how having a child with Down syndrome may impact these practices and the family.

Mothers who have children with and without Down syndrome were recruited to participate in electronic surveys (n = 51), interviews (n = 3), and focus groups (n = 6).

Correlation analyses were used to examine the relationship between physical activity levels, weight concerns, child feeding practices, and parents' eating behaviors.

Qualitative data were used to further explore these topics; data were transcribed and then

analyzed using thematic analysis. The physical activity habits of siblings with and without Down syndrome were associated with parents' habits and similar between siblings. Mothers' physical activity habits and past eating behaviors were not associated with child weight concerns, but were positively associated with some child feeding practices. Mothers appeared to be more concerned about the weight of their children with Down syndrome and more likely to impose certain feeding practices based on that concern; however, concerns stemmed from weight rather than presence of Down syndrome. Quality time as a family was also considered important and this time could be spent being physically active or encouraging health eating habits. The familial aggregation of physical activity habits and eating patterns between siblings with and without Down syndrome must continue to be explored.

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CHAPTER I

INTRODUCTION

An essential component of a health promoting household environment is a well-functioning family system. Thus, efforts to engage families to spend time together, communicate with each other, and develop strong family bonds are likely to promote self-esteem and, thereby, physical activity [and healthy feeding patterns]. (Ornelas, Perreira, & Ayala, 2007, p. 8)

Obesity among children and youth within the United States continues to be a crucial topic, examined by researchers from numerous disciplines (Chumlea & Cronk, 1981; Neumark-Sztainer, Story, Hannan, Stat, & Rex, 2003; Ogden, Carroll, Curtin, Lamb, & Flegal, 2010). The physiological and psychological comorbidities of obesity have increased the concern for the rising obesity rates. Recently the environment in which many youth in the United States are developing in has been termed an ‘obesogenic’ environment (Golan & Crow, 2004; Yao & Roberts, 2001). An obesogenic environment is one that promotes obesity rather than ameliorating or supporting preventive factors; a setting which promotes energy consumption and discourages energy expenditure. Significant contributors to the development of this environment among youth today are low physical activity levels (Ornelas et al., 2007), irregular eating habits (Ventura & Birch, 2008), and other health-related parenting practices (Davison & Birch, 2001; Joyce & Zimmer-Gembeck, 2009) which are directly or overtly modeled and encouraged by parents or caregivers.

Physical inactivity among youth and adults is continually on the rise in the United States (Sallis, Prochaska, & Taylor, 2000) which provides fuel to the ever-present obesogenic nature of our society. Along with decreased daily physical activity levels, another contributor to the declining health of our nation's youth are the manner in which foods are initially presented to children (Neumark-Sztainer, Story et al., 2003). Physical activity habits, motivation to be consistently active, eating patterns, and the ability to recognize hunger satiation are influenced during the formative years by parenting practices and are strongly correlated with obesity (Bauer, Nelson, Boutelle, & Neumark-Sztainer, 2008; Johnson & Birch, 1994; Kalakanis, Goldfield, Paluch, & Epstein, 2001). Physical activity habits are often shaped and observed by the behaviors of siblings and parents, while eating patterns are largely influenced through parent feeding practices. The intergenerational transfer of physical activity habits and eating patterns are considered a major contributor to the familial aggregation of obesity patterns (Johnson & Birch, 1994; Wardle, Sanderson, Guthrie, Rapoport, & Plomin, 2002).

Children with disabilities, specifically Down syndrome, are also developing in these obesogenic environments and experience disproportionately high levels of obesity and physical inactivity compared to their peers without Down syndrome (Rubin, Rimmer, Chicoine, Braddock, & McGuire, 1998; Whitt-Glover, O'Neill, & Stettler, 2006). Certain physiological and behavioral factors that are specific to Down syndrome have been associated with causation of this additional weight. These factors include, congenital heart disease (Cronk et al., 1988), low resting metabolic rate (Luke, Sutton, Schoeller, &

Roizen, 1996), hypothyroidism (Carr, 1995) lack of motivation (Meneer, 2007) and stubbornness to participate in activities (Medlen, 2002), and the fact that frequency of participation in moderate to vigorous physical activity is lower compared to their peers or siblings without disabilities (Murray & Ryan-Krause, 2010; Rimmer, Yamaki, Lowry, Wang, & Vogel, 2010; Whitt-Glover, O'Neill, & Stettler, 2006).

Children with Down syndrome are also prone to difficulties with oral-motor development. This may lead to delays in the progression of eating solid foods and ultimately independent feeding (Medlen, 2002). Delays in feeding independence coupled with a high tendency towards obesity has been associated with the high restriction and control used in the feeding practices of mothers who have a child with Down syndrome (O'Neill, Shults, Stallings, & Stettler, 2005). A combination of environmental factors such as physical inactivity and eating issues along with secondary disabling conditions likely advance children with Down syndrome to higher rates of obesity than what they are genetically predisposed (Grammatikopoulou et al., 2008). However, there is a paucity of evidence to support this statement.

Statement of the Problem

Approximately 1 in 971 children are born with Down syndrome in the United States (Shin et al., 2009) and a disproportionate number are considered to be obese - 30% among children with Down syndrome (Harris, Rosenberg, Jangda, O'Brien, & Gallagher, 2003; Rimmer et al., 2010), compared with 17% among children without Down syndrome (Ogden et al., 2010). For children with Down syndrome, the family can often

be the sole outlet for learning health promoting habits, as few community and after school physical activity or sport programs target children with disabilities (Menear, 2007). Lack of programming opportunities has been associated with low daily physical activity levels (Rimmer et al., 2010; Whitt-Glover et al., 2006; Yamaki Rimmer, Lowry, & Vogel, 2011) and can be considered a contributor to the obesogenic environment. True causation cannot be asserted related to whether the cause of the high tendency toward obesity among children with Down syndrome is related to secondary disabling conditions or the obesogenic environment in which the children develop. Grammatikopoulou et al. (2008) concluded that “Obesity in children with Down Syndrome [*sic*] [DS] increases with age. Although children with DS have a genetic predisposition to become overweight, obesity may worsen beyond genetic expectation as they develop . . . and become more independent” (p. 265). A discussion is thus warranted.

A multitude of health concerns have been associated with Down syndrome yet there is a paucity of literature that has investigated parenting practices related to physical activity and feeding among this population. However, Davison and Birch (2001), have suggested that some parenting strategies related to physical activity or eating may not only be implemented as preventive efforts to eliminate obesity but they may also be a reaction to a child who is already obese. Researchers (e.g., O’Neill et al., 2005; Sharav, & Bowman, 1992; Whitt-Glover et al., 2006) have provided evidence that parent feeding practices differ between siblings with and without Down syndrome, and that significant differences in physical activity levels exist between siblings. However, specific evidence

has not been documented which investigates how parenting practices relate to the physical activity levels between siblings with and without Down syndrome.

Previous researchers targeting parents who have children with and without Down syndrome, have reported mixed findings related to the impact that a child with a disability may have on the family (Cuskelly & Gunn, 2006; O'Neill et al., 2005). One disadvantage which has been documented is the lack of quality time spent together due to additional time spent with the child with special needs (O'Neill et al., 2005). While other researchers (Cuskelly & Gunn, 2006) have documented few negative family associations related to having a child with Down syndrome. Promoting and participating in physical activity and other health enhancing activities as a family has been linked to increased quality time and parent-child bonding (Bauer, Neumark-Sztainer, Fulkerson, Hannan, & Story, 2011; Flett, Moore, Pfeiffer, Belonga, & Navarre, 2010; Neumark-Sztainer, 2007; Ransdell, Dratt, Kennedy, O'Neill, & DeVoe, 2001). However, findings such as these have yet to be investigated among families who have a child with Down syndrome.

Ample evidence-based guidance for parents of children with Down syndrome exists regarding the physiological anomalies and behavioral tendencies that are typical to this population; however, minimal information is available related to how the family as a unit can encourage healthy lifestyle habits (e.g., physical activity and healthy eating) in spite of these factors that predispose one towards obesity. Parents' lifestyle habits, specifically related to physical activity and eating patterns have been documented to be strongly associated with those of their children (Birch & Fisher, 1998; Epstein, Wing, Penner, &

Kress, 1985; Epstein, McCurley, Wing, & Valoski, 1990; Joyce & Zimmer-Gembeck, 2009; Ornelas et al., 2007; Wright, Wilson, Griffin, & Evans, 2010).

However,

Very little research has been conducted on obesity in children with Down syndrome, the role physical anomalies play in the development of obesity, behavioral and psychosocial aspects that place children at risk for excessive weight gain, or the efficacy of prevent[ing] obesity. . . [among] children with Down syndrome and their families. (Murray & Ryan-Krause, 2010, p. 318)

Thus, the paucity of evidence regarding the development and encouragement of healthy lifestyle habits among this population support the need for such further investigation.

Purpose

The purpose of this study was twofold. First, to investigate the relationship between mothers' physical activity levels, past eating behaviors, and child feeding practices on the physical activity levels and weight concerns among their children with and without Down syndrome. Second, to further explore these practices between siblings and investigate how having a child with Down syndrome may impact these practices and the family.

Overview of Method

What is most fundamental is the research question - research methods should follow research questions in a way that offers the best chance to obtain useful answers. Many research questions and combinations of questions are best and most fully answered through mixed research solutions. (Johnson & Onwuegbuzie, 2004, pp.17-18)

The use of a mixed approach design (Creswell & Plano Clark, 2011; Lieber, 2009; Saks & Allsop, 2007) during data collection allows full exploration of a topic. In this

study, the basic premise was to explore parenting practices related to physical activity and child feeding practices. These practices have been investigated separately, but have not been fully explored among families who have children with and without Down syndrome. As many aspects of this study have yet to be investigated, using a mixed approach that combines both quantitative and qualitative data collections techniques is thus warranted to allow the opportunity to gather data in rich detail. Data collection has been separated into two sections, Phase I and Phase II.

Phase I

Introduction. Data collection for Phase I included the use of surveys to obtain information from participants. Surveys were electronically distributed to mothers and fathers with multiple children, including one with Down syndrome. Participants were recruited from several Down syndrome parenting discussion boards and online subscriber lists. Only completed surveys from mothers were analyzed ($N = 51$), as only a small number of fathers participated ($n = 2$).

Hypotheses. The hypotheses for Phase I of this investigation were as follows: (a) There will be associations between the self-reported physical activity levels of mothers, children, and the family (Kalakanis et al., 2001; Moore et al., 1991); (b) There will be a significant relationship between mothers' self-reported physical activity levels and concern for their children's weight; (c) There will be a significant relationship between mothers' self-reported eating behaviors (i.e., cognitive restraint, uncontrolled eating, and emotional eating) and concern for their children's weight (Johannsen, Johannsen, &

Specker, 2006); (d) There will be a significant relationship between self-reported child feeding practices and concern for their children's weight (Baughcum, Burklow, Deeks, Powers, & Whitaker, 1998, Faith et al., 2004; Keller, Pietrobelli, Johnson, & Faith, 2006); and (e) Mothers will exhibit more restriction, pressure to eat, monitor eating, and have more weight concerns toward their child with Down syndrome compared to their child without Down syndrome (Johannsen et al., 2006; O'Neill et al., 2005).

Phase II

Introduction. Data collection for Phase II consisted of researcher-led focus groups and one-on-one interviews which were audio recorded and later transcribed, along with reflexive journals, analytical memos, and member checks. Participants for Phase II were purposefully selected from Phase I participants based on interest. Geographical proximity to focus group and interview session locations was not a concern, as sessions were completed in person and through the free online telephony service, Skype.

Research questions. The attention of qualitative research methods, specifically interviews focus and groups, is to point out the unknown or to provide clarification for a problem (Krueger, 1994). Thus, the use of hypotheses for Phase II of this study would be inappropriate. The second purpose of this study was guided by four research questions: (a) If physical activity habits or feeding practice differences exist between siblings, to what do mothers attribute these differences; (b) How do mothers feel about the potential for the encouragement of lifestyle habits (physical activity and healthy eating) related to the promotion of quality family interaction (family connectedness); (c) What, if any, are

the mothers' perceptions of the impact that having a child with Down syndrome has on the health of the family; (d) How do perceptions of the importance of the healthy lifestyle habits align with actual lifestyle habits?

Conceptual Filter

Families have been determined to be a powerful medium in which children can learn and develop lifelong habits, including those related to physical activity and eating (Epstein, Wing, Koeske, & Valoski, 1986). Habits learned from family members can be positive or negative and often interactionary (Bandura, 1978). Bandura's (1977) Social Cognitive Theory (SCT) has been used to explore how human behaviors are impacted and encouraged reciprocally; including those related to physical activity, eating patterns, and the family (Neumark-Sztainer, Story, et al., 2003; Ransdell et al., 2001). Bandura's SCT along with its basic analytic principle of reciprocal determinism (1978) describes behavior as a reciprocal process influenced by the interacting factors of the external environment (i.e., outside settings, surroundings), cognitive processes (i.e., the internal and cognitive events that affect perception), and behavior (past and current behaviors or experiences of the individual; Bandura, 1974; 1986).

This current investigation builds on Bandura's work as a means of expanding reciprocal determinism. In the past, reciprocal determinism has been used to describe the developmental process of behaviors which are associated with a healthy lifestyle (i.e., physical activity habits and healthy eating patterns as influenced by parents; Neumark-Sztainer, Hannan, Story, Croll, & Perry, 2003; Ransdell et al., 2001).

Reciprocal determinism provides a rationale for how an individual's behavior is not only shaped by the immediate environment, but how the environment is shaped by the behavior of that individual (Bandura 1978). Thus, each action is itself a reaction. The foundation for the use of reciprocal determinism within this exploration is that the condition of obesity itself has an impact on parenting techniques related to physical activity habits and feeding patterns, but also that the predisposition to or potential for obesity development among children with and without Down syndrome can be a contributing factor. Through the lens of reciprocal determinism, perceptions of parenting practices from those who have children with and without Down syndrome can be potentially identified as actions or reactions to their previous habits, those of their children, or the environment.

Significance

Several aspects of this study provide a unique outlook on factors that largely contribute to the health of families who have children with and without Down syndrome. Physical activity and child feeding patterns are two factors which can strongly influence the development of obesity and are considered to be largely developed during the formative years (Epstein et al., 1990). In the past, researchers have investigated the development of these patterns individually. However, to more fully understand the intergenerational transfer of this condition these patterns need to be investigated simultaneously. Specifically among populations who are genetically predisposed to high levels of obesity (i.e., children with Down syndrome), comparisons need to be made

between siblings and their parents. This present investigation used a mixed approach design to do just that.

Data collected through cross-sectional means, does not have the potential to provide conclusive evidence related to causation, as data collected at single time periods can only lead to associations. However, as new topics emerge, in depth information must be ascertained in order to acquire a wealth of knowledge to assist practitioners and to lead to the development of effective interventions. This is the basis for using a mixed approach design (i.e., questionnaires, focus groups, and interview sessions) to explore the physical activity patterns and child feeding techniques used by mothers on their children with and without Down syndrome. A clear understanding of this intergenerational transfer of habits which so emphatically influences the health of children is warranted.

Families who have children with Down syndrome have asserted that they experience high levels of stress and lack quality time spent with their families (Mulroy, Robertson, Aiberti, Leonard, & Bower, 2008), in addition to low physical activity levels and unhealthy feeding habits. To date, this investigation is the first of its kind to not only explore physical activity habits and child feeding pattern differences between siblings with and without Down syndrome, but also to explore the role of the family. Discussions during focus group sessions targeted how having a child with Down syndrome impacts the health of the family and whether physical activity participation and meal planning could be a potential form of family connectedness. Results from this investigation have

the potential to uniquely and simultaneously impact the physical and psychosocial well-being of families who have children with and without Down syndrome.

Potential results from this study offer guidance to practitioners in the field in a way that no other investigation has to date. The nature of focus groups and interview sessions allow for discussion content to be shifted based on group dynamics, thus there is the potential to explore factors that have yet to be identified by practitioners but which truly impact parents and families. The implications for this study are designed to provide a foundation to understand how parenting practices differ between siblings with and without Down syndrome, related to physical activity habits and child feeding practices, and whether having a child with Down syndrome influences the health of the family. The obesogenic environments in which youth are developing have led to a health crisis in the United States. Obesity and physical inactivity levels continue to rise and efforts to explore these interactions within the family have the potential to shed light on the intergenerational transmission of obesity, and the impact this familial aggregation has on children with and without Down syndrome.

Definition of Terms

In the following section, conceptual and functional definitions of terms are provided that are used throughout the following literature review:

Down Syndrome: Down syndrome (or Trisomy 21) is considered a genetic chromosomal disorder which has been estimated at approximately 11.8 per 10,000 births born each year in the United States (Shin et al., 2009). Individuals with the condition

have the distinguishable attribute of having an extra partial or complete chromosome 21, for a total of 47 chromosomes. Certain physiological and behavioral characteristics are associated with Down syndrome, up to 300 clinical signs have been identified with some having a higher frequency than others, including but not limited to: mild to moderate intellectual disability; “small teeth, abnormally aligned teeth, furrowing of the tongue, slanting of palpebral fissures, flat occipital area, small ears, a flat nasal bridge, and strabismus [i.e., cross eyed]” (Pueschel et al., 1982, p.171); congenital heart disease; low resting metabolic rate (Cronk et al., 1988; Luke et al., 1996); and lack of motivation and stubbornness (Medlen, 2002).

Eating Habits: “Eating behaviors evolve during the first years of life as biological and behavioral processes directed towards meeting requirements for health and growth” (Savage, Fisher, & Birch, 2007, p. 22). “Parents influence their children’s eating not only through the food they make available to children, but also through their child-feeding strategies, and role modeling of appropriate eating behavior” (Johnson & Birch, 1994, p. 654). Healthy eating habits are characterized by the ability to recognize satiation, self-regulate portion size, and lack of emotional eating; while disorganized eating habits are characterized as the inability to recognize satiation, eating when bored, and eating for reasons other than hunger (Hood et al., 2000; Stunkard & Messick, 1985).

Family Connectedness: “Closeness to mother and/or father, perceived caring by mother and/or father, satisfaction with relationship to mother and/or father, feeling loved and wanted by family members” (Resnick et al., 1997, p. 825). “Family connection has

been consistently related to healthy youth development and a reduced risk for emotional distress, substance use, . . . [and] unhealthy weight control” (Eisenberg, Olson, Neumark-Sztainer, Story, & Bearinger, 2004, p. 792). “The family is an ideal mutually reinforcing environment in which healthy behaviors can be introduced, accepted, and maintained” (Gruber & Haldeman, 2009, p. 2).

Intergenerational Transmission/Familial Aggregation of Obesity: The notion that environmental and familial factors which influence obesity are so strong that they have the potential to counter obesity-related genetic influences (Wardle et al., 2002). The rapid increase in obesity in the last 30 years has led some researchers to believe it is the environment and familial factors, which constitute the transfer of behaviors from one generation to the next. These behaviors are considered to encourage obesity, rather than eliminate it (Agras, Hammer, McNicholas, & Kraemer, 2004).

Obesogenic Environment: An environment that encourages the consumption of excessive energy and discourages energy expenditure, that promotes obesity rather than ameliorating or supporting preventive factors among children and youth, or a setting which promotes energy consumption and discourages energy expenditure (Golan & Crow, 2004; Yao & Roberts, 2001). Obesogenic families are ones in which the ‘mothers and fathers ha[ve] high dietary intake and low physical activity’ (Davison, Francis, & Birch, 2005, p. 1980).

Parent/Child Feeding Patterns/Practices: “[Child] feeding practices have evolved as parental responses to perceived environmental threats to children’s well being” (Savage

et al., 2007, p. 28). Child feeding patterns/practices are considered to be “behavioral strategies parents employ to control what, how much or when their children eat” (Ventura & Birch, 2008, p. 4). Thus, parenting practices have been considered to be “less trait-like and more responsive to context . . . parenting practices may differ across children within the same family depending on the child, age, gender, and weight status” (Ventura & Birch, 2008, p. 4). These behaviors also include, but are not limited to: “pressuring children to eat, using foods as a reward, restricting access to select foods or groups of foods, modeling or use of food to pacify or control” (Baughcum et al., 1998; Ventura & Birch, p.4). Patterns such as these are considered disorganized and can lead to unhealthy eating habits. Feeding practices have been identified in categories, similar to those of parenting styles; categories vary depending on the source but for this discussion will include: emotional feeding, instrumental (reward) feeding, excessive prompting, and restricting food (Wardle, et al., 2002). Parenting practices are related to but distinctly different from parenting styles, in that they are strategies which are used to socialize children (Ventura & Birch, 2008).

Weight Status: The number identified by an individual’s body mass index (BMI) or other measure of body composition and then coded with a weight category equates to their weight status. This can be by estimation of weight status category or an exact measure of weight and height and then converted to a BMI category. Current gender-specific weight status categories are identified as: Children with a BMI above the 95th percentile and adults with a BMI above 30 are considered obese. Children with a

BMI between the 85th to 94th percentile and adults with a BMI between 25-29.9 are considered overweight. Children with a BMI between the 5th to 84th percentile and adults with a BMI between 18.5 to 24.9 are considered healthy weight. Children with a BMI below the 4th percentile and adults with a BMI below 18.5 are considered under weight (Ogden et al., 2010; World Health Organization, 1995).

Summary

The purpose of this present investigation was twofold. First, to investigate the relationship between mothers' physical activity levels, past eating behaviors, and child feeding practices on the physical activity levels and weight concerns among their children with and with Down syndrome. Second, to further explore these practices and investigate how having a child with Down syndrome may impact these practices and the family. Children with Down syndrome have been identified as at-risk for developing obesity at an early age, and sibling differences exist regarding physical activity levels and feeding patterns. Few researchers (Menear, 2007; O'Neill et al., 2005) to date have investigated the family dynamics of this specific population related to physical activity and feeding patterns; two areas that have been identified as factors that impact obesity among children. Evidence has been presented, which supports the notion that physical activity and eating patterns are shaped by those within the family. However, without a clear understanding of these dynamics among families who have children with and without Down syndrome or the impact a child with Down syndrome has on the health of the family, conclusions cannot be declared.

In Chapter I, I have provided the rationale for this study and a clear explanation of the motivation for targeting such a specific population. In the following Chapter II, a literature review is presented which provides the reader with a detailed foundation of the content and gives the reader a more thorough understanding of my lens as a researcher.

CHAPTER II

LITERATURE REVIEW

A better understanding of how parenting affect[s] child behavior patterns regarding eating and activity levels, independently and in conjunction with cultural norms and specific parenting behaviors, may help to guide the development of more comprehensive and more effective prevention and treatment programs for overweight children. (Rhee, Lumeng, Appugliese, Kaciroti, & Bradley, 2006, pp.2052-2053)

Overview

The framework of this study was developed from previous investigations in which researchers explored the physical activity habits and feeding patterns among families who have children without Down syndrome. Although similarities can be made, the dynamics within families who have a child with Down syndrome can be strikingly different compared to families who do not have a child with Down syndrome. The following literature review has been separated into 10 sections. In the first section I assess the quality of the literature by implementing the National Health Medical Research Council's (NHMRC, 1995; 1999) guidelines for the systematic identification and review of scientific literature. In the second section, an introduction is provided which reintroduces the reader to the content. In the third section, I provide a detailed explanation of the conceptual filter which will be used to assist with theme identification during data analysis in Phase I and Phase II of the results. In the fourth section, a description is provided for the obesogenic environment and variables that contribute to the escalating obesity rates among children and youth. In the fifth section, I address the development of

physical activity habits and how previous investigations identify the family as a contributor to these habits. Similarly in the sixth section, a discussion is presented regarding the development of eating patterns and how child feeding techniques can be considered the foundation for those habits.

Next, the seventh section of this literature review provides a description of Down syndrome, with a review of the existing evidence related to the obesity levels, physical activity habits, and eating pattern research among this population. In the eighth section, I present how having a child with Down syndrome can impact aspects of the family. In the ninth section, evidence is presented related to the concurrent family benefits of leading a lifestyle that includes consistent physical activity and healthy eating habits. In the tenth and final section, this review is concluded with a summary of the sections.

Assessment of Literature Quality

The quality of a research investigation is limited to the quality of the literature that has been used to provide support for the direction of the investigation (Lohr, 2004). Thus, an evaluation for the literature used in this present investigation is an essential component to ensure that this present investigation becomes a high quality document. The implementation of the National Health and Medical Research Council's (NHMRC; 1995; 1999; 2000a; 2000b) approach to quality literature assessment can not only provide a *grade* for each research article, but also an overall rating for the literature.

The NHMRC's (1995; 1999; 2000a; 2000b) guidelines for the systematic identification and review of scientific research have not only been used to assess the

literature quality in various journals in a multitude of disciplines (Butow, Lobb, Meiser, Barratt, & Tucker, 2003; Chalmers & Pearson, 2005; Tsiros, Coates, Howe, Grimshaw, & Buckley, 2010), but the evaluation process has been reevaluated on three separate occasions (Merlin, Weston, & Tooher, 2009). The evaluation process of individual research will be discussed, followed by an explanation of the evaluation process for the entire body of literature. Individual research can be assessed using the NHMRC's three dimensions of evidence (i.e., strength of evidence, size of effect, and appropriateness of outcomes).

Strength of Evidence

Level of Evidence: reflects the potential for each investigation to sufficiently answer the research question of inquiry.

Quality of Evidence: refers to how the methodology of each study must be investigated to critically evaluate the risk of bias.

Statistical Precision: includes the outcomes of an investigation which are limited to the data collection techniques and statistical tests that were used to obtain results (NHMRC, 2000b).

Size of Effect

Size of effect: refers to the point estimate's distance from the null value provided within results. The size of the effect practically refers to the impact the intervention will have on a population or individual (NHMRC, 2000b).

Relevance of Evidence

Appropriateness of the Outcomes: refers to whether the outcomes of the investigation are appropriate for the population or individual.

Relevance of Study Questions: reflects the extent to which the results of the study are applicable or generalizable to the population or individual (NHMRC, 2000b).

The range to grade the quality of individual research studies, based on the above criteria, uses a six level scale (i.e., Level I, II, III-1, III-2, III-3, and IV). Level I studies are systematic reviews of literature, Level II studies are Randomized Control Trials (RCTs), Level III-1 studies are pseudorandomized controlled trials, Level III-2 studies are comparative studies with concurrent controls (i.e., non-randomized experimental trials, retrospective cohort studies, case-control studies), Level III-3 studies are comparative studies without concurrent control groups, and finally Level IV studies are case series or cross-sectional studies which include most correlational investigations (Merlin et al., 2009). Qualitative investigations were also considered cross-sectional, Level IV studies.

Once the individual studies have been evaluated, the results provide the data relevant to assess the entire body of literature. There are five components with which to grade an entire body of literature, according to the NHMRC (2000a; 200b). The assessment components are the level of evidence, consistency among articles, overall clinical impact, generalizability, and applicability. The range to grade the quality of a body of literature, based on the above criteria, uses a four level scale (i.e., A, B, C, and D). An A grade

asserts that the body of literature can be considered as a trusted guide for practice, a B grade can be considered as a trusted guide for practice in most conditions, a C grade provides general recommendations which can be applied with care, and finally a D grade equates to a weaker body of evidence in which recommendations which can be applied with caution.

High quality literature can provide a solid foundation for a high quality investigation. The following sections demonstrate implementation of the NHMRC assessment of literature. The body of literature which has been provided to support this investigation has been graded at the B level, which was obtained from identifying the level of quality for each individual research study. According to NHMRC (2000a; 200b), this Level B equates to a good grade of evidence and that the information can be considered supportive in most situations. Individual grades of the research articles used as supportive literature are demonstrated within each reference citation following the conceptual filter section. Reference citations that do not include a level of evidence indicate a book or commentary article that did not have the necessary qualities or criteria related to this assessment. Individual research grades based on level of evidence from the NHMRC assessment along with investigation summaries are located in Appendix A. This current body of literature included 14% of Level I studies, 4% of Level II studies, 60% of Level III studies, and 22% of Level IV studies.

Literature Introduction

Generally, parents provide the initial guidance and lifestyle model related to behavior and habit formation for children. This is evident among many aspects of a child's life, including behaviors related to the development of consistent physical activity and healthy eating patterns (Epstein et al., 1986; Flett et al., 2010), habits which are essential for a healthy lifestyle. However, a clear understanding of the development of these habits between siblings with and without Down syndrome has yet to be fully established. With the multitude of evidence that has documented the high percentages of children and youth who continue to be overweight and physically inactive, a combined, multi-disciplinary effort needs to be made to encourage the simultaneous development of physical activity (Epstein et al., 1990) and healthy eating habits. This approach should be combined with the notion that the family can foster healthy habits to combat these issues, for the reason that parents can be a model for children with and without Down syndrome (O'Neill et al., 2005). However, evidenced-based research that targets these variables simultaneously, to date, as not been located. Using a conceptual filter to better understand the basis for the development of certain health-related habits or behavioral patterns can provide a solid foundation for this discussion.

Conceptual Filter

A theory has the potential to provide the reader with both an explanation and a connection between the literature, methodology, and results. "Social Cognitive Theory (SCT) in its totality specifies factors governing the acquisition of competencies that can

profoundly influence physical and emotional well-being as well as the self-regulation of health habits” (Bandura, 1998, p. 624). Identifying factors which lead toward health promotion through a social cognitive lens has been widely suggested among various disciplines (Bandura, 2005; Neumark-Sztainer, Story et al., 2003; Ransdell et al., 2001). The basic premise of SCT is that the processes of learning or changing behaviors is reciprocal and influenced by the interaction of three factors; (a) cognitive mechanisms, (b) behaviors, and (c) the environment (Bandura 1977; 1986).

Bandura (1998; 2005) concluded that the three interacting factors have the potential to impact health-related behavioral choices. Health-related habits (i.e., physical activity and eating) are rooted from childhood and strongly influenced by parents and the family (Epstein et al., 1985; 1990). These habits can be reciprocally learned through observation and imitation, which are considered forms of modeling. Modeling is considered a key agent when discussing how behaviors are shaped through social cognitive means.

Parents and the family can be a powerful social and environmental medium through which children learn and model their behaviors during the formative years (Epstein et al., 1990). Bandura (2004) stated that “the quality of health is heavily influenced by lifestyle habits . . . [and] if the huge health benefits of these few habits were put into a pill, it would be declared a scientific milestone in the field of medicine” (p. 143). Thus, if lifestyle habits which lead to increased mortality along with high quality physiological and psychological well-being are shaped during childhood and strongly associated with habits of parents, understanding how these habits are not encouraged or maintained

across populations, including between siblings with and without Down syndrome, must be more fully understood.

Reciprocal determinism provides another element of supportive explanation for several aspects of the development of behaviors which are associated with a healthy lifestyle (Bandura, 1978; Granich, Rosenberg, Knuiman, & Timperio, 2010). Reciprocal determinism is considered the basic analytic principle of SCT. Through the lens of reciprocal determinism, an individual's behavior is not only shaped by the immediate environment, but the environment is also impacted by the behavior of the individual (Bandura 1978). Thus, the relationship is interactionary and each action is itself a reaction.

This underlying principle has the potential to provide a coherent lens with which to view the factors that impact the prevalence of overweight and obesity among children with and without Down syndrome. The basis for the rationalization is that the presence of obesity impacts parenting techniques related to physical activity habits and feeding patterns. There is also the concern of the predisposition for children with Down syndrome to become obese which may impact parenting techniques. Evaluation of health-related parenting practices among families who have children without Down syndrome have often described this relationship as bidirectional (Ventura & Birch, 2008).

Children with Down syndrome experience various conditions which have been associated with obesity, including certain congenital anomalies, metabolic disease, and behavioral tendencies associated with sedentary lifestyles (Chumlea & Cronk, 1981). For

this reason, physicians prepare parents of children with Down syndrome by educating them with projections that their child may become overweight and obese. However, concrete knowledge regarding whether the high prevalence of overweight and obesity among children with Down syndrome is caused collectively by genetics has yet to be confirmed. However, similar to their same age peers, the obesity rates among children with Down syndrome have been steadily increasing for decades (Rimmer & Yamaki, 2006). The exponential rate cannot be explained by genetics alone. These rising rates provide support for the perception that obesity rates among children with Down syndrome may also be highly associated with environmental factors (e.g., parenting practices, obesogenic environment), similar to their peers without Down syndrome.

Understanding whether there are differences between the physical activity behaviors parents' model for their children or how the development of child feeding techniques may differ between siblings with and without Down syndrome may provide some insight. Bandura's SCT and reciprocal determinism have been used to explain a multitude of health-related behaviors. These theories will be used as a conceptual filter in conjunction with quantitative and qualitative results to describe the development of physical activity habits and feeding patterns, as well as, their impact of the family.

Obesogenic Environment

The physiological cause for obesity and excess weight gain is an imbalance between energy intake and energy expenditure (Beamer, 2003; Level I). The genetic make-up of an individual can significantly impact one's predisposition for obesity; however, dramatic

increases in the prevalence of obesity among youth and adult populations in the last three decades have led researchers to conclude that environmental factors have a significant impact on body composition and its development (Agras et al., 2004; Level III-2). For instance, obesity rates among children and adolescents with and without Down syndrome within the United States have been on the rise since the 1980's (Deckelbaum & Williams, 2001, Level I; Mokdad et al., 1999, Level IV; Ogden et al., 2010; Level III-3; Rimmer & Yamaki, 2006; Level I). The current prevalence of overweight and obesity among children and adolescents in the United States is 31.7% (Ogden et al., 2010; Level III-3). This prevalence has increased so rapidly that the impact of environmental factors, specifically physical activity, sedentary lifestyles, and eating patterns, continue to be primary targets for investigation (Quarmby, Dagkas, & Bridge, 2011; Level III-3). The dramatic increases in the prevalence of obesity in the last three decades in the United States and other developed nations, provide a strong case for an examination of factors that lead to an 'obesity promoting' environment.

Researchers (e.g., Han, Lawlor, & Kimm, 2010; Level I; Schwartz & Puhl, 2003; Level I) have even conjectured that the dramatic increase in the percentage of obesity has been so significant that this statistic actually provides evidence that the explanation of weight gain cannot be primarily linked to genetic predispositions. Growing up in an obesogenic environment with little encouragement for physical activity, along with inconsistent feeding techniques that ultimately lead to unhealthy or irregular eating patterns — is considered the recipe for an obesogenic environment. This has truly

become a social problem (Egger & Swinburn, 1997 Level I; Golan, Kaufman, & Shahar, 2006; Level III-1). The American or Western lifestyle has become known throughout the world as one that encourages sedentary lifestyles, promotes fast food, and encourages disproportionate weight gain; all of which are hallmarks for an obesogenic environment (Wang & Lobstein, 2006; Level III-2). A combination of physical inactivity and unhealthy eating patterns actually increase the propensity toward obesity development, both of which are primary characteristics of an obesogenic environment.

An important notation that must be made when discussing the impact of parenting practices related to factors that impact lifestyle health habits is the bidirectional or reciprocal nature of the parent-child relationship. As most evidence supporting this relationship comes from cross-sectional data, causal relationships cannot be inferred; however, the bidirectional nature of the parent-child relationship supports the notion that parenting practices related to physical activity habits or child feeding practices may be a reaction to the child's behavior (Davison & Birch, 2001; Level III-3; Joyce & Zimmer-Gembeck, 2009; Level III-3), rather than the precursor or direct cause. These bidirectional influences must be considered as interpretations are developed based on cross-sectional or observational research (Ventura & Birch, 2008; Level I). The potential for the presence of these obesogenic factors among families who have children with and without Down syndrome is probable. However, without a more clear understanding of the development of these habits for all populations, the current generation may be the first to have a shorter lifespan than their parents (Wang & Lobstein, 2006; Level III-2). The

processes, by which these habits develop, will be discussed in detail in the following sections.

Physical Activity Pattern Development - The Family

The family has the potential to be a powerful avenue for change and habit formation during the developmental years (Epstein et al., 1990; Level II). Although many physical activity habits and eating patterns children learn are related to sibling interaction and skills learned in school, parents provide the initial developmental model for physical activity and other healthy lifestyle habits (Ornelas et al., 2007; Level III-3). Parents' physical activity habits are directly correlated with child and adolescent lifestyle habits (Epstein et al., 1990; Level II). Children who have physically active parents are more likely to also be physically active (Kalakanis et al., 2001; Level III-3; Moore et al., 1991; Level III-3; Mulhall, Reis, & Begum, 2011; Level III-3). Conclusions have been made from a systematic literature review of cross-sectional studies, that the physical activity habits of mothers and fathers, and overall support and attitude about the importance of physical activity have a positive relationship with the habits of their children (Edwardson & Gorely, 2010; Level I). Similarly, findings from Mulhall and colleagues (2011; Level III-3) demonstrated that other than gender, the only other significant predictor of adolescent physical activity level was "family fitness" (p. 246), which was identified as engagement in regular physical activities together.

The relationship between a parent and child's physical activity habits can be more closely explained through modeling, parental involvement and encouragement (Kohl &

Hobbs, 1998; Level I; Wright et al., 2010; Level IV). Parents use a variety of strategies, both deliberate and unconscious, to impact the behavior of their children. Physical activity habits are no different. Parents can have a positive impact on the habits of their children by visibly being physically active (i.e., modeling), if the child perceives parents to be physically active, or through support for the child's activity.

Modeling physically active behavior is the most direct way parents can encourage the development of consistent physical activity habits (Edwardson & Gorely, 2010; Level I). This is not just a coincidence. As children watch their parents participate in adult sport teams, walk the dogs after dinner each night, or attend fitness classes, children are overtly learning how to make physical activity a regular part of their day. Madsen, McCulloch, and Crawford (2009; Level III-2) have demonstrated that girls' physical activity levels can be predicted by the activity levels of their mothers and fathers. When mothers and fathers modeled physically active behaviors, accurate predictions were made regarding the children's habits at 3, 5, 7, and 9 years. Thus, habits during the formative years mirror those of the parents. In a comparative study using accelerometers to assess physical activity levels of parents and their children (i.e., 4 to 7 years old), children who had two physically active parents were 5.8 times more likely to be physically active compared with children who had two inactive parents (Moore et al., 1991; Level III-3).

Not only are the physical activity habits of children associated with those of their parents, the level of activity is also highly associated. The more consistently children observe their parents being physically active, or the perception of activity, actually

increases the likelihood that a child will participate in not just activity, but moderate to vigorous physical activity (MVPA). Moderate to vigorous physical activity is the distinction between movement and heart healthy movement that prevents obesity (Ruiz et al., 2006; Level III-3). Trost and colleagues (1997; Level III-3) reported that this was true for mothers and daughters, but not for sons. Mother's physical activity level was considered to be a significant predictor of MVPA among girls, but not for boys. Kalakanis and colleagues (2001; Level III-3) documented the duration and intensity of physical activity levels from a sample of 51 parents and their children who were obese. Conclusions from this study not only provide support for the strong relationship between activity levels of parents and children, but also the inverse relationship between physical activity levels and weight.

Another documented form of habit formation related to physical activity among children has been parental support. Support from parents has been significantly linked to the level of physical activity or sport participation among children. For instance, Lubans, Foster, and Biddle (2008; Level I) completed a systematic review of literature to identify determinants of physical activity in children and parental support was determined to be a powerful mediator. Parental support for physical activity can transpire in a multitude of forms, including verbal encouragement, monetary support, or logistic support (Davison, Downs, & Birch, 2006; Level III-2; Edwardson & Gorely, 2010; Level I; Sallis, Alcaraz, McKenzie, & Hovell, 1999; Level III-3; Wright et al., 2010; Level IV).

Verbal encouragement from parents can emerge in the form of positive supportive words or attitude related to physical activity. Attitude for activity and level of priority a parent places on being physically active can impact a child's physical development by sheer frequency of task completion. The higher the priority a parent places on an action or skill, the more often the child will have the opportunity to practice those skills. The physical activity habits of teenage girls are more likely to be positively influenced by encouragement from mothers rather than fathers, whereas the physical activity habits of teenage boys are more likely to be positively influenced by encouragement from fathers (Bauer et al., 2008; Level III-3). Although, the gender of the parent may be a variable in the magnitude of influence, nonetheless influence on physical activity behaviors can be observed.

Another form of support that can be construed as the most literal form is that of monetary support. The amount of monetary support parents provide for children can directly impact the level of physical activity, most specifically for activities that require significant financial support (e.g., purchasing equipment, paying gym membership, or sport team fees; Edwardson & Gorely, 2010; Level I; Thompson et al., 2009; Level IV; Wright et al., 2010; Level IV). Although, ability to provide monetary support can be limited by socioeconomic status, there are many physical activities that parents and children can participate in together that do not require substantial financial support (e.g., walking around the neighborhood, going to the park, making a homemade obstacle course).

Logistic support from parents in the form of transportation to activities has been demonstrated to be a significant social predictor of physical activity level in elementary age boys and girls, more so than physical activity attitude, verbal support, or individual competence (Sallis et al., 1999; Level III-3). The only other variable that more accurately predicted the physical activity levels of fourth and fifth grade boys and girls was parents' physical activity level. Similarly, when investigating the influence of parenting practices on physical activity levels of girls, Davison, Cutting, and Birch (2003; Level III-3) concluded that both logistic support and direct modeling of habits were highly associated with physical activity habits. Providing transportation to practices, leading or coaching events, and attending sporting activities as a family are other forms of logistic support that can be provided by parents to promote the development of consistent physical activity habits in children (Edwardson & Gorely, 2010; Level I).

On the other hand, children can also learn to be physically inactive or sedentary. Sallis and colleagues (1999; Level III-3) have demonstrated that negative behaviors can also be modeled by parents. Negative behaviors related to physical activity can be described as being physically inactive for consistent time periods or practicing sedentary habits at times that could be spent being physically active, such as television viewing or video gaming. Strong evidence exists confirming the correlation that parents who are physically inactive or sedentary are likely to have children who are also physically inactive (Gordon-Larsen, McMurray, & Popkin, 2000; Level IV; Moore et al., 1991; Level III-3). Children who observe their parents come home from work each night and

turn on the television, are learning behaviors that lead to a sedentary lifestyle. Following a 6-year longitudinal study which examined obesogenic and nonobesogenic family environments, Davison and colleagues (2005; Level III-1) concluded that an obesity-promoting environment can be molded from parents' behavior. When weight status was controlled during analysis, the physical activity habits of parents were significantly associated with the activity and television viewing habits of their daughters. Thus, girls in the obesogenic group exhibited lower personal physical activity habits and increased television viewing over time.

While physical activity habits are shaped through support from parents, inactive or sedentary habits can also be shaped by other aspects of the family, including habits of other family members or the lifestyle of the family. Sedentary behaviors have been highly associated with the sociodemographics of the family. For instance, Gordon-Larsen and colleagues (2000; Level IV) analyzed data from the 1996 National Longitudinal Study of Adolescent Health and concluded that physical inactivity or sedentary levels were significant and inversely correlated with maternal education level and family income. On the other hand, physical inactivity and serious neighborhood crime levels were determined to have a significant and positive relationship. Another family dynamic that might be considered direct or indirect could be child weight concerns. Davison and Birch (2001; Level III-3) concluded that there is a significant inverse relationship between a child's perception of their physical ability and parents' weight concerns for the child. As

parents' weight concerns for their child increased, the child's level of perceived ability for physical tasks decreased.

Other dynamics within the family can have a potential impact on the physical activity levels of the child, not simply the family demographics. Parenting techniques not at all related to physical activity have been used to accurately predict adolescent physical activity level. These include, but are not limited to: parental monitoring (e.g., curfew enforcement, limiting television viewing, controlling food choice), parent-child communication (e.g., frequency with which parents talk to children about dating, personal problems, or schoolwork), and parental engagement (e.g., time spent together at a variety of events; Ornelas et al., 2007; Level III-3). Physical activity habits can be strongly influenced by various dynamics in the family, including parents own active and sedentary habits, encouragement of activity and even parenting practices not related to health habits such as parent-child communication. A combination of these factors within the family seem to play a role in shaping a child's habits related to healthy lifestyle living. Similarly, the development of eating patterns, which strongly influence long term health, have been consistently linked to parent feeding practices (Joyce & Zimmer-Gembeck, 2009; Level III-3).

Eating Pattern Development - The Family

Children's eating habits are developed and strongly associated with parent feeding techniques or parenting practices related to eating (Johnson & Birch, 1994; Level III-1). When child eating and parent feeding patterns were first associated with obesity among

children, parenting styles was the initial evaluator of the parent-child relationship (Rhee et al., 2006; Level II). Although parenting style can be an important determinant of childhood habits, it has been suggested that feeding patterns may have a stronger and more direct relationship with the development of healthy eating habits (Costanzo & Woody, 1985; Joyce & Zimmer-Gembeck, 2009; Level III-3). Healthy eating habits are characterized by the ability to recognize satiation, self-regulate portion size, and lack of emotional eating (Hood et al., 2000; Level III-3; Johnson & Birch, 1994; Level III-1). Child eating habits are learned through a multitude of direct and indirect parent feedings practices, thus in order to understand how to preclude the development of disorganized eating habits (i.e., inability to recognize satiation, eating due to boredom, eating for reasons other than hunger) which have the potential to lead to a propensity for obesity, child feeding pattern development within the family must be clearly outlined (Keller et al., 2006; Level III-3).

The more restrictive parents are with their child feeding techniques, the more likely their child is to engage in disinhibited eating (Joyce & Zimmer-Gembeck; Level III-3). Disinhibited eating is characterized by difficulty with stopping eating once the action has begun, regardless of feelings of satiation (Johnson & Birch, 1994; Level III-1). Restrictive feeding is considered to be a negative dimension of parenting practices related to feeding. Restrictive techniques include encouraging children to eat in the absence of hunger and encouragement of *cleaning the plate* despite satiation (Johannsen et al., 2006; Level III-2). Restriction can also include controlling times or amount of food and

monitoring the exact amount of food intake. As parents implement high control with feeding practices or consistently monitor child food intake, the result can lead to an increased desire for overconsumption in the absence of parents or when monitoring has ceased.

These practices of constantly controlling or monitoring a child's food intake or regulation can indirectly teach children to ignore internal cues for hunger or satiation and promote the reliance of external or social cues from others (Birch & Fisher, 2000; Level IV). On the other hand, Spruijt-Metz, Lindquist, Birch, Fisher, and Goran (2002; Level III-3) evaluated the relationship between mothers' child feeding practices and adiposity and determined that rather than food monitoring or restriction, pressure to eat was the most significant predictor of variance in total fat mass. Pressure to eat was greater for children with whom parents had the least amount of weight concern and for those who were not overweight. This finding was also confirmed by Keller et al. (2006; Level III-3) who investigated the impact of shared environments between siblings. Conclusions were made from both investigations that some child feeding practices may be more indirectly related to weight or weight concern.

The bidirectional influence of parent feeding practices on not only the child's eating habits but also weight has been widely investigated (Joyce & Zimmer-Gembeck, 2009; Level III-3; Keller et al., 2006; Level III-3; Saelens, Ernest, & Epstein, 2000; Level III-3; Webber, Cooke, Hill, & Wardle, 2010; Level III-2). Ventura and Birch (2008; Level I) completed a review of 66 articles which investigated the effect of parenting on child

eating and weight status. This review of largely cross-sectional studies revealed that despite a lack of randomized controlled trials, a majority of results demonstrated an influence or an association between parenting practices, child eating, and child weight status. The practices which had the greatest and most negative impact were pressure to eat and the restriction of food. Other investigators (Webber et al., 2010; Level III-2) who compared maternal feeding practices and child weight using a longitudinal analysis demonstrated the relationship to be more “child-responsive” (p. 1426), in that the mother’s feeding practices influenced the weight of her child rather than the practices being influenced by the child’s weight.

Birch and Fisher (2000; Level IV) demonstrated that the influence of mothers’ eating habits and perceptions of their own weight status were also influential. Results demonstrated that mothers exhibited a higher level of control and restriction toward their daughters’ eating habits when: (a) they perceived their child to be struggling with their weight, (b) they were at future risk for development of weight issues, or (c) the mothers themselves had difficulty regulating their own personal food intake and assumed their child would have the same problem. Similarly, Cutting, Fisher, Grimm-Thomas, and Birch (1999; Level IV; Level IV) and Hood et al. (2000; Level III-3) demonstrated that mothers with disorganized eating behaviors were more likely to have children prone to obesity. While, Whitaker, Deeks, Baughcum, and Specker (2000; Level III-3) concluded that there was not a significant relationship between the eating behaviors of mothers or

fathers and the weight status of their children; however, this study examined associations between parents who had preschool-age children.

Some mothers even felt that having a heavy child was a marker of good parenting, and thus increased their child's food intake or encouraged weight gain through certain feeding practices. Baughcum and colleagues (1998; Level III-3) concluded following focus groups with mothers that feeding practices were intentionally changed to encourage weight gain among children from certain ethnic backgrounds. "In the context of a bidirectional parent—child feeding dynamic, a potential key variable involved in the association between parent restriction and children's weight may be a parents' concern about their children's weight" (Joyce & Zimmer-Gembeck, 2009, p. 732; Level III-3). Thus, the concern for potential weight gain among children may be a mediating factor in the parent-child relationship pathway which influences the parenting practices.

Although, strong support has been documented, other investigations have demonstrated that there is not a significant relationship between child feeding practices and child adiposity. Saelens and colleagues (2000; Level III-3) examined the impact of maternal child feeding practices among children who were obese and non-obese. Researchers concluded that results from this investigation did not support the claim that strong maternal control related to feeding practices was associated with childhood obesity. However, results did confirm that maternal weight history and eating habits can be used to predict a child's future weight. Similarly, Johannsen and colleagues (2006; Level III-2) evaluated the relationship between parents' controlling feeding practices and

child weight status using a correlational design with self-report measures, and their findings did not yield a significant relationship between the variables. Though a strong relationship was not documented, post-hoc analysis of differences determined that fathers who used more restrictive feeding practices had daughters with a higher percentage of body fat.

Factors which contribute to the obesogenic environment have had a variable impact on different population groups. For instance, according to population-based obesity statistics, certain population groups experience a disproportionately higher rate of obesity. These groups include: low socioeconomic status communities, certain ethnic minority groups (Han et al., 2010; Level I), and individuals with disabilities (Rimmer et al., 2010; Level IV). Among persons with disabilities, individuals with Down syndrome exhibit the greatest disproportionate prevalence of obesity compared to the overall population (Rimmer et al.; Level IV). To fully understand these disproportionate rates, an in depth discussion of the condition known as Down syndrome, or Trisomy 21 follows.

Children with Down Syndrome

Down syndrome, or Trisomy 21 as it is still referred to in parts of Europe, is the most frequently occurring chromosomal condition, and the prevalence has increased by 31.1% since 1979 with an approximated 11.8 per 10,000 children born in the United States (Shin et al., 2009; Level IV). The explanation and identification of Down syndrome comes from the presence of an additional partial or complete chromosome 21 within the somatic cells. Robert Langdon Down was the first physician to provide a description for

individuals with the condition that now bears his name (Down, 1866; Rynders & Pueschel, 1982).

There are three different types of Down syndrome that have been identified. The standard Trisomy 21, which includes an additional chromosome 21, is the most common with an estimate of 95% of cases (Hook, 1982). Another form has been termed Translocation Trisomy 21, which is identified when a portion of the extra chromosome 21 is located on another chromosome, this occurs in approximately 3% of cases. Similar to Trisomy 21, individuals with Translocation Trisomy 21 have an extra chromosome 21, and will exhibit a majority of parallel characteristics. Mosaicism is the third and least common form of Down syndrome, occurring in approximately 2% of cases. This form can occur due to various chromosomal abnormalities. Individuals with Mosaicism exhibit many characteristics similar to other cases with Down syndrome; the degree of similarity depends on the percentage of cells and location of cells within the extra chromosome (Carr, 1995; Hook, 1982).

Children with Down syndrome have numerous physiological, cognitive, and behavioral traits that are considered typical for the condition; however, each individual is unique in those characteristics and their developmental environment strongly influences their overall growth (Sharav & Bowman, 1992; Level III-3). As physical and physiological characteristics are determined by one's genetic make-up, children with Down syndrome will have a physical similarity to their biological parents; however, other physiological traits exist which are typical for the condition. Some physiological

commonalities which can be identified from birth include; a single transverse palmar crease, heart murmur, congenital heart disease, and brachycephaly (Carr, 1995).

Although not an exhaustive list, other characteristics that occur with a higher frequency but may not be identifiable from birth include; oblique placement of eyes, hyperflexibility, protruding mouth, hypotonic muscle tone, furrowing of the tongue, slanting palpebral fissure (Carr, 1995; Pueschel et al., 1982), hypothyroidism, and a decreased basal metabolic rate (Cronk et al., 1988; Level III-3; Luke et al., 1996; Level III-2),

There are distinct traits which are common among most with Down syndrome, severity, frequency, and individual uniqueness within these traits does persist (Pueschel et al., 1982). These traits which are often seen in children and youth with Down syndrome are also prevalent among those without the chromosomal condition and thus not indicative of the cause for disability or identification of the condition. Although physicians do refer to some physical checklists for identification, a chromosomal examination is the official determinant of the condition. However, some of the more severe medical and cognitive comorbidities have been identified as an explanation for individuals with Down syndrome who exhibit a lower functional ability.

Cognitive and personality traits among individuals with Down syndrome vary widely. Specific intellectual capacity ranges from an average competence, typically characterized by an IQ of 70 to severe intellectual disability which can be characterized with an IQ below 30. Average range variations in intellectual capacity have been observed between

40 to 60 IQ points (Carr, 1988; Level III-2; Connolly, Morgan, Russell, Fulliton, & Shea, 1993; Level III-2) and have been demonstrated to decline with age. Personality traits which have been considered typical to children with Down syndrome also vary, descriptions have ranged from pleasant and easy going to difficult and unpredictable (Carr, 1995), which are highly similar to populations without Down syndrome. A lack of motivation and stubbornness to participate in activities has also been documented (Medlen, 2002); however, environmental and developmental circumstances have largely been identified as the primary cause for these individual variations.

Certain physiological factors that are specific to Down syndrome have been associated with causation of an excess amount of adipose tissue. In fact, approximately 30% of children with Down syndrome are considered obese (Grammatikopoulou et al., 2008; Level IV; Rimmer et al., 2010; Level IV), this percentage is much higher compared to a 17% obesity prevalence among children without Down syndrome (Ogden et al., 2010; Level III-3). These rates do not include the prevalence of overweight among this population which has been estimated at over 50% (Harris et al., 2003; Level IV; Pitetti & Fernhall, 2004; Level III-2). A combination of environmental factors such as physical inactivity and eating issues along with secondary disabling conditions likely advance children with Down syndrome to higher rates of obesity than what they are genetically predisposed. The following sections will address the development of physical activity and eating patterns among children with Down syndrome and how the family can play an integral role in that process.

Physical Activity

Over a decade ago, Rubin et al. (1998; Level III-3) guided researchers toward the health and well-being of children with Down syndrome noting that there continues to be an increase in overweight and obesity overtime, at rates which are greater than the general population. Due to the high obesity rates among persons with Down syndrome, almost twice that of their cross-aged peers (Rimmer & Yamaki, 2006; Level I), the development of these habits must be understood immediately in order to assist parents and practitioners to positively impact current and future generations before they become another statistic. However, little has been done to positively impact the physical activity levels of this population.

There has been a paucity of evidence that exists regarding comparisons of parents' physical activity levels and children with Down syndrome; however, several comparisons have been made between siblings with and without Down syndrome. For instance, Sharav and Bowman (1992; Level III-3) examined the physical activity levels of siblings with and without Down syndrome to determine differences that may persist in their home environment. Conclusions were made that the siblings with Down syndrome were not only significantly less active, but preferred indoor activities. Results from this investigation also demonstrated that there were not significant differences in body composition, as measured by Body Mass Index (BMI), among siblings. This led the researchers to conclude that children with Down syndrome have a similar reaction to genetic and environmental influences related to obesogenic factors, thus lifestyles that are

focused on healthy living can impact children with and without Down syndrome. On the other hand, Whitt-Glover and colleagues (2006; Level III-2) evaluated the physical activity patterns between siblings with and without Down syndrome. Unlike the previous study which evaluated activity level based on questionnaires, this investigation objectively measured physical activity with accelerometers. The researchers demonstrated that children with Down syndrome exhibited not only less daily physical activity, but less vigorous activity, for shorter durations, and had significantly higher BMI scores.

Certain physical and motor occurrences among children with Down syndrome may impact their development and ultimately their daily physical activity habits. The onset of walking is often delayed about one year compared to children without Down syndrome (Carr, 1995) and irregular running gait and balance issues can also be present (Pitetti & Fernhall, 2004; Level III-2). Mahy, Shields, Taylor and Dodd (2010; Level IV) conducted semi-structured interviews with 18 adults with Down syndrome and their support staff and parents, regarding facilitators and potential barriers for physical activity habits. The authors concluded that primary facilitators were support and participation from others along with level of interest in the activity. Primary barriers to participation in physically active behaviors were lack of support and interest, as well as medical concerns. These results provide evidence for the conclusion that facilitators and barriers to physical activity for individuals with Down syndrome may not be different from other populations.

Other researchers have attempted to fill the research gap with descriptive investigations. Sheilds, Dodd, and Abblitt (2009; Level III-3) piloted a project that documented the low physical activity levels of children with Down syndrome and concluded that the sample, although very small, provided evidence that this population of children do not meet daily recommended physical activity levels. The authors concluded that physical activity levels were too low to maintain good health. Menear (2007; Level IV) interviewed parents and examined perceptions of having a child with Down syndrome, related to health and physical activity habits. Menear's conclusions, based on the feedback from mothers, related to outside influences of physical activity participation (i.e., lack of sponsored programs, ineffective physical educators) for the child and did not include a component of nutrient intake or parent modeling. According to this sample of mothers, the patterns of low physical activity levels appeared to be highly related to lack of programming, environmental constraints, and lack of interest from their children with Down syndrome.

Frey, Buchanan, Sandt, and Taylor (2005; Level IV) completed a similar investigation regarding barriers and correlates of physical activity. Surveys, interviews, and objectively measured physical activity levels were obtained from 12 adults participating in Special Olympics; participants did not have Down syndrome but all had an intellectual disability. A primary conclusion made by the investigators was that the individuals who should be highly invested in health promotion (e.g., parents, caregivers, and teachers) were most likely to enforce and personally model sedentary behavior.

Interview responses demonstrated that mothers felt children should only play outside in the presence of adults, bicycle routes were not safe for independent riding, and that even coaches recommended that while playing golf the children should use a golf cart instead of walking the course. Barr and Shields (2011; Level IV) also identified that mothers of children with Down syndrome were concerned for their child's safety while playing outside independently and included that not having a consistent peer group prevented physical activity.

Although evidence has consistently documented low physical activity levels, clinical experimental trials have demonstrated that children with Down syndrome can achieve desired weight loss and fitness goals through exercise programs (Ordoñez, Rosety, & Rosety-Rodriguez, 2006; Level III-3). Ordoñez and colleagues prescribed a 12-week aerobic exercise program for 22 adolescent males with Down syndrome. Significant reductions in weight loss and increases in level of physical fitness were documented among all participants; however, intervention details were not provided regarding the exact type of physical activity and the families of the participants were not involved. As this was not a longitudinal or follow-up study, conclusions regarding retention of weight loss cannot be made. However, sample size was low and the rigorous exercise schedule may be difficult to transition into the daily life of families who have children with and without Down syndrome.

Other areas of investigation have been limited to general statements (i.e., time constraints, limited family outings; Mulroy, et al., 2008; Level IV) and to date only one

investigation was located that examined issues within the families that could have a positive impact on the lifestyle of families who have children with and without Down syndrome (O'Neill et al., 2005; Level III-3). Similar to populations without Down syndrome, the variation of healthy lifestyle habits and influences of those habits is immense (Quarmby et al., 2011; Level III-3). In order to fully understand the impact the environment can have on obesogenic factors, an understanding of the development of eating patterns among children with Down syndrome is warranted.

Eating Patterns

Children with Down syndrome not only exhibit delays in motor development, but difficulties in the onset of other milestones that can be directly linked to difficulties with eating. For instance, children with Down syndrome are prone to difficulties with oral-motor development. This may lead to delays in the progression of eating solid foods and ultimately independent feeding (Medlen, 2002). Delays in feeding independence coupled with a high tendency towards obesity has been associated with the high restriction and control used in the feeding practices of mothers who have a child with Down syndrome (Grammatikopoulou et al., 2008; Level III-3; O'Neill et al., 2005; Level III-3).

Eating patterns among children with Down syndrome can often be limited or partly influenced by a decreased ability to masticate which has been linked to having a delayed sucking reflex (Medlen, 2002) and may enhance gastrointestinal problems (Rimmer et al., 2010; Level IV). These patterns can lead to parent feeding challenges and ultimately

irregular eating habits for the child. Delays in the progression from soft to hard food can often present the illusion of pickiness, when in fact the child may not be physically able to chew the substance (Hopman et al., 1998; Level III-2). This can often prevent parents from introducing new foods based on the assumption that their child is a finicky eater. However, Hopman and colleagues have demonstrated that as parents become aware of their child's potential intellectual and developmental delays, the natural adaptation to treat their child with Down syndrome like an infant (e.g., prolong use of a bottle as a primary feeding strategy or delay onset of introduction to solid food) may continue longer compared to other children.

Similar to their siblings without Down syndrome, eating patterns among children with Down syndrome can be directly related to the types of feeding techniques used by parents. Some parents use more stringent or restrictive feeding techniques, often not allowing their child to eat independently or self-regulate their own portion size. For instance, O'Neill and colleagues (2005; Level IV) documented that parents were more preoccupied with their child's weight and their own personal responsibility for feeding and restricting food, rather than teaching their child with Down syndrome to self-regulate portion size or understand the feeling of satiation (i.e., cease eating once the feeling of hunger no longer exists). These investigators also reported that BMI scores were higher for the sibling with Down syndrome. These results are consistent with investigators who demonstrated that there is a reciprocal relationship between parent restriction of food and

overweight among children without Down syndrome (Joyce & Zimmer-Gembeck, 2009; Level III-3).

Grammatikopoulou and colleagues (2008; Level III-3) examined the nutrient intake and anthropometry of children with Down syndrome, and concluded that although “children with Down syndrome have a genetic predisposition to become overweight; obesity may worsen beyond genetic expectation as they develop food choices and become more independent” (p. 265). As previously stated, food choices and eating patterns can be directly shaped by feeding techniques implemented directly or indirectly by parents (Johnson & Birch, 1994; Level III-1).

The development of eating habits among children with Down syndrome has been associated with parents’ actions. For instance, O’Neill and colleagues (2005; Level IV) used the *Child Feeding Questionnaire* (Birch et al., 2001; Level IV) to compare the child feeding practices between siblings with and without Down syndrome, parent responses were compared for each child. Major findings indicated that parents used more restrictive and controlling feeding practices for children with Down syndrome, compared to children without Down syndrome. Higher controlling or restrictive feeding practices were also positively correlated with BMI. Conclusions were made that parents’ controlling or restrictive behaviors could potentially be linked to increases in the child’s tendency toward overweight. However, due to the cross-sectional nature of the survey, whether the feeding patterns were influenced by the child’s weight or the child’s weight changed once the restrictive feeding practices began is not yet known.

Parenting practices related to physical activity encouragement and feeding techniques for children with and without Down syndrome have the potential to be reciprocal. These practices can also be impacted by contextual and situational factors; factors that can potentially impact these practices are age, socioeconomic status, ethnicity, and gender. Although the presence or absence of having a child with Down syndrome has not been directly linked to changes in parenting practices of health-related habits, some researchers have pointed towards the strong impact that a child with a disability has on other aspects of the family (Mulroy, et al., 2008; Level IV).

Families and Children with Down Syndrome

All families experience certain stressors as children grow and develop, and as parents attempt to mold them into young adults. However, the experiences of families who have children with and without Down syndrome can be different. Even still, it is often the parents' reaction to or interpretation of those stressors which eventually determine the impact on the family. For instance, Mulroy and colleagues (2008; Level IV) have documented that parents who have a child with Down syndrome experience high levels of stress and anxiety regarding their family. On the other hand, Dabrowski and Pisula (2010; Level IV) concluded that stress level was not a consistent predictor of family health, among parents who have children with Down syndrome; rather the family's ability to cope with stress determined family health. Similarly Carr (1988; Level III-2) examined several factors among families who have children with Down syndrome over time and also concluded that parents had mixed emotions regarding the impact of their

child with Down syndrome. While some mothers exhibited high levels of self-reported depression, still other parents reported benefits which included an increase in compassion and tolerance for siblings without Down syndrome, and that “through the presence of the Down’s syndrome person [*sic*] family ties had been strengthened and the family kept together” (p. 419).

Evidence exists that supports the relationship between positive psychological health and living a consistently physically active lifestyle, benefits which can include decreased depression and stress (Belanger et al., 2011; Level III-2). For families with multiple children, including one with Down syndrome, healthy lifestyle habits would thus have a multitude of benefits. Researchers (Giallo & Gavidia-Payne, 2006; Level IV; Mulroy et al., 2008; Level IV) have reported in relation to family quality time that parents who have a child with a disability mentioned that they cannot “show support together, [or be together] at recreational activities ... it is always one [parent] or the other” (Mulroy et al., p. 223; Level IV). These same parents also mentioned a disadvantage of having a child with Down syndrome to be “[lack] of quality family time” (Mulroy et al., p. 222; Level IV); as much of time is divided between developmental programs or therapies.

Another factor unique to families who have a children with Down syndrome, or other disability, may be related to decisions about care into adulthood (i.e., group homes, independent living). Physical activity has actually been used to assist with this dilemma. For instance, Ordoñez et al. (2006; Level III-3) concluded that the decision to target an adolescent population was to investigate the potential for significant weight loss and

fitness enhancement for the purpose of promoting “functional independence and interaction with others, which may eventually improve social integration” (p. 418).

Parenting a child with a developmental disability can add sources of stress not experienced by parents who have children that are typically developing. However, often the child’s disability is not the primary determinant of whether a family will exhibit high levels of stress. Dabrowska and Pisula (2010; Level III-3) documented that the coping strategies that parents implement to manage stress and the perception of whether the stressors are positive or negative determined the level of stress. Coping with stress (i.e., managing time schedules, additional child therapies, or academic struggles) using emotion-oriented techniques such as guilt, blame, or avoidance are positively associated with anxiety and depression. On the other hand, task-oriented coping strategies such as active problem solving or collaborative decision making between parents are negatively associated with those same health conditions. Although, there were no differences in the stress levels between mothers and fathers who had a child with Down syndrome, parents who had a child who was typically developing exhibited fewer stress markers. It was reported that the greatest stress for families who had a child with Down syndrome were limitations on opportunities for the family to spend time together.

Concurrent Family Benefits

Family cohesion, communication between family members, and encouragement from parents have been reported to be a significant predictor of physical activity levels and eating patterns among children and youth (Flodmark et al., 1993; Level III-1; Ornelas et

al., 2007; Level III-3). Physical activity and eating habits, like many other habits learned during the formative years, are directly shaped by the habits of parents and can often transition from childhood into adulthood (Epstein et al., 1990; Level II). Thus, children who learn to enjoy regular participation in physical activity and learn to naturally moderate their food intake have the potential to become healthy and active adults. Whereas children who learn to regulate food intake by social rather than internal cues and practice a consistently sedentary lifestyle, have the potential to become unhealthy and inactive adults or will have the challenge of learning these habits through secondary or outside family sources. Once these lifestyle habits are formed, positive or negative, they can often be difficult to counteract.

The family can be an important avenue for physical activity and eating habit change and retention (Bauer et al., 2011; Level IV). The time a family spends encouraging physical activity and healthy eating can also be another avenue for quality time spent together. For instance, results from interview sessions following a mother-daughter physical activity-based intervention, demonstrated that according to opinions from participants, spending quality time was the most positive aspect of the activities (Ransdell et al., 2001; Level III-1). There is a consensus among researchers that physical activity cannot only be used to enhance physiological health, but also the psychological health of all involved - including the family as a unit (Epstein et al., 1990; Level II; Puhl, & Heuer, 2009; Level I; Schwartz & Puhl, 2003; Level I).

Encouraging health promotion through the family unit can have powerful effects on many aspects of the family. Healthy weight, greater consumption of fruits and vegetables, and smaller intake of carbonated beverages, among others are all linked to a close knit familial environment and families who eat dinner together (Gruber & Haldeman, 2009; Level I). Not only can families learn new ways to interact with one another, but the parents can regain their role as the primary model for their adolescents' behavior (Hardman, Horne, & Lowe, 2009; Level II). Though there is a consensus about the positive impact that families can have on healthy habits, a paucity of evidence exists that includes families who have a child with a disability.

By simultaneously investigating associations between physical activity levels and child feeding patterns among families who have children with and without Down syndrome, researchers may be able to provide guidance that can not only impact the physiological aspects of families (i.e., eating patterns, weight status) but also psychological aspects of families (i.e., impact of parent modeling on activity, enhance the life quality of the family unit). This interaction has also been termed family connectedness (Eisenberg et al., 2004; Level III-3). The combination of promoting both the physiological and psychological aspects of a family has often been neglected within research among families who have children with and without Down syndrome.

As the obesity epidemic persists, researchers investigating the familial aggregation of habits have discussed the promotion of physical activity and healthy eating patterns as having a dual purpose for the health of the family. The family has even been considered

“a key component in healthy adolescent development” (Eisenberg et al., 2004, p. 792; Level III-3). Evidence has been documented that families who participate in physical activity, prepare and plan healthy meals, and regularly eat dinner together have a high social and psychological well-being (Bauer et al., 2011; Level IV; Flett et al., 2010; Level IV). Planning and preparation can also be time for quality interaction, modeling of healthy habits, and bonding between children and parents. Through telephone interviews with parents who have school age children, Thompson and colleagues (2009; Level IV) investigated this very interaction. Findings supported the notion that parents were aware of the many physical and psychosocial benefits of family physical activity; however, few reported the consistent participation in physically active tasks together. Most notably, Thompson and her colleagues reported that a majority of family time was spent in sedentary tasks and when the family did choose physically active behaviors, most two parent households paired off with one or more children due to scheduling conflicts.

A focus on parent-adolescent emotional relationships along with consistent participation in physical activity can lead to increased self-esteem, as documented by Ornelas and her colleagues (2007; Level III-3). Conclusions were also made that a well-functioning family structure may be the essential component when promoting health in the family environment. Results from this investigation not only provided support for, but also recommended that future efforts simultaneously target family bonding through increased quality time and physical activity participation for the promotion of emotional health. The psycho-social ramifications (Puhl, & Heuer, 2009; Level I; Schwartz & Puhl,

2003; Level I) for families living in an obesogenic environment, consistently physically inactive, and practicing inadequate feeding and eating patterns can have a strong impact on the future for all family members. However, using the family to encourage activity and healthy eating can impact the psycho-social nature of the child and provide a powerful medium to encourage family connectedness and family values. Yet, due to the interactionary nature of the family structure which can often be limited by scheduling or lack of motivation, awareness for the benefits of being connected as a family through health-related habits may not be enough.

Summary

To summarize, during the developmental years the physical activity habits and eating patterns among children with and without Down syndrome are largely influenced by the family environment. Researchers (Epstein et al., 1990; Level II) have demonstrated that the physical activity and eating habits shaped during childhood can build the foundation for future habits. Children who have physically active parents with healthy feeding practices are more likely to adopt these healthy promoting behaviors. Whereas, children who grow up in households that encourage sedentary habits, with irregular eating habits, will likely adopt and continue those later in life.

These habits are not only influenced by the environment, but they also have the potential to significantly impact the environment itself. Reciprocal determinism (Bandura, 1977), the basic analytic principle of Bandura's SCT (1977), has been used to explain the interaction between cognition, behavior, and the environment. As the

prevalence of obesity continues to rise, researchers must investigate the development of factors related to weight change among unique populations. The family has a powerful role in the development of these patterns, especially among children with Down syndrome who due to certain genetic anomalies are predisposed to higher rates of obesity. Using high quality methodological techniques to gather evidence-based results to more clearly understand the interaction of and the development of these obesogenic factors within families who have children with and without Down syndrome is a necessity. This evidence would have the potential to provide guidance to improve both the physiological and psychological domains among these families.

In Chapter II, I have provided a literature review that builds a foundation for the reader and provides support for the rationale of this study. In the following Chapter III, a detailed explanation of the methodology is provided, which includes a description of data collection procedures and analysis which has been completed. The method section has been separated into Phases I and II, to ensure clarification for the reader.

CHAPTER III

METHOD

“An emphasis on perspectives brings together attitudes, opinions, and experiences in an effort to find out not only what part’s think about an issue but also how they think about it and why they think the way they do” (Morgan, 1997, p. 20).

Children with Down syndrome are disproportionately overweight and obese compared to the general population and their siblings; however, a clear understanding of the familial aggregation of influential factors have yet to be investigated between siblings with and without Down syndrome. The purpose of this study is twofold. First, to investigate the relationship between mothers’ physical activity levels, past eating behaviors, and child feeding practices on the physical activity levels and weight concerns among their children with and with Down syndrome is presented. Second, to further explore these practices between siblings and investigate how having a child with Down syndrome may impact these practices and the family. The methodology of this study is presented in this chapter and is comprised of four sections. These are as follows: Research Design, Phase I (i.e., Participants, Instrumentation, Procedures, and Data Analyses), Phase II (i.e., Participants, Procedures, and Data Analyses), and Data Triangulation.

Research Design

The familial aggregation of parenting practices related to physical activity habits and child feeding patterns have been previously explored among families who have children

without Down syndrome, but this study was the first of its nature to explore these factors between siblings with and without Down syndrome. A mixed approach design (Creswell & Plano Clark, 2011; Lieber, 2009; Saks & Allsop, 2007) was developed to investigate these complex family dynamics and parenting practices which have yet to be explored between siblings with and without Down syndrome. In this investigation, data collection and analysis have been separated into two phases, Phases I and II (see Figure 1). Phase I includes survey distribution with quantitative data analysis, and Phase II includes interviews and focus groups with qualitative data analysis. The use of questionnaires during Phase I served to establish a foundation of information with which to guide discussion topics during Phase II. The basis for using focus groups and interviews during Phase II was to provide an avenue for gathering rich data. Due to the synergistic nature of group interviews and the format of a semi-structured script; the focus group and interview data collection technique allowed the potential to bring about a variety of rich information that may not have been acquired by using a single methodology.

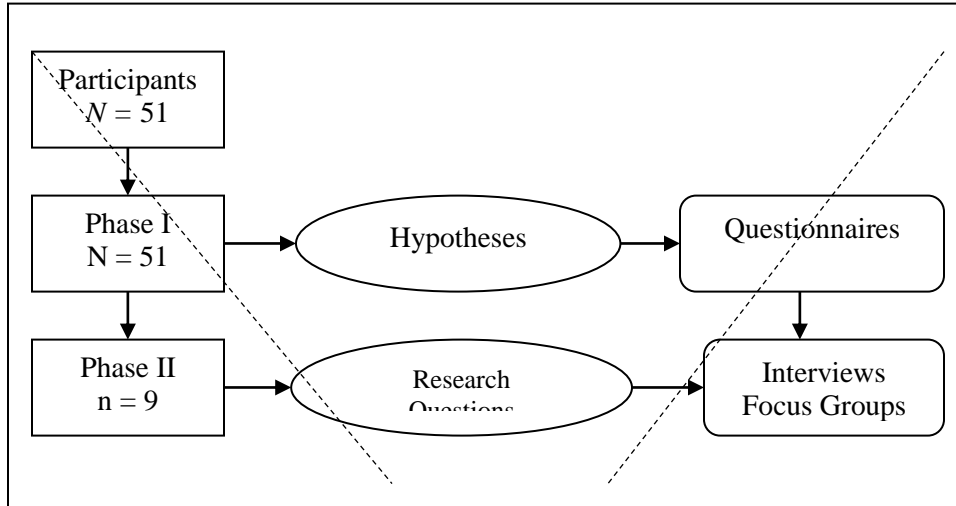


Figure 1. Visual representation of Phases I and II

The purpose of a mixed approach design is not to replace single method research (i.e., quantitative or qualitative methods), but more accurately to compliment them by maximizing the strengths and minimizing the weaknesses (Johnson & Onwuegbuzie, 2004; Lieber, 2009). The goal of this current investigation was to deeply explore the perspectives of a unique population (i.e., parents who have multiple children, including one with Down syndrome). By identifying and understanding concepts that may lead to multiple and potentially unexpected viewpoints, the researcher is less restricted by the limitations of the study as the method combination has the potential to allow for an understanding of dynamic factors (Creswell & Plano Clark, 2011; Saks & Allsop, 2007). Targeting these multiple complex variables allows a fewer number of participants to be sought; however, the assumption was made that parents would be highly invested in the

topic of health-related information about their family and children. With the combination of questionnaires, focus group sessions, and one-on-one interviews, all possible efforts have been made to increase the strength and quality of this study by providing a foundation for data triangulation (Wolcott, 1990).

Phase I

Participants

Efforts were made to recruit as many participants as possible, with a goal of at least 176 participants (e.g., 88 mothers, 88 fathers) in Phase I. The approximate participant goal was based on an a priori power analysis which was calculated to predict sufficient statistical power for analysis. Inclusion criteria for participants were parents (mother or father) who were over the age of 18 years, English speaking, and had multiple children, including one child with Down syndrome that currently lives with the parent. There were no other inclusion or exclusion criteria. Although male and female participants were recruited, only two males were interested in participation following recruitment, therefore only data from the female participants were used. The unique nature of the inclusion criteria inherently limited the potential population; a total of 60 female participants attempted the questionnaire. Questionnaires that were not finished or incomplete were excluded from data analyses, leaving a final sample size of 51.

Sibling age difference or child birth order were not exclusionary factors, as it was the parent's perspectives of parenting practices rather than the interaction between siblings that was being investigated. The minimum age of the children was limited to 7 years and

the parent who completed the questionnaire must have been currently living with their children (e.g., rather than having a child living in a group home, institution, or away at college). The age limitations of children were based on a previous investigation (Cuskelly & Gunn, 2006) which targeted siblings with and without Down syndrome from the perspective of the parents. For purposes of this study, the age of 7 years was selected as a minimum age so that the child's "disability was apparent in everyday functioning" (Cuskelly & Gunn, 2006, p. 919) and that parents would have had at least 7 years of parenting practices to reflect on and make comparisons.

For the purposes of this study, potential participants were parents with multiple children, including one with Down syndrome whose children matched the appropriate age ranges and currently lived with their parents. Cohabitation with parents was an inclusionary criterion for the reason that recall of past parenting practices may not have been as accurate as responses that were linked to parenting practices that were being exhibited presently.

Parents were recruited from the electronic mailing lists of non-profit organizations, online national public blogs, and discussion boards, including: the Down Syndrome Guild of Dallas, DOWN-SYN list, National Association for Down Syndrome Discussion Board, UpsNDowns, National Down Syndrome Society (NDSS), and the Down Syndrome Research Foundation (DSRF). These organizations and blogs target parents who have a child with Down syndrome. All of the discussion board lists are free and open to the public; the only criterion to become a subscriber is to possess an electronic

mailing address. All possible participants, regardless of communication avenue were contacted electronically notifying them that participants were being recruited to complete surveys for a project with the goal of better understanding the physical activity levels and feeding patterns within families who have multiple children, including one with Down syndrome.

Instrumentation

Self-report measures have been used consistently by researchers to assess physical activity levels and other health-related lifestyle habits (Brown et al., 2003; Mokdad et al., 2003), as this method is considered to be more cost-effective compared to participant observation or the use of pedometers and accelerometers. Participants were asked to complete an electronic questionnaire which included four sections; demographics, the *International Physical Activity Questionnaire*, the *Child Feeding Questionnaire*, and the *Three-Factor Eating Questionnaire*. The full questionnaire took approximately 30 to 45 minutes to complete (Appendix B).

Demographics section. The first section of the electronic questionnaire consisted of a demographics page which surveyed participants regarding their age, marital status, gender, number of children, age of children, socioeconomic status, maternal education level, and ethnicity.

International physical activity questionnaire. The *International Physical Activity Questionnaire (IPAQ)* was the second section of the survey. The *IPAQ* was developed by a team of physical activity experts with the intention of producing a valid measure that

could be used to assess physical activity levels in numerous countries (Craig et al., 2003). The *IPAQ* short version is a self-report measure used to obtain data on health-related physical activity behaviors. Responses from the *IPAQ* are used to estimate the amount of daily physical activity or exercise a person has performed in the past 7 days. The survey has 4 questions that target physical activity behaviors of varying intensities (e.g., vigorous, moderate, and walking). Acceptable reliability and validity have been documented in 12 countries (Hallal & Victoria, 2004), with test-retest reliability scores considered adequate (e.g., Spearman $r = .70$ to $.97$; Craig et al., 2003).

Child feeding questionnaire. The third section was the *Child Feeding Questionnaire* (*CFQ*; Birch et al., 2001; Costanzo & Woody, 1985), which is a 31-item self-report forced choice instrument that evaluated parent's feeding attitudes and "use of control in feeding their children [along with attitudes and] concerns about their child's weight status and eating behaviors. [It is also designed to probe parents about their] perceptions about their own weight when they were children" (Johannsen et al., 2006, p. 432). The survey includes variables of (a) perceived responsibility; (b) perceived parent weight; (c) perceived child weight; (d) parent concern about weight; (e) parent's food restriction; (f) amount of pressure from parent to eat food; and (g) monitoring of child's food intake. The instrument has been deemed a valid and reliable measure using multiethnic populations with internal consistencies above 0.70 for the seven factors (Birch et al., 2001; Faith et al., 2004). This includes one sample of parents with a child with Down syndrome; Cronbach's alpha scores were documented to be higher than 0.71 for all

factors (O'Neill et al., 2005). Parents were asked to complete the *CFQ* twice, once for each child to identify parenting practices of each child.

Three-factor eating questionnaire. The *Three-factor Eating Questionnaire (TFEQ;* Stunkard & Messick, 1985) is a self-report questionnaire comprised of three subscales that assess eating behavior. The original questionnaire contained 51 items, yet an 18-item form with identical subscales has been recently demonstrated to be a psychometrically valid and reliable measure of parent eating behaviors among various populations (Hood et al., 2000; Karlsson, Persson, Sjostrom, & Sullivan, 2000). The subscales measure variables of cognitive restraint (e.g., restricting calories to control body weight), uncontrolled eating (e.g., disinhibition and hunger, difficulty stopping eating or inability to resist emotional cues to eat when not hungry), and emotional eating (e.g., eating due to loneliness or mood). Test-retest reliability has been demonstrated to be high for the *TFEQ* ($a = .92$) and when compared to two other dietary restraint measures it had the highest discriminate validity and was considered to be the least susceptible to dissimulation (Allison, Kalinsky, & Gorman, 1992). Cronbach's alpha for each subscale of the 18 item measure has been demonstrated to be 0.76 for cognitive restraint, 0.83 for uncontrolled eating, and 0.85 for emotional eating, respectively (Karlsson et al., 2000).

Procedures

Following approval from the Institutional Review Board Committee (Appendix C), the research procedures were initiated. An electronic message was used to recruit possible participants who were members of/or subscribers to one of the following electronic mail

lists, non-profits electronic mail lists, or public listservs: Down Syndrome Guild of Dallas, DFW Area Moms-special needs, DOWN-SYN list, Bellaonline Forum-Special Needs Children section, National Association for Down Syndrome Discussion Board, UpsNDowns, NDSS and DSRF. All discussion board lists that were sought are free and open to the public, the only criterion to become a subscriber is to possess an electronic mailing address. The electronic message contained an external link that connected the potential participants to a cover letter, which described the purpose of the study and procedures, and link to the four part questionnaire. Return of the completed electronic questionnaire constituted informed consent, as stated on the cover letter.

Data Analysis

First, descriptive statistics were calculated for the purpose of organizing participant information to determine distribution of individuals in categories including; gender, age of children with and without Down syndrome, socioeconomic status, maternal education level, and ethnicity. Pearson's correlation coefficient and Spearman Rank were used to analyze the data for potential relationships, and a dependent t-test was used to determine between group differences. Further explanation of analyses, along with complete survey results are presented in Chapter IV.

Phase II

Participants

Possible participants for Phase II were selected from the original population from Phase I. A purposeful sampling method has been recommended for use regarding

research which involves interview and focus groups (Seidman, 2006; Wolcott, 1990). This sampling procedure is ideal for the data collection techniques in which participants with “shared perspective[s] on [a] research topic may be able to generate meaningful discussions” (Morgan, 1997, p. 55) that could potentially lead to comprehensive exploration of the study variables. As the purposes of this study were to provide a deeper understanding of “complex human issues” (Marshall, 1996, p. 524) within a naturalistic setting, probabilistic or random sampling would not have been appropriate or productive in this case.

The only inclusion criterion that varied from the Phase I participant sample was participants’ time availability for focus groups or one-on-one interviews. Interested participants who were within geographical proximity of the researcher were able to participate in face-to-face interviews or focus groups. Interested participants who were not within geographical proximity of the researcher were able to participate; the only requirement was to have internet access and a membership to the free online telephony service, Skype. Availability, interest, and participant’s schedule determined the final sample size for Phase II. There were a total of 9 participants, 2 focus groups (i.e., 3 in each session; 1 conducted in person, 1 conducted online through Skype), and 3 one-on-one interviews (i.e., 1 conducted in person, 2 conducted online through Skype).

Group homogeneity. Purposeful sampling is necessary when targeting a unique sample such as, mothers who have children with and without Down syndrome. In order to obtain access to this group, online forums were targeted to make contact. Ultimately

though, individual self-selection to participate in both the surveys (e.g., which asked for approximately 30 to 45 minutes of time, anonymously) and the interviews or focus groups (e.g., which asked for a more substantial amount of time and loss of anonymity) dictated the final participant groups. These concepts must be considered as it brings to light the potential similarities and uniqueness of the participant group.

A full description of the demographics of Phase II participants is provided in Chapter IV; however, a few concepts must be considered. All participants self-selected to participate in a project investigating health-related parenting practices between siblings with and without Down syndrome. It can be assumed that a certain level of interest in the discussion topic, whether to share information with others or gain information from others, can be inferred. Another unique aspect of these participants is that all mothers were married to the children's fathers; none were single, divorced, or widowed. All mothers identified themselves as a stay at home mother, either presently or at some point during their children's early development.

Although, the homogeneity of a participant group can be superficially considered a methodological weakness, presently this sample adds a layer of strength. Because the participants in the interviews and focus groups have such similar characteristics, their attitudes and perceptions during discussions can be uniquely compared. The groups' high level of homogeneity adds depth to the data.

Procedures

Focus groups and interviews. Focus groups and interviews were the primary data collections techniques used in Phase II of this investigation. Focus groups and interviews have been used to explore a predetermined topic (Krueger, 1994; Morgan, 1997). Within this technique the researcher outlines the major themes for discussion; however, the interactions of the group or individuals responses to questions ultimately frame the discussion and thus the results. Focus groups and interviews have been previously used to gather health-related information from parents regarding physical activity habits (Menear, 2007) and parent feeding practices (Baughcum et al., 1998; Neumark-Sztainer, Hannan, et al., 2003).

Focus groups and interviews allow participants the opportunity to respond to open-ended questions with responses that may not have been possible with a questionnaire. The number of target factors within the purpose of the study and the size of the research team both drive and limit the target focus group size and number of group and individual sessions (Morgan, 1997). Generally, more than one focus group and interview are recommended to ensure topic saturation. However, the more homogenous a group of participants, the fewer the number of groups that are needed. The purpose and combination of focus groups and one-on-one interviews was to provide comparisons between discussions, further explore research questions, and ensure topic saturation.

The goal in targeting focus group and interview participants is homogeneity in background, but not in attitude (Krueger, 1994). Homogeneity in background allows

participants the ability to relate to one another, thus feeling comfortable enough to share personal stories, while diversity in attitude can expectantly lead to rich discussion (Greenbaum, 1988). For this investigation, homogeneity of participants' background was evident.

The sample size goal for interview and focus group participants was not an exact number but rather a general range that has been suggested to produce an effective environment (Greenbaum, 1988; Stewart & Shamdasani, 1990). The smaller the group the more difficulty there may be in generating in depth conversation, while the greater number of individuals may cause difficulty moderating the group. However, the purpose of a study drives the foundation of a focus group; thus, the size of the group was guided by the goal of the study, the topic itself, and participant interest, availability, and self-selection (Morgan, 1997; Krueger, 1994).

Data collection. An electronic message was sent to all participants from Phase I, which inquired about their interest to be a participant in at least one but up to three focus group sessions or a one-on-one interview, in person or through the free telephony service, Skype. No male participants demonstrated interest in being interviewed, thus only female participants were interviewed. Level of interest from Phase I participants dictated the final number of individuals in the focus groups and number of one-on-one interviews. Once level of interest was established, meeting times were determined through the use of electronic correspondence. Session times and locations (i.e., in person only) were based on convenience for participants. In person focus group and one-on-one interviews were

completed in participants' home, at their request. The day of the sessions, participants completed the written consent form. Prior to sessions, individuals who participated online through Skype, were mailed the consent form with a stamped return addressed envelope.

On the day of the interview or focus group, once participants arrived or logged on to Skype, I, as the PI, communicated all information to participants verbatim from the interview script (see Appendix D). Once participants all arrived, any questions about the study were answered and a brief introduction to ease the participants took place.

Participants were given a notepad and alerted that if at any time they had additional information about a topic, that either they did not feel comfortable sharing with the group or were not allowed the opportunity due to discussion length; they should use the notepad to document their thoughts. Participants were then signaled that the audio recording would begin.

A semi-structured interview model was used during the focus groups and one-on-one interviews, which allowed for less variability between the sessions. Semi-structured interview guides have been used within qualitative research to ensure that all related areas of topic are targeted within interviews (Steward & Shamdasani, 1990; Wolcott, 1990). A concept known as 'reiterating the invitation' is a process that is used to assist during the interview and provides evidence for the need for semi-structured interview guides. By reiterating the invitation, the researcher listens to responses from participants to determine the direction of future questions. The semi-structured interview script was developed to target discussions that highlight the main points of the purpose statement.

The script was slightly modified following data collection and analysis from Phase I. By using this approach and a semi-structured interview guide, efforts were made to provide an open sharing environment and to explore a broad range of possible discussion topics (Chase, 1995). Refocusing prompts were used when conversations during interviews or focus groups shifted from the purpose of the study.

There were 11 discussion questions and each one was read aloud individually, and all participants were given a printed copy of the questions for the benefit of visual learners. Participants were also instructed not to state their name, but notified that if names were mentioned they would be eliminated from the transcribed data. Participants were given as much time as desired to discuss questions before moving on the next one. At the end of interview questions, all participants were asked if they would participate in a member check, which involved reading over the session transcript, providing comments related to accuracy of content, and potentially providing future comments for themes generated during analysis, all agreed. The length of each focus group or interview session did not exceed 90 minutes; this amount of time has been recommended as an adequate time frame to engage in rich discussion without overwhelming the participants (Morgan, 1997; Seidman, 2006). All focus groups and interviews began and transpired in this manner. All focus group and interview participants were offered a \$25 dollar compensation for their time as a participant in the session (Morgan, 1997).

Building rapport. Building rapport between the interview and interviewee is not only a necessary component within the investigation process, but it has the potential to impact

the quality of information that can be obtained. Rapport has been described as “a harmonious relationship,” “a basic sense of trust,” (Spradley, 1979, p.78) and “a balancing act” (Seidman, 2006, p.96). Developing a strong rapport with participants while also maintaining a certain level of formality was a goal prior to data collection. In all communication to participants the goal was to establish and maintain a sense of trust, respect, and interest. Trust and respect were sought through the verbal assertion that all interview and focus groups sessions would be in a setting and time that was convenient to participants. Evidence that this trust was established prior to interview and focus groups was apparent in that participants who agreed to meet in face-to-face meetings, opened their homes for the sessions.

A continued pursuit to maintain these layers of rapport and a sense of interest were also sought after once the sessions began. All participants, in person and online, were asked to share a story or past experience of their choice to *break the ice* and to cultivate a level of comfort with other focus groups participants and myself during the one-on-one interviews. All participants appeared genuinely interested to share something unique about their family and to hear stories from others. Another concrete evidence for the high level of rapport that was established and maintained was the participants’ willingness to not only assist with future potential interviews but also to complete member checks of the transcripts and themes.

As the topic in question for the participants was one of particular importance, health of children and family, most if not all participants were interested in my interest and drive for

exploration. All attempts were made each time this question of investigator motivation was asked to be honest and forthcoming, yet not to provide personal opinions regarding direction of health-related behaviors; in that I did not want my own personal feelings or experiences about health to impact the participants.

Data Analysis

Audio recorded interview data were transcribed verbatim, with the elimination of identifiable data. Data were inputted to *QSR Nvivo 9* software, this software was used to assist with the initial coding process. Descriptive group clusters or chunks were initially identified as the initial layer of coding. Clusters were identified based on key variables of the investigation, previous literature, research questions, and the conceptual filter (Miles & Huberman, 1994). These larger clusters were then used to build a 'start list' to begin the in depth coding process. Code definitions were developed to ensure consistency regarding the identification of codes and a domain analysis (Spradley, 1979) was used to make certain that all relevant material had the potential to be identified and properly coded. Data were coded and then revised multiple times throughout this descriptive process.

Following coding, potential themes were developed and identified with the assistance of *QSR Nvivo 9* software and recommendations from committee members. Analytical memos were completed throughout the coding and recoding process to assist with identification of patterns and themes. Themes were compared with recurring content and were focused from broad to narrow as frequency and pattern connections were made

(Krueger, 1994; Silverman, 2011). As themes began to emerge, major themes were highlighted according to relevance with research questions. Highlighted themes were then put into a table for the purpose of providing a visual representation to further identify and organize main theme outcomes. Parts of emergent themes were then compared with hypotheses, research questions, and theoretical filters (i.e., Social Cognitive Theory and Reciprocal Determinism); this process was based on the procedures of other researchers (Neumark-Sztainer, Story, Perry, & Casey, 1999; Ransdell et al., 2001) who have used these same theories to make comparisons in health-related data obtained by means of interview and focus groups. Emerging interpretations and themes were discussed with research advisors to lessen the personal bias and to “provide a robust check against one person’s perspective having an unchallenged interpretive influence” (Fereday, MacDougall, Spizzo, Darbyshire, & Schiller, 2009, p. 5). Additional findings and unexpected themes unrelated to Phase I hypotheses or Phase II research questions were also examined. Transcripts from all focus groups and interviews are presented in Appendix E. Participants’ responses were organized according to speaker’s initials. When responses overlapped with other participants’ responses as signaled prosodically or non-verbally, transcript symbols were adapted from Heritage (1984). Researcher analytic memos are documented as annotations and identified within each transcript.

Reliability and Triangulation

To ensure that the processes of data collection and analyses were credible and valid, several techniques have been used throughout this investigation. Triangulation is one consistent method used in research studies to increase the validity and credibility of an investigation (Brantlinger, Jimenez, Klingner, Pugach, & Richardson, 2005; Silverman & Marvasti, 2008). Various aspects of an investigation can be triangulated to corroborate one another, including but not limited to the methodology, analyses, and theoretical framework.

Methodological Triangulation

Methodological triangulation was inherent in this investigation in that multiple data sources were used. In this investigation data sources included; questionnaire responses, transcribed focus group and interview data, researcher reflexive journals, analytical memos, and member checks which were completed by participants following the sessions. The purpose of using these multiple data sources was to support one another and enhance the level of reliability within the investigation. By obtaining data of similar content from different contexts the ability to triangulate affairs, as well as confirm or disconfirm conclusions, has been enhanced (Silverman, 2011).

Member checks to ensure transcription accuracy were completed by all participants. Following the sessions, participants were electronically mailed the transcribed material, asked to read it and provide changes, and/or make any relevant additions to the material. An external auditor also reviewed the audio recordings and transcripts to ensure accuracy

of transcription. Thus, the consistency of interview content transcribed has been enhanced which adds an element of credibility to the material (Skukauskaite, 2012). Prior to and after each session and during transcription, I completed a research reflexive journal entry (see Appendix F). This entry included self-report material related to my attitudes toward topics or participants, initial reactions of responses, and any other beliefs or experiences that could potentially impact or confound the interview data and analyses (Brantlinger et al., 2005; Denzin, 2001; Silverman & Marvasti, 2008). The reflexive journal entries, along with analytical memos were used to assist the analysis and data coding, thus providing another layer of triangulation within this investigation.

Analytical Triangulation

As with a mixed approach design, an element of synthesis between the data sets is necessary to generate conclusions; this can be obtained through the implementation of multiple types of analyses, which ultimately provides another element of triangulation and thus validity across the data sources. Individual analyses of both the quantitative and qualitative data sets were completed and then the results were comparatively discussed to provide both support for and authentication of findings, as well as to provide cross-data validity checks (Wolcott, 1990). Further validation of the qualitative data was provided with external auditing of transcripts, codes, and themes completed by an individual on the research committee with significant knowledge of the research topic and research procedures (Krueger, 1994; Morgan, 1998). This individual inspected the material and provided insight during the coding process to ensure not only that adequate procedure

was followed, but also that theoretical saturation occurred without additional bias from the researcher.

Two participants, one from a focus group and one from an interview, were asked to provide member checks related to the themes which were generated through qualitative analyses. Participants' comments were used to further support investigation conclusions. To increase the likelihood that readers will be able to relate to and transfer these findings (Brantlinger, Jimenez, Klingner, Pugach, & Richardson, 2005); thick description and detail was provided related to participant interview responses. With verification from an external auditor and an expert qualitative researcher related to the coding process, theme identification and overall conclusions, credibility of the analyses process is enhanced which ultimately speaks to the level of internal consistency within this investigation.

Theoretical Triangulation

The theoretical filter described in Chapters I and II (i.e., Social Cognitive Theory and Reciprocal Determinism), has been used to independently and interdependently assist with the thematic analysis. Bandura's principle component within Social Cognitive Theory (1986), reciprocal determinism, has the potential to provide insight into the interactionary nature of the parent-child relationship as it is associated with health. Behaviors from mothers not only have the potential to shape the behavior of the children, but the actions of the children can influence those of the mothers, the present investigation is the first to explore this interaction among families who have children with and without Down syndrome. By comparing survey results and thematic results with

the theoretical filter the potential to prevent researcher bias related to the results and discussion has been lessened. The implementation of these strategies allow for additional perspectives or lenses with which to view the data and allow comparisons to be made with other researchers' findings.

In Chapter III, I have provided a detailed explanation of the methodology used during this investigation. In the following Chapter IV, both quantitative and qualitative data which have been collected and analyzed are presented. The results section has been separated into Phase I and Phase II, to ensure clarification for the reader.

CHAPTER IV

RESULTS

“The family is the primary social institution influencing young children, thus, it is likely that many modifiable risk factors for childhood obesity have substantial roots within the family context” (Ventura & Birch, 2008, p. 2).

Overview

The purpose of this study was twofold. First, to investigate the relationship between mothers’ physical activity levels, past eating behaviors, and child feeding practices on the physical activity levels and weight concerns among their children with and with Down syndrome. Second, to further explore these practices between siblings and investigate how having a child with Down syndrome may impact these practices and the family. A mixed approach design (Saks & Allsop, 2007; Creswell & Plano Clark, 2011; Lieber, 2009) that combined both quantitative and qualitative data collection techniques was used.

In order to investigate the primary purpose, data were collected using an electronic self-report questionnaire with four sections; demographics: the *International Physical Activity Questionnaire* (Craig et al., 2003), the *Child Feeding Questionnaire* (Birch et al., 2001; Costanzo & Woody, 1985), and the *Three-Factor Eating Questionnaire* (Stunkard & Messick, 1985). A correlational design was used to examine the potential relationships between physical activity levels, child feeding patterns, mothers’ eating behaviors, and weight concerns among families who have children with and without Down syndrome.

In order to investigate the second purpose, qualitative data were collected using audio recorded one-on-one interview and focus groups, which followed a semi-structured format. Data were transcribed verbatim and analyzed for major themes, member checks were completed to ensure transcription accuracy, and comparisons were made with analytical memos enhance the quality of data and assist with theme satiation.

In Chapter IV, results from both the quantitative and qualitative data that described the physical activity and eating habits among families who have children with and without Down syndrome are presented. Data are reported in this section and are addressed in the same order in which they were collected and analyzed. There are three sections in this chapter. Quantitative data were used to investigate the first purpose; the results are presented in the first section, Phase I Results, and are organized by descriptive statistics and study hypotheses. Qualitative data were used to investigate the second purpose and the results are presented in second section, Phase II Results, and are organized by within case narratives and cross case analyses related to the research questions. Finally, this chapter ends with a summary of the findings. In Chapter V, a discussion is provided that will interpret and synthesize all results.

Phase I Results

Initially both male and female participants were targeted for data collection ($N = 60$); however, some data were eliminated from analyses based on the low number of male participants ($n = 2$) and surveys that were incomplete, the final Phase I sample included 51 participants. First, descriptive statistics were calculated for the purpose of organizing

participant information to determine distribution of individuals in categories including; gender of children, age of children, self-reported weight status of mothers, socioeconomic status of family, ethnicity of mother, and maternal education level. Descriptive statistics are presented in Table 1.

Table 1
Descriptive Characteristics

Variable	Mothers	ChilWDS	ChilWOutDS
N	51	51	51
Gender, females	100%	41%	45%
Age (y)	42.76+/-7.63	8.46 +/- 5.06	11.14 +/- 6.30
Characteristics of the Mother			
Ethnicity	% or N or M +/- SD		
White, non-Hispanic	88%		
Hispanic	6%		
Asian Pacific Islander	1%		
Chose not to respond	4%		
Marital Status			
Married	94%		
Divorced, Single, Widow	6%		
Highest level of education			
High School	8		
Associate's	6		
Bachelor's	21		
Master's/Doctorate	16		
Household Income			
Below \$60,000	19%		
Above \$60,000	67%		
Chose not to respond	14%		
Self-Report Weight Status			
Underweight	2		
Average	31		
Overweight	16		
Markedly Overweight	1		
Chose not to respond	1		
Number of Children	3.33 +/- 1.42		

Note. ChilWDS = children with Down syndrome; ChilWOutDS = children without Down syndrome; N = sample total; y = years.

Hypothesis (a). There will be associations between the physical activity levels of mothers, children, and the family. Data did provide support for this hypothesis. There was a significant relationship between the physical activity levels of the children, family, and mothers. Pearson's correlation coefficient (Field, 2005) was used to analyze the relationship between the physical activity habits of the children, family, and mothers. Questionnaire data from the *IPAQ* targeted three types of physical activity habits: (a) walking, (b) moderate, and (c) vigorous activity. These scores were then used to calculate participants' average weekly time spent being active. Scatter plots were completed prior to analyses which determined the data were normally distributed and that there were no statistical outliers. Table 2 illustrates that the physical activity levels, measured by responses from the *IPAQ* data, between the mothers, children with and without Down syndrome, and family were significant and positively correlated.

Mothers' average weekly physical activity levels ($M = 2852.53$) were positively associated with the physical activity levels of children with Down syndrome ($M = 2760.57$, $r = .333$, $p = .017$), the activity levels of her child without Down syndrome ($M = 4519.65$, $r = .388$, $p = .005$), and the activity levels of the family unit (including at least 2 members present; $M = 1892.71$, $r = .440$, $p = .001$). Although, physical activity levels of mothers were positively correlated with the activity levels of children with and without Down syndrome and the family unit, it can only account for 11% of the variation in physical activity levels among children with Down syndrome ($R^2 = .11$), 15% among children without Down syndrome ($R^2 = .15$), and 19% among the family unit ($R^2 = .19$).

The physical activity levels of the children with Down syndrome were also positively associated with the physical activity levels of their siblings without Down syndrome ($r = .605, p < .001, R^2 = .366$) and the family unit ($r = .615, p < .001, R^2 = .378$). The physical activity levels of the children without Down syndrome were also significantly correlated with the activity levels of the family unit ($r = .491, p < .001, R^2 = .241$).

Table 2
Physical Activity Level Comparisons as Measured by the IPAQ

Variable	Mother	ChilWDS	ChilWOutDS	Family
Mother				
Pearson Correlation	1	.333	.388	.440
Sig. (2-tailed)		.017*	.005**	.001**
N	51	51	51	51
ChilWDS				
Pearson Correlation	.333	1	.605	.615
Sig. (2-tailed)	.017*		.000**	.000**
N	51	51	51	51
ChilWOutDS				
Pearson Correlation	.388	.605	1	.491
Sig. (2-tailed)	.005**	.000**		.000**
N	51	51	51	51
Family				
Pearson Correlation	.440	.615	.491	1
Sig. (2-tailed)	.001**	.000**	.000**	
N	51	51	51	51

Note. ChilWDS = children with Down syndrome; ChilWOutDS = children without Down syndrome.

* $p < .05$. ** $p < .01$.

Hypothesis (b). There will be a significant relationship between mothers' physical activity levels and concern for their children's weight. Data did not provide support for this hypothesis. There was not a significant relationship between mothers' physical activity levels and concern for their children's weight. In order to test this hypothesis, the

degree of association between mothers' physical activity levels and responses from the weight concern subscale from the *CFQ* were compared using Pearson's correlation (Field, 2005). Two separate analyses were completed; one for the children with Down syndrome and another for the children without Down syndrome. Prior to analyses, scatter plots were completed which determined there were no statistical outliers. The physical activity levels of mothers were not related to weight concerns for children with or without Down syndrome. In Table 3, analyses of these variables are provided.

Table 3
Mothers' Physical Activity Levels and Child Weight Concerns, as Measured by the IPAQ and CFQ

Variable	Weight Concerns	
	ChilWDS	ChilWOutDS
Physical Activity Levels		
Mean	9.39	6.82
Pearson Correlation	-.096	-.119
Sig. (2-tailed)	.504	.404
R ²	.009	.014
N	51	51

Note. ChilWDS = children with Down syndrome; ChilWOutDS = children without Down syndrome.

Hypothesis (c). There will be a significant relationship between mothers' eating behaviors and concern for their children's weight. Data did provide partial support for this hypothesis. There was not a significant relationship between mothers' eating behaviors of cognitive restraint and uncontrolled eating and weight concerns for their children. However, there was a marginally significant relationship between mother's level of emotional eating and weight concerns for their children. Prior to testing this hypothesis, scatter plots were completed which determined the data was not normally

distributed and that there were statistical outliers. Thus, in order to test for this hypothesis nonparametric analysis, Spearman Rank, were completed between mothers' *TFEQ* data responses and responses from the weight concern subscale from the *CFQ* data. Two separate analyses were completed; one for the children with Down syndrome and another for the children without Down syndrome.

The relationship between mothers' level of emotional eating and weight concerns for children with ($r = -.239, p = .091, R^2 = .057$) and without ($r = -.274, p = .052, R^2 = .075$) Down syndrome were marginally significant and negative. Mothers' emotional eating accounted for 5% of the variability in weight concerns for children with Down syndrome and 7% for children without Down syndrome. The relationship between mothers' level of cognitive restraint and uncontrolled eating were negative but not significant as related to weight concerns for children with and without Down syndrome. These relationships are illustrated in Table 4.

Table 4

Mothers' Eating Behaviors and Child Weight Concerns as Measured by the TFEQ and CFQ

Spearman's rho		Weight Concerns	
Eating Behaviors		ChilWDS	ChilWOutDS
Cognitive Restraint			
	Correlation Coefficient	-.134	-.005
	Sig. (2-tailed)	.349	.973
	R^2	.017	.00002
	N	51	51
Emotional Eating			
	Correlation Coefficient	-.239	-.274
	Sig. (2-tailed)	.091	.052
	R^2	.057	.075
	N	51	51
Uncontrolled Eating			
	Correlation Coefficient	-.088	-.196
	Sig. (2-tailed)	.539	.168
	R^2	.007	.038
	N	51	51

Note. ChilWDS = children with Down syndrome; ChilWOutDS = children without Down syndrome.

Hypothesis (d). There will be a significant relationship between child feeding practices and concern for their children's weight. Data did provide partial support for this hypothesis. There were significant relationships between some child feeding practices and child weight concerns. In order to test for this hypothesis, the degree of association between mothers' feeding practices (i.e., restriction, pressure, and monitoring) and responses from the weight concern subscale of the *CFQ* were compared using Pearson's correlation (Field, 2005). Two separate analyses were completed; one for the children with Down syndrome and another for the children without Down syndrome. Scatter plots

were completed prior to analyses which determined the data were normally distributed and that there were no statistical outliers.

The relationship between mothers' restriction of food ($M = 24.84$) and weight concerns for children with Down syndrome ($r = .382, p = .006, R^2 = .145$) was significant and positive, thus food restriction accounted for 14% of the variability in weight concern. The relationship between mothers' restriction of food ($M = 24.39$) and weight concerns for children without Down syndrome ($r = .334, p = .016, R^2 = .111$) was also significant and positive, thus food restriction accounted for 11% of the variability in weight concern

There was not a significant relationship between mothers' weight concerns for their children with Down syndrome and level of food monitoring or level of pressure while eating. Related to children without Down syndrome, there also was not a significant relationship between mothers' weight concerns and monitoring of food or level of pressure while eating. It must be noted that though the relationship was not significant, pressure to eat and weight concerns for children with Down syndrome had a positive trend, while this trend was negative among children without Down syndrome. Pressure to eat was also the only feeding practice that was greater among children without Down syndrome. Differences were not significant, but mothers were likely to impose more pressure for their children without Down syndrome to eat, compared to their children with Down syndrome. These results are presented in Table 5.

Table 5
Mothers' Feeding Practices and Child Weight Concerns as Measured by the CFQ

Variable		Weight Concerns	
Feeding Patterns		ChilWDS	ChilWOutDS
Monitoring Food	M(SD)	11.53	10.35
	Correlation Coefficient	.141	.147
	Sig. (2-tailed)	.325	.302
	N	51	51
Pressure to Eat			
	M(SD)	8.00	8.65
	Correlation Coefficient	.076	-.179
	Sig. (2-tailed)	.596	.209
	N	51	51
Restriction			
	M(SD)	24.84	24.39
	Correlation Coefficient	.382	.334
	Sig. (2-tailed)	.006**	.016*
	N	51	51

Note. ChilWDS = children with Down syndrome; ChilWOutDS = children without Down syndrome.

* $p < .05$. ** $p < .01$.

Hypothesis (e). Mothers will exhibit more food restrictions, pressure to eat, monitor eating, and have more weight concerns toward their child with Down syndrome compared to their child without Down syndrome. Data did provide partial support for this hypothesis. Mothers did exhibit significantly more responsibility, higher weight concerns, and were more likely to monitor eating for their children with Down syndrome compared to their children without Down syndrome. Survey results demonstrated that significant differences were not present regarding mothers' level of food restriction or pressure to eat when comparing mothers' child feeding practices between children with and without Down syndrome.

In order to test for this hypothesis, comparisons were made in child feeding practices as measured by responses on the *CFQ* and compared between siblings with and without Down syndrome using a dependent *t*-test. The independent variable was the presence or absence of Down syndrome, and the dependent variables were the four child feeding practices. To determine the substantive effect of the significant differences in practical terms, effect size has been calculated using Pearson's correlation coefficient *r* (Field, 2005). Homogeneity of all groups was assessed using Levene's Test for Equality of Variances (Field, 2005). Levene's test was completed (Table 6) and the assumption for homogeneity of variances was not violated, the variances were not significant.

Table 6
Test of Homogeneity of Variance

Variable	Based on Mean	Levene Statistic	Sig.
Concern ChilWDS		.288	.594
Concern ChilWOutDS		.907	.345
Monitor ChilWDS		1.404	.242
Monitor ChilWOut DS		.019	.891
Pressure ChilWDS		.164	.687
Pressure ChilWOutDS		.231	.633
Responsibility ChilWDS		2.143	.150
Responsibility ChilWOutDS		1.778	.189
Restriction ChilWDS		.236	.629
Restriction ChilWOutDS		1.141	.291

Note. $df1 = 1$, $df2 = 49$.

Mothers demonstrated a significantly greater responsibility related to feeding for their children with Down syndrome ($M = 12.43$, $SE = .317$), compared to their children without Down syndrome ($M = 10.84$, $SE = .480$, $t(50) = 4.740$, $p < .001$, $r = .56$). Related

to weight concerns, mothers' demonstrated significantly greater concern for the weight of their children with Down syndrome ($M = 9.39, SE = .527$) compared to their children without Down syndrome ($M = 6.82, SE = .533, t(50) = 4.02, p < .001, r = .49$). Mothers' demonstrated significantly higher levels of food monitoring toward their children with Down syndrome ($M = 11.53, SE = .420$), compared to their children without Down syndrome ($M = 10.35, SE = .509, t(50) = 2.841, p = .006, r = .37$). In Tables 7 and 8, descriptive statistics and analyses of these variables are presented.

Significant differences between mothers' child feeding practices related to food restriction were not demonstrated between children with and without Down syndrome. Similarly, differences in mothers' feeding practices related to pressure while eating were also not significant between children with and without Down syndrome. In Tables 7 and 8, descriptive statistics and analyses of these variables are presented.

Table 7
Descriptive Statistics of Mothers' Feeding Practices Between Children, as Measured by the CFQ

	Variable	M (SD)	SE
Children with Down Syndrome			
	Monitoring Food	11.53 (3.002)	.420
	Pressure to Eat	8.0 (3.71)	.519
	Responsibility	12.43 (2.27)	.317
	Weight Concern	9.39 (3.76)	.527
Children without Down Syndrome			
	Monitoring Food	10.35 (3.64)	.509
	Pressure to Eat	8.65 (4.404)	.617
	Responsibility	10.84 (3.43)	.480
	Weight Concern	6.82 (3.81)	.533

Note. M = mean; SD = standard deviation; SE = standard error.

Table 8
Mothers' Feeding Practice Differences Between Children, as Measured by the CFQ

Variable	Paired Differences		95% CI		t	Sig.
	M (SD)	SE	LL	UL		
Responsibility	1.58 (2.39)	.335	.915	2.261	4.74	.000*
Weight Concern	2.57 (4.56)	.638	1.287	3.850	4.025	.000*
Food Restriction	.45 (7.99)	1.120	-1.799	2.701	.403	.689
Pressure to Eat	-.65 (4.64)	.649	-1.952	.657	-.996	.324
Monitoring Food	1.18 (2.96)	.414	.345	2.01	2.841	.006*

Note. CI = confidence interval; LL = lower limit, UL = upper limit.

* $p < .05$, two-tailed.

In the following section, a description of the qualitative results collected during Phase II is presented.

Phase II Results

All participants from Phase I were sent an electronic message inquiring about their interest to participate in Phase II focus groups and interviews. Scheduling and geographical proximity to one another determined participation in one-on-one interviews or focus groups and whether the meetings were face-to-face or online. Thus, interested individuals from Phase I self-selected to be participants in Phase II of this investigation. In total, 9 participants took part in the qualitative Phase II. This reflected approximately 15% of the original sample from Phase I. All face-to-face sessions took place in participants' homes, and the online sessions convened at each individual's home computer. Results are first presented as within case narratives to provide an introduction and description of each participant. Following individual narratives, cross case analyses

is presented, organized by research questions and emergent findings. Pseudonyms have been provided for each participant to ensure confidentiality. Descriptive characteristics for Phase II participants are provided in Table 9.

Table 9.
Descriptive Characteristics of Phase II Participants

	Mother's Age	Number of Children	Age at Birth of ChilWDS	Birth Order ChilWDS	Geographic Area
Sharon	44	2	34	2 nd	Texas
Meghan	44	6	40	6 th	Texas
Lacy	38	3	32	3 rd	Texas
Veronica	35	3	28	1 st	Illinois
Sue	57	7	46	7 th	New York
Katie	45	3	35	2 nd	Maryland
Kenna	41	2	34	2 nd	California
Eva	49	2	33	1 st	West Virginia
Stacy	63	6	42	5 th	Texas

Note. ChilWDS = children with Down syndrome

Within Case Narratives

Focus group A. Sharon, Meghan, and Lacy all agreed to participate in Phase II of this investigation. Schedules were aligned and the face-to-face focus group took place at Sharon's home. Although the three mothers never met personally, a sense of familiarity was conveyed once they learned they had mutual friends and all mentioned they had possibly seen one another at a Down syndrome community event. Each participant was asked to share a unique story about their family to open the discussion and begin to build rapport with one another. Through this process, it was revealed that all three participants in this focus group shared certain unique similarities. For instance, all three were married, their youngest son had Down syndrome, all their children lived at home, they were white and of non-Hispanic origin, and all identified themselves as presently being

“stay-at-home moms”. This initial awareness of similarities seemed to increase their eagerness to participate. It was then quickly observed, based from participant comments, that all three mothers seemed to genuinely like one another and were happy to share information. Statements from participants recorded from researcher notes prior to audio recording included, “This is going to be fun.” “I’m ready to start the questions.” “I hope we can answer all your questions.”

Sharon. Sharon was a 44-year-old mother who opened up her home for the session. She was a petite, soft spoken woman with short light brown hair. She had a son with Down syndrome who was 10 years old and a daughter who was 13 years old. She described her family and both of her children as being physically active, but that her son was less active and harder to motivate. She also added that she felt she was always pushing both of her children to be more active. She said “as a family we are always pushing our kids to be active because I have a huge family history of obesity and so I feel like we are always fighting that.” Sharon reaffirmed this declaration once more by stating that being active and healthy is very important to her family, she then described her family history of obesity as “devastating.”

When asked about eating habits and feeding patterns, Sharon explained “I think both of my kids love to eat and so I think the habits that we have instilled in them are the same. I think we try to establish really good family habits.” She then went on to explain that there were certain Down syndrome specific eating characteristics that may have impacted her son’s eating habits differently compared to her daughter’s (e.g., his inability

to recognize satiation, dislike for certain food textures, difficulty when chewing certain foods which makes him seem picky).

Though a question was presented to the group regarding their level of weight concern for both children, the only detail Sharon provided related to her daughters' weight was to say that she was "athletic with strong calves". When asked by another mother if her son was of a healthy weight, she replied "he is. He's just now picking up a little bit of weight." She later stated that she attributed his slight weight gain to being at a pre-pubescent age. When asked about developmental differences between her children, Sharon mentioned a few Down syndrome specific health characteristics unique to her son. She described him as always having low muscle tone, that he has had a few minor choking incidents, and a delayed progression to solid foods.

Meghan. Meghan was a 44-year-old mother with long dark hair and she was very tall with an athletic build. She had six children, three girls and three boys including a set of twin boys. Her children ranged in age from her oldest 16-year-old daughter to her youngest son with Down syndrome who was 4 years old. She described her son with Down syndrome as not nearly as active as her other children, then later stated that the physical activity levels of her two oldest teenage daughters have steadily declined with age. She attributed this decline to being a teenager and the fact that they are "into other things." She explained that it is hard for their family of eight to be physically active together, but that she and her husband have recently started going to the gym regularly and had purchased a family membership. Meghan and her children occasionally take bike

rides together or go walking, but her son with Down syndrome cannot physically last as long as the other children. She mentioned that she hoped he will grow out of this as she attributed his lack of ability to his young age.

When asked about her children's eating habits, Meghan described her children by saying "they all eat the same kind of things," referring to fruits and vegetables and then explained that her son with Down syndrome is the least picky of them all. Meghan also said that her feeding patterns were similar for all the children in that she monitors the children's food intake and that they all have to ask permission for a snack. Her rationale for this rule related more to the economics of feeding a large family of eight, rather than worrying about the type or amount of foods they were each eating. She also stated that eating together is one of the most important activities you can do for your family. Evident from the following quotation, Meghan seemed to feel very strongly about the impact a parent can make on the health of her children through modeling desired habits, she remarked "I mean if you are lazy and don't go exercise your kids are going to see that. The importance you put on it, or not!"

When asked about family history and weight concerns of her children, Meghan made no reference to her own family history related to weight, but she did say that her two oldest daughters and her youngest son with Down syndrome are shorter and stockier, while the other children are "really really thin and built a little different." She did not attribute her children's body composition differences to behavior or family genetic predisposition, other than to describe three of her children as having similar body types.

When asked about different development influences between her children, she mentioned that her youngest son had a few Down syndrome specific eating characteristics, including a delayed transition to solid foods. She described his physical ability differences compared to her other children by explaining that his endurance has always been lower and less developed, and repeated that she hoped that with age he would grow out of it.

Lacy. Lacy was a 38-year-old mother who smiled often and was very outgoing. She had three children, a twin boy and girl who were 8 years old and her son with Down syndrome who was 6 years old. She shared that the physical activity levels of her children are all high and that her son with Down syndrome just wants to copy everything the others do. She also explained that their energy levels and interest for activity are the same, but she then described her youngest son as “ability wise obviously a lot slower.” Lacy’s son with Down syndrome attends a kindergarten program specifically for children with Down syndrome; at his school he attends physical education daily taught by an adapted physical educator. She mentioned that although there are no present concerns, she has concerns for his weight once he transitions to a regular elementary school where he will not have physical education daily and will likely not have a specialist as the teacher. She explained “I mean we’re all aware that our kids have a you know what’s the word? Propensity to be, to become overweight faster than other kids. So I mean it’s something that’s, it’s always in the back of my mind.” Lacy did not express this same concern about her twins who are already in elementary school, but unlike their younger brother, they both participate in weekly organized sports.

She described the eating habits of her three children as being similar, but that her son with Down syndrome is more open to trying new foods. She does monitor what all of her children eat but that her youngest son is the only one required to ask before getting snacks from the pantry; a rule she says her twins have outgrown since they are now 8 years old. Lacy expressed awareness of how her physical activity and eating habits impact her children. For instance, she is training for a marathon and her twins have both made comments that they also want to run a marathon. She then went on to say “the fact that they actually have that in their head, I mean when I was their age I had no clue that there were such things. So I think that’s kind of cool. Then I think maybe one day I can convert them into a runner, maybe one of them.” Related to her own personal eating habits, Lacy said “they are definitely aware of what you are eating.” She explained that she was trying to lose about 30 pounds and the twins noticed the changes she was making in her diet, more fruits and vegetables, and asked her why she changed her habits. She explained to them that she wanted to lose weight and become healthier.

Lacy also mentioned that her family loves to be active together, “not sitting in front of the TV you know doing something active is way more beneficial.” Overall Lacy described her family as healthy, with room for improvement related to healthy eating. She attributed her lack of immediate concern related to healthy eating to the fact that her family does not have a predisposition or tendency for obesity. The only Down syndrome health-related characteristics that Lacy mentioned, that may have influenced her son’s developing differently compared to the twins were his low muscle tone, chewing

problems when first learning to eat, and the elective removal of his tonsils and adenoids to prevent swallowing concerns.

Focus group B. Veronica, Sue, and Katie all agreed to participate in Phase II of this investigation. Schedules were aligned and the online focus group took place with the assistance from the free online telephony service, Skype. The video on the Skype service was not working as planned, thus each participant had only auditory feedback to connect them with the group and no physical characteristics of the participants were available, except the cover profile picture saved to participants' Skype account. The three mothers had never met personally, but seemed eager to share their stories with technological aid from the Internet. For instance, Sue commented that she was not very "tech-savvy" and that one of her sons had helped to get everything set up and she was "excited to do the interview online." The other two mothers made similar statements about being new to Skype, but happy to answer questions about their family. As geographical proximity did not limit this focus group, the mothers represented three different regions of the United States. The age of children varied from 3 to 29 years old, including one mother who was pregnant. All participants were married and other than Sue who had three children out of the house, the rest of mothers had all of their children currently living at home.

Veronica. Veronica was a 35-year-old mother of three children; two girls and one boy, and she was pregnant with her fourth. Her children ranged in age from 3 to 7 years old, and her oldest daughter has Down syndrome. Veronica's children were the youngest of all Phase II participants and she was the only mother who was pregnant. When asked

to share something about her family she communicated that she had just made the decision to go back to school and become a pediatric physical therapist, inspired by her daughter with Down syndrome. She began by saying that though her children were close in age and one might think they would have similar physical activity levels, in fact they did not. She then stated that her “daughter with Down syndrome definitely isn’t as active as the other two.” When asked to describe why she felt there was such a difference in their physical activity levels, she described the difference as being related to her daughter’s personality and not due to her having Down syndrome. She also added that her daughter with Down syndrome was not as motivated to initiate physical activity and gets tired more quickly. Veronica then stated that she and her husband have not figured out how to activate her yet, but she will sometimes join in and play games with her siblings.

When discussing the eating habits of her three children, Veronica described them all as very different. She described her son as a “meal time, snack time, like on time, you know clears his plate kind of kid;” her middle daughter as very picky but loved sweets; and her daughter with Down syndrome as her “health food junkie.” She said their family does not have a lot of food rules and that she felt it was “important that they stop when they’re full, especially [daughter with Down syndrome] with the whole obesity issues.”

Veronica described her family as “an active family um we do our best to eat healthy um you know don’t totally restrict ourselves.” She mentioned that she is trying to be more physically active to be an example to her children, but that their busy schedule

makes it hard and she hopes once the children get older it will become easier. When the group was asked about family history or weight concerns for their children, she did not make a reference to the weight of any of her children, other than to acknowledge that she was aware of the tendency for children with Down syndrome to become overweight. Veronica also mentioned a few Down syndrome specific eating and health-related issues that may have impacted her daughter's developing differently, compared to her other children. For instance, her daughter with Down syndrome had surgery for a blockage in her intestine which caused digestion issues early on and was associated with a year of not trusting food. She also had a few gagging concerns and once her tonsils and adenoids were removed the issue was resolved. Other than those differences, Veronica communicated that she tried to establish similar healthy habits for all of her children and said that "being healthy is definitely a priority in our family."

Sue. Sue was a 57-year-old mother of seven; five boys and two girls. Her children ranged in age from her oldest son who was 29 years old to her youngest son with Down syndrome who was 11 years old. Four of her children lived at home, and her oldest son and two oldest daughters lived close by. When asked to share something about her family Sue, who seemed to be a very soft-spoken woman, stated that her family lived in a small college town and that her two oldest daughters were married.

Sue described all of her children as physically active and said they enjoy sports; however, her son with Down syndrome lacks a peer group like her other children had growing up. She explained that her other children were more active growing up, "because

they would hop on a bike or go run or walk over to a neighbor's house and [son with Down syndrome] doesn't have that." She said that there were opportunities for him to be active, but that without a network of friends outside the family he was not as physically active. Unlike the others, when her son with Down syndrome does not have someone to do something with "he'll watch a movie or play a video game or do something more sedate." If the whole family goes hiking, all the children will go and Sue felt like they really seemed to enjoy those times together.

When asked about feeding strategy differences between her children, Sue mentioned that she has a few techniques that are different for her son with Down syndrome because he is a pickier eater compared to her other children and that he has what she described as "certain Down syndrome related eating issues." She stated that he has always had an "aversion to certain textures of food," and because of that he would not eat fruits and vegetables and has always had a pretty severe gagging reflex. Instead of fighting that battle she tried to sneak foods in smoothies so she could be sure that he was getting all the nutrients he needed, this was something she never "had to do for her other children." She felt it was very important for "all of her children to have a healthful diet."

When asked about any weight concerns that she may have for her family Sue responded that "from the beginning when I found out that [son] had Down syndrome I decided to do all I could to make him as healthy as possible." She said she does not worry about obesity and that she has always encouraged him and all of her children to be as

active as possible and she was aware that it affected their “well-being and the brain and the whole bit.”

Katie. Katie was a 45-year-old mother of three boys, ranging in age from 8 to 12 years old. Her middle son was 10 years old and has Down syndrome. When asked to share something about her family, she stated that she never planned on having children for fear that one might have a disability. She then said “I just was never comfortable around children with special needs,” “and I just didn’t want to risk it and then here we are uh 10 years later and I have [son with Down syndrome], very ironic.” There was a brief silence before the next person spoke.

When asked about the physical activity levels of her children, Katie replied that her son with Down syndrome was just as physically active, coordinated, and talented as her other two sons. She described all her children as physically coordinated and stated that this came from their “father not mother because I am definitely not coordinated.” She then described how they all play football, baseball, and soccer in the backyard together. She expressed that the only drawback or difference her son with Down syndrome has had compared to his brothers “was related to him having Down syndrome.” She recognized that his main difference was his inability to play on organized sports teams. She described her son with Down syndrome as getting very distracted in organized settings, that he loses his comfort level of knowing everyone, and can lose interest in the game very quickly. On the other hand, her other two sons have always played on sports teams. She did not feel that her son with Down syndrome became tired more quickly as he plays

all day long in the backyard, but that he becomes distracted and just sits down during organized games.

When another mother in the focus group asked about peer groups and children with Down syndrome, Katie responded that her son with Down syndrome did everything with his brothers, probably because they were so close in age. She then expressed that her older and younger son's peer groups always included her son with Down syndrome and that someone was always outside playing "and they always go together."

When asked to describe the eating and feeding patterns of her children, she said that of her three boys her son with Down syndrome was the best eater because "he did not have an aversion to pretty much anything" and that he always asked for seconds; whereas her other two sons were picky. She then continued that though her sons ate quite a lot, they take after her husband and "clearly they have a good metabolism." She never had any Down syndrome related feeding issues with her son and she added that he was the only one in the family who did not crave sweets or chocolate; however, he really liked soda even though they no longer kept it in the house. She later explained that when her son with Down syndrome was younger she used soda as a reward during potty training or for good behaviors, something that she considered unnecessary for her other two sons.

As Katie continued to describe the eating habits of her sons, she stated that her oldest son has always been very picky and her youngest son would try anything. She then added they all "burn a lot of energy" playing outside and that her son with Down syndrome was "just so active and um I think his body just needs fuel." She continued by saying, "and

the more active he is, the more he'll eat." While describing eating habits, Katie mentioned "I remember being ya know at some point I did have some concerns because you do um see like older kids with Down syndrome that tend to be heavier," but then added that this was not something she worried about for any of her children because of their high level of physical activity. When asked about feeding strategies, she responded that "we're not a clean the plate type of people, we'll just say eat til you're full." Katie felt confident that all of her sons were able to recognize when they were full, though she did not include a statement of whether she directly taught this skill or whether it may have been overtly learned.

When asked about a family history or potential weight concerns for her family, Katie responded that she did have some history of obesity and diabetes within her family but that "for us it's really about healthy eating, it's really always been about healthy eating and sitting together as a family at 5:30, providing healthy snacks and absolutely being physically active." She also commented that although they did not eat organic food, she felt very strongly that she has taught her children to make good choices regarding food and to always eat in moderation. She said that her family history of obesity has always been in the forefront of her mind and that once her son was diagnosed with Down syndrome that too impacted her thinking. However, she claimed that after her own "novice research" about health and Down syndrome, she decided she would encourage all of her children to be active and healthy, as they were all capable of anything.

Interview, Kenna. Kenna agreed to participate in Phase II of this investigation. Schedules were aligned and the one-on-one interview took place with the assistance of the free online telephony service, Skype. The video on the Skype service functioned as planned, thus video and auditory feedback were present during this interview. Kenna was a 41-year-old mother of two girls, her older daughter was 11 years old and her younger daughter with Down syndrome was 7 years old. Something unique that Kenna shared about her family was that she and her daughters enjoyed hula dancing together and they regularly performed around the community at special events.

Kenna described her two daughters as having very different physical activity levels. She stated that her younger daughter with Down syndrome was more physically active and more motivated to be active, compared to her older daughter. She said her older daughter “can sit and watch an entire movie or ya know if I let her, she would watch TV all day long,” and that though she had played soccer and seemed to enjoy it, she was still not as physically active as her younger sister. Kenna described her daughter with Down syndrome as her “gross motor queen” and stated that she did not really have any physical delays; she’s good at climbing, and loves running and playing outside. The only Down syndrome health-related issue that her daughter had was pediatric arthritis, which sometimes caused her to slow down but on those days they would go to the indoor swimming pool. Whereas, her other daughter would prefer to just sit inside all day. When asked about why she felt the girls had such different levels of physical activity she attributed the differences to interest and personality. She then said her daughter with

Down syndrome was similar to her husband, always wanting to go somewhere and do something; whereas, her older daughter was more like her, “a homebody.” She also said that the four of them would hike together and ride bikes, they have an adapted tandem-like bicycle that her daughter with Down syndrome would ride on as she could not yet ride independently. When asked to describe how she felt quality time can be spent together, Kenna replied that being active together is “much higher quality than sitting watching a movie together.”

When asked to describe the eating habits of her children, Kenna described her daughters as having similar habits, except that her older daughter really enjoyed sweets while her younger daughter with Down syndrome would eat “chicken and rice” at every meal. She continued by saying that neither of the girls are picky eaters and they both like their fruits and vegetables. Kenna also stated that even though the girls’ food preference differences were slight, she had different strategies and food rules for each daughter based on their eating habits. For instance, since her oldest daughter often craved sweets, Kenna decided she was only allowed sweets on the weekends. Kenna then described that her youngest daughter with Down syndrome had issues with “portion control,” so when she had snacks such as pretzels or chips she had to put them in a bowl rather than eating out of the bag. Kenna said that she monitored the amount and type of food eaten by both girls and they both had to ask permission when snacking “because ya know they run and grab unhealthy snacks” or they would try and snack right before dinner.

Kenna mentioned that when she and her husband learned their younger daughter had Down syndrome they decided they wanted to be a more active family. She said “we knew she was gonna have some potential for weight issues and so we knew that we had to step it up.” Kenna described that both daughters have had some minor weight issues growing up, but that presently their “body mass index is good.” When asked to describe what she felt was most important to the health of her family, Kenna closed by saying, “we get our good healthy foods and so that’s important to all of us, and it really isn’t as much about the weight but ya know, being active and having good exercise and eating good food so ya know um one is not more important than the other.”

Interview, Eva. Eva agreed to participate in Phase II of this investigation. Schedules were aligned and the one-on-one interview took place with the assistance of the free online telephony service, Skype. The video on the Skype service functioned as planned, thus video and auditory feedback were present during this interview. Eva was a 49-year-old mother with two children, one boy and one girl. Her son was 13 years old and her daughter with Down syndrome was 16 years old. Something unique about Eva was that she was a teacher and very transparent about her abilities and what she called her “failings as a mother.” For instance, she said “you make time for what you want to make time for,” she has considered herself as a barrier to physical activity for her family. She said “I’m busy and I get home from work and want to work on dinner or work on whatever so if I’m not in it [referring to physical activity], then it’s not happening and I don’t necessarily want to do it my own self so that’s just me telling the truth.”

Eva described the physical activity habits of her children as being very different. She said that her daughter with Down syndrome was very high energy, but “she’s not as likely to get up and do physical things,” as she preferred to be on the computer, though she has participated and did well in Special Olympics. Eva described her daughter as “very trim,” and continued with “I really don’t probably make her get out as much as I probably should.” On the other hand, she described her younger son as very physically active, always playing sports, and that she often encouraged him to go outside and play with his friends. Eva also stated that her son would love to play with his sister and though he was three years younger they were not on the same playing level as has always been more skilled. She then stated that because her daughter with Down syndrome was so hard to motivate and her son seemed to enjoy playing down the street with his friends, she did not “hold her feet to the fire” enough to make it happen. When asked what she attributed the differences in her children’s physical activity levels, she said she did not think it was gender, “no I really think it’s because he doesn’t have Down syndrome.”

Eva described the eating habits of her family as very different for the reason that her husband has diabetes, her son has what she described as “horrendous” food allergies, her daughter was on a feeding tube until she was 8 years old, and she described herself as a stress eater. She said that she cooked meals that everyone could eat, not one meal for her son or another for her husband, “for us ya know as a family.” She said she monitored the foods eaten by both her children to ensure they were receiving the proper nutrients. She claimed she monitored her son’s habits because of his food allergies and her daughter’s

because of several Down syndrome specific health issues. For instance, her daughter was born with a heart defect, had several surgeries, and was fed through a feeding tube for such a long time that the long process of teaching her how to eat has been a constant. She claimed they were still introducing new foods as she still did not want to eat “certain textures.” She felt certain that if her daughter had not had a feeding tube for so long her eating habits “would be more like us.” She stated that both of her kids were “really really skinny” growing up, her daughter because of the feeding tube and her son because of food allergies, and they used to worry about getting “enough food” in them, so she was just thankful that they were eating.

When asked about any weight concerns she had for her children, she responded by talking about the amount of encouragement she provided for her children’s physical activity habits. She said “I probably allow her to get out of it because we’re so thankful that she’s trim and very physically capable in her own way. So we’ve been really lucky. There’s a lot of children with Down syndrome that are very chubby.” She also mentioned that she felt genetics played a big role in her family, as her daughter was very trim like her husband’s side of the family while her son was more “big boned” like her side of the family. Regarding her son, she expressed that she was interested to see how his weight may change once he went through puberty, for the reason that he “has the propensity if he sits around to put on some pounds.” She concluded by saying “there’s a genetic component to it and lack of physical activity,” “because kids used to come home and

they'd be outside and now half the kids are doing something else or there's nobody to play with."

Eva also described that her family loved to spend quality time together being physically active, but that they did not do it enough. She even posed a question speaking in third person, "gee Eva, the fact that it's really good you think that would encourage you to do more um but it really doesn't." She said the health of her family was important but that "I'm part of it too cause like the mom who really likes to be up doing stuff all the time, she would come home and do that."

Interview, Stacy. Stacy agreed to participate in Phase II of this investigation. Schedules were aligned and geographical proximity allowed a face-to-face interview which Stacy offered to have at her home. Stacy was a 63-year-old mother of six. Her oldest son was 33 years; her youngest son who was 21 years has Down syndrome and lived at home, along with her youngest daughter who was 18 years old. Stacy shared that something unique about her family was that all of her children's names began with the same letter, she had two grandchildren, and she worked part-time as a crossing guard. A comment that Stacy shared which provided support for her dedication to the health of her family was her reaction when the doctor told her that her son had Down syndrome. The doctor told her "well you've got a Down syndrome child so I'm going to be seeing you a lot," Stacy said she immediately thought "not if I have anything to do about it you won't!"

When asked to describe the physical activity levels of her children, Stacy started by saying, “I made sure that they were all exposed to the possibility of a movement program.” She then went on to describe that all six of her children have been involved in various sports throughout the years and that she always encouraged them to pursue their interests. She mentioned that while growing up, she encouraged them to be well-rounded; some played soccer, track, basketball, and the girls did gymnastics. She commented that they tried many sports for their son with Down syndrome, but often he was not interested and “he sat down in the middle of the field.” The only physical activity Stacy mentioned that her son with Down syndrome participated in that the others did not was hippotherapy. A local horse riding program provided free services for children with special needs; she described how the program “really strengthened his abdominals,” and that prior to the program “he had no muscle tone.” Stacy also shared that though she did not consider herself to be really active; she made sure to always “keep them in activity.”

When asked about the eating habits of her children, Stacy began by stating that her oldest son had severe food allergies and after his birth they began to eat naturally and nothing was as she described, “pre-prepared.” She felt from that healthy example the others just “learned good dietary habits,” but that her youngest two children were the pickiest. She then described that her son with Down syndrome did have trouble learning to swallow and chew but that she made no dietary changes for any of the children, even though they were “picky.” She was adamant that “you’re in this family and you’re eating

what we are.” Stacy also felt like she set the pace for eating and said “I tried to pass on as much as I could to the kids and I think I did a pretty good job.”

Stacy went on to not only describe the eating habits of her children but also included how she felt those habits influenced weight and described their family history related to weight. She expressed that her son with Down syndrome did not like sugar or sweets, a habit that she believed allowed him to “stay slim cause you know Down’s children have a tendency to be heavy and he’s always been, [of]course his Dad’s 6’5 and skinny as a rail so he’s inherited a little bit.” She also described how her daughter who tended to be more like the heavier side of the family, had to change her eating habits as she entered her late teens. She described her daughter’s food preference as eating “a lot of carbs” and explained a conversation they had about her habits, “I said ya know [daughter without Down syndrome] you tend to be like your father’s side and you’ve got a big derriere and we talked about the weight thing and she’s, she’s self-conscious of it and she’s tending more towards the salads, drinks water and eats vegetables instead of [pause] the junk.”

When asked about how her family spent quality time together and whether she considered physical activity as an option, she said she never thought of activity “in that way,” mostly because her husband was a worker “so a lot of the time that was the physical activity,” “raking, cutting down tree branches or stuff like that.” She described family time at her house as sitting down watching a movie together, though she said that her son with Down syndrome had become quite the “loner” and even if they watched one of his favorite movies “he won’t sit with us.”

When asked about what has shaped her feeding patterns, Stacy answered that her own perspective on eating was shaped and related to the fact she and her husband grew up on farms, and “you ate what you had and food was for nourishment.” So she felt that attitude has influenced how people eat nowadays and how active or inactive they were, especially related to her children as “teenagers.” She went on to say that she just tried to be consistent by giving them healthy foods, and she made healthy eating and good choices a priority and “then it became a habit.” Stacy also added that “the most important thing you can do for your family is feed them properly.”

Cross Case Analyses

Presentation of findings of the cross case analyses are organized according to research questions and emergent findings based on Phase II participant responses. Elements of reciprocity between variables have been identified and are infused as relevant. This process is based on procedures from previous researchers (Neumark-Sztainer et al., 1999; Ransdell et al., 2001), who similarly identified elements of Social Cognitive Theory (1977) and Reciprocal Determinism (Bandura, 1978) within health-related behaviors. Verbatim quotes from participants are labeled in terms of age of participant, number of children, and whether they participated in a focus group (FG) or one-on-one interview (I), and in person (IP) or online through Skype (S). For example: 38, 3, FG-IP.

Research question (a). Based on responses from participants, physical activity habit differences seemed to exist between siblings with and without Down syndrome; however,

feeding practice and eating pattern differences between siblings were not as apparent.

Mothers attributed habit differences and similarities to numerous factors.

Physical activity. Mothers described their children with and without Down syndrome as being physically active, yet a majority described their child with Down syndrome as less active. Only one mother stated that her daughter with Down syndrome was more active than her other children. In the following quotations mothers described differences in the physical activity levels of their children.

“If we decide to go out in the backyard and kick the ball around, the other 2 [children without Down syndrome] are definitely very excited and are the first ones out there where [daughter with Down syndrome] it just depends on what mood she’s in.” (35, 3, FG-S)

The only mother, who described her child with Down syndrome as more active, stated that, “[Daughter with Down syndrome] loves to be doing things outside and she’s very active. She’s, I call her my gross motor queen! Yeah because she’s just, there’s not [pause] delay as far as gross motors skills. She’s really just good at it all. Ya know she can scale a wall and she’s good at climbing, ya know we have a play structure outback and she’ll go just play on her own or she tries to get her sister to come outside with her. Whereas [daughter without Down syndrome] could just stay inside all day and watch TV.” (41, 2, I-S)

“He’s [child with Down syndrome] not nearly as active as they are because they can play outside and go ride bikes all over the neighborhood and he does want to go out there and I have to be with him otherwise he would just run down the street and keep running. But as far as swimming like she said [another mother] and activities he likes to do what they [siblings] do he just, but he does get tired.” (44, 6, FG-IP)

“The age of [son with Down syndrome]’s development um affected his ability to participate but you know [pause] now that he is 10 he’s just as active [pause] um as the other 2. I mean I would say just as active and um probably just as coordinated and talented as um as a typical child his age I mean he can [pause] you know he can catch the ball and he can, he bats and he plays football he scores on soccer I mean he definitely um is physically coordinated.” (45, 3, FG-S)

“[Son with Down syndrome] has 4 older brothers and an athletic sister he has opportunities to be active however [pause] because he doesn’t have um [pause] a network of friends outside the family like my other children do he probably is not as physically active so if he doesn’t have someone to do something with he’ll watch a movie or play a video game or do something more sedate.” (57, 7, FG-S)

“They are [pause] very different, I [pause] mean I feel like as a parent I am always pushing both of them to be more active. [Daughter without Down syndrome] is active, she’s in cross country right now, she plays soccer. Um, [Son with Down syndrome] played soccer he didn’t like it, it was just too much running. He likes a little sprint and he’s done. Like a little race and then he’s done, um. He likes, like he seeks out sensory activities so that’s very different for him.” (44, 2, FG-IP)

Another mother described her son with Down syndrome’s physical activity levels as “very similar to [siblings without Down syndrome] as far as he wants to copy everything they do. We have a trampoline outside, they go out there he wants to be out there jumping. But [pause] I think energy level and interest level is definitely similar. I think he wants to be involved in all the same things they do. They play, he plays, he plays hard.” (38, 3, FG-IP)

Another mother described her children as being “pretty active,” but that her son with Down syndrome was not very active. When continuing to comment on his level of inactivity she stated that “he’s just, they need a lot of motivation.” Further probing determined that her use of the term *they* was meant to describe children with Down syndrome. (63, 6, I-IP)

As discussions continued related to the physical activity habits of children, mothers approached the discussion of physical activity comparisons between children based on age. The following excerpts provide examples.

“As far as energy level I don’t think it’s a whole lot different than the twins [siblings without Down syndrome] when they were his age. He’s really active um ability wise [pause] obviously he’s a lot slower which impacts him a little bit.” (38, 3, FG-IP)

“I think that they [pause] no [son with Down syndrome]’s not as active as they were at the same age, he [pause] can’t last as long as they do but I think that is his age maybe, I hope.” (44, 6, FG-IP)

Evident from the following quotations, study participants felt there were differences in the physical activity levels of their children. Differences were apparent by the different techniques in which mothers used to motivate or encourage their children to be more active. A majority of parenting practices appeared to be reciprocally related to the habits and behaviors of their children, though there was not a consensus regarding the motivational techniques related to the presence of Down syndrome. For instance, one mother described a strategy she used to encourage her child with Down syndrome to be more physically active, while another mother confirmed that she used the same technique for her child without Down syndrome. For instance:

“If [her son with Down syndrome]’s been sitting in the house too much I’ll say come on let’s go jump on the trampoline or come on let’s go over to the bike path and take a walk or so. And I didn’t have to do that too much with my older kids.” (57, 7, FG-S)

“I definitely need to activate [daughter with Down syndrome] more than the other kids. The other kids just kind of do it [referring to physical activity] on their own and again with them being so close in age I think they’re starting to get [daughter with Down syndrome] motivated to do more things but you know being cold outside now they just run circles around the house sometimes!” (35, 3, FG-S)

“I would say I do that with um with uh [son with Down syndrome] as well, but I do that for all the kids [pause] like they’ll be sittin inside and I’ll be like guys, what are you doin it’s a beautiful day go outside! And they’re like NO we don’t wanta go outside we wanta play video games or we wanta watch a movie and I’ll say no it’s too pretty of a day and I’ll say ya know go outside for at least an hour and then you can come back.” (45, 3, FG-S)

A range of perceived factors that mothers attributed to the similarities and differences in the physical activity levels between children were described. There was not a general consensus specifically related to barriers for children with or without Down syndrome, factors that impacted activity level included: presence of Down syndrome, personality,

age, motivation, interest, presence of other sedentary tasks, inability to play outside independently, lower physical ability, and lacking a peer group.

“We have had [son with Down syndrome] on team sports but he gets very um [pause] distracted. You know? He’ll, he’ll wanta play for like 5 minutes and then he’ll just like sit down or it’s [pause] just very hard for him to play [pause] organized sports.” (45, 3, FG-S)

“[Daughter with Down syndrome] does get tired quicker than the other kids. And I don’t think it’s that she’s not interested in what’s going on but she will sit down you know instead of stand up and wait in line with the other kids. She’ll sit down and wait in line.” (35, 3, FG-S)

“Like volleyball, when [daughter Down syndrome] was in season for volleyball it was twice a week for an hour. Um but then that’s it. Like [son without Down syndrome] might go to basketball practice for an hour an a half or 2 hours and then he’ll also shoot around here, we have a basketball hoop and stuff and so he’ll hook up with his friends and do some more. And for [daughter Down syndrome], that’s it. She goes and they do it and then she’s done.” (49, 2, I-S)

“[Daughter with Down syndrome] needs a purpose [pause] and if they’re just doing things like drills [pause] um they were in a track and field class last summer and she, she loves to run, so I thought she would love it but she didn’t and it was too drill oriented and it just didn’t have a purpose for her and I think she lost interest for that reason.” (35, 3, FG-S)

“I don’t think he’s [son with down syndrome] tired I just think he’s distracted or you know during the backyard play their playing with friends he knows everyone, everyone kind of knows him and I think there’s just a higher comfort level there. And when he’s playing organized sports he doesn’t know the other team and he doesn’t, he just gets, he loses interest very quickly.” (45, 3, FG-S)

“The other 2 are definitely like outside exploring more and doing that kind of stuff and I think it’s just more her personality [daughter with Down syndrome] versus necessarily having Down syndrome.” (35, 3, FG-S)

“I think for [son with Down syndrome] it’s more social [referring to physical activity] and if there are people doing it ah [pause] that he knows or that he’s related to, or he’s not interested.” (57, 7, FG-S)

“Oh yeah, that’s [son with Down syndrome] too. He’s very, it is a social aspect and the comfort level so. When he is playing and he knows every, all the players [pause] he’s good. But the organized sports just really doesn’t seem to work for him.” (45, 3, FG-S)

“I think just personality. [Daughter with Down syndrome]’s just more [pause] active, she likes to go places. Ya know she’s always ready to go. No matter the time, day or night. And [daughter without Down syndrome], she a homebody. And she likes to be at home and stay inside and just ya know, be a homebody.” (41, 2, I-S)

“I think he, no I really think it’s because he doesn’t have Down syndrome.” This mother went on to say, “although I do think that boys tend to be in lots of ways more active but I also think that trend is shifting and there have been more and more sports for girls to play.” “I really think its [daughter with Down syndrome] because she is who she is and she doesn’t want to do it.” (49, 2, I-S)

“She’s not necessarily that motivated by that [referring to the family being physically active outside together] and just sometimes she wants to sit down and watch a movie or play with her baby doll instead of taking that motivation of us being outside together.” (35, 3, FG-S)

Another mother stated that her daughter with Down syndrome was more active “because she is younger and she doesn’t have the attention span to sit and do things for longer periods of time. Whereas [daughter without Down syndrome] can sit and watch an entire movie or ya know if I let her, she would watch TV all day long.” Later she shared that she will turn the TV off for her daughter without Down syndrome while her daughter with Down syndrome “gets bored of a show or a TV, movie or something. So she’ll get bored and get up.” (41, 2, I-S)

“Because they [siblings without Down syndrome] would hop on a bike or go run or walk over to a neighbor’s house, in the other neighborhood and um [son with Down syndrome] doesn’t have that. And they might walk down to the store to get something to eat and you know [son with Down syndrome] will do that if one of his older siblings is doing that but because of a lack of a peer group in the area [pause] he’s probably less active.” (57, 7, FG-S)

“And they’ll chase each other, and [daughter with Down syndrome] will jump up and join in that right away. So I’m starting to see that her siblings will be more of a motivator for her and hope that once she does develop that peer group that her peers will be but as far as my husband and I, we’re definitely not motivators for her.” (35, 3, FG-S)

“And I would say for he’s [son with Down syndrome], he does do the things that his brothers do because they are so close in age.” This mother continued to say that her son with Down syndrome does not have his own group of friends but that “he’s friendly with

his brothers' friends and I think the fact that they are so close in age, that's what give him a quote, peer group. So he'll, he will go outside and play. Because 9 times out of 10 [son without Down syndrome]'s goin outside to play or [other son without Down syndrome]'s going outside to play and they always go together." (45, 3, FG-S)

Feeding practice and eating patterns. Although there were strong differences in the physical activity levels between siblings with and without Down syndrome, the eating habit and feeding pattern differences between siblings were not as apparent. Some mothers mentioned that their children liked to snack, were picky, or would eat anything regardless of feeling full. However, there were no clear differences or consistent patterns between children related to the presence of Down syndrome. Some parents attributed slight eating differences to specific health issues associated with Down syndrome (e.g., feeding tube, gastrointestinal issues, or a gagging reflex), yet most mothers described habits based on the individual. However, similarities appeared to be consistent with the types of feeding practices the mothers used among all children. Parents mentioned various rules they implemented related to food choices and snacking, the rules were usually for all the children or the rules were implemented for the purpose of encouraging or discouraging a child's specific eating habit. For instance:

"Uh, and her preference really is to have a lot of sweets. And so we've had to put some restrictions, on that." When probed further she described that she did not have the same restrictions for her daughter with Down syndrome, she stated "[Daughter with Down syndrome], her favorite food is chicken and rice! That's what she wants, she would eat that all the time, 3 meals a day, she would snack on that. Um [pause] and she's not, she doesn't like a lot of junk food or sweets especially." Later she described a rule that applied to both daughters, "they do need to ask me before they want anything. Both of them do. Because that's just, I don't want them running and grabbing, because ya know they run and grab unhealthy snacks." (41, 2, I-S)

When asked about her feeding practice differences between siblings, one mother responded that she monitored the food intake of her daughter with Down syndrome more so than her son for the reason that she is pickier and not as likely to go after healthy foods, so she monitors what she eats “in order for her to get the vitamins in those foods!” (49, 2, I-S)

When asked about eating habits and feeding patterns within their family, some mothers mentioned their child’s weight or weight concerns which shaped their feeding patterns and how they purposely encouraged or discouraged certain eating habits in their children. The following excerpts provide evidence:

“Yeah, so [son with Down syndrome]’s just not into [pause] the sugar stuff and I think that’s why he’s so, stays slim cause you know Down’s children have a tendency to [pause] be heavy and he’s always been, course his Dad’s 6’5 and skinny as a rail so he’s inherited a little bit but uh he’s just not into sweets.” (63, 6, I-IP)

“We have definitely indulged [daughter with Down syndrome], mostly because she’s been so underweight and we’ve been more worried about getting some weight on her. We’ve let her eat kind of whatever she wants, we’re just so glad [son without Down syndrome] used to be really really skinny because with his food allergies and trying to get enough food in him was really hard, with both the kids.” (49, 2, I-S)

Similarities were observed in descriptions from mothers related to the eating habits they were concerned about and how those habits may have shaped their feeding patterns. The similarities were related to the close monitoring of food or worry related to the type and amount of food for their children with Down syndrome and children without Down syndrome who had the potential for future weight gain. Potential concern for weight provides an example of how overt and indirect perceptions or actions can impact the health-related parenting practices. For instance:

“But again, I think it’s the Down syndrome specific things that are a little different. Like [pause] I don’t know when I’m full. [pause] Or I don’t know when I’m hungry.” (44, 2, FG-IP)

“I mean all my kids are good at stopping when they are full and um maybe not necessarily eating as much as they should at each meal or snack but [pause] I think it’s more important that they stop when they’re full, especially [daughter with Down syndrome] so [pause] with the whole obesity issues.” (35, 3, FG-S)

This same mother further described the eating habits of her son [without Down syndrome] who she previously mentioned “has the potential for future weight gain.” “So now we’ve recently started talking about stopping when you’re full because I don’t want him to get into bad habits.” She later identified bad habits as feeling like you have to “clean your plate” even when not hungry. (35, 3, FG-S)

“But obviously we have to set [referring to food rules] I mean we’re all aware that our kids have a [pause] you know a what’s the word? Propensity to be, to become overweight faster than other kids? So I mean it’s something that’s, it’s always in the back of my mind. I’m like okay [pause] not that I’m overly worried about it at this point but it’s something I know I have to keep in my head.” (38, 3, FG-IP)

“So we’ve kind of gone back and forth with our weight as well as a family. So for this family, so for our kids that has always been more in the forefront of our minds um because of our family history. We also have a family history of diabetes, so um for us it’s really about healthy eating, it’s really always been about healthy eating and sitting together as a family at 5:30. Ya know providing healthy snacks and um absolutely being physically active. And making good choices.” (45, 3, FG-S)

As discussions continued related to eating habits of children, as previously described mothers attributed numerous factors to those differences. Another recurring theme from mothers was the mention of how their own personal eating habits have impacted the habits of their children. Some mothers became aware of their own “unhealthy habits,” recognized the reciprocity in these behaviors, and made changes so as not to encourage those habits in their children. While other mothers simply explained the habits to the children or made an attempt to hide them.

For instance, an exchange between participants in a focus group was as follows:
“Yeah! It’s funny because when they were littler, I would put them to bed and now they are staying up later and I’d usually have my little night time snack you know?”

[laughter] And now [pause] my daughter's [without Down syndrome] up til 9 o'clock, 10 o'clock and" (44, 2, FG-IP)

"she catches you?" (38, 3, FG-IP)

"Yeah! So I'm eating healthier at night. You know? I know it's like I can't just sit in there with my cereal" (44, 2, FG-IP)

"So the awareness of their awareness makes a difference?" (Principal Investigator)

"Yeah, yes." (44, 2, FG-IP)

"My oldest daughter, I'll see her standing at the island eating. I'll see her get something out of the fridge and I'll tell her to sit down and I'm thinking oh my gosh I do that to! So and which they tell you not to do that, fix yourself a little plate and sit down and eat it. But with hurryin and tryin to get the kids to this and I have found myself, not eating a meal but just snacking or putting something in my and she does that a lot! And I'm like [daughter without Down syndrome] go sit down and eat! And take a sip of water in between each bite. But I mean she's seen me do that too." (44, 6, FG-IP)

"I'm a sweet breakfast person um so up until probably recently I've tried to hide it from them um again it's a choosing your battles thing with a 2 and 3-year-old it's hard for them to understand uh it's getting to the point now that I can say I'm mommy and [laughter] and I can have my vices! And so far that's worked for them. You know occasionally we'll break the rules for them and we'll have a donut for breakfast in the morning or something and it's more of a treat to them." (35, 3, FG-S)

"I think definitely they [personal eating habits] impact our family. Because if I ate how I wanted I would just be they would be eating the same things, and if I ate whenever I wanted I couldn't tell them not to do that. So I think it's definitely tied together. I mean we are like a herd." (44, 2, FG-IP)

The following excerpt describes a mothers attempt to teach her daughter about portion size and sweets. Following several attempts, she decided to wait until her daughter was in bed to have her own treat:

"Um, well if I'm gonna have ice cream or something like that I'll wait til after they go to bed." (41, 2, I-S)

"Really?" (Principal Investigator)

"[laughter] I fight that part!" (41, 2, I-S)

"And is that from past experience or is that something you just kind of wanta hide from them?" (Principal Investigator)

"Um no because [daughter without Down syndrome] will say well you're having ice cream, so why can't I have ice cream? Because I'll show her a pint of ice cream and say, this for me is going to last 4 times! Whereas for her it would be 1 or 2! Um so yeah and I'll show her I'll have a little bit of ice cream and I'll show her the top of it, now this is how much I've eaten that's 1 serving for me. So the rest will go and I'll have a little bit

more tomorrow and a couple more nights after that. So she's noticed and she um she thinks it's not really fair and she'll say things like you're o well you're um shoving it in my face or something like that. So I said well okay so I'll just have my little bit of ice cream when you're in bed." (41, 2, I-S)

As the discussions continued related to children being picky or preferring different foods, some mothers made similar comments related to the notion that the family as a unit would not only eat meals together, but all consume the same foods.

"No dietary changes, it's like [pause] you're in this family and you're eating what we are." (63, 6, I-IP)

"We eat together, so we don't eat separately we don't eat different things either. I'm not [pause] my husband actually does the cooking and we are not a short order cook!" (44, 2, FG-IP)

"And I think that parents make a huge mistake when they indulge that, ya know my mom, her parents just had no money and they had 8 kids and lived in this sweet little house, but it was little. And you know what? They all grew up to be amazing good eaters and ya know everything sit down. And not picky, they ate their vegetables, and there was just not fussing and I think you know you don't fuss when you don't have a choice. And we're so indulged, all of us, including me that because there's just so much more money in the United States then when my mom was growing up that, it's a negative." (49, 2, I-S)

Research question (b). There seemed to be a consensus between all mothers that there was a high potential for the encouragement of lifestyle habits (i.e., physical activity and healthy eating) related to quality family interaction, yet not all mothers felt confident in their personal ability or their family's ability to consistently execute those intentions. Mothers seemed to view family connectedness related to physical activity and eating in various ways. Mothers were aware that activity and eating times can be great bonding and interaction opportunities to pass along healthy lifelong habits and spend quality time together, and some described that they were already actively doing this with their family.

However, some mothers asserted that they had not yet considered or implemented this idea, but felt it was a great concept and that they plan to add or hope to add this to their family's routine. The encouragement and execution of certain habits based on the future benefit for the family unit demonstrates the reciprocity between parents' beliefs, actions, and the desire to impact others. One mother described her family's weekend ritual that she felt demonstrated how they already implement healthy eating, physical activity, and family quality time simultaneously. For example:

“What we do is a on Saturdays and Sundays the kids, well it's more driven again by my husband but so on Sundays we'll watch football I'll usually read a book [laughter] and they'll watch football and alternate between like commercials or games and they'll go outside and play and then they'll come back inside but our Sunday ritual is um [pause] a salad bar. So we go to the store and we go um get all the makings for a salad and then um we set it up on our kitchen table and then they will pretty much make um their own um salad [pause] and that is like their favorite they're just thrilled to death to do it!” (45, 3, FG-S)

Physical activity. Mothers examples varied related to the types of physical activities their family performed while spending time together; however, all agreed that time spent as a family being active was considered high quality. Statements were also made that physical activities provided more opportunity for family bonding compared to sedentary tasks.

“That's a much higher quality than sitting watching a movie together [laughter]! Yeah, we'll go [pause] also our housing area has a big playground in the middle of it so we'll go to the playground and let the girls play and walk the dog and do all kinds of stuff like that. And I feel like that's really important and that's what we like to do as a family, it's ya know go bike riding and playing at the playground and ya know (.2) I love hula dancing.” (41, 2, I-S)

“Um, we absolutely do not spend enough quality time in a physical way together [pause] because when we do do it, it's really good.” (49, 2, I-S)

“I think the being physical together, not sitting in front of the TV together you know doing something active is way more beneficial. It feels like we’re doing something as a family, whereas if you’re all sitting there on the couch. It doesn’t really feel like you are doing something as a family.” Later this mother went on to explain “Yeah, because you’re not really interacting when you are watching TV. You know, when you are out throwing, playing soccer, or playing baseball or something you are interacting.” (38, 3, FG-IP)

“That’s usually what we do as far as when we spend time, on the weekends we usually do something together and it’s usually something active. I think that’s, that’s how we think of physical activity. Yeah, family time is more physical rather than just sitting around.” (41, 2, I-S)

“And to me it’s much higher quality because you are in nature I mean I just love that. Or if we’re on a bike ride together.” (44, 2, FG-IP)

Referring to being physically active as a family, one mother described “When you get them done afterwards you feel really good about it I don’t know what it is.” (38, 3, FG-IP)

“It’s a good bonding experience for all of us. That’s usually what we do as far as when we spend time, on the weekends we usually do something together and it’s usually something active.” (41, 2, I-S)

Though there was a general consensus that being active as a family unit was beneficial and even enjoyable, even still consistent barriers to having family physical activity time were mentioned. A reoccurring theme that mothers described when explaining family attempts to be active together was that family members often “branched off.” The reasons mothers gave for branching off included: age and ability of children or specifically for the child with Down syndrome. Other explanations for branching off ranged from wanting to include everyone in their preferred activity or allowing children to participate at their desired pace. Some mothers viewed this as a negative, some felt it was inevitable with multiple children of various ages and abilities,

while still some mothers purposefully adapted aspects of the selected activities to include everyone and prevent branching off. These examples highlighted the presence of reciprocal determinism within the family setting. Mothers were aware of the abilities and limitations of their children, whether they made the decision to branch off or change the physical activity, and their decisions were directly or indirectly influenced by their surroundings. The following quotations provide examples:

One mother described the process of planning physical activities that include the whole family unit as “hard basically.” She then continued “I wouldn’t trade my family for anything, but I think having a big family and all going out and doing something physically active together [pause] is more challenging I’m sure there are people that do it. But you know if you have a 2-year-old and a 16-year-old.” (44, 6, FG-IP)

“Um [pause] well yeah that’s what we [pause] well last winter was the first time I think that was the first winter that [son with Down syndrome] even attempted to go out on skis, so I would go up the hill with the older kids and my husband would stay down on the bunny slope with [son with Down syndrome].” (57, 7, FG-S)

“And what we have done is we have gone tubing um as oppose to going skiing because [son with Down syndrome] isn’t quite there yet. But for that matter neither is [son without Down syndrome] or [son without Down syndrome] but then if we do have instances where there is something that [son with Down syndrome] just physically can’t do, then [husband]’ll take [sons without Down syndrome] and I’ll take [son with Down syndrome] or [husband]’ll take [son with Down syndrome] and I’ll take [sons without Down syndrome].” (45, 3, FG-S)

“We try if we’re gonna do something that’s like fun family time, we try, well we do we make it to where we can all do it together. Cause that’s just not, I mean you can’t have family time without everybody, so like I said, we’ve adapted things where we put the trail-a-bike on the back of my bike and if we would go do something like running um we’ve done that in the past where we’ll go for a walk and we might run for a bit.” (41, 2, I-S)

During one of the focus groups, the following exchange occurred between participants:

“So you guys break up [pause] from others so that everybody can kind of do what they want?” (Principal Investigator)

“Right.” (38, 3, FG-IP)

“We do that too.” (44, 2, FG-IP)

“Because I mean you don’t want a [pause] make them slow down all the time just because I mean I would it is the same with any younger sibling. But it’s just with our kids [children with Down syndrome] there is just a bit more of a delay.” (38, 3, FG-IP)

A mother of six from the same focus group explained later:

“Well in our house it depends on abilities. And that happens with us just because our ages of kids are so different but [son with Down syndrome] doesn’t get to participate in certain things. Part of it is because he can’t and um [pause] I don’t think we have enough family, entire family physical activity. I mean we just don’t.”

“But maybe, you’ll have mom and son activity time?” (Principal Investigator)

“Yeah, I mean I’ll go bike riding with him a lot [pause] before it was crazy hot over the summer and even in the fall. But I’ve got the 16 and 15-year-old girls, and then the younger kids are much younger and now that they are getting older they definitely are wanting more separation kind of. I mean I think they like when we are altogether but I think they often have something else they would rather be doing. Because of their age, and they are girls – especially one of them.” (44, 6, FG-IP)

Another focus group participant explained why her family branched off for some activities:

“And I mean sometimes you do have to split up, which I hate but I just always feel a little bit sad but they don’t want a yeah. There’s some natural resentment anyway even with the best kid in the world [pause] they are just going to naturally resent the special needs a little bit you know and the slowing down and so you just have to be really creative and keep them challenged.” (44, 2, FG-IP)

“But you don’t want to sacrifice the (fun) of the others.” (38, 3, FG-IP)

“Right.” (44, 2, FG-IP)

Eating. As mothers began to discuss eating as it related to family interaction or family quality time, a variation of factors emerged. Evident from the following quotations, a common theme among responses was that eating as a family was a necessary act that could not only be used to teach children healthy eating habits but could also be enjoyable for all involved. Some mothers described eating as a time to implement healthy habits while others mentioned that time together as a family was high quality, regardless of whether the food was considered “healthy.”

“Okay, well [pause] a lot of our time together as a family is uh based around food. [laughter] um guys get really excited about [pause] eating!” (57, 7, FG-S)

“I’d say there’s maybe 2 nights a month where we don’t sit down and have dinner as a family together and I think that for us it’s just kind of checking in our day. So I see that ya know family meals are pretty important as quality time as well.” (41, 2, I-S)

“Most of the time we eat at the table because that’s how I like it. [pause] And I think we should be together as much as possible.” When asked about whether her family planned meals together, this same mother admitted that her family did not prepare meals together and made the comment, “that seems to me to be a great thing to help teach your kids for the future when you’re not right there telling them what to do. When they have to think for themselves.” (49, 2, I-S)

“We don’t go out to dinner a lot, I mean it’s a big deal. So when we do, everyone enjoys it. I mean as far as healthy eating, probably not so much. But it’s definitely quality time.” (44, 6, FG-IP)

“We had good times at the table and it was [pause] most of the time fairly healthy food, I tried to promote that.” (63, 6, I-IP)

One mother described mealtime as being multipurpose, she explained “Yeah, we’ve read the studies about meal times and how it keeps them out of gangs, drugs, school. Right and when it was a little more difficult we would ask open ended questions like what was the best thing about your day today and what was the worst thing? Yeah, so even then [daughter with Down syndrome] was participating. And we’re always open to new suggestions and new things.” (41, 2, I-S)

Research question (c). Mothers described different ways in which their child with Down syndrome impacted their family; however, related to the health of their family a majority of mothers responded that they became more health conscious, proactive and sought health education for their family as a result of having a child diagnosed with Down syndrome. Most parents did not want their children to have any negative experiences which were preventable. Several mothers described the health of their children with Down syndrome as a target area for prevention. Parents recognized that

their children with Down syndrome would likely have physical, cognitive, and social barriers during their lifetime and health was perceived as a modifiable area that could be positively impacted. They felt that by instilling positive health habits at an early age, this would prevent their child from another life struggle. Thus, as parents envisioned the life of their child, the diagnosis of Down syndrome was an environmental contributor that influenced how decisions about health were made and what behaviors of the child and the family unit would be encouraged or discouraged. For instance:

“Yeah, like I said being healthy is definitely a priority in our family. But the things we’ve discussed like the lack of motivation and things like that I don’t see as much in [daughter with Down syndrome] even as a 4 and 5-year-old, she should be active constantly. That and [pause] just the challenges she will have cognitively just dealing with life in general. I want her to have that up front, healthy habits, so it’s just there and it’s not something she has to think about.” (35, 3, FG-S)

“Well yeah so family history is a factor and I think Down syndrome is a factor too that’s kicked us into gear. Because there’s, we can’t I just don’t really want [son with Down syndrome] to um have that against him as well. Because I think that could really affect his lifestyle. And then my daughter tends to be like my family history, ya know like loves to eat loves to, I mean she likes to be active too so and I just didn’t have the opportunities as a kid and my husband didn’t either. Looking forward to activities or eating healthy or you know having bikes er just doing all those things um I think sometimes you just, maybe go extreme. I don’t know. But it’s like I don’t want my kids to have I just want them to have so much more opportunity then I had to feel good about themselves, to be strong, active and healthy.” (44, 2, FG-IP)

“Oh well, let’s see. I guess from the beginning when I found out that [son] had Down syndrome I decided to do all I could to make him as healthy as possible. I nursed him longer than the other babies, and I’ve tried to give him really good food. And he’s as active, an active child, ya know even when he watching a movie or playing a video game he’s on his feet ya know hoppin’ around. So if anything I would be concerned because he’s underweight. Yeah, so I don’t worry about obesity. I do try to keep him active because it also affects his well-being and the brain and the whole bit.” (57, 7, FG-S)

During a discussion of physical activity habits between her children, one mother described that she and her husband “decided when she [daughter with Down syndrome]

was born” to make the kids active and to be an active family. When probed further about the origin of this comment, she responded “That was specifically because of the Down syndrome. We knew that she was gonna have potential for weight issues and so we knew that we had to step it up.” Later she commented, “So I think my health issues and then I think [daughter with Down syndrome]. Ya know it all started with [daughter with Down syndrome] and her health issues and we’ve even looked at maybe taking gluten out of her diet and just trying to you know mess around with our diets and see if we can live a little healthier lifestyle based on what we put in our bodies.” (41, 2, I-S)

Research question (d). Mothers described that healthy lifestyle habits were very important for their family and they wanted to encourage those habits among their children; however, not all habits of families aligned with their beliefs. For instance, one mother described that being healthy was important for her family, but that sometimes “she’s busy.” Another mother stated that when it was a priority and in the forefront, habits aligned but as seasons or schedules changed, so did priorities. Belief about the importance of living a healthy lifestyle or exhibiting habits that led to a healthy lifestyle could be moderated by weight concerns; regardless of whether the concern for weight was due to family history or the presence of Down syndrome. Not only could the element of reciprocal determinism be observed between mother and child, but the environment also strongly contributed to how behaviors were executed. Ultimately the level of priority that families placed on these actions seemed to be the determining factor related to the habits of their family. The following excerpts provide evidence:

When asked how she felt her family’s actions related to their feelings about health, one mother responded “Yes, definitely for us. Like we have to keep balance. And say, are we doin too much or do we have time for that. But definitely both are a priority for us and again it’s because of what I think I shared before in the other question about our family history and because we want to do certain things we have to be in shape to do those things.” (44, 2, FG-IP)

One mother was asked what most impacted whether her family was physically active on a daily basis, her response was “It’s very important to us. It’s a priority for us.” She later continued by adding “Um, I mean just overall health. I mean everything goes hand in hand, your eating habits, your activity habits. Your physical and mental well-being for sure.” (35, 3, FG-S)

“I mean the weights important but I think it’s really just about putting good foods in your body and whole foods” (41, 2, I-S)

“I think we are definitely physically active [pause] and healthy. And we eat, [pause] my kids eat salmon and we cook and we eat, we felt [it was all] really important. We have felt that this is a high priority [pause] because of our family history [of being overweight], which is like devastating. So I guess for us, the family history is the factor that’s impacting.” (44, 2, FG-IP)

One mother explained, “I am not really active, but like I said I’ve kept them active and had them, what I and when I was in high school even after I got my driver’s license my favorite thing was bike riding, biking, and so I guess that kind of [pause] passed on. But I’ve been too busy, when we were running the business, schooling, and raising the kids, I didn’t have a lot of time for that for a lot of activity but I kept them in the activity so that’s really how it impacted my kids and my husband likes to do stuff and he did some sports and he’d get out with the kids once in awhile.” (63, 6, I-IP)

“We give [daughter with Down syndrome] healthy foods and we try to keep her as active as possible and we’ll keep pushing that as much as we can but ya know, and we just do the best we can. Or seconds or whatever and you know putting your fork down and talking, so we’ll make sure that we are modeling all this stuff as we sit down for dinner ya know with her, she might just be eating and so we’ll ask her you know how was your day what did you do and make it more social and so she has time to realize that she is full and she doesn’t ya know need anymore.” (41, 2, I-S)

Two mothers who previously described that being active and eating healthy were very important for their children and family also commented that because their children were not currently overweight they often did not take the time to encourage healthy lifestyle habits that they knew were beneficial. The quotations below describe the mothers’ feelings about their children with Down syndrome and how health-related parenting practices changed in the absence of excess weight.

“I probably allow her to get out of it [physical activity] because we’re so thankful that she’s trim and very uh physically capable in her own way. So we’ve been really lucky. There’s a lot of children with Down syndrome that are very chubby.” Then later she continued with “I’ve said this earlier and I’ll repeat it again I probably won’t say it right but I hope you’ll get it, I’m resting on my laurels, and on the fact that [daughter with Down syndrome]’s pretty stinkin healthy without a whole lot of physical intervention from me and I’ll just kind of allow that. And I’m sort of lucky, cause if she were chubby I would do something because I just don’t want that for her. I don’t want her to be chubby.” (49, 2, FG-S)

“I think we are physically active but there’s room for improvement in the healthy eating area! [laughter] You know and I don’t know if that’s because we’re not [pause] my family’s not necessarily, not predisposed for weight gain and stuff. Not so much when we’re younger, but definitely when you’re older it kicks in. I think there’s definitely the opportunity to live healthier. Yup, there’s definitely things that shouldn’t be in our pantry.” (38, 3, FG-IP)

The following exchange provided another example of the influences on health-related parenting practices:

“So do you think the, the lack of [weight] concern impacts how much you encourage her?” (Principal Investigator)

“Probably, it does at this point in life and the fact that we’re just a busy little family and her mother [speaking in 3rd person] doesn’t exercise enough her own self. That’s part of it too is me. Less about my son and more about me.” (49, 2, I-S)

Mothers were also aware that their own personal behavior impacted the behavior and beliefs of their children, and thus a majority of participants felt they were making a conscious effort to model healthy activity and eating habits. Some families appeared to make this a priority always, while some described seasons in which promoting physical activity or healthy eating may not always have been a priority. Some mothers mentioned that not only did children notice their healthy habits, but that unhealthy habits could also be learned. The following excerpts provide clear examples of the reciprocity within the family related to eating habits and how immediate changes from both parent and children shaped behaviors. For instance:

“If we didn’t do any of those things [being active or eating healthy] the kids wouldn’t do them either. So I think it’s really important. I think if we didn’t do it, that would cut their opportunities down to almost nothing, but I just think that they know if it’s important. I mean if they know it’s not important to you it won’t be important for them.” (44, 2, FG-IP)

“Uh, I think [pause] I think that the parents, whatever the parents make the priority directly impacts the children, obviously because it’s what we would choose to give our time and attention to so I uh I do care a lot about my kids being healthy.” (49, 2, FG-S)

“Definitely I mean, I think anyone would say that. I mean if you are lazy and don’t go exercise your kids are going to see that. The importance you put on it, or not.” (44, 6, FG-IP)

“We just wanted to keep them active and their dad liked to play baseball and he was interested in sports and he played basketball for a while when he was in college, intramurals too so. We just kind of naturally flowed into it.” (63, 6, I-IP)

One mother reflected on how she felt her habits impact her children’s physical activity habits, “Uh, they do less than they would do, honestly because of that cause yeah [pause] that’s one of the things about me that’s definitely not my shining star moment as a mom.” (49, 2, FG-S)

“Ya know it’s challenging as a parent to balance everything. So I go through phases [pause] where the focus is more on academic type stuff or then the focus ends up being on physical activity or things like that um so [pause] and again being seasonal obviously it’s easier to be more creative to think of things to do during the summer [pause] or when it’s warmer outside. So it probably just depends on what my focus is at the time. Yeah what I feel like we go through the phases, we get through an academic phase and I’m like we’re really lacking in our activity so we’ll start focusing on that.” (35, 3, FG-S)

“I guess you could say in a way it was a priority and then it became habit.” This mother went on to explain that, “I just tried to pass on as much as I could to the kids and I think I did a pretty good job.” She also stated that they were successful because, “Well we were so consistent.” (63, 6, I-IP)

Emergent findings. As the participants’ responses guided the direction of the interviews and focus groups, there was an emergent theme that was repeatedly documented across participants that was not explicitly relevant to research questions. The

major recurring theme was related to weight concerns among children and how mothers would make changes within the habits of their family if there was a potential concern for weight. There was a consensus among parents that making changes to the eating habits of their children would be easier than trying to regulate or encourage more physical activity if there was a need for weight management. Some mothers had this opinion because they felt they had control over their children's eating habits, while others felt their children were already physically active and it would be difficult to encourage more activity. For instance, mothers described changes they would make if their family had possible weight concerns:

“Eating, well both but eating.” (12-7 FG)

“Just kind of overall general, blanket impression I think food would be easier to control for our family.” (57, 7, FG-S)

One mother described that she would first make changes to the eating habits of her children, and when probed about her rationale she responded “Yeah, because my kids don't go with me to the grocery store!” (38, 3, FG-IP)

Another mother responded that she would also target eating habits before physical activity if there were weight concerns with her children for the reason that, “sometimes it just feels so overwhelming to try and get all that activity in.” (44, 2, FG-IP)

“I would probably change what food she gets first and then try to think through what to do for the physical activity, because I don't know 100% of what I would do. I would definitely spend time, I would do way more for my children than I would do for myself. Because that I can control, much more easily.” She provided further support for her statement with, “I probably would do the eating habits first, and either put something away because we have definitely indulged her [daughter with Down syndrome who was earlier described as thin], mostly because she's been so underweight and we've been more worried about getting some weight on her.” (49, 2, I-S)

“It would probably be, be the eating habits because they’re just, their physical activity I think is totally fine. And [laughter] I think if anything’s gonna go it’s gonna be the eating habits.” (45, 3, FG-S)

Summary

To summarize, quantitative and qualitative methods were analyzed in this chapter to closely examine the physical activity levels and eating habits among families who have children with and without Down syndrome, from the perspective of mothers. In the context of SCT (Bandura, 1977) and Reciprocal Determinism (Bandura, 1978) it could be assumed that there was an element of interaction or reciprocity between the physical activity levels, eating behaviors, child feeding practices, and quality family interaction among families who had children with and without Down syndrome. Within the limitations of this study, results did provide support for reciprocity of these variables between mothers, their children, and the family unit.

Quantitative evidence from electronic questionnaires demonstrated that there were strong relationships between mothers’ physical activity levels and the activity levels of their children with and without Down syndrome, and the family unit. There was also a statistically significant relationship between mothers’ physical activity levels and the activity levels of their children with and without Down syndrome and the family unit. Therefore, the data provided support for the interactionary nature of the physical activity behaviors within the family.

On the other hand, significant relationships were not demonstrated between mothers’ physical activity levels and weight concerns among children with or without Down

syndrome. Thus, confirming statements about reciprocity cannot be made about the association between activity level and weight concerns. However, reciprocity in the relationship between weight concerns and mothers' behavior of emotional eating were documented to be marginally significant. Though marginal, this positive association was demonstrated to be stronger among children without Down syndrome compared to siblings with Down syndrome. Finally, inferences cannot be made regarding the interactionary nature of weight concerns for children with or without Down syndrome and mothers' cognitive restraint or uncontrolled eating behaviors.

Based on the present data, it was further suggested that significant relationships were identified between the feeding practices of food restriction and child weight concerns, but not for pressure to eat or food monitoring. This evidence establishes an element of reciprocity between some child feeding practices and weight concerns among children with and without Down syndrome. Finally, there were differences between siblings with and without Down syndrome related to some feeding practices and weight concerns from mothers. Mothers' exhibited more responsibility related to feeding, food monitoring, and had more weight concerns for their children with Down syndrome; while there were not differences in mothers' level of food restriction or pressure to eat between siblings.

Qualitative evidence from interview and focus group responses provided rich detail and allowed participants the opportunity to explain their thoughts and feelings related to physical activity and eating habits between siblings, and how having a child with Down syndrome may impact these practices and the family. Similar to quantitative data, a

majority of mothers felt their children with Down syndrome were less physically active than their other children and that their own personal activity levels impacted their children and family. Similar to quantitative data, mothers also appeared to more closely monitor the eating habits and have greater weight concerns for their children with Down syndrome. It must be noted that parents seemed to also monitor and restrict the eating habits of their children they perceived as having a potential weight concern.

Another finding that supported quantitative data was that though mothers' eating habits were not associated with weight concerns for children, mothers' did recognize the impact that their own personal eating habits had on the habits of their children. Other notable qualitative findings not targeted through questionnaire data included that a majority of mothers perceived their child with Down syndrome to have a positive impact on the health of their family, they perceived that the encouragement of physical activity and healthy eating could coincide with quality family interaction, and that the premise of healthy lifestyle habits aligning with actual lifestyle habits can be mediated by perception of health importance and current priorities. These results provided partial support for the interaction and reciprocal nature of some health-related parenting practices within families who have children with and without Down syndrome. However, the level of variance between variables and the limitations of the study, which will be discussed in the next section, should be considered while contemplating these results.

In Chapter IV, I have provided an explanation for the results of this investigation. In the following Chapter V, a synthesized discussion of both the quantitative and qualitative

results is presented. A discussion of this data along with a comparative dialogue of related literature may provide insight to this potential interactionary relationship between health-related parenting practices within families who have children with and without Down syndrome. The discussion will also include research limitations, study implications, and final conclusions.

CHAPTER V

DISCUSSION

Parents should understand the interplay of genetic, environmental, and familial influences in disease expression. Identifying the obesogenic agents in the environment and parental behaviors that influence childhood weight problems is critical for the development of effective prevention and treatment programs.
(Golan & Crow, 2004, p. 46)

Overview

This chapter provides a discussion of the results of mothers' physical activity levels, past eating behaviors, child feeding practices, and weight concerns between siblings with and without Down syndrome. Further evidence is also discussed related to the impact that having a child with Down syndrome potentially has on these practices and the family. Data from this present investigation were collected and analyzed using a mixed method approach, a discussion of the results was presented in two sections, and the data were synthesized and presented in the following discussion. This chapter consists of four sections: (a) Discussion, (b) Conclusions, (c), Limitations, and (d) Recommendations.

Discussion

Bandura (1998) and other researchers (Neumark-Sztainer et al., 2003; Ransdell et al., 2001) have declared that SCT (Bandura, 1977) and Reciprocal Determinism (Bandura, 1978) can be used to provide support and provide explanation for developmental processes within behavior. The interactionary context of SCT and the reciprocity that is the underlying component of Reciprocal Determinism have the potential to be a

foundational filter to understand health-related practices within the family. These practices can directly or indirectly promote an obesogenic environment (Bandura, 2005; Wright et al., 2010), influence mothers' health-related parenting practices (Granich et al., 2010), and impact children with and without Down syndrome, the former who have a strong propensity toward obesity (Rimmer et al., 2010). Relationships within families have a certain reciprocity that is inherent, due to a genetic connection, emotional closeness, or literal proximity (Golan & Crow, 2004). The physical activity levels and feeding practices that a parent directly encourages or inadvertently sets on children may be connected to the behaviors or reactions of the child, a statement which provides support for the reciprocal nature of health-related parenting practices (Bauer et al., 2008; Joyce & Zimmer-Gembeck, 2009; Keller et al., 2006).

Physical Activity

Based on this investigation, there were statistically significant relationships between the physical activity levels of children with and without Down syndrome, mothers, and the family unit. Qualitative data were used to enhance quantitative findings which indicated that mothers' physical activity levels influenced the activity levels of their children and family. Not only were associations between physical activity levels documented within quantitative results, but qualitative findings demonstrated mothers' awareness of how their behaviors influenced their children. One mother expressed that "if we didn't do any of those things [being active or eating healthy] the kids wouldn't do

them either. So I think it's really important. I think if we didn't do it, that would cut their opportunities down.”

These findings support the literature related to the interaction between physical activity levels and family members (Bauer et al., 2008; Davison et al., 2005; Kalakanis et al., 2001; Moore et al., 1991) who suggested a reciprocal or potentially interactionary relationship between these factors (Wright et al., 2010). Although, previous researchers (Madsen et al., 2011; Trost et al., 1997) have determined strong associations between the physical activity patterns of mothers and children, few if any have investigated these associations among children with Down syndrome (Menear, 2007; Whitt-Glover et al., 2006). Reciprocal determinism (Bandura, 1978) provides support for this relationship in that the physical activity levels of children with and without Down syndrome can both be impacted by the habits of the mother; whether to encourage active or sedentary behaviors. Though, causation cannot be inferred from the present cross-sectional data, quantitative and qualitative results demonstrated a positive relationship, which allows support for conclusions that active mothers had active children while inactive mothers had inactive children (Kalakanis et al., 2001; Moore et al., 1991; Mulhall et al., 2011).

On the other hand, findings from quantitative results related to the relationship between the physical activity levels of mothers, children, and the family unit were in direct contrast to findings from Thompson and colleagues (2009). Investigators concluded based on that investigation that “being physically active as a full family unit may be a mythical ideal” (p. 271). Present qualitative findings were similar, as one

mother shared during a focus group that being active as a family is “hard basically.” She then continued by stating;

“I wouldn’t trade my family for anything, but I think having a big family and all going out and doing something physically active together [pause] is more challenging, I’m sure there are people that do it.”

Few researchers have investigated the relationship between physical activity levels and the family unit. However, evidence is available to support the findings from this present study. For instance, adolescents’ self-reported physical activity levels have been demonstrated to be significantly related to self-reported levels of activity for the entire family unit. Mulhall and colleagues (2011) sampled a large and ethnically diverse group of adolescents and concluded that along with other environmental factors, both the active and sedentary patterns of the family, termed “family fitness” (p. 246), impacted the children. Thus, the element of reciprocity was evident.

Quantitative and qualitative findings from the present investigation related to physical activity level comparisons between siblings with and without Down syndrome were contradictory. Based on the quantitative results, relationships between the variables were analyzed and evidence supported a positive relationship. Though the relationship was considered statistically significant, effect sizes were considerably small. On the other hand, qualitative results from mother’s responses during interviews and focus groups established that siblings without Down syndrome exhibited slightly higher physical activity levels. The former finding which cannot be supported by literature may be

explained by the use of a self-report online questionnaire which required mothers to document the physical activity habits of their children. The qualitative findings were similar to the findings of past researchers (Sharav & Bowman, 1992; Whitt-Glover et al., 2006). Mothers expressed differences in the physical activity levels between their children with and without Down syndrome. Both Sharav and Bowman (1992) and Whitt-Glover et al. (2006) reported that children with Down syndrome were significantly less active than their siblings. Based on the quantitative findings, conclusions demonstrated that there was significant relationship between siblings and the physical activity levels of children without Down syndrome were slightly higher than their siblings with Down syndrome. Sharav and Bowman (1991) also used a self-report third party assessment of physical activity level, whereas Whitt-Glover et al. (2006) used accelerometers to obtain an objective measurement of sibling physical activity levels.

Presently, the positive relationship documented between parent and child activity level provides support for the findings of Davison et al. (2003), as well as, Thompson et al. (2009). This support allows speculation that the physical activity levels of children with Down syndrome are impacted by family members similar to siblings without Down syndrome. This current cross-sectional evidence connects the idea that health-related behaviors are highly interactionary within families and also among children with Down syndrome. Whether these associations were evident due to parent encouragement or physical modeling cannot be presently inferred.

Physical activity similarities and differences can also be explained related to the amount of encouragement provided by parents. The findings of previous researchers were similar related to encouragement and physical activity (Edwardson & Gorely, 2010; Sallis et al., 1999; Thompson et al., 2009; Wright et al., 2010). Present evidence from interviews and focus groups support the notion that parents' provided support for their children's physical activity habits using a number of avenues. Mothers expressed that they supported the physical activity habits of their children with and without Down syndrome with verbal encouragement, modeling of habits, purchasing equipment, and driving them to practice (Bauer et al., 2008; Edwardson & Gorely, 2010; Sallis et al., 1999).

The only type of supportive difference that was evident was related to organized sports teams. A majority of mothers described that their children without Down syndrome participated more frequently on organized sports teams. One mother explained that "my oldest and youngest [children without Down syndrome] play on organized sports and we have had [son with Down syndrome] on team sports but he gets very um [pause] distracted." Mothers' responses related to what they attributed the supportive differences between their children with Down syndrome were similar to previous investigators physical activity support comparisons. Differences were related to lack of interest (Mahy et al., 2010), past unsuccessful participation attempts due to inattentiveness or lack of skill (Pitetti & Fernhall, 2004), and gender (Wright et al.). These findings were similar to Menear (2007) who demonstrated that mothers felt their

children with Down syndrome also lost interest in activities as they became older and that without participation from their siblings, motivation was not apparent.

Another explanation that can be provided for quantitative results of physical activity comparisons and for the high levels of activity that mothers described about their children during interviews and focus groups may be related to the unique participant characteristics. For instance, findings from a longitudinal population-based survey (Gordon-Larsen et al., 2000) demonstrated a significant and positive relationship between physical activity level, family income, and maternal education level. The present findings support this evidence, through analysis of the participant's demographics it was determined that a majority of participants considered their family to be at a high socioeconomic level, most mothers had earned college or post-graduate degrees, and 94% of mothers were married. This allows speculation that parents who are more educated and higher socioeconomic backgrounds may be more aware of the benefits of physical activity and more likely encourage activity for their children (Han et al., 2010). Researchers (Davison et al., 2003; Moore et al., 1991; Quarmby et al., 2011) have also documented that children from two parent homes were more physically active, and that children's level of activity has been highly associated with number of active parents.

Physical Activity and Weight Concerns

Quantitative and qualitative evidence did not support a relationship between mothers' physical activity level and weight concerns for children with or without Down syndrome. To date, no investigations have been located that support associations between mothers'

physical activity levels and child weight concerns. Using SCT and Reciprocal Determinism as the conceptual lens, one might posit that activity patterns could be related to weight concerns, similar to findings from investigators who targeted concern for weight and other health-related parenting practices; such as child feeding patterns (Ventura & Birch, 2008). Physical activity level has been considered a behavior which impacts weight status; however, presently support cannot be provided related to an association between mothers' physical activity habits and child weight concerns.

Davison and Birch (2001) provided the only available supportive literature for the theory of reciprocity related to physical activity and weight concern. These investigators examined weight status and parent reaction among preschool age girls and determined there was a significant, inverse relationship between parental concern for weight and perceived physical ability among the girls. Although, no direct measure of physical activity level was documented; the connection between concern for weight and perception of physical ability could be speculated as an example of the reciprocity between parents' health-related parenting practices and children's health-related behaviors. However, this relationship was only slightly supported.

Quantitative findings did not establish a significant relationship between mothers' physical activity habits and child weight concerns, this result could be explained through other associated variables, qualitative findings, and past literature. For instance, there was a significant relationship between food restriction and child weight concerns (Birch & Fisher, 2000; Keller et al., 2006; O'Neill et al., 2005). Participants expressed during

interviews and focus groups what they would do if weight concerns did exist for their children with or without Down syndrome. A majority of mothers explained how they would first make modifications to their children's food intake; rather than attempting changes to physical activity habits or increase their own physical activity levels for the purpose of modeling desired habits. One mother even described that "it's overwhelming to try and get all that activity in."

Eating Behaviors and Weight Concerns

The relationship between mothers' past eating behaviors and child weight concerns was not significant. Based on the quantitative analysis of data, it is suggested that associations cannot be made between mothers' level of cognitive restraint, uncontrolled eating, emotional eating, and weight concerns of children with and without Down syndrome. These results are contradictory to previous investigators (Birch & Fisher, 2000) who documented a relationship between mothers eating behaviors, and concluded that when "parents have trouble controlling their own food intake, [they] assume that their children cannot do so either" (p. 1059). Though, results were similar to findings from Johannsen et al. (2006) and Whitaker et al. (2000), actual weight status rather than weight concern was the comparative variable. Findings from these investigators supported that there was not an association between cognitive restraint, disinhibited eating (i.e., uncontrolled), emotional eating and weight of their children. Although covariates were not presently targeted, these previous investigators concluded that mothers' weight and restrictive child feeding practices may be stronger mediating factors

related to child weight status or perceived child weight status, compared to their eating behaviors. It must be noted that contrary to the present investigation, these investigators targeted only children without Down syndrome.

To date no known research comparisons have been made between mothers' eating behaviors and weight concerns for children with and without Down syndrome; however, previous researchers (Saelens et al., 2000) have compared the influence of mothers' eating behaviors between siblings who were obese and nonobese. Researchers have not demonstrated a relationship between child weight concerns and mothers' level of cognitive restraint or uncontrolled eating; whereas Saelens and colleagues (2000) documented positive associations. Though, the primary difference between siblings in that investigation was the presence of obesity not Down syndrome.

Results can also be comparatively discussed with the investigators' findings related to eating behaviors of parents and actual child weight. For instance, Hood et al. (2000) concluded that disinhibited eating among parents was only associated with child obesity levels when combined with dietary restraint, rather than weight concerns alone. While Cutting and colleagues (1999) investigated the familial patterns of adiposity related to parents eating behaviors, they demonstrated that maternal dietary disinhibition and maternal weight status were highly predictive of child weight status. Thus, mothers who exhibited difficulty with stopping eating once the action had begun, regardless of feelings of satiation, were more likely to be overweight and have daughters who were also overweight.

Actual weight status or perceived weight status can have a significant influence on many aspects of parenting. For instance, Costanzo and Woody (1985) investigated obesity proneness and asserted that parents have a strong developmental control over their children's health-related behavior when personal eating behaviors cannot be regulated or the perception is high that the child will develop problematic health behaviors (i.e., obesity). Evidence from this present investigation does not support Costanzo and Woody's conclusions, as only a marginal relationship was documented by quantitative findings related to child weight status and mothers' emotional eating. Though few indicated strong weight concerns for any children during interviews and focus groups, numerous mothers described themselves as emotional or stress eaters and were concerned that their children may adopt those same habits. Again, no significant relationships were documented from quantitative data related to mothers' eating habits and child weight concerns. This allows speculation related to families who have children with and without Down syndrome, in that child weight concerns and mothers' eating behaviors may not be reciprocally related (Bandura, 1978). Though, mothers' eating behaviors, a child's actual weight (Hood et al., 2000), and other mediating factors (Johannsen et al., 2006) have been previously documented to have a relationship with weight concerns.

Feeding Practices and Weight Concerns

Quantitative and qualitative results from this investigation support the positive relationship between some child feeding practices and weight concerns. Based on these

findings, associations can be made between food restriction and weight concerns, while associations cannot be made between weight concerns, pressure to eat, or level of food monitoring among this sample of children with and without Down syndrome. Based on the qualitative results, mothers expressed that they have changed their feeding patterns based on the weight of their children with and without Down syndrome. However, they also expressed that if they had future weight concerns they would be more likely to modify their own feeding practices rather than making changes to the physical activity habits of their children. For instance, one mother stated that “I would probably change what food she gets first and then try to think through what to do for the physical activity.” While another mother agreed that it would be easier to impact their child’s weight by making changes to feeding practices, “because my kids don’t go with me to the grocery store!”

Quantitative results provided supportive evidence for the significant relationship between restriction and child weight concern which can be supported by other investigators (Birch & Fisher, 2000; Keller et al., 2006; Spruijt-Metz et al., 2002). “Restrictive practices were highly correlated with concern for child’s weight” (Spruijt-Metz et al., 2002, p. 584), this relates to the current findings in that quantitative results related to restriction were the only child feeding practice associated with weight concern. Interview responses provided support in that mothers feeding patterns became more restrictive as concerns for their child’s weight increased. Birch and Fisher (2000) remarked that there is a bidirectional relationship between parents and children related to

feeding patterns and weight status. These findings and the present results support Bandura's (1998; 2004) identification of health promotion by social cognitive means; in that the direct or indirect influence from one individual can impact the health-related behaviors of another, as well as the reverse.

On the other hand, mothers' concern for weight status was not significantly related to pressuring a child to clean their plate, eating in the absence of hunger, or monitoring food intake. For instance, Spruijt-Metz et al. (2002) examined these child feeding practices and weight status; however, a direct measure of weight status as measured by Body Mass Index (BMI) was used to make comparisons. Contrary to the present findings, Spruijt-Metz and colleagues concluded there was a significant relationship between pressure to eat and weight status but not monitoring or restricting food. Based on these results, investigators confirmed there was a significant relationship between weight concerns and actual weight status, in that mothers who had weight concerns for their children were accurate in those feelings. Similar conclusions were reported by Joyce and Zimmer-Gembeck (2009) related to parent food restriction and child weight status; the relationship was direct but less significant and likely mediated by the child's disinhibited eating patterns.

Feeding practices have also been investigated in relation to changes in weight status overtime. Webber et al. (2010) demonstrated that increases in child weight over time can be used to predict increases in mothers' food monitoring and lower pressure to eat. This provides support for the present investigation related to directional differences in

mother's level of pressure between children with and without Down syndrome. Though not assessed longitudinally in this present investigation, conclusions can be made based on quantitative results that mothers had higher weight concerns for their children with Down syndrome. Quantitative results also generated a positive trend, though not significant, in the relationship between pressure to eat and weight concerns for children with Down syndrome, and a negative trend for children without Down syndrome.

Qualitative results were similar to the findings of O'Neill et al. (2005), mothers actually pressured their children without Down syndrome to eat more often, than their children with Down syndrome. Mothers provided an explanation for directional differences during interviews and focus groups related to pressure to eat. A majority of mothers expressed that they had fewer weight concerns for their children without Down syndrome and these children were more likely to exhibit picky eating. For instance, one mother explained:

Yeah at my house [pause] I do [pressure my children to eat] especially since my [child without Down syndrome] is very picky and doesn't necessarily like to eat the healthy foods. Um [pause] she has to [pause] take certain bites of things if she tells me she doesn't like it, she still has to take a couple bites of it.

Parental feeding patterns have also been examined to determine the predictive impact on child weight status. For instance, Faith et al. (2004) examined mothers and fathers' feeding patterns over time in relation to child BMI. Researchers concluded that high levels of food monitoring predicted a lower BMI while high levels of restriction and pressure to eat predicted a higher BMI among children. Current findings do not support the findings from Faith and colleagues, as weight concerns for children were significantly

related to food restriction, but not for food monitoring or pressure to eat. This was supported by interview and focus group responses in that mothers expressed that they restricted food based on child weight, monitored the habits of all children, and pressured children to eat to ensure proper nutrient intake. It must be noted that though significant relationships were calculated and did not provide support for previous researchers' data (Faith et al., 2004), effect sizes for the quantitative data were considerably small.

Results from the qualitative findings allowed further explanation for the nonsignificant relationship between weight concerns and food monitoring. Mothers mentioned that they monitored the food for their children with and without Down syndrome and gave numerous explanations for this feeding practice. For instance, mothers discussed how economics, age of children, desire to ensure healthy eating patterns, and not wanting children eating too close to dinner time all influenced their feeding practices.

Child weight, rather than the presence of Down syndrome seemed to be more influential related to the feeding practices parents used. Their ultimate intentions when implementing or making changes to feeding practices were to positively impact the health and weight of their children (Baughcum et al., 1998; Faith et al., 2004).

Siblings With and Without Down Syndrome

Mothers described the primary differences between their children related to numerous physical and social characteristics that consistently coincide with Down syndrome.

Mothers described how their children with Down syndrome had numerous characteristics

specific to the condition that may have impacted physical activity and eating habit developing differently. For instance, consistent with other descriptions of children with Down syndrome (Carr, 1995; Connolly et al., 1993; Medlen, 2002; Pitetti & Fernhall, 2004; Pueschel et al., 1982), mothers expressed that their children exhibited delayed walking onset, low muscle tone, lack of motivation, gastrointestinal complications, cardiorespiratory issues, delayed progression to solid foods, and metabolic concerns. Mothers felt that some of these health issues were of particular interest related to the physical activity and eating habit differences between their children.

When asked about physical activity differences, one mother described that her son was more active than her daughter, for the reason that he did not have Down syndrome. Other explanations that were discussed related to low physical activity levels included; lack of motivation or interest in activities (Mahy et al., 2010), fewer community opportunities (Menear, 2007), not having a consistent peer group, and parent presence needed during activity for encouragement or safety (Barr & Shields, 2011). In the present investigation, mothers did express that when motivation to participate was evident and a peer group was present, their children with Down syndrome had the potential to be as active as their other children. For instance, one mother expressed during a focus group that her son with Down syndrome:

Has opportunities to be active however [pause] because he doesn't have um [pause] a network of friends outside the family like [the] other children do, he probably is not as physically active so if he doesn't have someone to do something with he'll watch a movie or play a video game or do something more sedate.

A concern was also mentioned that with age, availability for peer groups will continue to decrease for their children with Down syndrome.

The present findings were similar to O'Neill et al. (2005) who also compared child feeding practices in siblings with and without Down syndrome. For instance, level of monitoring and responsibility was higher among children with Down syndrome and significantly different when compared between siblings. However, O'Neill and colleagues also determined that pressure to eat and restriction of food were significantly different when comparing feeding practices between siblings with and without Down syndrome. Presently, the direction of results related to feeding practices were similar in that mothers were more likely to pressure their children without Down syndrome, while placing higher food restrictions on their children with Down syndrome. However, mothers stated during interviews and focus groups that they were more likely to place food restrictions for the purpose of weight management or age, rather than due to the presence of Down syndrome.

Mothers demonstrated significant differences in level of food monitoring, with higher levels of supervision related to feeding their children with Down syndrome. It must be noted that this higher level of monitoring among children with Down syndrome could be related to the question content for the survey as questions did not specifically identify certain types of food, rather the mothers' behaviors when introducing the food. While the monitor subscale explored how often sweets, snack foods, and high fat foods were monitored by mothers. Thus, mothers who were concerned for their child's present or

future weight would likely monitor sweets, snack foods, and high fat foods more often compared to their children with low weight concerns. This was confirmed in the interview and focus group responses, many children with Down syndrome did not favor sweets or snack foods compared to their siblings, thus food preference may have guided mothers' level of food monitoring. Children with a stronger preference for sweets or snack foods were more likely to have eating behaviors monitored or restricted. This provided support for the reciprocity between children's eating behaviors and mothers' feeding practices among children with and without Down syndrome. Findings from other investigators (Keller et al., 2006; O'Neill et al., 2005; Spruijt-Metz et al., 2002) resulted in a similarly significant relationship between weight concerns and food monitoring.

Mothers demonstrated greater responsibility about feeding their child with Down syndrome compared to their other children. Quantitative and qualitative results support past evidence (Keller et al., 2006; O'Neill et al., 2005). Mothers exhibited greater responsibility for feeding and higher weight concerns for their children with Down syndrome. A greater responsibility for feeding might also be compared to other family dynamics which have been investigated among families who have a child with Down syndrome (Barr & Shield, 2011; Mulroy et al., 2008). These investigators have demonstrated that parents spent a great deal more time with their child with Down syndrome compared to their siblings. Although causation cannot be asserted from either instance, the reciprocity in the notion of parent time commitment for a child and the

greater amount of perception for responsibility in feeding may provide another example of reciprocity within this family unit.

Quantitative evidence in this present investigation can be used to demonstrate differences between mothers level of weight concern between children similar to previous investigators (O'Neill et al., 2005), mothers had greater weight concerns for their children with Down syndrome. Although a direct assessment of child weight was not evaluated among siblings, the explanation for why mothers' concern for weight was significantly higher among their children with Down syndrome can be supported by previous researchers' findings related to weight index among children with Down syndrome. For example, Rimmer et al. (2010) investigated the obesity rates among adolescents with intellectual disabilities and reported that those with Down syndrome were two to three times more likely to be obese compared to the general population.

Similarly, Grammatikopoulou et al. (2008) and Luke et al. (1996) examined obesity rates among children and adolescents with Down syndrome and reported high obesity levels. Thus, these results allow for speculation that not only did mothers have greater weight concerns for children with Down syndrome, but those concerns may have been accurate based on population obesity rates for children with Down syndrome. In the past, mothers' concern for child weight has been reported to have a significant relationship with direct assessment of overweight in children (Keller et al., 2006). However, evidence from qualitative findings in this present investigation supported conclusions that weight concerns for children with Down syndrome were not similar to quantitative results or

population based obesity rates. During interviews and focus groups, a majority of mothers described all of their children as being a healthy weight and most had few future weight concerns. As the obesity rates among the population in this present investigation were not similar to population rates, the uniqueness of the sample must be considered. All families in question were from two parent homes, had a high socioeconomic status, and high maternal education levels. Though, weight status was subjectively measured, a majority of mothers were self-identified as health conscious or expressed that living a healthy lifestyle was important to their family.

Importance of Health

Similar to previous findings (Ordonez et al., 2006), mothers expressed that the health of their children and family was important, but they were mostly concerned with their child with Down syndrome. Though comparative evidence was not located, mothers from this present investigation expressed that having a child with Down syndrome actually initiated the implementation of healthy lifestyle habits within their family. Mothers mentioned that once their child was diagnosed with Down syndrome, their family's health became a priority.

Mothers expressed an awareness of the unique social and physical challenges that their children with Down syndrome may experience, and a majority felt the health for all their children was a potential area of change. However, the level of importance parents placed on physical activity (Edwardson & Gorely, 2010) and healthy eating along with weight concerns for their family promoted an environment that either consistently

encouraged healthy lifestyle habits or discouraged them (Sallis et al., 1999). For instance, mothers provided some contradictory statements expressing that the importance of their family's health was high; yet in the absence of weight concerns, follow through and modeling of physical activity and healthy eating habits were often infrequent. Mothers' awareness was high related to how their own personal habits encouraged and discouraged activity and healthy eating (Davison et al., 2005), and that as weight concerns for children were low they were less concerned about overall health (Keller et al., 2006). Evidence from interviews and focus groups in this present investigation provided support that weight concern may be a mediating or influential factor for the encouragement of healthy habits (Joyce & Zimmer-Gembeck, 2009; Ventura & Birch 2008; Webber et al., 2010), regardless of belief about the importance of health.

Dabrowska and Pisula's (2010) concluded that perception and management of stress related to having a child with a disability can confound other negative effects. For instance, mothers explained that they were aware of potential barriers related to the health of their children with Down syndrome and already had current and future plans to make changed. Specific strategies included: scheduling organized physical activity during the winter months, taking their child with Down syndrome to the gym, putting vegetables in smoothies to ensure adequate nutrition, and encouraging healthy eating habits (e.g., portion control and the ability to recognized hunger satiety) while eating dinner as a family. Though stress levels were not presently measured, these strategies described by mothers can be considered task-oriented strategies. Dabrowski and Pisula (2010)

examined parents who had children with and without Down syndrome, and concluded that implementation of task-oriented coping strategies, rather than emotion-oriented strategies, were linked to fewer stress markers.

Though participants expressed that the health of their family was of great importance, mothers' actions to consistently promote this philosophy were not always aligned. Mothers explained that the combination of busy schedules, interest from children, and lack of weight concern led to less encouragement for activity and healthy eating choices. These results are similar to Thompson et al. (2009) who stated that even though mothers recognized the physiological and psychological benefits of consistent physical activity and healthy eating, habits did not always align with beliefs. Conclusions could be made that weight concern for children may be an influential factor related to obesogenic environments; as the habits and beliefs of mothers in this investigation that were not aligned were associated with low weight concerns. To date no other supporting or disconfirming evidence could be located related to the environment among families who have children with and without Down syndrome.

Family Connectedness

It has been widely documented (Bauer et al., 2011; Eisenberg et al., 2004; Flett et al., 2010) that there can be a multitude of physiological and psychological benefits for families who are physically active and regularly eat dinner together. Based on qualitative findings from this investigation, a majority of mothers seemed keenly aware of the benefits of participating in physical activity as a family. Mothers even expressed that they

felt quality time was greater when their family spent time being physically active rather than sedentary (Ransdell et al., 2001). For instance:

I think the being physical together, not sitting in front of the TV together you know doing something active is way more beneficial. It feels like we're doing something as a family, whereas if you're all sitting there on the couch. It doesn't really feel like you are doing something as a family.

Evidence can also be provided that mothers felt having dinner as a family was important to the social relationship within their family and was also considered an important time to teach healthy habits. One stated:

I'd say there's maybe 2 nights a month where we don't sit down and have dinner as a family together and I think that for us it's just kind of checking in our day. So I see that ya know family meals are pretty important as quality time as well.

However, unlike explicit statements about physical activity, related to quality time and eating mothers did not express a difference in the level of quality based on whether food was considered healthy or unhealthy. Mothers also agreed that the concept of family meal planning was an important technique that could be used to increase time spent together and teach healthy habits (Bauer et al., 2011; Gruber & Haldeman, 2009), though few mothers had or were presently implementing this within their family.

Similar to qualitative findings from other investigators (e.g., Mulroy et al., 2008; Thompson et al., 2009), mothers in this investigation mentioned that activities which included the whole family unit are enjoyable, but difficult. Thus, descriptions were provided that family members often branched off during activities, based on interest, ability, or for the child with Down syndrome.

If we do have instances where there is something that [son with Down syndrome] just physically can't do, then [husband]'ll take [sons without Down syndrome] and I'll take [son with Down syndrome] or [husband]'ll take [son with Down syndrome] and I'll take [sons without Down syndrome].

While other mothers expressed that family time cannot occur without all members present, and thus they would modify the activity to include everyone (i.e., tubing instead of snow skiing, using a tandem during family bike rides). Another mother defended her family's practice of branching off; explaining that always changing the activity or lowering the intensity to include the child with Down syndrome was not always fair to the other children. Lack of fairness or adequate quality time spent with the sibling who does not have a disability has been documented as a concern for parents (Giallo & Gavidia-Payne, 2006; Mulroy et al., 2008). Mothers who cited branching off during physical activity time also described how their family spent a great deal of time in sedentary activity (i.e., watching television, playing board games). Though the practice of family quality time spent in sedentary tasks has been documented (Thompson et al., 2009), it must be noted that presently the mothers who described their family quality time as mostly sedentary had five or more children.

Results from the present study are consistent with previous evidence (Gruber & Haldeman, 2009; Hardman, Horne, & Lowe, 2009) which have demonstrated that a close knit familial environment can be centered around physical activity participation and healthy eating; however, this present evidence is unique in that it extends the notion of family connectedness while promoting healthy lifestyle habits to families who have children with and without Down syndrome.

Conclusions

These findings provide support that children with and without Down syndrome are similarly influenced by the familial aggregation of physical activity habits and child feeding practices. Evidence from this study allows suggestions to be made that the physical activity habits from both children with and without Down syndrome are impacted by habits from mothers and the family unit. Reciprocity was not apparent related to mothers' physical activity levels and past eating behaviors as related to child weight concerns. Similar to previous researcher's findings, child feeding practices were associated with weight concerns. Mothers' feeding practices were more likely to be modified based on weight concerns for their child, rather than the presence of Down syndrome.

Findings from the present investigation documented that mothers felt their child with Down syndrome had a positive impact on the health of their family. Mothers explained that the Down syndrome diagnosis made them more proactive related to positively influencing the health of their child and subsequently the whole family. In addition, though mothers felt that the health of their family was important, habits to promote physical activity and healthy eating did not consistently align with this philosophy. Finally, physical activity and eating were considered a potential avenue for family connectedness among families who have children with and without Down syndrome.

Limitations

The limitations of this study must be considered while evaluating results. First, the sample size was small and the participants' demographics were uniquely similar (i.e., two parent households, similar ethnicity, high socioeconomic status and educated). Thus results from this investigation may not generalize to all populations. However, the uniqueness of the sample revealed rich and specific details among mothers who have children with and without Down syndrome. Though the sample may have been small and homogenous, transferability of these findings to similar populations has likely been enhanced by using this purposeful sample (Seidman, 2006; Wolcott, 1990).

A second limitation was the use of self-report measures for all variables, rather than an objective measure for physical activity or direct observation to assess child feeding practices. Self-report questionnaires have been consistently used to obtain health-related information (Mokdad et al., 2003), and all measures presently used have been deemed psychometrically valid and reliable internationally, and with diverse populations (Birch et al., 2001; Hallal & Victoria, 2004, Karlsson et al., 2000).

A third limitation is related to the use of self-report measures. The tendency for participants to answer survey, interview, or focus group questions in a particular direction based on the social desirability of the subject matter could be a potential limitation. Electronic questionnaires were used to obtain data during the quantitative portion of data collection; participants did not provide identifying personal information and were reminded that responses would be anonymous. Though, the nature of interviews and

focus groups prevented anonymity, participants were encouraged to be honest with all responses. The contradictory nature of some responses during focus groups provided support that participants responded honestly to questions.

The fourth limitation is related to the use of a single gender (i.e., mothers), during data collection and analyses. Though differences between mothers and fathers have been documented related to their perceptions and influences on physical activity habits and feeding patterns (Johannsen et al., 2006), the sample size limited gender comparisons. Though recruitment attempts were made to include both mothers and fathers, the number of fathers who self-selected to participate was very low and their responses were eliminated from analyses.

Recommendations

Based on results from this investigation, there are numerous areas recommended for future researchers to pursue:

1. Future researchers should replicate these findings and expand the scope of this investigation to include more diverse populations for the purpose of making comparisons based on ethnicity, socioeconomic status, and between mothers and fathers. Comparisons should also be made between siblings from various disability groups; including, Autism Spectrum Disorders, Intellectual Disability, or Obesity.
2. Causal inferences could not be clearly inferred as the present investigation used a cross-sectional design. Therefore, future researchers should use experimental

designs, with randomized controlled trials if possible, to make specific comparisons between health-related parenting practices and determine effectiveness of or guidance for a best practices model.

3. Future researchers should further explore barriers and facilitators to the obesogenic environment. Specific variables should target a reduction of these negative factors among families who have children with and without Down syndrome.
4. An emergent theme that was repeatedly documented during qualitative analyses related to mothers opinions about making behavior changes if weight concerns ensued. Future researchers should investigate these beliefs with various populations, to confirm findings and expand on mothers' beliefs related to prioritization of eating habit changes before physical activity habit changes.

Based on results from this investigation, there were several areas of recommendation for practitioners to target while working with families who have children with and without Down syndrome to improve health-related parenting practices:

1. Educate families about the positive and negative influences parents can have on physical activity and eating habits for children with and without Down syndrome.
2. Provide parent education related to the concurrent benefits of family quality time, physical activity, and healthy eating. Educate parents related to physical activity options for children and discuss including children in family meal planning

3. Educate parents about the potential for encouragement of healthy lifestyle habits to ameliorate some of the social and physical characteristics which are typical for children with Down syndrome. Explain how these can be preventive and ultimately they can encourage independence and functional ability.

In Chapter V, I have provided a discussion that included a synthesis of both quantitative and qualitative data as compared and contrasted to relevant literature. Included in this chapter were final conclusions, research limitations, and recommendations.

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APPENDIX A

NHMRC Assessment with Investigation Summaries

Summary of research articles reviewed in Chapter II: Literature Review

Investigators	Carr, 1988	Cronk et al., 1988
Level of Evidence	III-2	III-3
Article Keywords	DS, family, IQ	DS, BMI
Study Focus	Examines the development of a group with DS from babyhood to young adulthood and impact on their family	Examine the height and weight of children with DS from 1 month to 18 yrs
SCT (B, E, P)	B = Abilities (reading, writing, motor) E = Home, non-home reared P = IQ level, past experiences	Population based explorative study, B, E, P not significantly relevant
Design/ Data Coll.	Design: Longitudinal comparative with controls Data Coll: Researcher examined chil on 7 occasions from 6 wks to 4 yrs, and then again at 11 yrs and 21 yrs. A brief postal quest was sent to families at 16 yrs. Mothers were interviewed when child was 15 months, 4, 11 and 21 yrs	Design: Explorative longitudinal w/o controls Data Coll: (1; n = 89) 3 to 7 yrs: every 3 months for 3 yrs, (2; n = 255) Birth to 2 yrs: every month for 2 yrs, (3; n = 141) 1 yr to 18yrs: single evaluation, (4; n = 217) birth to 18 yrs: varying intervals, and (5; n = 28) infants: single evaluation in first month
Population	54 chil with DS (25 boys, 29 girls), their parents, age-matched control grp w/o DS	4650 observations of 730 children with DS
Outcome/Intrvn/ Context	Outcome: <i>Bayley Scales of Mental and Motor Development</i> (4 yrs), <i>Merrill-Palmer Scale</i> and <i>Reynell Language Scales</i> (11 yrs), <i>Leiter International Performance Scale</i> (21 yrs); transcribed interviews Intrvn: N/A; Context: Home setting	Outcome: BMI at intervals Intrvn: N/A Context: Clinical setting (Boston and Philadelphia)
Summary of Results	Females and high SES had sig higher scores on IQ over time with fewer declines. IQ decreases were greater in chil not raised at home (i.e., non-home-reared). Stressors within the family were indicated, but all parents spoke favorably and were proud. Some parents said "He is my lifeline," "If I had my time over again I'd want to have him again. I never regret having had him"	Children with DS had significant growth deficiencies, especially at infancy and adolescence. Children with DS had a tendency toward overweight during late infancy and throughout their development.

Note. BMI = Body Mass Index; Data Coll. = Data Collection; DS = Down Syndrome; Intrvn = Intervention; N/A = Not Applicable; SES = Socioeconomic Status; SCT = Social Cognitive Theory determinants (B = Behavioral; E = Environment, P = Personal); Sig = Significant/significantly; Wt = Weight; w/o = without; Yrs = Years of age; % = Percentile/Percent

Summary of research articles reviewed in Chapter II: Literature Review

Investigators	Epstein, Valoski, Wing, & McCurley, 1990	Moore et al., 1991
Level of Evidence	II	III-3
Article Keywords	Parent, Child, BMI, family intrvn	Parent PA, child PA
Study Focus	Examine the effects of a FBBT on weight, over 10 years in obese children	Investigate the influence of parents' PA on PA levels of children
SCT (B, E, P)	B = Adherence E = FBBT; Parent use of praise; Parent attendance; praise; Trtmnt grp P = self-monitoring	B = PA level E = PA level of parents P = Past experiences, parents observation
Design/ Data Coll.	Design: Prospective, RCT Data Coll: Baseline, Each yr -10 yrs.	Design: Longitudinal comparison w/o controls Quan: Accelerometer
Population	162 families (obese children 6 to 12 yrs)	100 (4-7 yr olds) children and their mothers (99) and fathers (92)
Outcome/Intrvn/ Context	Outcome: BMI, PA levels Intrvn: 4 trtmnt grps: Child/Parent diet + PA; Child diet + PA; Child/Parent diet; Child PA only Context: Clinical	Outcome: Long-term (1 year) assessment of PA (10 hrs per day; 5 consecutive days) Intrvn: N/A Context: Cohort from the Framington Children's Study; Baseline, 6 months
Summary of Results	Children in the child/Parent group had sig greater wt loss over time. Whole lifestyle (PA + Diet) family intrvn + reciprocal rnfrmnt produced more positive changes, at all points. Children in the child only group had increased wt	Children with PA mothers, 2 times more likely to be PA then children W/ inactive mothers. Boys W/ 2 parents PA were 7.2 times more likely to be PA then children W/ 2 inactive parents (Girls = 4.5 times; Average boys/girls = 5.8 times)

Note. Assoc = Associations/ed; Bhvr = Behavior; Btwn = Between; BMI = Body Mass Index; CFQ = Child Feeding Questionnaire; Crss Sect = Cross Sectional; Data Coll. = Data Collection; DS = Down Syndrome; Edu = Education; Envir = Environment; Exp = Experimental Group; FBBT = Family-based bhvrl trtmnt; Hr = hour; Indvl = Individual; Intrvn = Intervention; N/A = Not Applicable or Not Specified; MVPA = Moderate to Vigorous Physical Activity; Nutr = Nutrition; Par = Parent/Parenting; PA = Physical Activity; Qual = Qualitative; Quan = Quantitative; Quest= Questionnaire; RCT = Randomized Controlled Trial; SES = Socioeconomic Status; Self-esteem = SE; SCT = Social Cognitive Theory determinants (B = Behavioral; E = Environment, P = Personal); Sig = Significant/significantly; TFEQ = Three Factor Eating Quest; Thru = Through; Trtmnt Grp = Treatment Group; Wkly = weekly; Wt = Weight; w/o = without; Yrs = Years of age; % = Percentile/Percent

Summary of research articles reviewed in Chapter II: Literature Review

Investigators	Sharav & Bowman, 1992	Connolly, Morgan, Russell, Fulliton, & Shea, 1993
Level of Evidence	III-3	III-2
Article Keywords	BMI, DS, sibling, PA	DS, intrvn, IQ
Study Focus	To evaluate the effect of physical activity and caloric intake on the weight of children W/ DS and their siblings	Examine the long-term motor, cognitive, and adaptive functioning of a sample of adolescents with DS who experiences an early intrvn program
SCT (B, E, P)	B = dietary practices, PA E = familial, environmental factors P = DS, PA choice	Group comparisons of single interval data, B, E, and P not significantly relevant
Design/ Data Coll.	Design: Mixed Method (comparative) Data coll: Parents interviews, BMI, weekly caloric intake journal of siblings, estimate of daily PA levels	Design: Comparative with controls Data Coll: Pre and post intrvn comparisons of exp grp and control grp
Population	30 sibling pairs (1 W/ DS; ages 2 to 14 yrs) and parents who participated in the infant stimulation program at the Surrey Place Center	10 children with DS (7 girls, 3 boys) from an early intrvn (EI) program; 10 age-matched children with DS (6 girls, 4 boys) who did not participate in an EI program
Outcome/Intrvn/ Context	Outcome: Transcribed interviews by trained researcher Intrvn: N/A Context: Clinical setting (Canada)	Outcome: <i>Bruininks-Oseretsky Test of Motor Proficiency, Stanford-Binet IQ, Vineland Social Maturity Scale.</i> Intrvn: Retrospective comparison of children who previously received an EI program Context: University child development center (US)
Summary of Results	No BMI differences btwn siblings. Children with DS were considered less active by parents, preferred to play indoors. No caloric intake differences btwn siblings	EI grp had sig higher scores on IQ and adaptive functioning than the non EI grp. EI grp did not show decline in adaptive functioning with as typically seen in chil with DS.

Note. Assoc = Associations/ed; Bhvr = Behavior; Btwn = Between; BMI = Body Mass Index; Data Coll. = Data Collection; DS = Down Syndrome; Exp = Experimental Group; FBBT = Family-based bhvrl trtmnt; N/A = Not Applicable or Not Specified; MVPA = Moderate to Vigorous Physical Activity; Nutr = Nutrition; Par = Parent/Parenting; PA = Physical Activity; Self-esteem = SE; SCT = Social Cognitive Theory determinants (B = Behavioral; E = Environment, P = Personal); Sig = Significant/significantly; TFEQ = Three Factor Eating Quest; Thru = Through; Trtmnt Grp = Treatment Group; Wkly = weekly; Wt = Weight; w/o = without; Yrs = Years of age; % = Percentile/Percent

Summary of research articles reviewed in Chapter II: Literature Review

Investigators	Flodmark, Ohlsson, Ryden, & Sveger, 1993	Johnson & Birch, 1994
Level of Evidence	III-1	III-1
Article Keywords	Intrvn, diet, therapy, parent, child, BMI	Par, Eating style, BMI
Study Focus	Family intrvn may have greater long-term outcome compared to indivl trtmnt	Investigate intergenerational transfer of eating style, by assessing child food intake regulation
SCT (B, E, P)	B = Adherence E = FBBT; Dietary counseling (DC) only, Fmly therapy (FT) + DC P =Long-term retention	B =Eval eating style, ability to regulate food E = Par, child interaction P = Food selection choice
Design/ Data Coll.	Design: RCT Quan: BMI; skinfold; fitness level Data Coll: Baseline, 1 yr follow-up	Design: RCT 2 day meal test, child regulated amount of food intake. Intake measured Data Coll: <i>TFEQ</i> , <i>CFQ</i> , BMI of Parent and child
Population	44 obese children (10 to 11yrs) and their families	77 children (46 girls, 31 boys) 3 to 5 yrs; their mothers and fathers
Outcome/Intrvn/ Context	Outcome: Wt loss, fitness Intrvn: 14 to 18 months - DC only or DC + FT grps Context: Clinical	Outcome: Correlational comparison of parent/ child BMI, <i>TFEQ</i> , <i>CFQ</i> scores, and child's ability to self-regulate food intake Context: University preschool
Summary of Results	Body fat decreased in DC + FT grp; Body fat increased in DC only grp; Fitness levels increased in DC + Ft grp	Regression analysis determined parental control of feeding sig. predicted child's responsiveness to caloric density. Higher parent control of feeding was assoc with less responsiveness to caloric density

Note. BMI = Body Mass Index; CFQ = Child Feeding Questionnaire; Crss Sect = Cross Sectional; Data Coll. = Data Collection; DS = Down Syndrome; Edu = Education; Envir = Environment; Exp = Experimental Group; FBBT = Family-based bhvrl trtmnt; Hr = hour; Indvl = Individual; Intrvn = Intervention; N/A = Not Applicable or Not Specified; MVPA = Moderate to Vigorous Physical Activity; Nutr = Nutrition; Par = Parent/Parenting; PA = Physical Activity; Quan = Quantitative; Quest = Questionnaire; RCT = Randomized Controlled Trial; SES = Socioeconomic Status; Self-esteem = SE; SCT = Social Cognitive Theory determinants (B = Behavioral; E = Environment, P = Personal); Sig = Significant/significantly; TFEQ = Three Factor Eating Quest; Thru = Through; Trtmnt Grp = Treatment Group; Wkly = weekly; Wt = Weight; w/o = without; Yrs = Years of age; % = Percentile/Percent

Summary of research articles reviewed in Chapter II: Literature Review

Investigators	Luke, Sutton, Schoeller, & Roizen, 1996	Egger & Swinburn, 1997
Level of Evidence	III-2	I
Article Keywords	BMI, DS, obesity, eating	Obesogenic environment
Study Focus	Measure nutrient intake and body composition in children with DS, to understand dietary barriers in prevention and treatment of obesity	Examination and review of the environmental influences of food intake and PA
SCT (B, E, P)	B = Energy intake and expenditure E = Home environment, weight P = Past experiences, weight	B = PA habits, food E = Physical surroundings P = Macro, micro experiences, sociocultural impact/attitude
Design/ Data Coll.	Design: Comparative W/ control Data Coll: Baseline comparisons	Design: Sys Rev, call to action, and commentary Data Coll: N/A
Population	10 children with DS and 10 children w/o DS (control); all 5 to 11 years	No inclusion or exclusion criteria were provided
Outcome/Intrvn/ Context	Outcome: 3 day food recall, energy expenditure (doubly labeled water method), body comp with bioelectrical impedance analysis and skinfold thickness Intrvn: N/A Context: Hospital setting	Outcome: Develop and ecological model with an explanation of mediators, moderators, and influences Intrvn/context: N/A
Summary of Results	Body composition did not sig differ, but both groups were overweight. Energy intake was lower among DS	Current efforts of obesity prevention are not successful. This model suggests that the force that drives obesity is the 'obesogenic' environment rather than the genetic or metabolic pathology of the individual

Note. BMI = Body Mass Index; Data Coll. = Data Collection; DS = Down Syndrome; Edu = Education; Envir = Environment; Intrvn = Intervention; N/A = Not Applicable or Not Specified; MVPA = Moderate to Vigorous Physical Activity; Nutr = Nutrition; Par = Parent/Parenting; PA = Physical Activity; Qual = Qualitative; Quan = Quantitative; Quest= Questionnaire; SCT = Social Cognitive Theory determinants (B = Behavioral; E = Environment, P = Personal); Sig = Significant/significantly; TFEQ = Three Factor Eating Quest; Thru = Through; Trtmnt Grp = Treatment Group; Wkly = weekly; Wt = Weight; w/o = without; Yrs = Years of age; % = Percentile/Percent

Summary of research articles reviewed in Chapter II: Literature Review

Investigators	Trost et al., 1997	Baughcum, Burklow, Deeks, Powers, & Whitaker, 1998
Level of Evidence	III-3	III-3
Article Keywords	PA, Par,	Feeding styles, obesity in children
Study Focus	Investigate the factors that influence PA of boys and girls	Identify maternal beliefs and practices about child feeding, assoc with childhood obesity development
SCT (B, E, P)	B = PA level E = Influences P = Self-Efficacy	B = Food intake E = Weight perception of child from mother P = Mothers' past weight
Design/ Data Coll.	Design: Prospective Comparison w/o controls Data Coll: Self-report PA and self-efficacy measure	Design: Comparative w/o controls Data Coll: 4 focus groups
Population	202 rural 6 th grade children (64% African American, 55% female)	Groups: 15 Dieticians from government WIC program, 3 groups of 14 mothers (14 to 34 yrs), children (12 to 36 months) enrolled in WIC
Outcome/Intrvn/ Context	Outcome: MVPA assessment, baseline, 1 year later. Context: School setting Intrvn: N/A	Outcome: Transcribed data Context: All assoc with Supplemental Nutrition Program for WIC Intrvn: N/A
Summary of Results	Girls most influenced by: self-efficacy, enjoyment, mother's PA level Boys most influenced by: self-efficacy, beliefs about community sports	Mothers believed that a heavy infant was a marker for good parenting. Mothers feared children were not getting enough to eat and would intentionally go against WIC guidelines. Used food as a reward

Note. Data Coll. = Data Collection; N/A = Not Applicable or Not Specified; MVPA = Moderate to Vigorous Physical Activity; PA = Physical Activity; SCT = Social Cognitive Theory determinants (B = Behavioral; E = Environment, P = Personal); Sig = Significant/significantly; Thru = Through; Trtmnt Grp = Treatment Group; Wkly = weekly; WIC = Women, Infants, and Children; Yrs = Years of age; % = Percentile/Percent

Summary of research articles reviewed in Chapter II: Literature Review

Investigators	Hopman et al., 1998	Kohl & Hobbs, 1998
Level of Evidence	III-2	I
Article Keywords	Eating habits, children, DS, BMI	PA, youth
Study Focus	Investigate nutritional status, patterns of breast-fed, energy adequacy, and nutrient intake in children with DS	Understand to development of and potential determinants to the PA behaviors of children and youth
SCT (B, E, P)	B = Eating habits of child E = Breast fed, parents actions P = Presence of DS	Population based lit rev, B, E, P not significantly relevant
Design/ Data Coll.	Design: Comparative with controls Data Coll: Single interval	Design: Sys Lit Rev Data Coll: N/A
Population	44 children with DS (birth to 4 yrs); 37 children w/o DS	Selection criteria and number articles were not included
Outcome/Intrvn/ Context	Outcome: BMI, dietary intake and nutr assessment collected via interview Intrvn: N/A Context: Clinical setting (Netherlands)	Outcome: Categorized into potential determinants: Physiologic, developmental; environmental; psychological, social, and demographic Intrvn/Context: N/A
Summary of Results	DS did not impact prevalence of breast feeding, introduction of solid foods was up to 12 months after children w/o DS. BMI of both groups were considered to be age appropriate	Greatest impact on PA in youth is the interaction of 3 factors (physiologic, environmental, and psychosocial). Also, present level of phys fitness, parent level of PA, impact PA

Note. BMI = Body Mass Index; Data Coll. = Data Collection; DS = Down Syndrome; Envir = Environment; Exp = Experimental Group; Intrvn = Intervention; N/A = Not Applicable or Not Specified; MVPA = Moderate to Vigorous Physical Activity; Nutr = Nutrition; Par = Parent/Parenting; PA = Physical Activity; SES = Socioeconomic Status; Self-esteem = SE; SCT = Social Cognitive Theory determinants (B = Behavioral; E = Environment, P = Personal); Sig = Significant/significantly; Sys Lit Rev = Systematic Literature Review; w/o = without; Yrs = Years of age; % = Percentile/Percent

Summary of research articles reviewed in Chapter II: Literature Review

Investigators	Rubin, Rimmer, Chicoine, Braddock, & McGuire, 1998	Cutting, Fisher, Grimm-Thomas, & Birch, 1999
Level of Evidence	III-3	IV
Article Keywords	DS, Obesity	Parent eating habits, Child BMI
Study Focus	Establish the prevalence of overweight and obesity among a group of individuals with DS	To examine parental characteristics assoc with overweight and eating behaviors in children
SCT (B, E, P)	Population based, single variable exploration B, E, P not significantly relevant	B = Child energy intake E = Parents' BMI, eating behavior P = Past experiences, Food choice
Design/ Data Coll.	Design: Crss Sect retrospective comparison Data Coll: Single interval	Design: Crss Sect (no comparisons) Data Coll: Baseline
Population	283 individuals with DS (15 to 69 yrs; 146 males, 137 females); 126 lived with family and 157 lived in a group home	75 Preschool children (ages 3 to 7 yrs; 40 boys, 35 girls) and their parents
Outcome/Intrvn/ Context	Outcome: BMI Intrvn: N/A Context: Participants living setting (family home or group home)	Outcome: <i>Parent Eating Inventory</i> , Child and Parent BMI, Child energy intake evaluation Intrvn: N/A Context: School and Laboratory setting
Summary of Results	All participants had a higher prevalence of overweight compared to the general population. BMI was higher among those living at home, compared to a group home	Maternal disinhibition predicted child overweight among daughters. Family influence on child weight differs by gender of parent and child

Note. Assoc Bhvr = Behavior; BMI = Body Mass Index; Crss Sect = Cross Sectional; Data Coll. = Data Collection; DS = Down Syndrome; Edu = Education; Envir = Environment; Intrvn = Intervention; N/A = Not Applicable or Not Specified; MVPA = Moderate to Vigorous Physical Activity; Nutr = Nutrition; Par = Parent/Parenting; PA = Physical Activity; Self-esteem = SE; SCT = Social Cognitive Theory determinants (B = Behavioral; E = Environment, P = Personal); Sig = Significant/significantly; Yrs = Years of age

Summary of research articles reviewed in Chapter II: Literature Review

Investigators	Mokdad et al., 1999	Sallis, Alcaraz, McKenzie, & Hovell, 1999
Level of Evidence	IV	III-3
Article Keywords	Obesity prevalence	Child PA
Study Focus	Investigate the prevalence of obesity	Investigate child's PA level over time, determine predictor variables
SCT (B, E, P)	Population based explorative study, B, E, P not significantly relevant	B = PA level E = Parent behavior P = PA preference, past experiences
Design/Data Coll.	Design: Crss Sect Data Coll: Population based	Design: Comparative, longitudinal, w/o controls Data Coll: Accelerometer, parent index, 1-day recall, BMI, baseline and 20 months
Population	Used a multistage random digit dialing method to select a representative sample of participating states, 18 years +	370 girls, 362 boys (4 th , 5 th graders), with reports from parents
Outcome/Intrvn/Context	Context: Data from Behavioral Risk Factor Surveillance Survey. Data Coll: Telephone survey by state departments from 1991 to 1998. Intrvn: N/A	Outcome: PA levels, BMI over 20 months Context: Observed at school Intrvn: N/A
Summary of Results	Increase in obesity rates among all populations. Greatest increase among ages 18 to 29 yrs and Hispanic ethnicity. Georgia had the greatest increase in obesity at 101.8%	Child PA most assoc with activity preference and frequency of parent transportation. Child's PA levels declined from 4 th to 5 th grade. 3 to 6% for boys; 7 to 12% for girls

Note. Assoc = Associated; Bhvr = Behavior; Btwn = Between; BMI = Body Mass Index; CFQ = Child Feeding Questionnaire; Crss Sect = Cross Sectional; Data Coll. = Data Collection; DS = Down Syndrome; Edu = Education; Envir = Environment; Exp = Experimental Group; FBBT = Family-based bhvrl trtmnt; Hr = hour; Indvl = Individual; Intrvn = Intervention; N/A = Not Applicable or Not Specified; MVPA = Moderate to Vigorous Physical Activity; Nutr = Nutrition; Par = Parent/Parenting; PA = Physical Activity; SCT = Social Cognitive Theory determinants (B = Behavioral; E = Environment, P = Personal); Sig = Significant/significantly; TFEQ = Three Factor Eating Quest; Thru = Through; Trtmnt Grp = Treatment Group; Wkly = weekly; Wt = Weight; Yrs = Years of age; % = Percentile/Percent

Summary of research articles reviewed in Chapter II: Literature Review

Investigators	Birch & Fisher, 2000	Epstein, Paluch, Gordy, & Dorn, 2000
Level of Evidence	IV	III-1
Article Keywords	Par feeding style, BMI	Intrvn, BMI, PA, Parent
Study Focus	Invest the influence of mothers eating habits and perceptions of their own weight status along with that of their child	Increased PA vs. decreased sedentary bhvr on obesity; FBBT
SCT (B, E, P)	B = Child weight E = Moth influence P = Direct or indirect influence, choice, past behaviors	B = Adherence; PA level E = FBBT P = Trmnt grp; past efforts
Design/ Data Coll.	Design: Crss Sect Quan: <i>CFQ</i> ; Restricted access quest; BMI	Design: RCT Quan: BMI Data Coll: baseline, 6, 12, 24 months follow-up,
Population	197 mothers with children (5 yrs)	90 families (obese children 8 to 12 yrs)
Outcome/Intrvn/ Context	Development of a structural equation model to explain interaction of factors	Outcome: Wt loss, PA level Intrvn: Wkly meetings for 6 months Context: Clinical
Summary of Results	Mothers exhibited a high level of control and restriction toward daughters' eating habits when: (1) they perceived the child to be obese or at risk and (2) the mothers had difficulty regulating their own personal food intake, assuming their child would have the same problem	Both grps had BMI decreases. Decreases in sedntary bhvr can impact participants

Note. Bhvr = Behavior; Btwn = Between; BMI = Body Mass Index; *CFQ* = Child Feeding Questionnaire; Crss Sect = Cross Sectional; Data Coll. = Data Collection; DS = Down Syndrome; Edu = Education; Envir = Environment; Exp = Experimental Group; FBBT = Family-based bhvrl trtmnt; Hr = hour; Indvl = Individual; Intrvn = Intervention; N/A = Not Applicable or Not Specified; MVPA = Moderate to Vigorous Physical Activity; PA = Physical Activity; RCT = Randomized Controlled Trial; SES = Socioeconomic Status; Self-esteem = SE; SCT = Social Cognitive Theory determinants (B = Behavioral; E = Environment, P = Personal); Sig = Significant/significantly; Thru = Through; Trtmnt Grp = Treatment Group; Wkly = weekly; Yrs = Years of age; % = Percentile/Percent

Summary of research articles reviewed in Chapter II: Literature Review

Investigators	Gordon-Larsen, McMurray, & Popkin, 2000	Hood et al., 2000
Level of Evidence	IV	III-3
Article Keywords	Adolescent PA, envir determinants	Parent eating attitudes, child BMI, child PA and eating habits
Study Focus	Investigate envir & SES determinants of PA and phys inactivity patterns among US adolescents	Investigate the extent to which parents' degree of dietary self-control affects the development of excess body fat in children
SCT (B, E, P)	B = Par in PA class, community programs, MVPA and sedentary level E = Encourages or discourages PA P = Choice to be PA or not be PA	B = Child PA, Energy intake of children E = Parents' eating attitude, behaviors P = Past experiences
Design/Data Coll.	Design: Crss Sect Quest Data Coll: MVPA level, SES, hours of physical inactivity	Design: Comparative w/o controls Data Coll: Longitudinal, over 6 years
Population	17, 766 US adolescent (white, black, Hispanic, Asian)	92 (3 to 5 yrs) children and their parents
Outcome/Intrvn/Context	Outcome: PA level Context: Data from National Long. Study of Adolescent Health Intrvn: N/A	Outcome: Parents' self-reported TFEQ data, Child BMI, Child PA level (accelerometers) Intrvn: N/A Context: Children and families enrolled in the Framingham Children's Study
Summary of Results	MVPA was lower and phys inactivity was high for black and Hispanic adolescent MVPA was positively assoc with daily PE classes and community/recreation program participation. SES, maternal education, family income were pos correlated with MVPA. Crime rate was inversely correlated with MVPA	Parents with high levels of disinhibited eating (along with high dietary restraint), may encourage the dev of excess body fat in children. Parent modeling of unhealthy eating may directly or indirectly mediate this relationship

Note. Bhvr BMI = Body Mass Index; Crss Sect = Cross Sectional; Data Coll. = Data Collection; Envir = Environment; Intrvn = Intervention; N/A = Not Applicable or Not Specified; MVPA = Moderate to Vigorous Physical Activity; PA = Physical Activity; Quest= Questionnaire; RCT = Randomized Controlled Trial; SES = Socioeconomic Status; Self-esteem = SE; SCT = Social Cognitive Theory determinants (B = Behavioral; E = Environment, P = Personal); Wkly = weekly; Wt = Weight; w/o = without; Yrs = Years of age

Summary of research articles reviewed in Chapter II: Literature Review

Investigators	Saelens, Ernest, & Epstein, 2000	Whitaker, Deeks, Baughcum, and Specker, 2000
Level of Evidence	III-3	III-3
Article Keywords	Mothers, feeding style, BMI	Child BMI, Parents' BMI, eating behaviors
Study Focus	Investigate the relationship btwn maternal feeding practices and weight using discordant sibling design	Understand risk factors for the development of obesity in early childhood, the association between child's adiposity and parents' eating behaviors and BMI were examined
SCT (B, E, P)	B = eating habits of child; obese or non obese E = Maternal feeding practices P = mothers perceptions	B = Obese or non obese child E = Parents' eating behaviors, BMI P = Past experiences
Design/ Data Coll.	Design: Comparative w/o controls Data Coll: BMI, <i>CFQ</i> , <i>TFEQ</i>	Design: Crss Sectional comparisons over time w/o controls Data Coll: Child weight at 3, 6, 12, 24, and 36 months. <i>TFEQ</i> data: baseline
Population	18 families who have obese and non obese children dyads (36 total; 7 to 12 yrs)	Parents of 85 children (3 yrs, 49 boys, 36 girls) from previous research cohort
Outcome/Intrvn/ Context	Outcome: Quest data Context: Clinical setting; families were given a monetary incentive to participate Intrvn: N/A	Outcome: Parents' self-reported <i>TFEQ</i> data, Parent BMI, Child BMI, Child Percent Body fat Intrvn: N/A Context: Clinical
Summary of Results	Maternal control of child feeding is not related to child obesity. Maternal weight history and eating habits do have an impact on child future weight and child health independent of weight status	No significant relationship between child BMI and parents eating behaviors. Mothers and daughters (only) had a significant relationship between child body fat and parent BMI

Note. Btwn = Between; BMI = Body Mass Index; *CFQ* = Child Feeding Questionnaire; Crss Sect = Cross Sectional; Data Coll. = Data Collection; Intrvn = Intervention; N/A = Not Applicable or Not Specified; PA = Physical Activity; Quest= Questionnaire; RCT = Randomized Controlled Trial; SES = Socioeconomic Status; SCT = Social Cognitive Theory determinants (B = Behavioral; E = Environment, P = Personal); *TFEQ* = Three Factor Eating Quest; Yrs = Years of age

Summary of research articles reviewed in Chapter II: Literature Review

Investigators	Birch et al., 2001	Davison & Birch, 2001
Level of Evidence	IV	III-3
Article Keywords	Child feeding practices	Child PA perception, weight concern, BMI
Study Focus	Calculate and provide a confirmatory factor analysis of the <i>CFQ</i>	Examine the relationship between weight status and self-concept in preschool girl and whether parental concern for weight or restriction of food was assoc with negative self-evaluation.
SCT (B, E, P)	Confirmatory factor analysis, B, E, and P not significantly relevant	B = Physical ability E = Parent concern, restriction of food P = Perceptions of self, past experiences
Design/Data Coll.	Design: Confirmatory factor analysis using 3 independent samples Data Coll: 3 samples to determine validity and reliability	Design: Comparative w/o controls Data Coll: BMI, parent's survey responses
Population	S1: 394 mothers and fathers (children 5 to 9 yrs) S2: 148 mothers and fathers (children 8 to 11 yrs) S3: 126 Hispanic mothers and fathers (children 7 to 11 yrs)	197 girls (5 yrs) and their parents
Outcome/Intrvn/Context	Outcome: <i>CFQ</i> data from 3 samples Intrvn: N/A Context: not provided	Outcome: <i>CFQ</i> , BMI Intrvn: N/A Context: Clinical setting
Summary of Results	Internal consistencies for 7 factors were above 0.70. 4 of the 7 factors were related to child weight, which provides initial validity. <i>CFQ</i> is considered an acceptable measure to assess child feeding perceptions, attitudes, and child weight status.	Girls with higher BMI reported lower body esteem and perceived cognitive ability. Higher parental concern for weight was assoc with lower perceived physical ability. Higher maternal restriction of food was assoc with low perceived physical and cognitive ability among girls with high BMI, but not low BMI

Note. Assoc = Associations/ed; BMI = Body Mass Index; *CFQ* = Child Feeding Questionnaire; Crss Sect = Cross Sectional; Data Coll. = Data Collection; Intrvn = Intervention; N/A = Not Applicable or Not Specified; PA = Physical Activity; SCT = Social Cognitive Theory determinants (B = Behavioral; E = Environment, P = Personal); Yrs = Years of age

Summary of research articles reviewed in Chapter II: Literature Review

Investigators	Deckelbaum & Williams, 2001	Kalakanis, Goldfield, Paluch, & Epstein, 2001
Level of Evidence	I	III-3
Article Keywords	PA, family, Eat, environment, genetics	Child PA, Parent PA, obesity
Study Focus	Review of studies to generate discussion related to the comorbidities or obesity and the impact of environmental influences	Measure the level and pattern of MVPA and examine predictors of activity in child who are obese.
SCT (B, E, P)	Population based lit rev, B, E, P not significantly relevant	B = PA level, impact of obesity E = Parents' PA level P = Past experiences, impact of obesity
Design/ Data Coll.	Design: Sys Lit Rev Data Coll: N/A	Design: Quasi-Exp, w/o control Data Coll: Pre to Post PA levels, BMI
Population	Inclusion and exclusion criteria not listed	51 families (1 parent, 1 child) with obese children (BMI > 85 th %). Morbidly obese excluded
Outcome/Intrvn/ Context	Context: Discussion of worldwide influences, indicators, and comorbidities of obesity Intrvn/Context: N/A	Outcome: Demographics Baseline BMI of child PA level – TriTrac accelerometers Intrvn: PA collected during summer months (37 families); winter months (14 families). Parent and child wore TriTrac 2-4 dys/wk
Summary of Results	Obesity rates have increased worldwide, no longer considered a Western problem. Persistence of childhood obesity into adulthood is evident. Comorbidities include: Diabetes, orthopedic and psychological issues	Regression models determined that parent PA improved prediction of children's PA, the number of bouts but not duration of PA.

Note. Data Coll. = Data Collection; Envir = Environment; Exp = Experimental; Intrvn = Intervention; N/A = Not Applicable or Not Specified; MVPA = Moderate to Vigorous Physical Activity; PA = Physical Activity; Qual = Qualitative; Quan = Quantitative; Quest= Questionnaire; RCT = Randomized Controlled Trial; SES = Socioeconomic Status; Self-esteem = SE; SCT = Social Cognitive Theory determinants (B = Behavioral; E = Environment, P = Personal); Sig = Significant/significantly; Sys Lit Rev = Systematic Literature Review; w/o = without; Yrs = Years of age

Summary of research articles reviewed in Chapter II: Literature Review

Investigators	Davison, Downs, & Birch, 2002	Spruijt-Metz, Lindquist, Birch, Fisher, & Goran, 2002
Level of Evidence	III-2	III-3
Article Keywords	Par support, PA, girls	Feeding patterns, BMI
Study Focus	Examine the pathways by which parental support of PA across ages 9 to 11 years predict PA at 11 yrs.	Evaluate the relation between mothers' feeding practices and child BMI in boys and girls from 2 ethnic populations
SCT (B, E, P)	B = PA E = Amount of support P = Past experiences	B = Behaviors that impact weight E = Mothers' feeding patterns B = Past experience, weight concern
Design/ Data Coll.	Design: Longitudinal, comparative cohort. Data Coll: at ages 5, 7, 9, and 11 yrs; Interviews, Quest (Self-Perception Profile; Parent Activity Support Scale, PA checklist)	Design: Comparative Data Coll: Baseline with 3 follow-up diet recalls
Population	Original participants of large cohort, girls ages 5 to 15 yrs. 174 non-Hispanic white girls and their mothers and fathers	74 white children (25 boys, 49 girls); 46 black children (22 boys, 24 girls) and their mothers
Outcome/Intrvn/ Context	Outcome/Context: Data was collected in the household with a trained researcher with only 9, 11 year intervals analyzed Intrvn: N/A	Outcome/Context: <i>CFQ</i> data, BMI, ethnic differences, 3 24 hour dietary recall diaries Intrvn: N/A
Summary of Results	Higher perceived competence at 9 yr, predicted higher parental support at 11 yr, which led to higher PA of girls. Encouragement and support were highly recommended	Child feeding practices explained variance in total fat mass more so that energy intake between 2 ethnically different populations. Ethnicity and gender did not contribute to variance in BMI

Note. BMI = Body Mass Index; *CFQ* = Child Feeding Questionnaire; Crss Sect = Cross Sectional; Data Coll. = Data Collection; DS = Down Syndrome; Edu = Education; Envir = Environment; Exp = Experimental Group; FBBT = Family-based bhvrl trtmnt; Hr = hour; Indvl = Individual; Intrvn = Intervention; N/A = Not Applicable or Not Specified; MVPA = Moderate to Vigorous Physical Activity; Nutr = Nutrition; Par = Parent/Parenting; PA = Physical Activity; Self-esteem = SE; SCT = Social Cognitive Theory determinants (B = Behavioral; E = Environment, P = Personal); Yrs = Years of age

Summary of research articles reviewed in Chapter II: Literature Review

Investigators	Ransdell, Dratt, Kennedy, O'Neill, & Devoe, 2001	Beamer, 2003
Level of Evidence	III-1	I
Article Keywords	Family intrvsn, PA,	Obesity influence
Study Focus	Determine the effectiveness of an intervention purposed to facilitate positive life changes (i.e., physical self-perception) and to increase PA in mothers and daughters	Review and provide explanation for genetic influences on obesity
SCT (B, E, P)	B = Level of PA, type of PA E = Mother-daughter participation P = Past experiences, interest	B = PA, Eat E = Family P = Choice, Past behaviors, genetics
Design/ Data Coll.	Design: Pseudo-RCT Data Coll: Focus groups guided type of PA used in intrvsn, pre and post intrvsn, 6 months after	Design: Sys Lit Rev and overview (textbook)
Population	100 Mothers (34 to 46 yrs) and their daughters (12 to 15 yrs)	Inclusion and exclusion criteria not listed
Outcome/Intrvsn/ Context	Outcome: Focus group of mothers, Aerobic capacity, BMI, <i>Physical Self-Perception Profile</i> Intrvsn: 2 times a week, 24 sessions over 12 weeks (1.5 to 2 hours per) of family PA Context: University setting	Outcome: No specific variables listed, provide discussion of influences and discuss adequate treatments of obesity Intrvsn/Context: N/A
Summary of Results	No sig improvements in sport competence, physical condition, or strength over time. Mothers reported that the program provided valuable opportunities for mother-daughter bonding and sharing of feelings. Group differences in PA levels did not increase, but some individuals had dramatic increases (i.e., joined sport teams, fitness groups)	Discussed biological, social, and historical context of obesity. Obesity as a monogenic and polygenic disorder, traits or systems that influence obesity

Note. Crss Sect = Cross Sectional; Data Coll. = Data Collection; Envir = Environment; Intrvsn = Intervention; N/A = Not Applicable or Not Specified; MVPA = Moderate to Vigorous Physical Activity; PA = Physical Activity; RCT = Randomized Controlled Trial; SCT = Social Cognitive Theory determinants (B = Behavioral; E = Environment, P = Personal); Sig = Significant; Sys Lit Rev = Systematic Literature Review; Yrs = Years of age

Summary of research articles reviewed in Chapter II: Literature Review

Investigators	Davison, Cutting, & Birch 2003	Harris, Rosenberg, Jangda, O'Brien, & Gallagher, 2003
Level of Evidence	III-3	IV
Article Keywords	Par PA level, Parenting practices	BMI, obesity
Study Focus	Invest parents activity-related parent practices and how they relate to child PA	Assess the prevalence of obesity in a sample of Special Olympics (SO) athletes worldwide and to determine differences btwn US and other countries' SO athletes
SCT (B, E, P)	B = PA level E = Par practices P = Past experience with parent	Population based, single variable exploration B, E, P not significantly relevant
Design/ Data Coll.	Design: Comparative Data Coll: Par Quest, PA level quest BMI	Design: Crss sect comparative w/o controls, across 2 grps Data Coll: Single interval
Population	180 (9 yr old) girls and their parents	1,749 SO World Games athletes; 68% were from outside US; 32% were from US; Only criteria was willingness to participate (80% were 18 to 39 yrs; range 9 yrs to 40+)
Outcome/Intrvn/ Context	Outcome: Crss sect data collected as part of a longitudinal study (5 to 9 yrs). Only 9 yr old data used. Intrvn: N/A Context:	Outcome: BMI Intrvn: N/A Context: World SO Games
Summary of Results	Parents can have a positive influence on PA levels of child; through logistic support or direct modeling	US SO athletes were 2.7 times more likely to be at risk for overweight and 6.19 times more likely to be overweight

Note. BMI = Body Mass Index; Crss Sect = Cross Sectional; Data Coll. = Data Collection; Intrvn = Intervention; N/A = Not Applicable or Not Specified; MVPA = Moderate to Vigorous Physical Activity; Nutr = Nutrition; Par = Parent/Parenting; PA = Physical Activity; Quest= Questionnaire; SCT = Social Cognitive Theory determinants (B = Behavioral; E = Environment, P = Personal); Sig = Significant/significantly; w/o = without; Yrs = Years of age; % = Percentile/Percent

Summary of research articles reviewed in Chapter II: Literature Review

Investigators	Schwartz & Puhl, 2003	Agras , Hammer, McNicholas, & Kraemar, 2004
Level of Evidence	I	III-2
Article Keywords	Childhood obesity, family	Parent BMI, Child BMI, SES
Study Focus	Examine literature to provide a comprehensive discussion of the challenges facing families who have obese children	Determine risk factors for childhood overweight and obesity
SCT (B, E, P)	Population based lit rev, B, E, P not significantly relevant	B = Child's tantrums, amount of sleep, PA level E = Par weight, concern for weight, feeding practices P = Choice, Past behaviors
Design/ Data Coll.	Design: Sys Lit Rev Data Coll: N/A	Design: Prospective Study. Data Coll: BMI of child, Par; Self-reported feeding practices, parenting behaviors, accelerometry
Population	Inclusion and exclusion criteria are not specified other than topic areas.	150 children (0 to 9.5 yrs; 74 boys; 76 girls)
Outcome/Intrvn/ Context	Outcome: Societal messages, parent's challenge, role of food and modeling, Intrvn/Context: N/A	Outcome: % of risk factors Intrvn/ Context: N/A
Summary of Results	Children who are obese are stigmatized by others and parents are given conflicting advice on how to help related to eating. Obese children experience low self-esteem, are often disorganized or picky eaters, can self-regulate food when taught, and are highly susceptible to parent and peer modeling	5 risk factors were found: Parent overweight, low parent concern for thinness, persistent child tantrums with food, less sleep during childhood

Note. BMI = Body Mass Index; Crss Sect = Cross Sectional; Data Coll. = Data Collection; Hr = hour; Indvl = Individual; Intrvn = Intervention; N/A = Not Applicable or Not Specified; PA = Physical Activity; Par = Parenting; SCT = Social Cognitive Theory determinants (B = Behavioral; E = Environment, P = Personal); Sig = Significant/significantly; Sys Lit Rev = Systematic Literature Review; *TFEQ* = Three Factor Eating Quest; Thru = Through; Trtmnt Grp = Treatment Group; Wkly = weekly; Wt = Weight; w/o = without; Yrs = Years of age; % = Percentile/Percent

Summary of research articles reviewed in Chapter II: Literature Review

Investigators	Eisenberg, Olson, Neumark-Sztainer, Story, & Bearinger, 2004	Faith et al., 2004
Level of Evidence	III-3	III-2
Article Keywords	Family meals, adolescent well-being	Child feeding practice, child BMI
Study Focus	Determine the assoc btwn frequency of family meals and indicators of adolescent health and well-being	Examine the 2 yr stability of parent feeding attitudes and prediction of child BMI
SCT (B, E, P)	Population based explorative study, B, E, P not significantly relevant	B = Eating, PA E = Parent feeding attitude P = Past behaviors, choice
Design/ Data Coll.	Design: Crss Sect Comparative w/o control Data Coll: Single collection	Design: Longitudinal comparative w/o controls. Data Coll: Child BMI measured at 3, 5, 7 yrs. Parent <i>CFQ</i> measured at 5, 7 yrs
Population	4746 adolescents from ethnically and SES diverse communities (US)	57 families, enrolled in an Infant/ Growth Study. Either low or high risk for obesity
Outcome/Intrvn/ Context	Outcome: School based survey Intrvn: N/A Context: School setting	Outcome: Child BMI, parent feeding attitudes, <i>CFQ</i> subscales: responsibility, restriction, control, monitoring, weight concern Intrvn/Context: N/A
Summary of Results	26 % ate 7 or more family meals a week and 23% ate 2 or fewer family meals a week. Frequency of family meals was inversely assoc with tobacco, alcohol, and drug use, depressive symptoms (lack of SE) and suicide.	<i>CFQ</i> scores were stable 5 to 7 yrs. Perceived responsibility at 5, predicted reduced 7 yr BMI for low risk. Child wt concern and perceived child wt predicted increased BMI for high risk. Monitoring predicted reduced 7 yr BMI for low risk. Restriction predicted higher BMI, pressure to eat predicted reduced BMI for high risk

Note. BMI = Body Mass Index; *CFQ* = Child Feeding Questionnaire; Crss Sect = Cross Sectional; Data Coll. = Data Collection; Intrvn = Intervention; N/A = Not Applicable or Not Specified; PA = Physical Activity; SES = Socioeconomic Status; Self-esteem = SE; SCT = Social Cognitive Theory determinants (B = Behavioral; E = Environment, P = Personal); Sig = Significant/significantly; Wkly = weekly; w/o = without; Yrs = Years of age; % = Percentile/Percent

Summary of research articles reviewed in Chapter II: Literature Review

Investigators	Pitetti & Fernhall, 2004	Davison, Francis, & Birch, 2005
Level of Evidence	III-2	III-1
Article Keywords	DS, BMI, MR, running gait, youth	Parent BMI, Child BMI, TV time, diet, PA level
Study Focus	Compare the results of 2 studies that investigated the running performance of youth with and without DS and mild MR	Invest PA levels, diet, TV time, BMI differences in parents and girls from obesogenic vs nonobesogenic families
SCT (B, E, P)	Single variables assessed (BMI, work capacity) B, E, P, not significantly relevant	B = PA level, TV time E = Obese vs Nonobese P = Impact of envir, PA or food preference
Design/ Data Coll.	Design: Comparative study with multiple group comparisons Data Coll: Baseline comparisons between groups	Design: Longitudinal comparative with pseudorandomized groups Data Coll: BMI, PA level, TV time, diet, over 6 yrs
Population	Study 1: 395 youth with mild MR (11 to 18 yrs) and 119 youth with DS. Study 2: From original sample, those with and w/o DS were age, gender, BMI matched to youth w/o DS/MR	197 families (girls assessed at ages 5, 7, 9, 11 yrs) 92% retention rate.
Outcome/Intrvn/ Context	Outcome: 20m shuttle run test to measure work capacity, BMI Intrvn/ Context: N/A	Outcome: Longitudinal data, BMI coll with DXA: <i>Dutch Eating Behavior Quest</i> ; PA coll with activity checklist, Children's PA scale; Girls = Progressive Aerobic Cardiovascular Endurance Run test Intrvn: N/A Context: Clinical
Summary of Results	Youth with MR but w/o DS showed sig higher running performance than youth with DS and youth w/o MR showed sig higher running performance than youth with MR, with and w/o DS	Envir is influenced by parents and directly impacts the children, related to dietary intake and PA level

Note. BMI = Body Mass Index; Data Coll. = Data Collection; DS = Down Syndrome; N/A = Not Applicable or Not Specified; MR = Mental Retardation; PA = Physical Activity;; Quest= Questionnaire; SCT = Social Cognitive Theory determinants (B = Behavioral; E = Environment, P = Personal); Sig = Significant/significantly; Wt = Weight; w/o = without; Yrs = Years of age; % = Percentile/Percent

Summary of research articles reviewed in Chapter II: Literature Review

Investigators	Frey, Buchanan, & Sandt, 2005	O'Neill, Shults, Stallings, & Stettler, 2005
Level of Evidence	IV	III-3
Article Keywords	Adult BMI, intellectual disability	Feeding, DS, Sibling
Study Focus	Examine perceptions of PA behavior of adults with mild intellectual disability	Compare feeding practices, BMI betwn siblings, 1 with DS, 1 w/o.
SCT (B, E, P)	Crss sect data collection, B, E, P, not significantly relevant	B = Eating E = Parenting practices P = Impact of feeding style
Design/ Data Coll.	Design: Crss Sect Data Coll: Qual, interpretive ethnography	Design: Crss Sect comparative btwn 2 grps Data Coll: Comparative overtime btwn siblings
Population	12 adults with an intellectual disability (23 to 45 yrs)	36 children with DS; 36 child w/o DS; 3 -10 years
Outcome/Intrvn/ Context	Outcome: Self-reported PA, interviews, diaries, acceleromtery, and observations Intrvn: N/A Context: Residence of participants	Outcome: BMI, <i>CFQ</i> scores Intrvn/Context: N/A
Summary of Results	Many PA barriers were reported, along with negative influences and lack of guidance from support systems related to PA	BMI higher among children with DS; Parent reported greater restriction, concern for child wt, feelings of responsibility, and pressure to eat for children with DS. Perceived child overweight was positively assoc with BMI, pressure to eat was inversely assoc with BMI

Note. Assoc = Associated; BMI = Body Mass Index; *CFQ* = Child Feeding Questionnaire; Crss Sect = Cross Sectional; Data Coll. = Data Collection; DS = Down Syndrome; Intrvn = Intervention; N/A = Not Applicable or Not Specified; MVPA = Moderate to Vigorous Physical Activity; PA = Physical Activity; Qual = Qualitative; SCT = Social Cognitive Theory determinants (B = Behavioral; E = Environment, P = Personal); Sig = Significant/significantly; Wt = Weight; w/o = without; Yrs = Years of age; % = Percentile/Percent

Summary of research articles reviewed in Chapter II: Literature Review

Investigators	Giallo & Gavidia-Payne, 2006	Golan, Kaufman, & Shahar, 2006
Level of Evidence	IV	III-1
Article Keywords	Disability, sibling adjustment	Par Style, PA, BMI
Study Focus	Investigated a range of child, parent, and family factors as predictors of sibling adjustment outcomes.	Improve health, parenting style, decrease obesogenic enviro with increased PA and proper nutr. Parent and/or children as focus.
SCT (B, E, P)	B = Stress-related bhvrs E = Parents' stress, coping ability P = Past experience, adjustment	B = Eating, PA levels; Adherence E = Trng sessions; Obesogenic factors; Par style P = Past efforts; Child as target, Child not as the target
Design/ Data Coll.	Design: Crss Sect Data Coll: Single interval collection	Design: RCT Data Coll: Baseline, 6 and 12 months
Population	49 siblings (7 to 16 yrs) and their parents. Each family had 1 child with a developmental, sensory, physical, or intellectual disability	32 children (6 to 11yrs, BMI > 85 th %) and their parents
Outcome/Intrvn/ Context	Outcome: <i>Self-Report Coping Scale, Sibling Daily Hassles and Uplifts Scale, Perceived Stress Scale, Strengths and Difficulties Quest-Parent Version</i> Intrvn: N/A Context: Surveys were mailed and returned	Outcome: BMI; <i>Family Eating Activity Habits Quest</i> , Parenting style differences btwn groups. Groups: Parent only target, Parent/Child target. Intrvn: 16 1hr (6 mon) Trng sessions; (Coping techniques, Par Styles, Par Support; Nutr/PA Edu)
Summary of Results	Family factors more strongly predicted sibling adjustment compared to siblings' own stress or coping level. Other predicting factors of sibling adjustment: SES, sibling group attendance, family time, parent coping, routines.	Child or Par Only had sig decreases in BMI; Both groups = PA increase; Decreases in snacks; No sig. group differences, but greater decreases in obesogenic factors in Par Only. No sig changes in Par styles. Authoritative style assoc with BMI decreases

Note. Assoc = Associations/ed; BMI = Body Mass Index; Crss Sect = Cross Sectional; Data Coll. = Data Collection; DS = Down Syndrome; Intrvn = Intervention; N/A = Not Applicable or Not Specified; PA = Physical Activity; Quest= Questionnaire; RCT = Randomized Controlled Trial; SES = Socioeconomic Status; Self-esteem = SE; SCT = Social Cognitive Theory determinants (B = Behavioral; E = Environment, P = Personal); Sig = Significant/significantly; w/o = without; Yrs = Years of age

Summary of research articles reviewed in Chapter II: Literature Review

Investigators	Johannsen, Johannsen, & Specker, 2006	Keller, Pietrobelli, Johnson, & Faith, 2006
Level of Evidence	III-2	III-3
Article Keywords	Par BMI, Child BMI, feeding practices, eating behaviors	Child feeding patterns, family enviro, child BMI
Study Focus	Investigate the effects of mothers' and fathers' eating behaviors, child feeding practices, and BMI on body fat percentage and BMI in children	Investigate whether maternal feeding attitudes toward children are part of the shared or non-shared home enviro and determine within family differences in feeding style and child weight status, a pilot study
SCT (B, E, P)	B = Child eating E = Feeding practices, eating behaviors P = Past experiences	B = Parent feeding habits E = Parent feeding patterns P = Past experiences, weight concern
Design/ Data Coll.	Design: Comparative with retrospective cohort w/o control Data Coll: Single interval	Design: Comparative w/o control Data Coll: Baseline comparisons between siblings
Population	216 parents (148 mothers, 68 fathers) of children (3 to 5 yrs)	15 sibling pairs (3 to 7 yrs) and their mothers
Outcome/Intrvn/ Context	Outcome: <i>TFEQ</i> , <i>CFQ</i> , Parent BMI, Child BMI, Intrvn: N/A Context: Clinical (BMI); home setting (survey)	Outcome: Sibling pairs, <i>CFQ</i> data, Child BMI Intrvn/Context: N/A
Summary of Results	Mothers exert a stronger influence on child weight and are more concerned with child eating behavior than fathers. Mothers with a high concern for child future weight, had a higher BMI	Responsibility, monitoring, child overweight were sig related. Mothers' reported greater weight concern and reduced pressure to eat in heavier children

Note. BMI = Body Mass Index; *CFQ* = Child Feeding Questionnaire; Data Coll. = Data Collection; Intrvn = Intervention; N/A = Not Applicable or Not Specified; Par = Parent/Parenting; PA = Physical Activity; RCT = Randomized Controlled Trial; SES = Socioeconomic Status; Self-esteem = SE; SCT = Social Cognitive Theory determinants (B = Behavioral; E = Environment, P = Personal); Sig = Significant/significantly; *TFEQ* = Three Factor Eating Quest; Yrs = Years of age

Summary of research articles reviewed in Chapter II: Literature Review

Investigators	Ordoñez, Rosety, & Rosety-Rodriguez, 2006	Rhee, Lumeng, Appugliese, Kaciroti, & Bradley, 2006
Level of Evidence	III-3	II
Article Keywords	PA, DS	Parenting styles, BMI
Study Focus	Determine weight loss of adolescent with DS during aerobics activity program	Determine the relationship between parenting styles (authoritative [high control, high sensitivity], permissive [low control, high sensitivity], authoritarian [high control, low sensitivity], neglectful [low control, low sensitivity] and overweight status in children
SCT (B, E, P)	B = Aerobic PA E = PA level controlled P = Choice to be PA, intensity level	B = Child's reaction to style E = Parenting style P = Past experiences, child's reaction to style
Design/ Data Coll.	Design: Comparative, no control Data Coll: BMI	Design: RCT with retrospective cohort comparisons Data Coll: Child's age 54 months, during first grade
Population	22 male adolescents with DS,	872 Children (original cohort 1364) and their parents 11% overweight; 82 % white
Outcome/Intrvn/ Context	Outcome: Pre-Post measures of BMI, SECA electronic weighing, skinfold thickness Intrvn: 12 week aerobic activity intrvn (water, land PA) Context: University setting	Outcome: Child BMI, parenting style over time Intrvn:N/A Context: 10 sites across US; home and lab setting with telephone interviews
Summary of Results	All participants had sig weight loss, all participants completed the study.	Children with authoritarian parents were the highest risk for overweight, permissive and neglectful parents were twice as likely to have overweight children than authoritative

Note. BMI = Body Mass Index; Data Coll. = Data Collection; DS = Down Syndrome; Intrvn = Intervention; N/A = Not Applicable or Not Specified; Par = Parent/Parenting; PA = Physical Activity; Qual = Qualitative; Quan = Quantitative; Quest= Questionnaire; RCT = Randomized Controlled Trial; SES = Socioeconomic Status; Self-esteem = SE; SCT = Social Cognitive Theory determinants (B = Behavioral; E = Environment, P = Personal); Sig = Significant/significantly; % = Percentile/Percent

Summary of research articles reviewed in Chapter II: Literature Review

Investigators	Rimmer & Yamaki, 2006	Ruiz et al., 2006
Level of Evidence	I	III-3
Article Keywords	ID, obesity	Children, obesity, MVPA
Study Focus	Highlight the high obesity rates among those with an ID, discuss environmental influences, and provide guidance for researchers	Examine the assoc of total PA and intensity level to CFV and fatness in children
SCT (B, E, P)	B = Actions E = Living setting P = Choice, past experiences	Population based explorative study, B, E, P not significantly relevant
Design/ Data Coll.	Design: Sys Lit Rev Data Coll: N/A	Design: Crss sect comparative w/o controls Data Coll: PA measured over 4 days
Population	No inclusion or exclusion criteria were provided	780 children (9 to 10 yrs); n = 413 from Sweden; n = 367 from Estonia
Outcome/Intrvn/ Context	Outcome: Discussion of trends in the US and around the world support the increase of research related to obesity prevention among individuals with ID Intrvn/Context: N/A	Outcome: PA with Accelerometer, ergometer to measure CFV, body fat with skinfold measurements Intrvn: N/A Context: Not specified data a part of the European Youth Heart Study
Summary of Results	Incidence of obesity in individuals with ID is equal to and in some cases higher; some cases up to 50-60% of sample were obese. Envir factors on obesity in those with ID become more important with age, depending on living setting (residential, institution, or family)	MVPA may have a greater influence on obesity prevention than PA at lower intensities and improved MVPA may improve CVF.

Note. Bhvr = Behavior; Btwn = Between; BMI = Body Mass Index; CFV = Cardiovascular Fitness; Crss Sect = Cross Sectional; Data Coll. = Data Collection; ID = Intellectual Disability Intrvn = Intervention; N/A = Not Applicable or Not Specified; MVPA = Moderate to Vigorous Physical Activity; PA = Physical Activity; SCT = Social Cognitive Theory determinants (B = Behavioral; E = Environment, P = Personal); Sig = Significant/significantly; Sys Lit Rev = Systematic Literature Review; Yrs = Years of age

Summary of research articles reviewed in Chapter II: Literature Review

Investigators	Wang & Lobstein, 2006	Whitt-Glover, O’Neill, & Stettler, 2006
Level of Evidence	III-2	III-3
Article Keywords	Childhood obesity prevalence	PA, siblings, DS, BMI
Study Focus	Summarize available information of recent trends in child overweight and obesity prevalence	Describe PA patterns in siblings with and w/o DS
SCT (B, E, P)	Population based lit rev, B, E, P not significantly relevant	Explorative study, B, E, P not significantly relevant
Design/ Data Coll.	Design: Sys Lit Rev and retrospective comparison of data Data Coll: N/A	Design: Explorative, comparative w/o controls Data Coll: Baseline
Population	Comprehensive search of databases. Inclusion crit: Published between Jan.1980 to Oct. 2005; Included school-age population in 25 countries; preschool age in 42 countries	28 child with DS and their 30 siblings w/o DS; all 3 to 10 years
Outcome/Intrvn/ Context	Outcome/Context: Compared with WHO’s Burden of Disease Program data for 2006 and likely for 2010 Intrvn: N/A	Outcome: PA patterns, BMI Intrvn: N/A Context: home setting
Summary of Results	Prevalence of overweight has increased worldwide (exceptions were school-age children in Poland and Russia; Infant and pre-school age in low income countries). Dramatic increases occurred in economically developed nations	Children with DS participated in less vigorous PA and for shorter bouts and had a higher BMI

Note. BMI = Body Mass Index; Crss Sect = Cross Sectional; Data Coll. = Data Collection; DS = Down Syndrome; Intrvn = Intervention; N/A = Not Applicable or Not Specified; MVPA = Moderate to Vigorous Physical Activity; PA = Physical Activity; SCT = Social Cognitive Theory determinants (B = Behavioral; E = Environment, P = Personal); Sig = Significant/significantly; Sys Lit Rev = Systematic Literature Review; Yrs = Years of age

Summary of research articles reviewed in Chapter II: Literature Review

Investigators	Menear, 2007	Ornelas, Perreira, Ayala, 2007
Level of Evidence	IV	III-3
Article Keywords	DS, health, PA	Par infl, adolescent PA
Study Focus	Investigate the healthy and PA levels of children with DS from the perspective of the parents	Investigate how the relationship btwn parent influences and adolescent PA differ by gender. Examine whether relationship is mediated by SE or depression
SCT (B, E, P)	B = Active or inactive behavior E = Motivation from others, programming, parent knowledge P = Enjoyment, past experiences	B = PA habits E = Parent influence P = Adolescent anxiety, depression, SE
Design/ Data Coll.	Design: Crss Sect Case Series Data Coll: Qual, 3 focus groups divided based on the age of children, a fourth focus group of all ages was formed for those with time constraints	Design: Comparative, w/o controls, longitudinal Data Coll: Quest (overall health), Interviews (MVPA levels) '95, '96.
Population	17 Parents (12 mothers, 5 fathers) who have children with DS (preschool, elementary, and adolescent ages)	13, 246 adolescents grades 7 -12 yrs
Outcome/Intrvn/ Context	Outcome: Transcribed data, 4 focus groups Intrvn: N/A; Context: Times and locations that were convenient to participants, not specified	Outcome: Relationship mediators Context: Data from National Long. Study of Adolescent Health; Interviews completed at child's home Intrvn: N/A
Summary of Results	Parents were aware of the health benefits of PA, social interaction was the primary and most motivating reason for PA for their children, adolescent children with DS need to learn individual sports due to lack of group programs, and parents recognized the need for assistance to get their children more PA.	Family cohesion, parent-child communication, parent engagement pos. predicted MVPA levels. Par monitoring was not assoc with MVPA levels. Emotional health of child was positively assoc with family cohesion and parent-child communication

Note. Crss Sect = Cross Sectional; Data Coll. = Data Collection; DS = Down Syndrome; Intrvn = Intervention; N/A = Not Applicable or Not Specified; MVPA = Moderate to Vigorous Physical Activity; PA = Physical Activity; Qual = Qualitative; Quest= Questionnaire; SE = Self-Esteem; SCT = Social Cognitive Theory determinants (B = Behavioral; E = Environment, P = Personal); Wkly = weekly; Wt = Weight; w/o = without; Yrs = Years of age

Summary of research articles reviewed in Chapter II: Literature Review

Investigators	Bauer, Nelson, Boutelle, & Neumark-Sztainer, 2008	Grammatikopoulou et al., 2008
Level of Evidence	III-2	IV
Article Keywords	Parent PA, Child PA	Eating, BMI, DS
Study Focus	Investigate assoc btwn parent-specific factors (Parent PA, encouragement, attitude) and adolescent PA levels over time	Assess nutrient intake and anthropometry in children and adolescents with DS (Greece).
SCT (B, E, P)	B = PA level E = Mother or father encouragement P = Parent attitude about PA; Child reaction to parent attitude	Population based explorative study, B, E, P not significantly relevant
Design/ Data Coll.	Design: Longitudinal Quan: PA + Eating Quests. Data Coll: Baseline, 5 years	Design: Comparative w/o controls Data Coll: Crss Sect comparisons between children and adolescents
Population	1130 males, 1386 females. Group 1 assessed at 12 yrs, 17 yrs Group 2 assessed at 15 yrs, 20 yrs	34 Child with DS (2 to 18 yrs)
Outcome/Intrvn/ Context	Outcome: BMI, Amt of MVPA, TV viewing. Quest comparisons at 5 yrs. Context: Clinical setting	Outcome: 3 day food record, BMI Intrvn: N/A Context: not specified
Summary of Results	Older females reported less parental caring about PA level compared to others. Girls assoc with maternal encouragement. Boys PA assoc with paternal encouragement	More than half reported eating 5 meals a day, most exercised twice a week, a majority were overweight and obese, and most consumed a diet more sufficient in micronutrients

Note. Assoc = Associations/ed; BMI = Body Mass Index; Crss Sect = Cross Sectional; Data Coll. = Data Collection; DS = Down Syndrome; Intrvn = Intervention; N/A = Not Applicable or Not Specified; MVPA = Moderate to Vigorous Physical Activity; Nutr = Nutrition; Par = Parent/Parenting; PA = Physical Activity; Quan = Quantitative; Quest= Questionnaire; SCT = Social Cognitive Theory determinants (B = Behavioral; E = Environment, P = Personal); w/o = without; Yrs = Years of age

Summary of research articles reviewed in Chapter II: Literature Review

Investigators	Lubans, Foster, & Biddle, 2008	Mulroy, Robertson, Aiberti, Leonard, & Bower, 2008
Level of Evidence	I	IV
Article Keywords	Child PA	Family, DS, siblings
Study Focus	A review of mediators in interventions to promote PA among children and adolescents	Examine to effects on other children when there is a child with an intellectual disability
SCT (B, E, P)	B = Level of PA E = Intrvsn type P = Self-efficacy	B = behaviors related to impact E = child with DS, parents behaviors P = Perceptions of sibling impact
Design/Data Coll.	Design: Sys Lit Rev Data Coll: N/A	Design: Crss Sect sibling comparisons from parents Data Coll: Crss Sect
Population	Comprehensive search of databases. Inclusion criteria: Quan assessment of PA and potential mediators; PA exp intrvsn; published in English	Parents of 186 children with DS and 141 girls with Rhett syndrome (Australia) age not specified
Outcome/Intrvsn/Context	Outcome: cognitive, behavioral, interpersonal mediators to PA that incorporated exp designs and validated quest Intrvsn/Context: N/A	Outcome: Quest responses Intrvsn: N/A Context: not specified
Summary of Results	Self-efficacy was most commonly assessed mediator; interpersonal factors were the least referenced mediator for PA	Parents identified benefits and disadvantages for siblings of children with DS or Rhett, higher SES yielded more disadvantages (i.e., time constraints, parent emotion, restrictions)

Note. Crss Sect = Cross Sectional; Data Coll. = Data Collection; DS = Down Syndrome; Intrvsn = Intervention; N/A = Not Applicable or Not Specified; PA = Physical Activity; Qual = Qualitative; Quan = Quantitative; Quest= Questionnaire; RCT = Randomized Controlled Trial; SES = Socioeconomic Status; Self-esteem = SE; SCT = Social Cognitive Theory determinants (B = Behavioral; E = Environment, P = Personal); Sig = Significant/significantly; Sys Lit Rev = Systematic Lit Review; Yrs = Years of age;

Summary of research articles reviewed in Chapter II: Literature Review

Investigators	Ventura & Birch, 2008	Gruber & Haldeman, 2009
Level of Evidence	I	I
Article Keywords	Parental feeding patterns, child weight	Family influence, obesity, PA, diet
Study Focus	Assess current evidence related to parenting and obesity (via children's eating) and to identify strategies that target parenting for obesity prevention	Emphasize the value of the family as a source of behavior change
SCT (B, E, P)	Population based lit rev, B, E, P not significantly relevant	Population based lit rev, B, E, P not significantly relevant
Design/Data Coll.	Design: Sys Lit Rev Data Coll: N/A	Design: Sys Lit Rev Data Coll: N/A
Population	66 articles met inclusion criteria: Published prior to Jan. 2007 that assessed parenting, eating, BMI	Inclusion and exclusion criteria not specified
Outcome/Intrvn/Context	Outcome: A majority of results were of cross-sectional data Intrvn/Context: N/A	Outcome: Discussion of the purpose of family-based approach and families as a support system, barrier and solution Intrvn/Context: N/A
Summary of Results	Substantial evidence exists that parenting impacts a child's eating and weight status, but designs and data collection techniques are not precise. Impacting factors: pressure, restriction, availability, BMI of family members	Support based on previous lit guides researchers to target the family when influencing the diet and PA behaviors of youth. The adult child relationship related to health behaviors is described as reciprocal

Note. Data Coll. = Data Collection; Intrvn = Intervention; N/A = Not Applicable or Not Specified; Par = Parent/Parenting; PA = Physical Activity; SCT = Social Cognitive Theory determinants (B = Behavioral; E = Environment, P = Personal); Sys Lit Rev = Systematic Literature Review

Summary of research articles reviewed in Chapter II: Literature Review

Investigators	Hardman, Horne, & Lowe, 2009	Joyce & Zimmer-Gembeck, 2009
Level of Evidence	II	III-3
Article Keywords	PA, family, intrvn	Parent feeding style, child BMI
Study Focus	Evaluate the effectiveness of a home based PA intrvn	Investigate assoc btwn parent food restriction and child BMI and to test how parenting context may influence of restriction of eating
SCT (B, E, P)	B = Change in PA levels, adherence E = Presence of pedometer P = Prnt-modeling, past efforts	B = Eating habits E = Parent feeding habits P = Awareness, past choices
Design/ Data Coll.	Design: RCT Data Coll: PA levels; BMI at Baseline	Design: Comparative w/o control Data Coll: Quest, self-reported Par BMI, child BMI
Population	32 girls (11 yrs) and families	230 caregivers of children aged 4 to 8 yrs (48% female)
Outcome/Intrvn/ Context	Outcome: PA change, Wt loss Intrvn: Exp group, control group; increase steps Context: Home-based	Outcome: Correlational comparison of BMI, <i>CFQ</i> , <i>Parent Feeding Dimensions</i> Intrvn: N/A Context: school setting, private space
Summary of Results	Sig increases in PA levels of parents and adolescents were observed from the exp group	Parent restriction of food was directly related to child BMI. Association betwn restriction and child's disinhibited eating differed depending on parenting context (feeding domain, supportiveness, coerciveness, chaotic parenting)

Note. BMI = Body Mass Index; *CFQ* = Child Feeding Questionnaire; Data Coll. = Data Collection; Exp = Experimental Group; Intrvn = Intervention; N/A = Not Applicable or Not Specified; Par = Parent/Parenting; PA = Physical Activity; Quest= Questionnaire; RCT = Randomized Controlled Trial; SCT = Social Cognitive Theory determinants (B = Behavioral; E = Environment, P = Personal); Sig = Significant/significantly; Trtmnt Grp = Treatment Group; Wt = Weight; w/o = without; Yrs = Years of age

Summary of research articles reviewed in Chapter II: Literature Review

Investigators	Madsen, McCulloch, & Crawford, 2009	Puhl & Heuer, 2009
Level of Evidence	III-2	I
Article Keywords	Child PA, parent modeling	Obesity, stigma, bias, societal attitude
Study Focus	Determine the impact of parent modeling on PA in girls from ages 9, 10 years to 18, 19 years	Expands previous findings of impact of obesity, weight biases, and ongoing research questions related to obesity
SCT (B, E, P)	B = Child level of PA E = active/inactive parents P = Choice, Past experience	Population based lit rev, B, E, P not significantly relevant
Design/ Data Coll.	Design: Comparative: Longitudinal data with retrospective cohort Data Coll: Longitudinal; Baseline, 1, 3, 5, 7, and 10 years	Design: Sys Lit Rev Data Coll: N/A
Population	1213 African American and 1166 Caucasian American girls (9 or 10 yrs at study start)	Inclusion criteria: Studies published btwn 2000 and 2008. Search engines: PsycINFO, PubMed, SCOPUS, ERIC, SPORTDiscus. Exclusion: unpublished manuscripts or dissertations
Outcome/Intrvn/ Context	Outcome: Habitual PA Quest (girls), Parent PA Quest Perception of Parent PA Quest; National Growth and Health study dataset Intrvn: N/A Context: home setting	Outcome: Keywords: weight, obese, BMI, bias, bullying, stigma, health, media, Intrvn/Context: N/A
Summary of Results	Girls with higher perceptions of parent modeling had higher PA levels over time (with predictions over time). Perception of parent PA predicted girls' PA than parent-reported PA level	Obese individuals experience: social stigma, weight bias, unemployment, lower wages, low self-esteem, and negative attitudes (e.g., viewed as lazy and responsible) from healthcare providers and others

Note. BMI = Body Mass Index; Data Coll. = Data Collection; Exp = Experimental Group; FBBT = Family-based bhvrl trtmnt; Hr = hour; Indvl = Individual; Intrvn = Intervention; N/A = Not Applicable or Not Specified; MVPA = Moderate to Vigorous Physical Activity; Nutr = Nutrition; Par = Parent/Parenting; PA = Physical Activity; Quest= Questionnaire; SCT = Social Cognitive Theory determinants (B = Behavioral; E = Environment, P = Personal); Sys Lit Rev = Systematic Literature Review; Yrs = Years of age

Summary of research articles reviewed in Chapter II: Literature Review

Investigators	Shin et al., 2009	Thompson et al., 2009
Level of Evidence	IV	IV
Article Keywords	DS prevalence	Family PA
Study Focus	Estimate the prevalence of DS among children and adolescents in the 10 regions of the US (ages 0 to 19 years)	Examine the types of activities (physical, sedentary) engaged in as a family and explore parents' perceptions of the importance, frequency, and barriers to family PA
SCT (B, E, P)	Population based explorative study, B, E, P not significantly relevant	B = PA behaviors (active, sedentary) E = Parent awareness, perception P = Past experiences
Design/Data Coll.	Design: Crss Sect Data Coll: Population based prevalence data	Design: Crss Sect Data Coll: Qual, Telephone interviews
Population	Exploration of live births of children with DS (1979 to 19 years), 10 US regions	30 parents (26 female, 4 male) of 10 to 11 yr old children (United Kingdom)
Outcome/Intrvn/Context	Outcome: Population based data analysis of live births from 1979 to 2003 Intrvn/context: N/A	Outcome: Interviews were transcribed for analysis Intrvn: N/A Context: Telephone interviews
Summary of Results	Prevalence increased by 31.1% from 9.0 to 11.8 per 10,000 live births in US. 2002 prevalence is 10.3 per 10,000	Parents were very aware of the benefits of PA and of family engagement in PA together, yet many reported little to no family PA regularly. Activity together was usually sedentary. Often parents would pair off with children due to scheduling

Note. Crss Sect = Cross Sectional; Data Coll. = Data Collection; DS = Down Syndrome; Intrvn = Intervention; N/A = Not Applicable or Not Specified; PA = Physical Activity; Qual = Qualitative; Quan = Quantitative; Quest= Questionnaire; SCT = Social Cognitive Theory determinants (B = Behavioral; E = Environment, P = Personal); Sig = Significant/significantly; Yrs = Years of age; % = Percentile/Percent

Summary of research articles reviewed in Chapter II: Literature Review

Investigators	Dabrowska & Pisula, 2010	Edwardson & Gorely, 2010
Level of Evidence	III-3	I
Article Keywords	Parent stress, DS mothers, fathers	PA, Family
Study Focus	Investigate stress of mothers and fathers who have child with DS, Autism, and children typically developing	Systematically review literature related to parent influence on PA in youth
SCT (B, E, P)	B = Ability to handle the stress E = Type of disability P = Perception of stress	Population based lit rev, B, E, P not significantly relevant
Design/ Data Coll.	Design: Crss Sect Comparison Data Coll: Quest	Design: Sys Lit Rev Data Coll: N/A
Population	162 parents (2 Parent households); Children: 51 with Autism; 54 with DS; 57 typically developing (2 to 6 yrs)	41 articles; Inclusion Criteria = Quan Design; with children or adolescents; child or Parent PA level with assoc (support, modeling, attitude) Exclusion Criteria = Sport, Sibling measure
Outcome/Intrvn/ Context	Outcome: Holroyd's 66 item Quest of Resources and Stress for families Intrvn: N/A Context: N/A	Outcome: 12 parental variables, 7 types of PA intensity Context: N/A
Summary of Results	Mothers and fathers of children with DS did not differ in stress level. Parents of children with Autism demonstrated more stress than others. Parents of children with DS, demonstrated more stress than those with children typically developing. Limited family opportunities are greatest stress for parents of children with DS	96 total, 41 eligible, 11 Longitudinal. Positive assoc btwn mother modeling and MVPA, parent involvement, father modeling, and overall support. Child perception of parent PA level is assoc with high child PA

Note. Crss Sect = Cross Sectional; Data Coll. = Data Collection; DS = Down Syndrome; Intrvn = Intervention; N/A = Not Applicable or Not Specified; PA = Physical Activity; Quan = Quantitative; Quest= Questionnaire; SCT = Social Cognitive Theory determinants (B = Behavioral; E = Environment, P = Personal); Sys Lit Rev = Systematic Literature; Yrs = Years of age

Summary of research articles reviewed in Chapter II: Literature Review

Investigators	Flett, Moore, Pfeiffer, Belonga, & Navarre, 2010	Mahy, Shields, Taylor, & Dodd, 2010
Level of Evidence	IV	IV
Article Keywords	Family, children PA	Adults, DS, PA
Study Focus	Determine aspects of PA in nature that youth find most and least appealing	Identify the facilitators and barriers to PA for adults with DS
SCT (B, E, P)	B = PA level E = Family envnt P = Interest in PA, past experiences	B = Active or inactive E = Supportive or not, routine P = Interest in PA, past experiences
Design/ Data Coll.	Design: Crss Sect Qual Data Coll: Focus groups, 3 youth, 3 adult	Design: Crss Sect Qual Data Coll: Single interval setting, one-on-one interviews
Population	23 youth (12.5 mean age), 19 parents (42.6 mean age) 38 of 42 = female	18 individuals (3 males, 15 females); 6 had DS (5 female, 1 male; median age 23 yrs) and 12 were support people (4 mothers of adults with DS; 8 staff who worked at least 6 yrs)
Outcome/Intrvn/ Context	Outcome: Focus groups were researcher led, audio recorded, and transcribed. Content analysis generated 3 themes Intrvn: N/A Context: Clinical setting	Outcome: Transcribed data from adults with DS and their support, content analyses generated 6 themes Intrvn: N/A Context: Home setting or group home (Australia)
Summary of Results	Themes: (1) youth enjoy nature, but could be more active; (2) adults appreciate nature, youth prefer competition; and (3) programs should promote and educate youth to engage in lifelong activities	PA facilitating themes: (1) support; (2) purposeful or fun PA; (3) apart of routine. Barriers to PA themes: (1) lack of support; (2) lack of interest; (3) medical or physiological factors

Note. Crss Sect = Cross Sectional; Data Coll. = Data Collection; DS = Down Syndrome; Intrvn = Intervention; N/A = Not Applicable or Not Specified; PA = Physical Activity; Qual = Qualitative; SCT = Social Cognitive Theory determinants (B = Behavioral; E = Environment, P = Personal); Yrs = Years of age

Summary of research articles reviewed in Chapter II: Literature Review

Investigators	Ogden et al., 2010	Rimmer, Yamaki, Lowry, Wang, & Vogel, 2010
Level of Evidence	III-3	IV
Article Keywords	Obesity	BMI, DS
Study Focus	Provide the most recent estimates of BMI among children and adolescents from 1999 to 2008	Explore the prevalence of obesity and related conditions in adolescent with intellectual and developmental disabilities (IDD)
SCT (B, E, P)	Factors not identified as this was a descriptive study	Population based explorative study, B, E, P not significantly relevant
Design/ Data Coll.	Design: Comparative Data Coll: Longitudinal comparison of populations using National Health and Nutrition Examination Survey	Design: Exploratory population based, Crss Sect
Population	3281 children (2 thru 19 yrs); 719 infants (birth thru 2 yrs)	461 parents of adolescents (12 to 17 yrs) with IDD (including DS)
Outcome/Intrvn/ Context	Outcome: BMI comparisons across time, with age/gender comparisons Context: Population Survey	Outcome: Parents' self-reported child BMI
Summary of Results	9.5% infants were obese; 11.9% of 2 thru 19 yrs were above the 97 th %; 16.9% of 2 thru 19 yrs were above the 95 th %; 31.7% were above the 85 th %	Youth with Autism and DS were more likely to be obese and overweight compared to other adolescents with IDD

Note. BMI = Body Mass Index; Crss Sect = Cross Sectional; Data Coll. = Data Collection; DS = Down Syndrome; Intrvn = Intervention; N/A = Not Applicable or Not Specified;; SCT = Social Cognitive Theory determinants (B = Behavioral; E = Environment, P = Personal); Yrs = Years of age; % = Percentile/Percent

Summary of research articles reviewed in Chapter II: Literature Review

Investigators	Webber, Cooke, Hill, & Wardle, 2010	Wright, Wilson, Griffin, & Evans, 2010
Level of Evidence	III-2	IV
Article Keywords	Child BMI, feeding practices	Parent modeling, PA
Study Focus	Investigate the direction of the assoc between parental feeding practices and children's adiposity in a longitudinal study	Examine how parental role modeling and parental social support influence PA in low income, minority adol
SCT (B, E, P)	B = Child weight E = Parent feeding practices P = Past experiences	B = Parent modeling E = Support from parents P = Past experiences, Interest
Design/ Data Coll.	Design: Comparative, retrospective, longitudinal Data Coll: Baseline, 3 yrs later	Design: Qual, crss sect Data Coll: 10 focus groups, same gender
Population	213 (initial) mothers of 7 to 9 years children 113 mothers (follow-up 3 yrs later)	52 Adol (22 male, 30 female) 10 to 14 yrs; 85% African American
Outcome/Intrvn/ Context	Outcome: <i>CFQ</i> , BMI Intrvn: N/A Context: School setting (UK)	Outcome: Transcribed data, thematic analyses Intrvn: N/A Context: School, recreation center
Summary of Results	"Child-responsive" model, mother's feeding practices influenced by child weight over time, rather than feeding practices influencing child weight	Themes identified: 1) parents engaged in a variety of PA with chil (e.g., walking, cycling, basketball) though infrequent; 2) sex differences were noted in support; 3) girls received more emotional support; 4) boys received more tangible support

Note. BMI = Body Mass Index; *CFQ* = Child Feeding Questionnaire; Crss Sect = Cross Sectional; Data Coll. = Data Collection; Intrvn = Intervention; N/A = Not Applicable or Not Specified; PA = Physical Activity; Qual = Qualitative; SCT = Social Cognitive Theory determinants (B = Behavioral; E = Environment, P = Personal); Yrs = Years of age

Summary of research articles reviewed in Chapter II: Literature Review

Investigators	Barr & Shields, 2011	Bauer, Neumark-Sztainer, Fulkerson, Hannan, & Story, 2011
Level of Evidence	IV	IV
Article Keywords	DS, PA, barriers	BMI, PA, family meals, SCT
Study Focus	Explore the barriers and facilitators to PA for children with DS	Examine the cross-sectional relationship btwn the family envir, PA, TV, soft drink intake, FV intake, and BMI in adolescent girls
SCT (B, E, P)	B = PA or inactive E = Family PA level, encouragement, community opportunities P = Past experiences, interest	B = Level of weight, PA, eating habits E = Parent bhvrs, modeling, access, reinforcers, social norms P = Past experiences, perceptions of encouragement
Design/ Data Coll.	Design: Qual Dat Coll: 18 interviews	Design: Crss sect comparative w/o control Data Coll: Single interval assessment, linear regression used for predictors
Population	20 parents (16 mothers, 4 fathers) of children with DS (2 to 17 yrs)	253 Girls (mean age 15.7, grades 9 to 12) and one of their parents
Outcome/Intrvn/ Context	Outcome: Transcribed interviews, thematic analyses Intrvn: N/A Context: Telephone and in person interviews at a neutral site	Outcome: BMI, <i>3-Day Physical Activity Recall</i> , novice quest to measure: soft drink intake, family food, TV and PA environment, Intrvn: N/A Context: University or school setting (US)
Summary of Results	Thems included facilitators to PA: 1) roles of family; 2) opportunity for social interaction; 3) organized programs for chil with DS; 4) interest. Barriers to PA: 1) char assoc with DS; 2) family responsibilities; 3) physical skill; 4) lack of programming	Positive assoc observed btwn family support for PA and girls' total PA, family meal frequency and girls' FV intake. Parent modeling of PA, TV, and soft drink and FV intake was consistently assoc with girls' bhvr

Note. Assoc = Associations/ed; BMI = Body Mass Index; Char = Characteristics; Crss Sect = Cross Sectional; Data Coll. = Data Collection; DS = Down Syndrome; FV = Fruit and Vegetable; Intrvn = Intervention; N/A = Not Applicable or Not Specified; PA = Physical Activity; Qual = Qualitative; SCT = Social Cognitive Theory determinants (B = Behavioral; E = Environment, P = Personal); Yrs = Years of age

Summary of research articles reviewed in Chapter II: Literature Review

Investigators	Belanger et al., 2011	Mulhall, Reis, & Begun, 2011
Level of Evidence	III-2	III-3
Article Keywords	PA, adolescence	Child PA, family, attitude
Study Focus	Examine why some individuals succeed in maintaining PA through adolescence, goal is to guide intrvn. Exploration included factors related to maintenance and decline of PA	Examine the relationship between sociodemographics factors, behavioral and family factors that influence PA patterns in adolescents
SCT (B, E, P)	B = PA level E = Social support, barriers to access P = Previous experience (decliner, maintainer), feelings of competence	B = PA level E = Family Fitness P = Past experience, attitude toward PA, activity preference
Design/Data Coll.	Design: Comparative (randomized groups) Data Coll: Initial survey, focus groups	Design: Comparative w/o control Data Coll: Crss Sect Survey
Population	515 children (grades 10 to 12), students were randomly selected for focus groups	1578 adolescents (12 to 13 yrs; 65% white; 37% qualified for free-reduced school lunch)
Outcome/Intrvn/Context	Outcome: <i>Physical Activity Quest-Adolescents</i> to determine PA level, high PA students randomly selected to 7 focus groups Intrvn: N/A Context: School setting	Outcome: Self-reported survey variables, ANCOVA used for categorical predictors Context: School setting Intrvn: N/A
Summary of Results	Both groups assoc PA with positive health outcomes. Maintenance of PA assoc with social enviro and feelings of competence. Decline of PA assoc with negative social validation, poor social support, or barriers to access	Positive attitude, rather than negative were assoc with exercise. Gender and family fitness, involvement were assoc with exercise

Note. Assoc = Associations/ed; Data Coll. = Data Collection; Enviro = Environment; Intrvn = Intervention; N/A = Not Applicable or Not Specified; PA = Physical Activity; SCT = Social Cognitive Theory determinants (B = Behavioral; E = Environment, P = Personal); Sig = Significant/significantly; Yrs = Years of age; % = Percentile/Percent

Summary of research articles reviewed in Chapter II: Literature Review

Investigators	Quarmby, Dagkas, & Bridge, 2011
Level of Evidence	III-3
Article Keywords	Child PA, sedentary activity, family
Study Focus	Explore psychosocial and envir factors that contribute to chil's participation in PA and sedentary
SCT (B, E, P)	B = PA choice E = Family structure: married, divorced, single P = Past experiences
Design/ Data Coll.	Design: Mixed method; quan and qual Data Coll: Survey, interview
Population	381 chil (11 to 14 yrs) from 3 inner city schools
Outcome/Intrvn/ Context	Outcome: PA Recall; Transcribed data Intrvn: N/A Context: School setting
Summary of Results	Boys and girls from single parent families spent more time in sedentary activity, received less parental support for PA, and lived in an envir that encouraged sedentary habits compared to children from intact families

Note. Data Coll. = Data Collection; Intrvn = Intervention; N/A = Not Applicable or Not Specified; PA = Physical Activity; Qual = Qualitative; Quan = Quantitative; SCT = Social Cognitive Theory determinants (B = Behavioral; E = Environment, P = Personal); Yrs = Years of age

APPENDIX B

Phase I Instrumentation

THE RETURN OF YOUR COMPLETED QUESTIONNAIRE CONSTITUTES YOUR INFORMED CONSENT TO ACT AS A PARTICIPANT IN THIS RESEARCH. YOU MAY STOP PARTICIPATION AT ANY TIME.

The following survey is divided into 4 sections, for a total of 100 questions.

I. Participant Profile

1. Gender: Male Female
2. Age: 18 - 25 26 - 34 35 - 44 45 - 54 55 +
3. Marital Status:
 Single, never married Married Divorced Separated Widowed
4. Number of children: 1 - 2 3 - 4 5 - 6 7 +
5. Do you have a child with Down syndrome between the ages of 10 to 22 years?
 Yes No
6. Age of child with Down syndrome:
 10 - 12 13 - 15 16 - 18 19 - 22
7. Do you have a child without Down syndrome between the ages of 8 to 19 years?
 Yes No
8. Age of child without Down syndrome:
 8 - 10 11 - 13 14 - 16 17 - 19
9. Highest level of education completed:
 High School Associate's Bachelor's Master's Doctorate
10. Total household income:
 \$10,000 - \$29,000 \$30,000 - \$59,000 \$60,000 - \$79,000 \$80,000 +
 Choose not to respond

11. Ethnicity:

- White, non-hispanic African American Hispanic
 Asian Pacific Islander Native American Choose not to respond

12. If you feel comfortable, please complete the following:

Personal height: _____ in/ft Personal weight: _____ lb.

II. International Physical Activity Questionnaire

We are interested in finding out about the kinds of physical activities that people do as part of their everyday lives. The questions will ask you about the time you spent being physically active in the **last 7 days**. Please answer each question even if you do not consider yourself to be an active person. Please think about the activities you do at work, as part of your house and yard work, to get from place to place, and in your spare time for recreation, exercise or sport.

Think about all the **vigorous** activities that you did in the **last 7 days**. **Vigorous** physical activities refer to activities that take hard physical effort and make you breathe much harder than normal.

Think *only* about those physical activities that you did for at least **10 minutes at a time**.

1. During the **last 7 days**, on how many days did you do **vigorous** physical activities like heavy lifting, digging, aerobics, or fast bicycling?

_____ **days per week**
No vigorous physical activities **→** *Skip to question 3*

2. How much time did you usually spend doing **vigorous** physical activities on one of those days?

_____ **hours per day**
_____ **minutes per day**

Don't know/Not sure

Think about all the **moderate** activities that you did in the **last 7 days**. **Moderate** activities refer to activities that take moderate physical effort and make you breathe somewhat harder than normal. Think *only* about those physical activities that you did for at least **10 minutes at a time**.

3. During the **last 7 days**, on how many days did you do **moderate** physical activities like carrying light loads, bicycling at a regular pace, or doubles tennis? Do not include walking.

_____ **days per week**

No moderate physical activities → *Skip to question 5*

4. How much time did you usually spend doing **moderate** physical activities on one of those days?

_____ **hours per day**
_____ **minutes per day**

Don't know/Not sure

Think about the time you spent **walking** in the **last 7 days**. This includes at work and at home, walking to travel from place to place, and any other walking that you might do solely for recreation, sport, exercise, or leisure.

5. During the **last 7 days**, on how many days did you **walk** for at least 10 minutes at a time?

_____ **days per week**

No walking → *Skip to question 7*

6. How much time did you usually spend **walking** on one of those days?

_____ **hours per day**
_____ **minutes per day**

Don't know/Not sure

The last question is about the time you spent **sitting** on weekdays during the **last 7 days**. Include time spent at work, at home, while doing course work and during leisure time. This may include time spent sitting at a desk, visiting friends, reading, or sitting or lying down to watch television.

7. During the **last 7 days**, how much time did you spend **sitting** on a **week day**?

_____ **hours per day**
_____ **minutes per day**

Don't know/Not sure

II. International Physical Activity Questionnaire (continued)

The following questions are identical to the above questions about the kinds of physical activities that people do as part of their everyday lives. When answering the questions below, respond related to the activities you feel are performed by members of your family; for example:

Your child with Down syndrome (**C W/ DS**), your child without Down syndrome (**C W/O DS**), and your family together (at least 2 family members present [**FAM**]). Think about all the **vigorous** activities that your family members have done in the **last 7 days**. **Vigorous** physical activities refer to activities that take hard physical effort and make you breathe much harder than normal.

Think *only* about those physical activities that your family members have done for at least **10 minutes at a time**.

1. During the **last 7 days**, on how many days did your family members do **vigorous** physical activities like heavy lifting, digging, aerobics, or fast bicycling?

C W/ DS

_____ days per week

No vigorous activity

→ *Skip to question 3*

C W/O DS

_____ days per week

No vigorous activity

FAM

_____ days per week

No vigorous activity

2. How much time did your family members usually spend doing **vigorous** physical activities on one of those days?

C W/ DS

_____ hours per day

_____ minutes per day

Don't know/Not sure

C W/O DS

_____ hours per day

_____ minutes per day

Don't know/Not sure

FAM

_____ hours per day

_____ minutes per day

Don't know/Not sure

Think about all the **moderate** activities that your family members did in the **last 7 days**. **Moderate** activities refer to activities that take moderate physical effort and make you breathe somewhat harder than normal. Think *only* about those physical activities that your family members did for at least **10 minutes at a time**.

3. During the **last 7 days**, on how many days did your family members do **moderate** physical activities like carrying light loads, bicycling at a regular pace, or doubles tennis? Do not include walking.

C W/ DS

C W/O DS

FAM

_____ days per week

_____ days per week

_____ days per week

No moderate activity

No moderate activity

No moderate activity

➔ *Skip to question 5*

4. How much time did your family members usually spend doing **moderate** physical activities on one of those days?

C W/ DS

C W/O DS

FAM

_____ hours per day
_____ minutes per day

_____ hours per day
_____ minutes per day

_____ hours per day
_____ minutes per day

Don't know/Not sure

Don't know/Not sure

Don't know/Not sure

Think about the time your family members spent **walking** in the **last 7 days**. This includes at work and at home, walking to travel from place to place, and any other walking that your family members might do solely for recreation, sport, exercise, or leisure.

5. During the **last 7 days**, on how many days did your family members **walk** for at least 10 minutes at a time?

C W/ DS

C W/O DS

FAM

_____ days per week

_____ days per week

_____ days per week

No walking

No walking

No walking

➔ *Skip to question 7*

6. How much time did your family members usually spend **walking** on one of those days?

C W/ DS

C W/O DS

FAM

_____ hours per day
_____ minutes per day

_____ hours per day
_____ minutes per day

_____ hours per day
_____ minutes per day

Don't know/Not sure

Don't know/Not sure

Don't know/Not sure

The last question is about the time your family members spent **sitting** on weekdays during the **last 7 days**. Include time spent at work, at home, while doing course work and during leisure time. This may include time spent sitting at a desk, visiting friends, reading, or sitting or lying down to watch television.

7. During the **last 7 days**, how much time did your family members spend **sitting** on a **week day**?

C W/ DS

C W/O DS

FAM

_____ **hours per day**
_____ **minutes per day**

_____ **hours per day**
_____ **minutes per day**

_____ **hours per day**
_____ **minutes per day**

Don't know/Not sure

Don't know/Not sure

Don't know/Not sure

Source: Craig et al., 2003

III. Child Feeding Questionnaire

INSTRUCTIONS: Using the scale below, please indicate how you would classify **your own** weight at each of **these 4 time periods** listed below (Please circle **ONLY ONE** choice for each period).

1. Your Childhood (5 to 10 years old)

- Markedly underweight Underweight Average Overweight
 Markedly Overweight

2. Your Adolescence

- Markedly underweight Underweight Average Overweight
 Markedly Overweight

3. Your 20's

- Markedly underweight Underweight Average Overweight
 Markedly Overweight

4. Currently

- Markedly underweight Underweight Average Overweight
 Markedly Overweight

Using the scale below, please select on number for each question which best corresponds to your answer. **Please answer about your child with Down syndrome.**

5. When your child is at home, how often are you responsible for feeding him/her?

- Never Seldom Half of time Most of time Always

6. How often are you responsible for deciding what your child's portion sizes are?

- Never Seldom Half of time Most of time Always

7. How often are you responsible for deciding if your child has eaten the right kind of foods?

- Never Seldom Half of time Most of time Always

Using the scale below, please indicate how you would classify **your child with Down syndrome's weight** at each of **these 4 time periods** listed below (Please circle **ONLY ONE** choice for each period)

8. Your child with Down syndrome during the first year of life

- Markedly underweight Underweight Average Overweight
 Markedly Overweight

9. Your child with Down syndrome as a toddler

- Markedly underweight Underweight Average Overweight
 Markedly Overweight

10. Your child with Down syndrome as a preschooler

- Markedly underweight Underweight Average Overweight
 Markedly Overweight

11. Your child with Down syndrome kindergarten through 2nd grade

- Markedly underweight Underweight Average Overweight
 Markedly Overweight

12. Your child with Down syndrome 3rd through 5th grade

- Markedly underweight Underweight Average Overweight
 Markedly Overweight

13. Your child with Down syndrome 6th through 8th grade

- Markedly underweight Underweight Average Overweight
 Markedly Overweight

Using the scale below, please circle one choice for each question which best corresponds to your answer.

Please answer about your child with Down syndrome.

14. How concerned are you about your child with Down syndrome *eating too much* when you are not around him/her?
 Unconcerned Slightly unconcerned Neutral Slightly concerned
 Concerned
15. How concerned are you about your child with Down syndrome having to diet to maintain a desirable weight?
 Unconcerned Slightly unconcerned Neutral Slightly concerned
 Concerned
16. How concerned are you about your child with Down syndrome becoming overweight?
 Unconcerned Slightly unconcerned Neutral Slightly concerned
 Concerned

Using the scale below, please circle one choice for each question which best corresponds to your answer.

Please answer about your child with Down syndrome.

17. I have to be sure that my child with Down syndrome does not eat too many *sweets* (*candy, ice cream, cake or pastries*).
 Disagree Slightly disagree Neutral Slightly agree Agree
18. I have to be sure that my child with Down syndrome does not eat too many *high fat foods*.
 Disagree Slightly disagree Neutral Slightly agree Agree
19. I have to be sure that my child with Down syndrome does not eat too much of his/her *favorite foods*.
 Disagree Slightly disagree Neutral Slightly agree Agree
20. I intentionally keep some food out of my child with Down syndrome's reach.
 Disagree Slightly disagree Neutral Slightly agree Agree

21. I offer *sweets (candy, ice cream, cake, pastries)* to my child with Down syndrome as a reward for good behavior.

Disagree Slightly disagree Neutral Slightly agree Agree

22. I offer my child with Down syndrome his/her *favorite foods* in exchange for good behavior.

Disagree Slightly disagree Neutral Slightly agree Agree

23. If I did not guide or regulate my child with Down syndrome's eating, he/she would eat too many *junk foods*.

Disagree Slightly disagree Neutral Slightly agree Agree

24. If I did not guide or regulate my child with Down syndrome's eating, he/she would eat too much of his/her *favorite foods*

Disagree Slightly disagree Neutral Slightly agree Agree

25. My child with Down syndrome should always eat all of the food on his/her plate.

Disagree Slightly disagree Neutral Slightly agree Agree

26. I have to be especially careful to make sure my child with Down syndrome eats enough.

Disagree Slightly disagree Neutral Slightly agree Agree

27. If my child with Down syndrome says "I'm not hungry," I try to get him/her to eat anyway.

Disagree Slightly disagree Neutral Slightly agree Agree

28. If I did not guide or regulate my child with Down syndrome's eating, he/she would eat much less than he/she should.

Disagree Slightly disagree Neutral Slightly agree Agree

Using the scale below, please circle one choice for each question which best corresponds to your answer.

Please answer about your child with Down syndrome.

29. How much do you keep track of the *sweets (candy, ice cream, cake, pies, pastries)* that your child with Down syndrome eats?

Never Rarely Sometimes Mostly Always

30. How much do you keep track of the *snack food (potato chips, Doritos, cheese puffs)* that your child with Down syndrome eats?

Never Rarely Sometimes Mostly Always

31. How much do you keep track of the *high fat* foods that your child with Down syndrome eats?

Never Rarely Sometimes Mostly Always

Source: Birch et al.,2004; Costanzo & Woody, 1985

Child Feeding Questionnaire (continued)

INSTRUCTIONS: Using the scale below, please circle one choice for each question which best corresponds to your answer. **Please answer about your child WITHOUT Down syndrome.**

1. When your child is at home, how often are you responsible for feeding him/her?
 Never Seldom Half of time Most of time Always
2. How often are you responsible for deciding what your child's portion sizes are?
 Never Seldom Half of time Most of time Always
3. How often are you responsible for deciding if your child has eaten the right kind of foods?
 Never Seldom Half of time Most of time Always

Using the scale below, please indicate how you would classify **your child WITHOUT Down syndrome's weight** at each of **these 4 time periods** listed below (Please circle **ONLY ONE** choice for each period)

4. Your child during the first year of life
 Markedly underweight Underweight Average Overweight
 Markedly Overweight
5. Your child as a toddler
 Markedly underweight Underweight Average Overweight
 Markedly Overweight
6. Your child as a preschooler
 Markedly underweight Underweight Average Overweight
 Markedly Overweight
7. Your child kindergarten through 2nd grade
 Markedly underweight Underweight Average Overweight
 Markedly Overweight

8. Your child 3rd through 5th grade

- Markedly underweight Underweight Average Overweight
 Markedly Overweight

9. Your child 6th through 8th grade

- Markedly underweight Underweight Average Overweight
 Markedly Overweight

Using the scale below, please circle one choice for each question which best corresponds to your answer.

Please answer about your child WITHOUT Down syndrome.

10. How concerned are you about your child *eating too much* when you are not around him/her?

- Unconcerned Slightly unconcerned Neutral Slightly concerned
 Concerned

11. How concerned are you about your child having to diet to maintain a desirable weight?

- Unconcerned Slightly unconcerned Neutral Slightly concerned
 Concerned

12. How concerned are you about your child becoming overweight?

- Unconcerned Slightly unconcerned Neutral Slightly concerned
 Concerned

Using the scale below, please circle one choice for each question which best corresponds to your answer.

Please answer about your child WITHOUT Down syndrome.

13. I have to be sure that my child does not eat too many *sweets (candy, ice cream, cake or pastries)*.

- Disagree Slightly disagree Neutral Slightly agree Agree

14. I have to be sure that my child does not eat too many *high fat foods*.

Disagree Slightly disagree Neutral Slightly agree Agree

15. I have to be sure that my child does not eat too much of his/her *favorite foods*.

Disagree Slightly disagree Neutral Slightly agree Agree

16. I intentionally keep some food out of my child's reach.

Disagree Slightly disagree Neutral Slightly agree Agree

17. I offer *sweets (candy, ice cream, cake, pastries)* to my child as a reward for good behavior.

Disagree Slightly disagree Neutral Slightly agree Agree

18. I offer my child her *favorite foods* in exchange for good behavior.

Disagree Slightly disagree Neutral Slightly agree Agree

19. If I did not guide or regulate my child's eating, he/she would eat too many *junk foods*.

Disagree Slightly disagree Neutral Slightly agree Agree

20. If I did not guide or regulate my child's eating, he/she would eat too much of his/her *favorite foods*

Disagree Slightly disagree Neutral Slightly agree Agree

21. My child should always eat all of the food on his/her plate.

Disagree Slightly disagree Neutral Slightly agree Agree

22. I have to be especially careful to make sure my child eats enough.

Disagree Slightly disagree Neutral Slightly agree Agree

23. If my child says "I'm not hungry," I try to get her to eat anyway.

Disagree Slightly disagree Neutral Slightly agree Agree

24. If I did not guide or regulate my child's eating, he/she would eat much less than he/she should.

Disagree Slightly disagree Neutral Slightly agree Agree

Using the scale below, please circle one choice for each question which best corresponds to your answer.

Please answer about your child WITHOUT Down syndrome.

25. How much do you keep track of the *sweets (candy, ice cream, cake, pies, pastries)* that your child eats?

Never Rarely Sometimes Mostly Always

26. How much do you keep track of the *snack food (potato chips, Doritos, cheese puffs)* that your child eats?

Never Rarely Sometimes Mostly Always

27. How much do you keep track of the *high fat* foods that your child eats?

Never Rarely Sometimes Mostly Always

Source: Birch et al.,2004; Costanzo & Woody, 1985

IV. Three-Factor Eating Questionnaire

Part I: Read the questions below and choose only one choice which best fits your behavior.

1. I deliberately take small helpings as a means of controlling my weight.

Definitely true Mostly true Mostly false Definitely false

2. I consciously hold back at meals in order not to gain weight.

Definitely true Mostly true Mostly false Definitely false

3. I do not eat some foods because they make me fat.

Definitely true Mostly true Mostly false Definitely false

4. How frequently do you avoid 'stocking up' on tempting foods?

Definitely true Mostly true Mostly false Definitely false

5. How likely are you to consciously eat less than you want?

Unlikely Slightly likely Moderately likely Very likely

6. On a scale of 1 to 8, where 1 means no restraint in eating (eating whatever you want, whenever you want it) and 8 means total restraint (constantly limiting food intake and never 'giving in'), what number would you give yourself?

1-Eat whatever I want, whenever I want it....Constantly limiting food intake, never 'giving in -8

1- 2- 3- 4- 5- 6- 7- 8-

Part II: Read the questions below and choose only one choice which best fits your behavior.

1. When I smell a sizzling steak or a juicy piece of meat, I find it very difficult to keep from eating, even if I have just finished a meal.

Definitely true Mostly true Mostly false Definitely false

2. Sometimes when I start eating, I just can't seem to stop.
- Definitely true Mostly true Mostly false Definitely false
3. Being with someone who is eating often makes me hungry enough to eat also.
- Definitely true Mostly true Mostly false Definitely false
4. When I see a real delicacy, I often get so hungry I have to eat right away.
- Definitely true Mostly true Mostly false Definitely false
5. I get so hungry that my stomach often seems like a bottomless pit.
- Definitely true Mostly true Mostly false Definitely false
6. I am always hungry so it is hard for me to stop eating before I finish the food on my plate.
- Definitely true Mostly true Mostly false Definitely false
7. I am always hungry enough to eat at any time.
- Definitely true Mostly true Mostly false Definitely false
8. How often do you feel hungry?
- Only at mealtimes Sometimes between meals
 Often between meals Almost always
9. Do you go on eating binges though you are not hungry?
- Never Rarely Sometimes At least once a week

Part III: Read the questions below and choose only one choice which best fits your behavior.

1. When I feel anxious, I find myself eating.
- Definitely true Mostly true Mostly false Definitely false

2. When I feel blue, I often overeat.

Definitely true Mostly true Mostly false Definitely false

3. When I feel lonely, I console myself by eating.

Definitely true Mostly true Mostly false Definitely false

This is the end of the questionnaire, thank you for participating.

Source: Stunkard & Messick, 1985

APPENDIX C

Institutional Review Board Approval



Institutional Review Board

Office of Research and Sponsored Programs
P.O. Box 425619, Denton, TX 76204-5619
940-898-3378 Fax 940-898-3416
email: IRB@twu.edu

July 21, 2011

Ms. Kelly Allums Featherston
9709 Waterhaven Dr.
Argyle, TX 76226

Dear Ms. Featherston:

Re: Parents' Perceptions of Physical Activity Habits and Feeding Patterns Between Siblings With and Without Down Syndrome (Protocol #: 16713)

The above referenced study has been reviewed by the TWU Institutional Review Board (IRB) and appears to meet our requirements for the protection of individuals' rights.

If applicable, agency approval letters must be submitted to the IRB upon receipt PRIOR to any data collection at that agency. A copy of the approved consent form with the IRB approval stamp and a copy of the annual/final report are enclosed. Please use the consent form with the most recent approval date stamp when obtaining consent from your participants. The signed consent forms and final report must be filed with the Institutional Review Board at the completion of the study.

This approval is valid one year from June 3, 2011. Any modifications to this study must be submitted for review to the IRB using the Modification Request Form. Additionally, the IRB must be notified immediately of any unanticipated incidents. If you have any questions, please contact the TWU IRB.

Sincerely,

A handwritten signature in dark ink that reads "Rhonda R. Buckley". The signature is written in a cursive style.

Dr. Rhonda Buckley, Co-Chair
Institutional Review Board - Denton

enc.

cc. Dr. Charlotte Sanborn, Department of Kinesiology
Dr. Ron French, Department of Kinesiology
Graduate School

APPENDIX D

Interview Script

Interview Script

Hello and welcome. Before we begin today, please carefully read and if you consent, sign and initial the consent, form there are 3 pages.

The audio recording equipment is already in place and I will now turn it on. If at any time you need to take a break or leave the room feel free to do so. The session will end after 90 minutes.

Thanks again for participating in this interview/focus group. Before we begin with questions, will you share your children's ages, gender, and a short story about your children or family.

I will now read aloud, the discussion questions. I'll read them one at a time and we'll discuss and move to the next as needed. You will be given as much time as desired to discuss questions before moving on the next one. Feel free to return to a previous question at any time.

Let's begin.

- 1) How do you feel the physical activity habits of your children (with and without Down syndrome) are similar or different? What impacts those behaviors?
- 2) How do you feel the eating habits or your feeding patterns for your children (with and without Down syndrome) are similar or different? What impacts those behaviors?
- 3) How do you feel your personal physical activity habits impact your children and family?

- 4) How do you support your children to encourage physical activity habits?
- 5) How do you feel your personal eating or feeding patterns impact your children and family?
- 6) How do you feel physical activity impacts the quality time your family spends together?
- 7) How do you feel the promotion of healthy eating impacts the quality time your family spends together?
- 8) How physically active and healthy would you consider your family to be? What factors are impacting?
- 9) What barriers do you feel your family faces related to being physically active or eating healthy? How do you feel your child with Down syndrome has been influential?
- 10) How much of a priority is being physically active and eating healthy to your family? How do you feel the actions of your family relate to that role?
- 11) How concerned are you about your children's weight? How does that impact your parenting practices related to feeding or physical activity?

APPENDIX E

Focus Group and Interview Transcriptions

Transcript, Focus Group A

Folder A 03/08 – 13m 42s

M, L, S

PI: I'm going to read the script. Okay, alright. The audio and video equipment is now in place and on, anytime you feel like you need to take a break or get up please do so. The session will last about 90 minutes, or pending when Mitzi has to leave. So, uh the official purpose of this study is to explore the development of physical activity and eating habits among families who have multiple children including one with Down syndrome from the perspective of the mothers. The target of exploration will be the potential relationships between um parents modeling habits, physical activity levels, and feeling differences between siblings, and perceptions of family barriers to healthy lifestyle habits. And the feeding pattern differences that I would love for you guys to talk about today focus more on the introduction of new foods, or kind of the feeding patterns used like restriction or control. Or the notion of cleaning your plate, rather than specific types of foods so not so much, number of vegetables, things like that. Focus more of the process of introducing them, feeding pattern strategies, and things like that. So think back to that.

So, um focus groups are completed with a small number of people based on a shared topic, obviously all of you have a wonderful shared topic (.2) your great children. So I will lead the focus groups but feel free to uh, openly discuss adjacent topics um as they come up. And (.2) okay alright.

So the first set of questions, wait actually before we a start the questions I think everyone has shared um you know how many children they have and kind of the ages of our kiddos and actually everyone has a, your children with Down syndrome are all boys, right?

Right.

Group: ((laughs)) ((Nonverbal affirmation))

PI: And so now I will read aloud the questions one by one and feel free to just jump in and discuss.

First one, and there is also a tablet right in front of you if you want to take notes while someone else is speaking and you kind of think of another topic to go off on, you know feel free to do that. So the first question for you to discuss is: Do you feel the physical activity habits of your children are similar or different? And if so, how? And what impacts those behaviors?

S: Physical activity habits(.2)? Do you mean play or do you mean?=

PI: =Physical activity habits could mean play, active play, there are also level of intensities that are defined as moderate to vigorous where there is huffing and puffing, where you can't talk a lot during, so intense activities could be something like sports, it could be something like how they spend their free time, whether they choose to go outside and jump rope or whether they choose to play video games. I would like you all to talk about how those behaviors are similar or how those are different.

L: I think Cannon's ((child with DS)) are very similar to Kelsey and Ethan's (Siblings without DS) as far as he wants to copy everything they do. We have a trampoline outside, they go out there he wants to be out there jumping. As far as energy level I don't think it's a whole lot different than the twins ((children without DS)) when they were his age. He's really active um ability wise (.2) obviously he's a lot slower ((quiet laughter)) which impacts him a little bit. But (.2) I think energy level and interest level is definitely similar. I think he wants to be involved in all the same things they do. They play, he plays, he plays hard.

M(to L): Does he ever get tired though after and want you to pick him up?

L: See I don't notice that. I don't notice that he's getting super tired but he doesn't do real extended long periods of exercise either [or do hard core types of exercises either=

M: [Right

L: =Though he did play T-ball with typically developing kids last summer. And he did good=

Group:= oh good, great

M: Hit and ran?

L: Yeah he was just slower. You know speed is not and what's it called the cadence?

Mitzi & PI: Gait, Gait

L: it's not the same as the other kids, so he's quite a bit slower.

M, L: ()

M: Well I think that since David is 4 he's not nearly as active as they are because they can play outside and go ride bikes all over the neighborhood and he does want to go out there and I have to be with him otherwise he would just run down the street and keep running. But as far as swimming like she said and activities he likes to do what they do he just, but he does get tired if we are (.1) if we're I don't know at an amusement park or at six flags we have six flags season passes he would um (.1) if we let him walk he would want to be carried or be put in a stroller because he (.2) can't last as long as they do but I think that is his age maybe, I hope^{1.2}

PI: So how would you compare that to when his siblings ((without DS)) were 4?

M: Um...

PI: Would it be similar or different?

M: .hhh ((clears throats)) let me think (.2). I think that they (1.5) no he's not as active as they were. Um (.2) swinging for instance. I mean we have to push him, they were able to pump and you know swing by themselves, and they could actually swim you know?

Swim across the pool. He ((child with DS)) can do that so. So it's like she ((motioning to L)) said his ability is not at the same level. Now he hasn't tried T-ball yet.=

L: = I agree though you know I mean as far as when they are able to do certain physical things...there's definitely a deal there.

S: Yeah

PI: Absolutely

(.5)

S: This is a hard question.

All: Yes, laughter

S: I mean my son ((with DS)) Jack is older right now, he's 10 and Anna's 13. And they are (.1) very different, I (.1) mean I feel like as a parent I am always pushing both of them to be more active. Anna is active ((child without DS)), she's in cross country right now, she plays soccer. Um, Jack ((child with DS)) played soccer he didn't like it, it was just too much running. He likes a little sprint and he's done. Like a little race and then he's done, um. He likes, like he seeks out sensory activities so that's very different for him so he likes basketball and he likes to swing and he loves to swim. So those activities he may seek out. Um my daughter may not necessarily seek out activities, and then as a family and I may just be complicating things because it is just so complex. As a family we are always pushing our kids, to be active because I have a huge family history of obesity and so I feel like we are always fighting that.³

Group: ((chatter)) ()

S: Um (.2) we always encourage them to ride their bikes and we are working on Jack's ((child with DS)) bike skills. He's still not there yet, he went through the bike program but we are still working on. So (.5)

PI: But you said you think because you are aware you said your family has a history of obesity? You maybe encourage them differently? Or encourage one more?

S: Well both. A lot more than I ever was. I also love the fact that we live in Texas in that most of the year I can say go outside. Go outside and play. And Jack ((child with DS)) won't want to, he'll want to sit with his IPOD and watch a movie or do his music (.2) or anything HE ((child with DS)) seeks more sedentary or sensory activities. But I still have to encourage the sensory activities. So I don't know if that's helpful or not.

All: laughter

PI: Yes, absolutely.

L: You know we, I just thought about that we do hiking a lot. Hiking...

PI: As a family?

L: As a family. And um I was trying to think about what you were saying when you asked the question about when your kids were this age, the same age as he is now ((child with DS)) and yeah we definitely don't I mean at 5 I would have expected my twins (children without DS) to basically walk the whole way. And we do end up putting him on our shoulders ((child with DS)). So yeah his ability as far as endurance,

Group: ()

L: but also when there are uneven surfaces and such (.2) ((group laughter)) he doesn't care for that much. He may be struggling with balance. () But he struggled for about a year, and when we started, he was just 4 ((child with DS)), started the camping/hiking thing. He was not into it at all.

Group: Hmm, uh huh.

L: It's like he's ((child with DS)), I don't know if it's because we are going more and he is getting used to it but he's going longer period without us having to pick him up and put him on our shoulders, so I don't know if it's an age thing but he definitely...

S: The key thing is to just keep working on it.

L: right. It definitely takes work.

S: We found ourselves parking and dropping him off to much, I mean he's 10 ((child with DS)) right? Just a couple months ago we were like NO we can park wherever and he can just walk in because

Group: Right?

S: Because we were just so used to being so slow for him or used to (.2) you know?

M: Right.

S: And it's just such a struggle again, it's like No he CAN walk! He can.

PI: So you think he might have learned that he didn't have to? Or he just got used to...

Group: ()

S: I think that the family dynamics, you have to be very careful not to just get in the ruts. Or not think he can't do it. He can, but at a different pace at a different developmental level timeline. But he can, but he's not going to be able to you know...run the distance.

PI: Hmm huh.

S: But eventually...

L: And I agree with you, the expectations you have to because you sometimes forget.

Group: ()

S: As a parent you just have to encourage him ((child with DS)).

PI: So how did he ((child with DS)) respond to you guys, you know continuing to park a little bit further away? Have you noticed anything? His response?

Group chatter: Yes, of course! ((Laughter))

S: Well you know the thing is he doesn't get mad if we park farther he just (.2) shrugs, or goes "mom"? Yeah, but I mean you do think about theme parks and stuff because he's 10 I mean I'm not going to put him in a stroller.

L: Right

PI: Absolutely

S: Um. (.3) It's done.

PI: It's been done, I have seen it.

S: We went to New York City a year a 2 years ago now and we did take the jogger because we just thought, that's the only way it's gonna work...to do the entire city so...now I'm not sure what we would do I think he just, we would have to modify our activities but we would have him walk. Or take the subway, you know? So.

Group: ((nodding, gestures of affirmation)) Hm huh. Yes.

S: But it's a challenge I think when you have a really active family, you know and we really like to cycle. We really like to do that. But I mean you adapt (.5) we bought a tandem. So like, you know adapt things...I don't know what else can we? ((looking to PI))

PI: No, that is great. Just to reaffirm you are adapting in that you just got additional equipment that way he wouldn't have to do it all by himself?

S: So we can take a family bike ride.

PI: Hm, yes.

S: So it's possible. I mean he can ride only short distances on his own.

L: I mean there's not really any studies that tell us, does the Down syndrome mean they are not as capable or I mean that they do have as much endurance, you know?

PI: I mean that's what we did talk about a little bit before.

L: yeah, there's not a

PI: the official stance is that there are genetic predispositions to obesity like a slower resting metabolic rate and heart disease or other things like that. And that's kind of the purpose of this because you know nobody really can state cause. You know there are the correlations, the associations, but you can really say cause and effect. You can't say here's the Down syndrome, here's the obesity. Because people in the general population.

Group: Yeah. Right. I guess.

S: Yeah, not to sound negative but we have a lot of strikes against, he has a lot of strikes against him. But we think (.1) how can we balance that out?

PI: Absolutely

S: He doesn't sleep the greatest that makes you more tired. So we try to make activities fun and keep you busy and keep you, honestly not obese at 10.

PI: And so related to sports, I know you all mentioned different things about sports. Have you guys you know we just talked about kind of, and we'll get to barriers in just a little bit, but just bringing up sports. Do you notice if there is an interest or encouragement difference? Maybe you encourage one differently? Or just the option of having the sports activities.

M: We give all our kids options to play. But my teenage daughters (without DS) are now at the age where they [laughter] don't want to. They both, well everybody played soccer actually, except for David ((child with DS)) and now the 16 year old (without DS) doesn't do anything. She's more into arts and music and choir and that's...her thing.

Group: ()

M: And she's like that's, I don't like sports. And I'm like okay.

Group: ()

M: Yeah and she has a bicycle too. And occasionally, I try to get her to ride it more. Just around our, you know, just around (pause) just kind of at a higher speed for a few laps just to get some kind of activity. Because I don't think she is active enough ((child without DS)). And then the younger one, the 15 year old, she just finished playing soccer. And...she's not interested in it anymore. She does like to run so...she'll go get or be in a 5K or something.

PI: Oh that's great.

M: And then the twins are into baseball and all that. And thin and very active and energetic, same with their younger sister ((all without DS)). And then David ((child with DS)) I would like to try and have him do T-ball. And I guess we'll try to do some sports that he can, and like I said I keep thinkin he's going to outgrow this endurance thing. But he's still, I can tell when he's, he just can't you know?

Group: Hm, yes.

M: His little legs are short and he can't walk as fast.⁴

S: What about blastball? Richland youth association.

M: Okay

S: You go to first base and you jump on the base and it makes this little noise
-----Doorbell rang. Tape was stopped-----

Folder B 04/08 35m 24s

L: Yeah, Cannon played (.1) he had not turned 5 yet so he was able to play with 3 and 4 year olds. Which was more (.) developmentally appropriate for him. [He was the same size=

PI: [Same size, sure=

L: =Yeah exactly. Exactly. And really just a year older. This was perfect.

PI: I think that's pretty common=

L: =I mean the kids didn't know any different. The only thing that was different was that he couldn't run as fast as they could. [So (.1) This was in the Spring ((spoke briefly with each other about Spring sport opportunities – hard to distinguish words)).

PI: [Right

L: This is was. It was kind of a leap of faith for us because you don't know how the other parents are going to respond. [You don't know how the other kids are going to responded. _And Cannon ((child with DS) is a great follower, you know he likes being (.1) [

M: [but you think at that age, it's the parents
[so is David=

L: = Yeah and so that helps.

M, L: (Yeah that helps, they want to do what the others do)

L: He's not one to run away and cry or whatever. He's like ooh other kids are doing it I'm going to do it. So, (.2) he's a participater which is nice.

M: ()

L: Because Special Olympics doesn't start til the Spring for our kids when they are [8?

Mitzi, S: [8.

Group: ()

S: But at the same time it's easier to include our kids when they are under 8. Like we've done rec soccer with Jack, we've done blast ball with him ((child with DS)), (.2) basketball we've done um upwards basketball with him he's doing that again he loves basketball, um what else we've done...(.2) you know swimming lessons and that kind of thing but as they get older that gets more challenging (.1) um to put them on a team that's way faster than he is [and whatever=

L: [hmm huh, right. The gap widens

S: = yeah and you have to kind of find the noncompetitive options, like upwards is not really competitive. So...(.2)

PI: what about more individual sports?

L: right like swimming and stuff.

S: Right but I mean as a family we see benefit to team sports for them and (.2) friendships, and () you know all those things that go along with it so um (.1) yeah.

PI: So kind of the benefit you see for both of those are the same as they get older the =

S: =benefits?

PI: The benefits you just spoke of the physical, psychological benefits of being a part of the team for both, for all of your kiddos, it's just the um (.2) the availability, (.2) changes as they get older?

L: And the acceptance I would say. Don't you think the acceptance of it? Because people get more competitive the older they get [more competitive

S: [opportunities I would say just really narrow down.
And that's a challenge. (.2) Um and I'm one to say you know if he wants to p::lay then he should play. So I want would really love to find more inclusive activities for him.

PI: Emm, hmm.

M: (.2) Right. Well have you heard or how do you feel about um I think this was in Keller we got an email from somebody on the board that coached my older daughter how they were going to start a (.) try to start a maybe a special needs type soccer program.

[But then everybody that plays has special needs. So their all kind of on the same (.2) you know endurance level and all. But then that goes along with the whole inclusive thing. [Right do you want them to be on the field

L: [Haven't heard that

S: [you know there's two sides to that some people feel really strongly about inclusion (and seclusion) in school and then some people feel adamantly about inclusion in community. =

M: = Right.

S: So, I think it's um, everybody's got a different opinion on that and I think in an ideal world I would love for him to be included and (.1) um with his typical peers (.2) but then we also have to have friendships with special needs so it's like as a Mom I'm doin both. Because I think it's so important but (.2) the bottom line for us is (.1) is his health ((child with DS) so...=

M:=Right.

S: If that's the only opportunity he has that might be our last (resort)=

M:= Like the older they get [yeah

S: [yeah that might be our choice. And if it's our only choice we do it. Some people wouldn't participate at all because they would feel so strongly that that's not an inclusive activity=

PI: =Hm, hmm.

S: Ya know? (.2) But I can't quite provide soccer at home and I mean I run but but I don't well I guess I could run more with Jack ((child with DS)). But he likes to walk the dogs so that's another thing we do to kind of...=

L: =See that's a good thing

Mitzi, PI=Right, yeah

L: I think just staying active is key.

S: And he ((child with DS)) says Sammy will pull me and (.1) HE DOES so that helps.

PI: So will you all walk as a family? Or just you and him?

S: Occasionally.

PI: Occasionally?

S: It's just like with the crazy schedules with the kids um (.2) it's a beautiful day we love to go out after dinner and take a walk (.3) but...

PI: How about on a night like tonight?

Group: laughs

S: On a night like tonight ((group laughing)) (the weather, yeah) (.3) we've got a cross country meet and yeah the weather, but the heat does really get us down in the summer the heat is really hard for him. It's a definite road block to fitness, other than swimming. So I'm very thankful that we have a pool because we try to get him to swim everyday if we can.

Group: (yeah)

S: (.2) um...

M: Does he actually swim, swim?

S: Oh yeah.

M: Yeah? That's good.

()

L: I think there is definitely a difference in the siblings though, because as I think about it when we've been camping before there have been times where we were like (.1) okay Kelsey and Ethan ((child without DS)) you guys go with Dad because they want to bike bike bike, continually bike. And if we bring Cannon ((child with DS)) along with his little bike (.1) it's like everybody slow down and not that that's a bad thing. I mean we love doing the family stuff to but sometimes they want to get out [and speed bike.

(laughing)

M:

[Right?

PI: So you guys break up (.1) from others so that everybody can kind of can kind of do what they want?

L: Right=

S:=we do do that too=

L: = because I mean you don't want a (.2) make them slow down all the time just because I mean I would it is the same with any younger sibling. But it's just with our kids ((children with DS)) there is just a bit more of a delay. Like I would say we definitely started things later with I mean we haven't put Cannon ((child with DS)) in swim lessons yet and we need to. But you know I think the other kids we started them at 3. Which (.2) I don't know (.) but you (.) there's definitely a delayed start getting into those activities.

S: And I mean sometimes you do have to split up, which I hate but [I just always feel a little bit sad but [they don't want a yeah. There's some natural resentment anyway even with the best kid in the world (.1) they are just going to naturally resent the special needs a little bit you know and the slowing down and so you just have to be really creative [and keep them challenged. It's kind of a broad question.

L: [RIGHT
[but you don't want to sacrifice the (fun) of the others
RIGHT]

PI: Right, yeah no it's absolutely and that's kind of purposely broad. So they're all broad.

Group: laughs

S: Well...I have trouble with that! I need a box to check!

PI: Well, we'll go ahead and move on to the next one. But again if you ever want to go back to another one, feel free. So the next question is very similar just kind of the topic changes do you feel the eating habits of your children with and without Down syndrome are similar or different? And if so, how? And what impacts those behaviors? So kind of the eating habits and the way you encourage them to eat. (.2)

M: I'd say for me they're exactly the same=

PI: =The same?

M: Yeah. They don't eat anything different than each other and really never have. Except when he ((child with DS)) was a baby, but they all ate different then when they were babies too. He only had a little bit of trouble chewing early on like (.2) he would try and swallow before he had chewed it all but (.2) he ((child with DS)) likes every single food that you give him and the others they ((children without DS)) are more particular. And even at his age they weren't as open as he is. I don't know if it's kind of a full thing or a flavor thing he rarely turns anything down. And like she said (motioning to S) he NEVER turns anything down. He just eats and eats and eats. Occasionally he'll, you know I say he doesn't get full either but that's really not true. If it's really good and he likes it he's gonna want more and more and more but if it's just kind of a (.2) this is okay...I mean he doesn't say this but he might just turn his head, because he's done. Which means he's done, I think.

PI: Yes. And you think that's different then his other siblings? Would they turn down a treat?

M: Well...no. You know that's interesting because I've done a program recently called the lightweight and I mean this isn't anything that this program came up but they teach that if you feed a child food and they get full, truly full and then you offer them ice cream they might take a bite or something but if they are really full then they won't eat it because they are just young children and they just know when they are full whereas he ((child with DS)) I think if it's something really good like that he will [Yeah! [Whereas the other kids are No I'm full and this just happened the other day. I was like y'all aren't gonna eat the treat? An they're like No we're full. So (.2) but I don't know.

PI: [He'll find room in there?

L: [Yeah I agree with that.

M: Well they all eat the same kinds of things. Fruits, vegetables, and they pretty much eat pretty healthy and he ((child with DS)) eats the most and the best (.2) of a variety of foods.

PI: Okay. (.2) So he's ((child with DS)) he's the least picky of them all?

M: (nods her head)

L: I'd say mine, he ((child with DS)) eats pretty much the same he may...he does have a preference for ketchup!

Group: laughs

L: I, I think that's pretty common.

M: You know they make it without high fructose corn syrup now?

L: There you go, um yeah he loves it. He wants ketchup on everything, but I mean he'll try new things. And then he'll either say hmmm I like it or neh. And he ((child with DS)) I mean oddly enough he'll eat salad, my other kids don't like salad. But then he will try something and he'll give us an honest yes or no answer. But I agree with you if there is something that is really really tasty, he'll just be like hmm, hmmmm, hmmmm, you know?

PI: So then you feel you have to monitor (.2) what he eats or how much he eats a little more?

L: Oh yeah, he gets into it a little more ((than the others)) (laughs) I mean when he finds a taste he likes (.4) it's almost like he won't stop.

M: Yeah.

L: but obviously we have to set (.2) I mean we're all aware that our kids have a (.3) you know a what's the word? Propensity to be, to become overweight faster than other kids. So I mean it's something that's, it's always in the back of my mind. I'm like okay...not that I'm overly worried about it at this point but it's something I know I have to keep in my head. Yeah=⁵

Sheila, M:=yeah, uh huh

L: Especially when they stop growing quite as much. You know there obviously not going to be as tall, except David's tall ((motions to Mitzi about her son with DS)).

M: Yeah (.2) he is tall.

PI: So, just to paraphrase, you said you kind of keep it in the back of your mind (.1) .hh thinking about the how much or the frequency of feeding and things like that you don't really, that's not something that you keep in the back of your mind?

L: Well not really, you know when he was little and we had ECI coming out, you know what ECI is? =

PI: =Yes, Early Childhood Intervention.

L: =Yeah. They did like a graph on his height and weight (.2) and percentage and such. So (.2) it kind of for a while his weight was over what it needed to be so I started tracking his calories and I actually realized I was feeding him way too much. And I don't do that now but I probably need to start doing that again just to see how many calories he's getting just cause[

M: [yeah I should do that to.

L: yeah you don't think about it you just kind of toss the food out! And say, here's 5 chicken fingers or whatever it is and (.2) you know I don't see what he eats a lunch at school either. I mean they tell you he ate about half but you don't really know which part of the half he ate!

M: Well the thing is that I find interesting I don't know if it's because of the Down syndrome but he can go a really long time without food too. Which I find (.2) it's odd! I mean he ((child with DS)) eats a lot and he likes to eat but he (.1) well he'll tell us when he is hungry. But he has gone, hours and hours before without eating. Just because we've been busy or whatever, I mean we'll give him a graham cracker or something. But I'm thinking how can he not be hungry? And you know it's not every day but I've just noticed that about him. I don't know if he doesn't feel the hunger or feel the full, maybe?

PI: If you asked him at those times if he was hungry do you feel he would tell you honestly?

M: Well (.4) .hhh I've just noticed that every once in a while. I mean if I'll say do you want to eat he'll sign eat usually. But when we have just been out and goin he hasn't had the opportunity to eat and no one else has either, but it doesn't seem to bother him=

PI: =Compared to the other kiddos ((children without DS)), where it might?

M: Yeah. And when he went to school last year from 12 to 3 which was really hard instead of the 8 to 11(.3) so if I gave him a little bit of lunch you know just because he had eaten a late breakfast, for instance. Okay and so maybe even sometimes that's all he had, is he had breakfast a little bit later so by the time he had to go to school he wasn't, he wouldn't have been hungry. And yet he would come home at 3:30 and yeah cause 12 to 3 you had to feed him before. Maybe he would come home and he wouldn't necessarily eat and maybe he wouldn't eat until dinner. I don't know it's kind of odd.⁶

S: I think Jack ((child with DS)) does that similarly. But yet if I ask if he is hungry he always says yes. So he is always interested in eating and getting that sensory feedback.⁷

L: [Yeah and I was going to ask if that was a sensory thing?

S: [Because he ((child with DS)) always wants something crunchy, he always wants goldfish but hhh. (.2) but overall I think that both of my kids love to eat and so I think the habits that we have instilled in them are the same. Because um (.2) part of the reason I need to keep Anna ((child without DS)) active is because she has a sweet tooth. You know so. Um (.1) I think we try to establish really good family habits, try to have breakfast together, we try to make lunches for the kids, again not every day but we try to have dinner together at home. So those kinds of habits are the same⁸. But again, I think it's the Down syndrome specific things that are a little different. Like... I don't know when I'm full (.1). Or I don't know when I'm hungry.

PI: So since you brought that up if you are at the dinner table and you say I don't think that he ((child with DS)) would be able to recognize hunger, do you guys have any specific rules as far as we have to clean our plate or whether you can get seconds?

S: I never have to tell my kids to clean their plate! (laughter) I wouldn't make them clean their plate. Because again I really want them to know when they are full because I want my daughter ((child without DS)) to know that. I really try to encourage, let's eat some more vegetables, but I don't have any rules about it. You know what I mean?

PI: Yes, uh huh.

S: Well, let's eat our dinner before our dessert! That is kind of a rule!

Group: laughter

M: yeah we have that rule too.

PI: yeah that's a good one!

M: My kids don't understand that one!

S: He'll get it later. But now it's probably really hard.

M: I mean he just melts down.

S: He's like you are so cruel mom.

Group: Laughter

L: We, we almost have to stop, we used to have a little child thing on our pantry and we took it off. [Because we're like eh, he's fine.

PI: [An actual child lock?

L: Well, like a little latch, child lock. Because he'll ((child with DS) just walk in there randomly and he'll grab like a dingdong or something and be like 'mom, mom?' ((hands gesturing)) Shake it and I'm like NO, NO! Wait til dinner, or after dinner you can have a snack. And then he'll go in and try a another snack.

PI: It's great that he'll ask. So you have set up a system where he knows he needs to ask.

L: Well (.3) I don't he knows, yeah he knows he needs to ask. Mainly because he can't get the wrapper open! [if he could get the wrapper open he'd be in there with his sweet tooth.

[laughter

PI: Do you think him differently than the twins? ((children without DS))? Would the twins be able to just go in?

L: You know just recently because they are 8, I mean the other day I walk in the pantry and my son ((child without DS) is eating cereal and I'm like WHAT it's 4:00! What are you doing?

(Laughter) We are not going to snack like 45 minutes before dinner, because we are early dinner eaters. So they have just gotten to that point that they can go in and grab what they want. And I'm not liking that because I would rather them ask and have a healthy type snack. Have healthy snack boundaries. Their like what's a healthy snack, no it's not a popart!

Group: Laughter

L: I mean, come on.

M: Well we definitely have the rule that you have to ask, even my 16 year old. They have to ask. But it's more of a eco, economic thing too. Because I've got 6 kids and they know I've gone to the store because the pantry looks full but that's for school. Not that they can't have anything but you know if there is 10 in a box and you all have 1 right now. You won't get one for school tomorrow. And that has just been their whole life. Even when we used to just home school and then now they go to school but I'm not just gonna buy a box of this and that. All individually wrapped. I mean I said anytime you want a banana or apple. I always have fruit on the counter and any time you want that you don't have to ask and they still even occasionally do. I like that.

PI: So if it's on the counter, or fruit it's free ranger?

S: I like that rule.

M: Yes. A banana seems to be more filling so I like that. Or I'll have grapes and fruits, and they're not as big a vegetable eaters so then they eat more fruit. They all ask to eat food which I like and then it's not necessarily though about a nutrition thing or that's too much it's more of an economic thing. And they know I'm really strict about that, so they usually do ask. But I have seen kids sneak some things, but they are kids.

S: I think it is a fine line. My kids ask to they kind of have to, it's just kind of established thing. But yet I try to be when they ask I try to be lenient but not with but I try to give them something, because you don't want them to resort to sneaking [because you don't want it to be a problem for them, but yet I will say no to the chips. Jack ((child with DS)) just wants potato chips all the time. And (.2)

M:

[right, exactly

M: But the thing is too and you have your rules but I know in the neighborhood when they'll go Theresa ((child without DS)) will come walking home with an empty package of grandma mini cookies, it's 5 o'clock in the afternoon, I'm going doesn't that mom ask you? And maybe she doesn't! And then one day with one of those little plastic bottles of kool-aid which we do not buy you know the little bottle that you just pop off and drink. I told her, I said never again do you have that especially at this time of day. If you're at a birthday party or something that's one thing

[

PI: [a special event?=
M:

=but that is a sugar drink, straight.

L: But you know you do struggle with that what other people do, you do. And your kids know that, especially well maybe not well I don't know I think Jack ((child with DS, who is older than L's son) might be more aware than ours ((child with DS) because he is older. Yeah but they're ((twins without DS) like so and so brings a Dr. Pepper in their lunch and I'm like so? Really? Seriously?

PI: So, um you kind of have that temptation with both kiddos? Or just one?

L: Cannon ((child with DS)) doesn't quite recognize it yet, but I don't know everybody sends their own individual lunches to school so I'm curious if they look at the other kids trays and go hey I want that, I've never had that.=

S: =I think they do <referring to noticing others' food> because it's something different. Jack ((child with DS)) wants to buy, there is a difference Anna ((child without DS)) does not want to buy lunch every day. Part of it's a social thing, but part I think he wants to get (.2) the junkiest thing on the menu! =

Group: [laughter

L: [moms gonna pack me something healthy.

S: Yeah! If there is any French fries, that's gonna be his choice. So (.2), am I going to buy today...no!

M: But he's a healthy weight and everything isn't he?

S: He is. He's just now picking up a little bit of weight, he doesn't have a belly but he calls it Shrek or something.

PI: Wait, did you say he calls it Shrek?

S: ((Laughs)) Yes, he's sayin that now! I'm like where did you get that from...Shrek! So it's like good I'm glad nobody is telling you you are fat at school. Because he's not, he's just starting to put on a little bit of weight and I think it is pre-pubescent. He is 10.

M: Well and my kids talk about David ((child with DS)) because of the low muscle tone in his belly and I'm like you kids. Okay all of you kids were...[and yeah. They always say stuff, he's chubby or fat and I mean he doesn't really get it I don't think but I'm going to tell them the older he gets they've got to stop. I know they are saying it in a cute affectionate way sort of but I don't like it [

S: [he's got a toddler belly
[but he'll start to thinking, I think, I'm
supposed to be that way. Or I get attention that way. =

M: = my belly goes over my pants kind of thing.

PI: Did I hear you make a comment –to the other kids ((children without DS)) – that you were like that when you were his age? So does that mean you notice that his ((child with DS)) body type is similar to your other children? Or do you feel he has this body type, because he has Down syndrome?

M: Yeah, no I think my oldest. He's ((child with DS)) built like she ((child without DS)) was. But not all of them, like the twin boys are just really really thin and built a little different. Yeah, but the girls, 2 of my girls ((children without DS)) he's ((child with DS)) built like them. My girls, the oldest and the youngest, both kind of are shorter and stockier.

PI: So do you think, I know you kind of um, you had said Lisa that you have that in the back of your mind. Have you noticed as their weight does change does that bring about concern or possibly change the way you might encourage or discourage different things?

S: I think so yes. Jack ((child with DS)) has put on a bit of weight =

M: =Yes.

S: And then you just realize, well we let a few things slip there. So you just kind of get back to so healthier habits.=

L: =Yeah, I agree.

S: Like, okay you can't have potato chips every day or (.2) no we're not going to Wendy's or whatever. He ((child with DS)) always wants the chicken nuggets and fries. You know? We had to do something last night, so it's Boston Market instead. Which I think is a little better.

PI: So if there was a problem, would you look immediately to eating habits or activity levels to make some change?

Group ((simultaneously)): Eating, well both but eating.

M: Yeah, both, but probably eating habits would be my first thing that I would think of.

PI: And what makes you say that.

Group: () control

M: Yeah, control. Like there are some things that I just don't buy. I mean for me too, I tell them it's for me.

S: Right, I won't buy a bag of cookies. If they want a cookie, or if we make a like on Friday we made homemade chocolate cookies. And I think that's okay. Plus it's less worry, it doesn't have all those chemicals in them so um but that's kind of for me too. So there is a little blurred line there too. Because that's my hot button food, it's cookies.=

M: =Right. And we don't buy chips we used to.

S: And there are so many good alternatives now too. I mean =

M:= Yeah we'll buy rice quakes, those little quaker minis or Chex mix, which is a little bit better than chip.

S: Yeah there's so many, there pretzels. Crisps, like folded thin flat pretzels.

PI: So just looking more for the alternatives?

S: yeah, because Jack ((child with DS)) likes the crunchy, but he didn't like those ((healthy, thin pretzel alternative)), so (.1) oh well.

Group: Laughter, right –that's how it does.

S: But you know what he loves popcorn, so we do popcorn instead. And he makes his own popcorn which is a great thing for him, puts it in the microwave, selects the numbers/time.

M: that's good.

S: those times for independence are important I think.

L: Yeah, see I worry <referring to potential for weight gain> about Cannon ((child with DS)) once he does start school. Because I was talking to a friend of mine who has a little girl with Down syndrome, that's in first grade. And at Kinderfrogs where he goes to school every day, and I don't know if they do it at the early learning center. But they have PE every single day and are out on the playground and just constant, there is a lot of physical activity.⁹

PI: They have an adapted PE teacher too, right?

(A 04/08 23m 52s)

L: They do, they have an adapted PE teacher too which helps. But you know then I think at school, what they have 2 days of PE? They have like maybe 15 minutes of recess. So there's a lot less physical activity and a lot more just sitting. You know a lot of the stuff they do in class right now involves them standing up and moving[

M: [whereas others places, yeah.=

L: = Yeah so I worry about school because I think she mentioned that with her first grader that she started to struggle a little bit with (.2) the weight.¹⁰ And I think that, and we were talking about it I was like do you think that maybe it's because she's not doing as much PE stuff everyday like she was doing at Kinderfrogs? She does, oh my gosh I never thought about that. =

S: =yeah, but the state requires a lot more now. Like they'll do 10 minutes of something every morning. They'll have PE at least twice a week.

L: Good.

M: I know mine have it 3.

L: but yeah it's definitely a change from everyday, to some days.

S: yeah

M: But the older they get the more it gets cut back. In high school, they don't, I think they have a semester of PE. So after that, they're doing nothing.

S: And it's sad, because my 7th grader does not have recess anymore. And that's quite an adjustment for her. And it's sad, but she's got athletics every morning. She's ((child without DS)) running every morning. But it's going to be a question for Jack ((child with DS)).

PI: And that will be a change for all the kids as they get older?

Group: Yes, yup.

L: And I think you are right, if they have a propensity to want to sit and watch TV too, and and DS and gaming=

M: =If that's a choice definitely. My kid ((child with DS)) would watch signing time or give him a video, if we give him the option.

PI: David, Jack ((child with DS))?

S: All day!

M: David. All day. But he does want to go outside, if I open the door and say let's go outside. He will. Yeah, but if he was watching a video and I were to say let's go outside he probably wouldn't. He would stay and watch the video, I think.

S: Jack says, no thank you!!!!

Group: ((erupting laughter from all)) Great, hilarious!

S: Okay, put your socks on. NO THANK YOU. Very politely. ((implying that's what her son would say))

L: But I think that is the trend with all kids, unfortunately.¹¹

PI: Nowadays?

S: It is. It's like more of that, what is that physics rule? (.2) If you are in motion, a body is motion stays in motion. [But once they are not in motion, they stay that way. So I feel like all day long I'm trying to keep them going. But once you get them not in motion. It's hard, harder to get them moving, get them into motion. And it may be a transition thing, it's harder to transition; it's a challenge for Jack ((child with DS)). But mostly just because it takes him way longer. He doesn't have a meltdown or a fit or anything. He's like (.3) hhhh for about 10 minutes ((S mimics him moving slowly)) and then you're like well now we don't have time to go for a walk. So...

Group: [Yes

L: Well that's my 8 year old daughter ((child without DS)).

PI: Yeah?

L: That's my typically developing 8 year old daughter, that's her.¹²

PI: Well, let's move on to the next question. Do you feel your personal physical activity habits impact your children and the family? If so how?

M: Definitely. I mean, I think anyone would say that. I mean if you are lazy and don't go exercise your kids are going to see that. The importance you put on it, or not. We just joined the Point in May ((local gym/recreation center/pool/track/classes)). And we have joined before, you know can join here and there. But the company my husband works for pays half the membership fee and it's a whole family membership, they can all go swimming. You know they can't all go do the weights I think you have to be over 14 or something. They can um (.1) utilize the pool and if they're 10 they can actually walk on the indoor track with a parent. But my husband and I just now are starting to, I mean I've been probably going about a month, regularly. Okay and I tell them that I'm doing that because I do that when they are at school. And then my husband does that when he gets home from work and what's interesting about it is that the kids are like, is Dad going to work out again? ((sadness implied)) They don't understand why he's doing it really and they don't, because he hasn't ever really worked out. I mean he did in college, but then since we've been married he just never really has worked out. And now he's doing it and then they just kind of miss him being at home. And they asked, is he gonna do this (.2) every night?¹³

PI: Do you all ever go together?

M: Well (.2) that's kind of hard. I mean I've taken David ((child with DS)) because they do have a daycare for him to go in, a little nursery type thing. Um, but I can do that like if I pick him up in a little while I can go to the gym with him. I can do my thing and he can be in there (.2) for free! And (.1) all of us have gone to swim, all of us have not gone to exercise.

PI: More because of logistics ((that's what kept you separate))?

M: Yeah logistics. Like Ryan ((husband)) has taken the boys on the basketball court and done some things with that and then I've taken the girls and we have gone swimming but that's, that's very rare that we've actually all gone up there I mean other than in the summer to swim inside. So we just need to make more time to use the inside part of the center during the winter.

PI: So do you think it would be feasible for the whole family to go and spend an afternoon like that together?

M: Yeah, and go swim. Yeah we would do that.

S: We did that over Christmas break there last year. We should go more often.

M: And they have special passes right now for 5 dollars[

S: [yeah that's what we used. And we need to do that again, because swimming I think is key for Jack ((child with DS)).

PI: And why, because he enjoys it because he is successful?

S: Because he seeks sensory activities if he doesn't get them he will and do this and tap ((makes tapping gesture with hands)) just to get sensory input. Or he just is unhappy I think he's just like me you know if I don't exercise, if I don't get outside and get a little sun. You know those December, January months. He's really just like, I mean yesterday he looked a little depressed. So I just kind of have to keep him going and do some fun stuff. But I definitely think that our habits affect our kids. I mean when my daughter ((child without DS)) was young I would run with her. She did this great little program called girls on the run and just (.2) such a good program. It's all volunteer but the moms have to be involved so you don't necessarily have to be a runner but I would run with her some and I would walk or jog a little bit with Jack ((child with DS)) and swim. But if we didn't do any of those things the kids wouldn't do them either. So I think it's really important. I think if we didn't do it, that would cut their opportunities down to almost nothing. Because at school they have PE and that's about it, and they could do activities

um (.2) like soccer and such and that would be it. So I don't know, but I just think that they know if it's important. I mean if they know it's not important to you it won't be important for them.

L: Right, like I run. And (.2) I'm training for a marathon! [

Group: [WOW! Good for you

L: But Kelsey and Ethan ((children without DS)) will say things like I want to run sometime. And Kelsey's like I think I can do a marathon sometime, and I'm like yeah, aah you're 8! I'm like it would take you about 5 or 6 hours you know? I'm just kidding, but anyway that fact that they actually have that in their head (.2) I mean when I was their age I had no clue that there were such things. So I think that's kind of cool. Then I think maybe one day I can convert them into a runner, maybe one of them. Maybe my son, my son's probably more likely[

M: [() 5Ks?

L: No just because it's like 20 bucks and you can just go have them run a mile, map it in the car. You know?

S: But do it once a year because it's really cool because the first thing, Anna ((child without DS)) and I have run a couple 5Ks together and it's really fun=

L: =Yeah I mean I think they would so love that they would get into it that kind of stuff. And you know the other thing I was thinking about that we do and they do with us is that we all do as a family is called geocaching? [the GPS scavenger hunt thing.

Group: [what's that

L: It's so awesome <geocaching> for families because it gets them out it gets them walking and hiking, we do it on our camping trips too. And then it makes it fun!

Group: G O...how do you spell that? Oh it makes it fun ((confirming))

L: It's like basically people will hide little treasures in little camo containers, waterproof containers and you get the GPS coordinates and basically search for it and when you find it you open it up and then there are trinkets or whatever=

S: =So these are organized =

L:=Yeah and then you can trade=

S: Wow, how fun. So this is an organized activity?

L: Yeah, they have it at like every park. Yeah you just go online, and you record your stuff online.

M: But (.2) how do they keep the stuff? I mean you have to be there in a certain time of day?

L: Oh no! You can do it all the time, I mean we have caches hidden in (.2) bear creek park ((nearby park)).

PI: Yeah and unless you are looking for it you won't find it.

L: Right because most of the time you won't see them out they are camoed and hidden really well. And (.3) yeah sometimes they get muggled, they call it muggled. It's fun it really is.=

S: Oh my gosh the kids would love that I've never heard of that.=

L: yeah it is but little things like that has helped the kids want to go hiking. I mean if we were just going hiking on a camping trip and there was no[reward. No way. I think that helps, I forget that's what we do to get them going sometimes when we go camping but they like it so.

S: [Yeah!

S: Yeah that's what we do when we bike riding, we like to have a destination.=

L:=Yeah, having a point to the trip is kind of nice. Because saying, let's just go exercise!

M,S: yeah!

S: Right, yeah that word is not the funnest word!

Group: laughing!

L: Because you could say lets ride our bikes to the river so we can go walk in the river, so you know? That works. They've got to have that motivator.

M: And the Keller Parks system is great, because we've started this past summer all biking and I mean David's ((child with DS)) in the little burley behind my bike riding along. And we all went except for my husband really far. You can go from my house in hidden lakes all the way to the softball field where it ends and that's pretty far. I mean that's probably 2, 3 miles. And never be, you cross Bear Creek Park one time and I mean everything else is under the bridge and safe=

S:=Its beautiful too.

M: It goes pretty far, but of course we don't go that far with the youngest because she ((child without DS)) can't, well she can go but she can't come back. Well she might be able to now, we usually go to a certain point and then turn back. We'll say let's go to the playground and then turn around and come back.=

L: Yeah! The playground incentive is good!

PI (To M): So once David ((child with DS)) is older do you plan or hope for him to have a bike and ride along? Or do you plan to keep him in the little burley?

M: ((hesitation, speaking slowly)) YYeahh. He'll be too big for that eventually.

S: those things are hard to pull.

M: Oh, it's hard to pull with him right now especially in the heat! No, I mean I want him to be able to ride a bicycle. That just seems so far away,

S: And we'll have to tell you about the program we were talking about. But that's for, they recommended 10 years and Jack did it when he was 9 and I wish we had waited.

Lose the training wheels is the program and we can talk about that later.

04/08 End of 35m 24s.

05/08 1m 26s/15m 10s start

PI: Do you feel your personal eating habits or feeding patterns impact your children? If so, how? So let me give you an example and of course all of you completed the survey just to kind of go back to one of the examples it gave on the survey related to your eating habits or patterns so like the amount of food or when you crave certain foods do you give in or not give in sometimes. Do you restrict yourself or have certain rules about food? Things like that just to give some examples, and how they impact your family.

S: I think definitely <referring to parents' eating habits> they impact our family. Because if I ate how I wanted I would just be (.2) they would be eating the same things, and if I ate whenever I wanted I couldn't tell them not to do that. So I think it's definitely tied together. I mean we are like a herd.¹⁴

PI: So you recognize the element of modeling?

S: Definitely. I mean we eat together, so we don't eat separately we don't eat different things either. I'm not (.) my husband actually does the cooking and we are not a short order cook! And he just loves to cook=

PI: Short order cook, that's funny.=

S: I mean I'm not doing to do that! We don't make different things. I think that goes back to a different question. But I definitely think it's definitely tied together and we ARE a family and we eat together. So (.2)=

M: = And that's one of the most important activities you can do for family.

S: Yeah! It's funny because when they were littler, I would put them to bed and now they are staying up later and I'd usually have my little night time snack you know?

((laughter)) And now...my daughter's up til 9 o'clock, 10 o'clock and[

L: [she catches you?

S: Yeah! So I'm eating healthier at night. You know? I know it's like I can't just sit in there with my (.2) cereal...

PI: So the awareness of their awareness makes a difference?

Group: Yeah, Yes.

L: They are definitely aware of what you are eating. Because I just lost some weight, I had put on some weight and it just snuck up on me with age. But I lost 30 pounds so while I was doing that, they were like so why are you eating that? Because I would be like I'm not eating bread. And they would be like, why? And I'm like because I'm trying to lose weight! And () so I think they are more aware of like [chicken's healthy versus biscuits are not healthy

M: right and the older they get[

S: And I used to be afraid to say things like that to my kids, like oh I can't eat that or can't have that. But now I think as they get a little older it's a good example to set. You know? I mean you can't eat whatever you want all the time, you just can't! [So.

You guys can have that burger, but I'm going to have to order that chicken. Because they love, we love our burgers. [

L: [Right.

[Yeah

M: The older they get they definitely notice what you are eating and what you're not eating.

L: Yeah, when they're little you can get away with murder. But when they're older they definitely notice, like my husband doesn't eat vegetables and they're like why does Dad not have to do that and why do I have to? And I like (Wes) would you like to answer that question?

Group: laughter

L: But he's ((husband)) actually tried some stuff now because of that. And I think they try things that you make (.2) what was it that I made the other day and I thought they wouldn't like it and they loved it. Gosh I can't remember, it was like grilled onions or something that I was not expecting. Something that I did not like til I was like 28!

M: That you put in something?

L: No I think it was just by itself.=

M: =Grilled onions. Wow!

S: I did hear recently that kids have way more taste buds than adults and that's why they are pickier.[But I also think socially they are affected.

Like she ((daughter without DS)) will (weigh) things more now because the kids at school will tell her it's gross. Like she used to eat guacamole and now she thinks it's gross. So I think peer input [is huge.

L,M: [I hadn't heard that, didn't know that.

[definitely

M: My oldest daughter, I'll see her standing at the island eating. I'll see her get something out of the fridge and I'll tell her to sit down and I'm thinking oh my gosh I do that to! So and which they tell you not to do that, fix yourself a little plate and sit down and eat it. But with hurryin and tryin to get the kids to this and I have found myself, not eating a meal but just snacking or putting something in my and she ((child without DS)) does that a lot! And I'm like Rachel go sit down and eat! And take a sip of water in between each bite. But I mean she's seen me do that too. So. And they also, I know my boys have come home from school asking me to buy ODD things very healthy things. Oh well so and so bought then and I want to try it snap peas!=

S:Ooh! Who is that friend, we're gonna have a playdate!

Group: Laughter! Who is that great mom? ((smiles))

M: Sugar snap peas in the little individual bag.

L: All the cool kids are eating snap peas!

M: And, and little baby cucumbers. Those little baby cucumbers, they just eat them raw. They are about the size of this pen and they're little baby cucumbers.

S: Oh my kids would love that!

M: And this one boy brings this stuff, and he is a really good friend of theirs. And so, sure if you'll eat them I'll buy them!

L: I agree with the peer pressure I know it's supposed to be about us but yeah at Kinderfrogs ((child with DS's school)) they'll try stuff like green bell peppers and hummus and carrots and stuff and stuff like cucumbers and stuff that I don't think Cannon will like or eat at home. I think because everybody else is eating it [yeah! He eats it too, I'm amazed! I mean hummus? I love hummus but I didn't think he would eat it. I mean my 8 years olds ((children without DS)) would not try it. They would be like oohhhh.

M: [Yeah, in front of him

PI (To L): Even if their ((twins without DS)) friends had it?

L: Well if their friends had it? Cannon would get it, he's like mmm ((eating gesture)). Yeah, I don't know if my 8 years olds would try it even if their friends ate it.

S: My kids like hummus, but some of them if you open it up the garlic is like so strong. So maybe try a different kind. It's like that shouldn't have that much garlic in it anyway.

PI: Alright, we'll move on the next question. This is a long one, a two part one. Do you feel physical activity impacts the quality time your family spends together? If so how? And do you feel the promotion of healthy eating impacts the quality time that your family spends together? If so, how? And we can just start with physical activity first. And I know we have already spoke about it a little.

S: Well I think, interesting angle on the question <physical activity as a family>. But I think it definitely does because (.2) I think it gives us more time together first of all ((under breath)) the quality of time. Okay these are hard questions, I think Yes!

L: I think the being physical together, not sitting in front of the TV together you know doing something active is way more beneficial. It feels like we're doing something as a family, whereas if you're all sitting (.) there on the couch. It doesn't really feel like you are doing something as a family.=

PI: =there's no bonding?

L: Right.

M: I mean it'd be better to play a game. A board game, which is what I always want to do but then my husband, turns on the football and I'm just going, and that is great for (Nick), Will and Dad. Because nobody really else=

L: Yeah, because you're not really interacting when you are watching TV[. You know, when you are out throwing soccer or playing baseball or something you are interacting.
M: [except with the TV

S: And to me it's much higher quality because you are in nature I mean I just love that. Or if we're on a bike ride together then we're =

L:=yeah endorphins, because exercise releases endorphins when you exercise. And so it just makes you feel good.¹⁵

S: Definitely, I mean we plan trips around this <physical activity>. We went to Colorado this summer and brought the tandem and so the quality is huge there for us.

PI: And now, I think Lisa you mentioned this and then you all agreed, talking about sometimes with activities the family gets divided. And so what can you guys speak to related to physical activity and quality time and how that can potentially get divided between mom taking these kiddos and dad taking these kiddos?

M: well in our house it depends on abilities. And that happens with us just because our ages of kids are so different but David ((child with DS)) doesn't get to participate in certain things. Part of it is because he can't and um (.2) I don't think we have enough family, entire family physical activity. I mean we just don't.

PI: But maybe, you'll have mom and son activity time?

M: Yeah, I mean I'll go bike riding with him a lot (.2) before it was crazy hot over the summer and even in the fall. But I've got the 16 and 15 year old girls, and then the younger kids are much younger and now that they are getting older they definitely are wanting more separation kind of. I mean I think they like when we are all together but I think they often have something else they would rather be doing. Because of their age, and they are girls – especially one of them. So it's more of a challenge and I'm not one that's sometimes up for that challenge. To sit there and think creatively, like what can we do that we will all think is fun. Because what I think might be fun, they don't. Like I would much rather us sit around and play board games, but of course that doesn't include David ((child with DS)). Let's go () sometimes and they're like no let's get a Redbox ((movie)) and just sit there and watch it. And I can't stand it, but I usually lose. I don't usually win that battle, so (.2) and they're like MOM you always want to play board games.

()

S: Yeah, we try to plan that, family game night. Because Jack ((child with DS)) can hold the cards and he can call the numbers or whatever and (.2) our neighbors called and they were like why don't y'all come over (.2) and we said Oh sure! We're not doing anything!

PI: So it got interrupted, and you said oh let's do that?

S: Oh yeah! Game night is something that we feel like we should do together but um I will also plan like playdates for Jack ((child with DS)) around like we'll have a ball game night. I have this one thing, I thought it went really well. His friends are all pretty much typical from school, if we see our friends with Down syndrome we have to make a plan we have to plan because we are all so busy. So anyways I said bring your ((back to description of fun night)) favorite ball or board game and so they brought a ball several of the guys and Adam, my husband's, been working with Jack and his ball skills just throwing so they played football for a while and then they came in and did some board games and that went really well. And the moms had a glass of wine, so that was like (.2) everybody loved it.

Group: Fun, something for everyone!

S: They kept saying, this is great let's do it again. It was just moms, and the boys were outside with my husband. But I thought it would be great to have another night with the dads too. And then they can have beer or whatever. And we're talking about healthy eating.

Group: Laughs

S: I think planning it. And we do kind of plan our weekends. One () and I'm like we are too busy, we need some downtime.

L: You do need downtime.

S: So we'll plan movie night. But which is easier this time of the year to do movies. Adam ((husband)) will say, he's a serious cyclist, I've got to get my ride in and then I'm going to come back tandem with Jack or you ride so we kind of plan those things.

PI: Okay, so he'll ((S's husband)) go ride his bicycle for his own health?=
S:=Yes he's very systematic. He's got to get his 2 hour ride in on Saturday and I'll say well I've got to get my run in and so we plan. Saturday is usually we have to plan Saturday. And a lot of times it's broken up. So I'll do something with Anna or he'll do something with Jack. But we try to keep it, we try to mix it up so I'm not, because honestly it feels like I'm the one who's always home with the kids or I'm the one home with Jack, so it's a challenge. Whole group family things are hard basically.

L: But when you get them done afterwards you feel really good about it I don't know what it is.

S: yeah, just planning that trip this summer that was a big deal, but we did it! And Jack loves to tandem. He asks for that all the time, but he hates riding his own bike because he has fallen a couple times.

PI: So he prefers the tandem?

S: Oh yeah! Because he can fly on the tandem. And he doesn't have to do a whole lot of work.

PI: I was going to ask how much of the work he does?

S: My husband has to work with him. Like come on Jack, we're going up a hill. Push, push, push.

M: So one is pedaling for the other?

S: () It does. But they are kind of on one chain.

M: Right, but if your husband is pedaling really fast how does your son keep up with that same speed of pedaling?

S: He does, he has to keep up. So, there's not. He will gear down. Or gear up and not have it so fast. So it's not super fast, because Jack wouldn't [we'll he you have to practice so we had to kind of build up to that for sure.

M: [or he'd just take his feet off right

PI: To clarify, you do have to have an element of balance for the tandem as the rider, but the front rider has the hard part.

S: Right, but he is getting better. You can't just do your own thing on the back. It's hard for the front person. But easier then pulling a trailer.

End 05/08 15m 10s

Start 06/08 5m 1s

M: Okay so the second part of this one, what does that mean?

PI: So we could look at so, do you feel the promotion of healthy eating impacts the quality time? So with this we could look at specific events, you could look at family meal planning [right going out to dinner, or grocery shopping and kind of planning a whole meal together. Have you guys ever thought of those things as quality time?

M: [going out to dinner

L: We have talked about meal planning (.2) .hhh ((laughs)=

M:=I've thought about it!

Group: Yeah thought about it! Sometimes not actually doing it!

L: We've never following through though.

PI: Okay. And why do you think that is?

L: Time. ((laughs)) Time management. Time management on my part. No, my kids love helping with stuff and sometimes it's me being A type and I'm like, NO. I will stir it.

PI: So this goes for all the kids?

L: Well, no Cannon I have not really, not involved him. Just because it's just not a clean thing. Then my other child who's a germaphobic gets all stressed out. DID CANNON PUT HIS FINGERS IN THIS? ((laughs)) You know? It's just a mess.

S: And that's like me, but I've had to let go.=

L:=really?

S: You have to let go and you have to have the mess. My husband's better about that because he does the cooking (.2) and to us we cook together. We try to cook together.

But=

L: =Great, see I think that's great =

S: =And our kids are a little bit older, I mean it's hard when they're young.

PI: Or you kind of give them their separate bowl.

S: Jack is just learning to beat eggs, and it's kind of a hard thing to do. So instead of stirring it, so I think that goes together with us promoting healthy eating habits and cooking together [yeah planning, like we don't plan really well.

L: [yeah I think it's a good goal

L (to M): Do y'all cook together?

M(to L): No, no we don't.

L: I mean I like the concept let's plan something and cook it together. And maybe you'll cook it and try it and then like it. And like something that you haven't that you thought you would never like, because you made it!

S: And you don't have to do it every night, I mean around the holidays you know when you are home.

M: I can't even imagine all 8 of us in the kitchen .hhh it seems like a nightmare!
((laughter)) But the girls sometimes help me but you know what I am not a real (.2) like you know your ((to S)) husband loves to cook. I wish my husband loved to cook and he doesn't and I don't either. So and the kids know that. They don't volunteer Mom can we help chop this or put a salad together. I mean I'm like Please COME HELP ME!

S: Do they have certain jobs? For the table or I'm trying to do that. [but I haven't really done a good job.

M: [well, ehk kind of

M: My husband grew up in a very um (.2) his mother was like a drill sergeant so he grew up that way and he doesn't push it as much on them. Probably because of that[and he grew up with 5 kids. And I grew up with just myself and my brother and I, you know I'm not really good at that either. I mean we have them all clear the table and we've tried to specific things you know but it's kind of faded away. The younger kids though are more willing to help just because it's fun to them sometimes whereas the older girls don't want to do it, they would rather be doing something for themselves. It's that selfish time.

S: oh interesting[

S: We're paying Jack now. Well because that's part of his goal at school he has to learn the difference between spending, earning, and saving money. So we just have single dollar bills, feed the dogs ((motions with her hand – here you go)), there you go. And he's saving it now, I can't believe it. He wants to get a movie we went to Walmart on Saturday and he did not get M&Ms which is interesting because he wants to save up, save up for a movie. He loves movies. ((Laughter)) Then I thought, let's pay him to eat his vegetables...then I thought (.2) that's probably not right!

Group: Laughter

M: We don't go out to dinner a lot, I mean it's a big deal. So when we do, everyone enjoys it. I mean as far as healthy eating, probably not so much. But it's definitely quality time. Because we're all around the big table and we let them order on their own and um that's just a highlight probably because we don't do it very often. Um (.2)

PI: You have 8 people in your family!

M: Yes!

Group: Laughter

M: Yeah and my husband will drive through Wendy's and get off the dollar menu and I'll say oh lets go sit down every once in a while. But as far as it being healthy, it's probably not. But we just look at it as that's good time together[Yeah a treat.

PI: [a treat

End 06/08 5m 1s

Start 07/08 8m 8s

PI: Would you consider your family to be physically, we'll just start with just physically active, would you consider your family to be physically active? If so, how? And what impacts your activity? I know we have already jumped on to this one.

L: Did you want M to answer the next 3 since she has to leave? And then we can jump in or did you want (.2) us to discuss?

PI: It, it really doesn't. We can just let be organic.

L: Okay.

M: I consider us to be physically active (.2) I mean we're not bikers and hikers, but if I just think of that you know (.1) do we get out physically and do things and move. Yes. Compared to others. I think, if I'm thinking of other families that I know that don't. Yes we do. You know other families whose kids do a whole lot of video and computer games. And we don't really allow that um (.1) hardly at all. There's not a lot of TV watchin or video games. But so in that context I'd say that we are physically active. But maybe not as much as somebody else. 16

PI: Okay.

L: I think we are physically active but there's room for improvement in the healthy eating area! ((laughing) [You know and I don't know if that's because we're not (.1) my family's not necessarily, not predispositions for weight gain and stuff (.2) .hhh Not so much when we're younger, but definitely when you're older it kicks in. [I think there's definitely the opportunity to live healthier. Yup, there's definitely things that shouldn't be in our pantry, so.

PI: [okay. [So the concern is there?

(.5)

S: I think we are definitely physically active (.1) and healthy. And we eat, (.1) my kids eat salmon and we cook and we eat we felt really important. We have felt that this is a high priority (.2) because of because of family history ((of being overweight)). Which is like devastating¹⁷ =

PI: =so the concern is there

S: Yes.

M: Well and I think too if you have someone that cooks (.1) and likes to cook, I think that helps a lot. I mean people that like cooking don't use I wouldn't think cook a bunch a [

S: well they don't make chicken nuggets[

Group: ((Laughs)) Right?

M: I mean casseroles or something?

S: Right.

M: yeah if you're gonna cook, you'll cook right. Not gravy or soupy casseroles.

S: Well some people do like cooking that.

Group: Laughs ()

S: So I guess for us, the family history is the factor that's impacting and um=

L(to S): =Yeah you guys are being a good role model, that's good.

M: Yeah, biking and guacamole!

S: hhh Well yeah so it's family history is a factor (.1) and I think Down syndrome is a factor too that's kicked us into gear. Because there's, we can't I just don't really want Jack ((child with DS)) to um have that against him as well[Because I think that could really affect his lifestyle. (.2) And then my daughter tends to be like my family history, ya know like loves to eat loves to, I mean she likes to be active too so and I just didn't have the opportunities as a kid and my husband didn't either. Looking forward to activities or eating healthy or you know having bikes er just doing all those things. (.1) um I think sometimes you just, maybe go extreme. I don't know. But it's like I don't want my kids to have I just want them to have so much more opportunity than I had (.2) to feel good about themselves, to be strong, active and healthy.

M: [Right!

M (to PI): Now the question what factors are impacting, are you saying (.2) what factors impact you to be physically active (.2) or not?=
PI:=Exactly, either way. A negative factor would be a barrier but there are also encouragers.=

PI:=Exactly, either way. A negative factor would be a barrier but there are also encouragers.=

M:=Right, right, right.

PI (to M): (.3) So did you want to add something to that?

M: Well (.2) I wouldn't trade my family for anything, but I think having a big family and all going out and doing something physically active together (.1) is more challenging I'm sure there are people that do it. But you know if you have a 2 year old and a 16 year old and [
Right, but well some people do!]=

PI: [you can't go snow skiing?

Group: = laughs

M: Well we don't but I mean some people do. If you were a hiking family and you have 10 kids you'd all go hiking and that's, we're not any kind of family like that. There's not a certain thing that we have that we just go do like physical activity. Everybody loves to (.2) swim and I mean physically active swimming, I know we all like to play in the water but I'm thinking (.2) of I guess exercising[You know, and I'm not a marathon runner so I don't think my kids are gonna be so I don't know.=

PI: [right.

PI:=Well you still think you can be active without having a specific..?=
M: =Right! I agree.
S: Without being competitive.
M: Very true.
S: Or (.2) elite.

M: =Right! I agree.

S: Without being competitive.

M: Very true.

S: Or (.2) elite.

L: I think there's definitely barriers though, my kids are so scheduled though [there's so much going on during the week it's hard to fit =

S, M: [oh yeah

S: I was thinking the same thing (.1) busy-ness. =

M, L, S: Right! =

M: =And that takes priority over something else=

S: =I mean there's homework. Homework takes priority.

Group: There's dinner, baths...

L: Yeah, so sometimes it's hard to even put in a 20 minute bike ride. Which is just kind of sad.

S: Yeah.(.2) And it's kind of seasonal=

L: Right now it gets dark early (.2). Yeah but it seems like they are way more scheduled with school and they're expected to do a more (.1) then we were when we were kids. [At least I think so.

S: [Right, yup.

S: And you just have to try to keep control on that. Because it's just=

M: Yeah, and birthday parties, I don't know about y'all but we have one every weekend!

Group: Laughs, oh!

M: You know 1 or 2 kids have a birthday party and=

S: We have the same thing this past Saturday. We had to say no to one. There was one on Friday and then Saturday that my daughter was invited to.

M: Oh yeah we've had one Friday, Saturday, and Sunday for somebody.

S: And you talk about unhealthy! I mean (.1) everyone had birthday cake and pizza at every single party (.2) and ((said smiling)) that's never a deterrent for us going! [()

Group: laughter [

PI: Have you ever thought about putting restrictions on that?=
 S: NO! Birthday parties are sacred. You can't limit it at birthday parties!

Group: Laughs

M: What I've noticed at birthdays that I've gone to recently, a gymnastics party, a trampoline party, laser tag. All kinds of parties where they are running around! [I mean swimming parties. (.2) It's not, I don't know what else you do at a party. Except when I was little we played pin the tail on the donkey!

S: [Yeah

S: yeah they have roller skating, which was a problem for Jack. He was invited to a friend's roller skating party a few months back (.2) but they have an arcade (.) so...

M: Right.

S: And then my daughter wanted to have an ice skating party, at grapevine, yeah and I said (.2) can all of your friends' skate. (.1) And she thought well? And I'm thinking do you have any special needs friends that can't skate? Of course they can skate MOM! Yeah, but then I said honey think about what happened with Jack you know just make sure all your friends can skate. So.

M: yeah, my 7 year olds been invited to an ice skating party this weekend and I'm thinking, okay (.2) 7 years old? I bet a lot of them are not gonna be able to skate!

Group: Laughs

M: I know she's been practicing her rollerblades which is similar but I, it'll be interesting. And then they said anyone else in the family, siblings or parents, can ice skate for 10 dollars or something. So a couple of my kids are like well we want to do it. So I'm like great! Activity!

S: Yeah, I just read you can burn 500 calories and hour ice skating. I find that hard to believe.

M,L: Maybe if you're skating hard, all around. ()

S: not if you're going like this ((hand motions – moving slowly))

Group: Laughs

S: But I think there are cost factors that can be impeding [] because I mean bikes cost money, and skating costs money[] and rollerblades.

M: [oh yeah

[right!

M: Golf? Yeah it's expensive.

S: My husband says golfing is not exercise.

M: But if you walk 18 holes, it can be () and if you're carrying your clubs. Right.

S: I think any movement is considered activity.

End 07/08 8m 8s

Start 08/08 23m 19s

L: Yeah I could see that being an issue with Cannon ((child with DS)), you know? Like later on.

S: Right and it you're not purposeful. We could all slow down.

L: Right, like I don't worry about it as much with Kelsey and Ethan. But yeah, I could see that. I mean he's (.) he's just, he's a solid kid. Luckily right now he's good physique (.2) but there is that .hhh sweet tooth! ()

PI: Right, and thinking back to the survey. Which, thank you all for completing it I know it was just horribly long.

L: No, it wasn't too bad.

PI: Great, well I think we might have one more question if you don't mind. Do you feel your family faces any barriers related to being physically active or eating healthy? Let's discuss. I know we've already talked about some barriers.

S: Physical abilities.

PI: Physical abilities.

S: Yes, that's definitely a barrier. Time (.2). I think we all said is definitely a barrier. Ah, ya know for us sometimes heat. In Texas it's a barrier.

L: Peer pressure. We talked about peer pressure being a barrier to healthy eating.

S: Oh right, I was just thinking of exercise.

PI: Peer pressure of (.), what do you mean? Encouraging negative habits?

L: Right. And then I would say a barrier would be like what you said, I can't control things while he's a school. You don't know what choices he's really making.

S: Which that means you just have to be even more vigilant at home.=

L: =Right.

S: Because you know that's going to happen.

PI: And so kind of there's a um (.2) you're aware of things that you're teaching him at home, because they're going to go off.

L: I think time's a big one for both physical activity and eating because if you think about it, if you don't have time you're not going to take the time to make a healthy dinner you know? But you're also not going to have time to get out and (.1) bike ride or take a walk or anything like that. Time is a huge one.

S: Yeah, because really going out to a sit down restaurant takes more time! [But then that leaves fast food[Which is very bad, so.

L: [Right

[Right, convenient food or fast food.

PI: Which can be much easier right?

L,M: Right.

L: That's when you're just like we'll make some mac n cheese and that's not healthy but just sometimes that's what you have to do.=

PI: It's quick.

L: Sometimes you just have to do that. It's quick and it gets the job done.

S: Yeah. Jack loves pasta so we keep pasta and red jar sauce on hand, and throw a little parmesan on top.

L: Do you use like whole wheat, would he notice the difference?

S: Nooo, my husband is the one who doesn't like the whole wheat!

PI, L: Oh, really?

S: Yeah, and he's Mr. Healthy! Mr. Healthy, fit fit fit. He's more old school when it comes to the Italian food. One time I made the whole wheat pasta and the kids loved it.

PI: Yeah I can't tell the difference.

S: It's a little chewyer. Yeah, but it fills you up and sticks with you longer. So, yeah I got to get some more of my stash! ((laughs))

PI: So having that staple available helps?

S: Yeah, I think it's ridiculous our pantry. It is. You walk in there and you go, there's just too much food! Costco you know? You just get like a (.2) food pantry! And then we really try, so again with time you just have to go to the store like every other day or so, if you want fresh lettuce and fresh and fresh fruit and so, Central Market has been great because it's right in the middle of town and we're, we're goin by it. So we have to make it more of a habit to stop in and grab something.

L: That's very true. But, that takes time. (.4) And the people who are working full, and I'm lucky not to work full time. But that (.1) I don't know how they, I mean I have 2 sisters who have kids and they are just running like chicken's with their heads cut off. And they don't always have time to do that=

S: =Nooo, right.

(.5)

S: And the reason we have time partly cause I'm home and because my husband works from home so (.1) he's on conference calls and he's cooking. Literally [He'll need to get out, and I'm like get out of the house. He needs to get out so he will go to the store,

or he will go to lunch er and grab some (.1) meat er fish and he can get something started around 3 o'clock if he needs to. It's not ideal, but sometimes he does. It's the schedules=

L: [wow.

L:=as a society.

PI: The busy American life.

L: Yes, definitely. Busyness is a (.1) factor.

PI: Okay, and just one more ladies. Is being physically active and eating healthy a priority within your family, if yes or no let's discuss. And how do you feel the actions of your family relate to that role?

S: Yes, definitely for us. Like we have to keep balance. And say, are we doin too much or do we have time for that. But definitely both are a priority for us and again it's because of what I think I shared before in the other question about our family history and because we want to do certain things we have to be in shape to do those things¹⁸ (). I'm not sure I follow the last part.

PI: So if you make it a priority and you think it's not a priority.

S: Oh, so how does it play out in our lives?

PI: Absolutely. What do your actions look like related to (.1) how you feel about it?

S: I think, I think we do! We stay busy with it so.

L:I think it's, it's definitely interesting because in my family we have always been physically active and I always make time to exercise and stuff, it's a priority for me. If I don't get out and run or exercise or workout or something I'm stressing. My husband (.2) does, not work out. I mean at all. Like his, so he likes doing the geocaching and stuff but honestly during the week, he doesn't do anything. He has no interest in lifting weights or anything like that. .hh So I'm kind of curious to see how that plays out in and we have always kind of had an issue about the sports thing. Because his thing is, I don't want sports to take over our life. And I totally agree with that; however, hhh I do want you to participate in 1 thing. And sometimes that is a lot with 3 kids. You know? But he was never really into the whole sports thing. Like I grew up playing soccer and doing other things and I do the running now and he doesn't always get why it's important to me because it's not something that has been (.1) important to him. And it's hard for him to understand that because he kind of lives in his little focused world. ((laughs)) But yeah, it's important to me and it is important for him but he just has a different perspective on it. [(.2) And the eating (.1) like I said before we definitely have some room for opportunity there you know to eat healthy and to incorporate vegetables, and more fresh foods and such versus convenience and you know unhealthy snacking habits and such but we're working on it and we're aware.] You know we try not to keep too much junk in the house. My husband usually does the grocery shopping and that's kind of changed a little bit recently but we try (.1) not to buy junk. Like if we don't have it in the house it's

not gonna get eaten, but if it is in the house, then it will unfortunately get eaten so. So that's our plan of action is to just try and keep it out of the house! I don't know if that answers the question=

PI: [yeah

[absolutely.

=perfect!

S: Ours has definitely gotten better as ours kids got older=

L: =really? Yeah!

S: Just the intensity of the care for your kids is so consuming when they're really little and the timing and just everything[I mean I think we've always worked on that and it has gotten better.

L: [right

L: And sometimes you just need something like this ((referring to being interviewed)) I know it sounds crazy but something like this discussion [to kind of bring you back to okay we need to focus on that. Because you kind of (.1) lose focus easily=

S: [oh yeah =and well especially with the holidays.

L: Exactly. (.2) But yeah I think the physically part if definitely a priority (.1) for me.

PI: I know we mentioned kind of looking at eating and activity as 2 different things and if you did have to make a change, which one is easier? And we spoke about both, do you all feel that one may be easier? I think you all said you may have an element of control more with food versus activity, do you think that is the consensus? That may be easier if to be encouraged for your kids to be healthy, eating habits versus physical activity levels.

S: Just kind of overall general, blanket impression I think food would be easier to control for your family.

L: Yeah, because my kids don't go with me to the grocery store!

S: yeah! And sometimes it just feels so overwhelming to try and get all that activity in.=

L: =Right.

PI: And you can control what you feed them?

S: right, you can pack lunches.

L: Especially at the younger age, like Cannon's age. He doesn't come up and say hey mom I don't want that in my lunch today. You know he's not quite at that age developmental level.

S: yeah, well even at 13 Anna was complaining about her lunches and so I said you have to make them every day. But that didn't work very well so, I'm making it now and she's grateful. So it's back to the control I guess.

L: But even when my kids are packing their own lunch I tell them, 1 main thing that's healthy, a vegetable or a fruit, you know which is usually an apple sauce. Because they are not big vegetable eaters. You know then you might have a little snack and then something to drink and maybe a piece of cheese or something like that. So you know I try

to explain the balance to them, although if it was my daughter's choice she would pack a bag of chips and a lunchable! Yeah, and I'm like how does that work

S: Don't read that label!

L: Oh I know, I know

Group: laughs

L: Luckily they don't like packing their lunch so they'll usually take school a lunch. And schools have gotten better. I mean they'll make you force you to pick, like you can't pick oh what is it you can't pick (.1) 3 bags of chips or whatever the chips cost anyway. They usually make you pick 2 sides, you know? And usually it's good stuff usually So, I don't know.[Right. You can get this OR that.

PI: [they have the OR option

S: Right, and you have to take a milk. You have to take a milk. Even if you throw it away and they do have a donation program which is good =

PI:=oh good.

L:I think they are moving in the right direction at school.

S: Right they are, but when my kids started school one of the main things my kids had every week was nachos with plastic cheese all on top we call it. And we talk a lot about protein and=

L: Yeah and I don't think they have that every day now because I worked at my kids lunch room last year not making the food but like as a monitor and so I got to see (.2) an that was eye opening. It was an eye opener for use so I'm like (.1) Well most of the time my kids didn't even eat what was on their tray. I'm like seriously?=
PI: =Really?

PI: =Really?

L: And I saw a lot of kids that would get the ice cream like every single day and I'm like are you kidding me?

S: They can only get it once a week at our school.

L: Oh really? That's good, that's what I tell my kids if you don't get your folder signed all week you can have an ice cream on Friday. So, but I caught my daughter a few times (.1) hello why do you have chips and an ice cream on your tray? Aaah, did you not know I would be walking by your table=

S: No I did not know that! ((laughs))

L: Uh, I'm here every day!

S: I think one thing that has really helped us is that we talk about protein [a lot. I mean if you have that chip there's not, I'll tell Jack it's not going to make you strong er whatever because I don't want my teenage daughter obsessed with fat grams[Or sometimes we just talk about trying to eat healthy and then I feel like I sound like a broken record but then we start looking at the grams of protein in that, grams of protein in whatever you're eating. ((the chips)) It's just not gonna fill you up, or satisfy you or make you stronger. Or build muscle, we talk about building muscle.

L:

[oh that's good.
[right!

PI: Yeah, that's great.=

L: = You know what, do you notice the schools talk about that stuff to a little bit more that they used to? [yeah I notice my kids will come home and say there's like an initiative there.

S: [they do!

S: Anna, they weigh the girls and boys in 7th grade in PE.=

L: =I didn't know that. Well actually I think in Elementary they do. Right?

PI: Yes, the standardized fitness testing. The Fitnessgram, height and weight are a component. They do this in 2nd through 12th grade=

S: =Yeah, 2nd grade. And she did the fitness thing and they count how many chin ups you can do. So that's kind of good. But with having girls we are careful about that, but we can't be too controlling with food either. Because you know that can cause eating disorders and stuff so we talk about healthy <eating> and gaining muscle and getting a lot of exercise. (.2) We joke about her rocks (.2) her calves. You know it's just like (pure) muscle

L: Yeah you want it to be positive.

PI: You want to encourage that?

S: Yeah, we don't want her to be obsessed with fat, because when I grew up it was all about being skinny, being fat or not fat. You didn't hear, it wasn't about building muscle or being fit really. [It was just about (not being fat) so hhh

PI, L: [Yeah, right.

L: well, I need to go home and start some meal planning. No! I really do want to do that.

S: Yeah, we try but we're not really great at it.

PI: Like you said it's not something that has to be done every day.

S: Well ideally I would love, my Type A is like like on Sunday I would love to have the whole week planned.

L: yeah, I would like to just have 1 meal a week planned like with like 1 kid. Like Kelsey you're going to plan this meal we'll do it together like we talked about that but we just have never followed through. You've got to have goals, you've got to have goals.

S: We have done that a few times and the kids really love that, to plan out the menu. But we haven't done that in a long time.

L (to PI): Did you get what you need? ((laughs))

PI: Of course, of course. And that is the wonderful thing about this design is that there is an agenda but it's so open that any is good. And it was good, that has been really rich discussion. Do you guys have any kind of, obviously you know the general topic I mean do you think there is anything that you wanted to communicate or wanted to elaborate on that maybe you weren't given the change to?

S: you know one thing we mentioned a bit earlier was food textures and it is a bit of an issue for my son.

PI: Just for Jack?

S: Little bit yeah for Jack. Not so much for Anna, well she doesn't like slimy things. You know how kids are, but we've had and it was only once but we have had a choking incident with Jack.

PI: And you think it was specially related to texture.

S: yeah, well he used to always take his hamburger apart and I didn't like that because he's picking at his food and we're trying to you know we don't want him to eat like that. So I'm like nope ((makes motion to combine hamburger)) and I feel terrible now so he choked on that hamburger that I made him eat with the bun and the hamburger and everything and it was just. I mean he was 9 years old and he had never had a choking incident so I didn't think anything of it and we were at 5 guys his favorite burger place and he had a joking incident and I don't know where that plays in but it's definitely an issue and it is an issue for kids with Down syndrome because of tone.[and swallowing [

PI:

[Absolutely

L: [and finding more space in their throat=

L: = and Cannon's had his tonsils and adenoids out I don't know if that will be an issue.

S: yeah, and low tone is huge

L: I think they say their tonsils are the normal size yet but their lower tone and the throat and the ability just may not be there. Yeah I agree=

S: =it's kind of scary.

L: Yeah I still like I don't know if I would have cut Ethan and Kelsey's food when they were his age but I still cut up Cannon's food fairly small.

S: yes, especially the steak and the chicken we have to cut it.

L: And he's not the best at chewing.

S: No because it takes them, I forget what the statistic is but it's a lot we might chew something anything we chew 20 times they chew 5 times.

L: Wow, I hadn't heard that.

S: Yeah and it's a estimate but it's those kind of numbers.

L: Yeah it's kind of like gum. I mean he ((Cannon)) can't chew gum because he swallows it.

S: We work on that in speech now but then I don't make anything. Anything that's kind of grainy he doesn't like to eat like, I mean there are things he likes bread and toast. But not mashed potatoes because (.2)[Well I think the swallowing is hard and it's kind of sticky and grainy and there's maybe 1 or 2 other things that he won't eat.

PI: [the consistency?

PI: That's interesting because I've heard other parents say that soft things like that are a lot easier to chew.

S: Well HE does not like mashed potatoes, no matter how salty or buttery they are. And he doesn't really like cooked potatoes either. He doesn't like baked potatoes or cut up

roasted potatoes. I guess I assumed it was a throat a swallowing issue, but it may be preference.¹⁹

PI: And what about did you all notice a difference in transition from soft food to hard food compared to your other children?

S: gosh, it's been a while.

L: hhm I mean it was definitely a slower progression to solid foods and I was more aware and I was just more aware of the gagging choking thing and he's always been a really good eater and I know a lot of others have had more severe issues with that so.

S: Yes, there is a huge gamut that way. There is, we were never. We could always eat by mouth. But we had to use different spoon techniques, we had to have an OT [yes! You have to teach them how to not thrust and lose half their food.

L: [because of the tongue thrust too

L: I definitely think it was a slower progression and a more cautious approach versus my typically developing 8 years olds.

PI: And do you think the other siblings were aware of differences at food time or how more focus was put on, I mean obviously you mentioned there is already somewhat of a divergence between the siblings because there is a hyper focus on the boys.

S: When she was little and feeding no, she was like 3 and 4, I mean they are pretty close in age just 2 years apart. Now, yes and no. So meal times can be a little bit stressful because we're a little bit messier you know? [Yeah

L: [there you go. Messy is a big deal, my kids don't like the messy

L: =Yeah, my kids are that way.

S: And I mean we'll try, like with the hamburger you try politely you know and I don't want him eating like this because he is 10.

L: Does he want to tend to use his fingers instead of a fork?

S: Sometimes but not always, but yeah if it's easier. And I've just always been a stickler for that.

L: I think with Cannon if he can get away with using his fingers. He'll do it.

S: Yeah, especially at that age. And you'll just have to keep working on it.

L: But he's definitely a messy eater.

S: And you're like it'll get better but it may always be a bit messier.

End 08/08 23m 19s

Annotations

¹ Task: This mother mentions that her child with DS is not as active as the other children because he cannot simply go outside and play alone like the others. Because he needs supervision that is a barrier.

² M states that he can't last as long "I hope" then there is a mention somewhere else in the transcript about his ability related to the fact that he has DS. She's not sure about why he is not as active, his age? Or his DS?

³ Her parenting practices could be perceived as preventive in that she is always aware of her familial history of obesity, but no mention of the prevalence of obesity for children with DS. Familial history seems to have impacted her practices more

⁴ Although not explicitly stated in this sentence, this mother alludes to the fact that she sees differences in not just the level but the physical abilities of her children, with the lowest ability among her son with Down syndrome

⁵ This mother shows some apprehension to bring up this comment about tendency toward weight gain. It seems as though she was about to say you have to set and I infer that she was going to start talking about setting food rules, but then she pauses and brings up (what seems to me based on the reaction of the group) the comment about well everyone knows our kids have a tendency toward...

⁶ This mother seems to feel that her child with DS really cannot recognize satiation because he is inconsistent with her other children. This could be a reason for a difference in level of restriction or monitoring between the other siblings, as she may have a higher confidence in the ability of her other children (without DS) to recognize satiation

⁷ Similarly this mother feels that her child with DS may not be able to recognize feelings of satiation but different from M, S's son will always say 'yes' to eating. S's son with DS is older than M's son with DS

⁸ S states here that because she is aware that her daughter has a sweet tooth, although currently there is not a weight issue, she does try to keep her active and wants to pass along healthy eating habits. Thus it seems that her parenting practices are a reaction to her daughters' affinity for sweets. Reciprocal Determinism

⁹ Concern for obesity is simply implied in this statement rather than explicitly mentioned. Was this intentional or considered a sensitive subject? As the other mothers were not aware of the weight of the other participants' children

¹⁰ Concern for obesity is discussed here as "struggle a little bit with (pause) the weight.

¹¹ Infers that all children, with and without Down syndrome, nowadays have a preference of sedentary activities over active ones

¹² The comparison here is made the barrier or preventer of physical activity is the slowness to transition. The comparison is made between 2 mothers' childrens' physical activity levels, a son with Down syndrome and a daughter without Down syndrome

13 The implication is made that the father in this family has recently started to workout at the gym, a behavior that has not been typical in the past. He is 'trying to be a good example and get healthy' but initially the kids don't understand what he is doing. Why is he working out again and being away from us? Inferring that the change for the children is hard because it is new and not something they have simply grown up with.

14 Such a simple concept, but such great awareness. My job as a parent is to teach my child about good food, provide it, and MODEL it.

15 The connection between family time spent during physical activity is greater than time spent being sedentary, better quality.

16 Second mention of how other American families spend a majority of time in sedentary activity. This provides more support for the uniqueness of this population compared to other families, in that they recognize that they are not the highest level of 'healthy' but compared to most American families they are higher.

17 When asked about overall health of the family this mom uses level of physical activity and types of foods and the definition of health, whereas other moms mentioned the absence of excess weight when asked about an evaluation of their family's/children's health.

18 Very purposeful in that they want to do future physically active tasks or take active vacations so she recognizes that they have to physically active on a regular basis for those future goals/trips

19 This comment is interesting. Her son with DS does not like a food that the rest of her family does and instead of considered it to be a simple food preference she (until this discussion) assumed that it was something DS related.

Transcript, Focus Group B

Folder B 01/06 0m 0s of 19m 16s

V, S, K,

Disclaimers

Principal Investigator (PI): Before we officially begin the questions, I would love for each of you (um) ladies to introduce yourself, tell where each of you are, I think we all know where everyone is by now. Tell your children's ages, their genders, and maybe something interesting you would like each of us to know (.1) so...why don't we start with S? S?

S: Okay (.2) um I am up in New York state where the cows are, not in New York City. Uh, my husband and I have 7 children, (.2) we have 5 boys ((phone rings in the background)) and (.1) 2 girls and um let's see they range in age from 29 to (uh) 11 and our youngest, Benjamin, is 11 (and he is the child with Down syndrome). And I have 2 married daughters.

PI: Wonderful, alright K why don't you go next.

K: Okay I am K (.1) I'm from Maryland and I, my husband and I have 3 children. Logan is 12, Carson is 8, and Aidan who is my child with Down syndrome is 10. And uh, what was the other thing you wanted to know?

PI: Just uh, something interesting, or if there is anything you would like us to know. I know it's a broad question ((laughter)).

K: Well, I was I was originally. Originally I did not want children and I did not want children because I did not want a child with special needs. I didn't want to risk it. And I realized that when I was probably about 14, 15 years old. And um (.1) when my husband and I were dating we discussed it and he was fine with it and then after we got married um (.2) we talked about it and discussed it he was fine with it and then about 5 years into the marriage he decided he wanted kids. So he had kind of changed his mind. And so I was still ah very against it, because again I didn't want to risk it or have a child with special needs. And I knew that I wanted more than 1 child so I would have to um (.2) ya know dodge the bullet twice. So when I was pregnant with the first, I mean physically I was absolute wreck, just because I was so nervous. So my blood pressure was off (.1) everything was just off. And um, and then Logan was born and he was typical and then every said to me it'll be so much easier now because it is your second. No, I was just as psycho [and then um I ended up going we were in Maryland at the time like I said we were transferred when I was pregnant. And we were in Maryland and one of my

favorite relatives passed away and we went home to Philadelphia for the funeral I was about 3 weeks out from my delivery date and I ended up going into labor, at the funeral! And so I go to the hospital, I did not know the doctor and I ended up delivering Aidan natural because the doctor said I wasn't in labor I was just having Braxton Hicks, he said that and then about a half hour later delivered Aidan! And then found out the next day that they suspected that he had Down syndrome. So um (.2) =

P: [(laughs)) okay

PI: Do you have a family history, may I ask, where was the concern=

K: No (.1) I just um (.2) a little on the psycho side I just had this feeling (.1) from literally I can remember exactly the conversation, I was 15 and I uh just was never comfortable around children with special needs, adults with special needs, and I just didn't want to a risk it and then here we are uh ya know 10 years later and I have Aidan, very ironic. (.2)

PI: Okay, Mrs. V, would you like to go next?

V: Yes, um. I don't have quite the elaborate story but um (.1) Lily is my oldest and she's almost 7 and she's ah my one with Down syndrome. And then I have Olivia who is 4, Sebastian is 3 and then we have number 4 due in April. =

PI: =Wonderful!=

V: Something interesting (.2) without telling my life story it won't be too interesting. I'm going to school right now to be a physical therapist, I want to specialize in peds I want to work in the school district inspired by Lily ((child with DS)) of course. (.2) Guess that's it.

PI: Okay great! And S would you mind repeating, the connection was lost for a bit and I would love to know the names and ages of all your children.

S: Okay, my oldest is Peter, he's 29, and I have a daughter named Kera she is 26, a daughter named Anna she's 24, son named Mark who's 21, and then I have a son named Joel and he's 19, and a son named John and he's almost 16. He's counting the days til he can get his learners permit, and then Benjamin is 11.

PI: And Benjamin, has Down syndrome?

S: Yes.

PI: Alrighty, great. That way we can speak personally about the kids and we don't say oh wait that one and we're not calling them all by their age and I just wanted to make sure I had that written down. ((Names will of course be changed to pseudonyms for the purpose of publishing)). Thank you all for sharing, you know, a little piece of your family personally, other than the other content which we will now get to. I don't know if you all can hear, but I have roofers at my house right now and they have music playing loudly I don't know if that is distracting at all?

S,K,V: Can't hear it, can't hear a thing.

PI: Great, I shouldn't have said a thing! ((laughter)) Okay so I will now read aloud the questions, I'll read them one by one, there are 10 and you know I'll give ample time in

between each question for you all to discuss and um (.1) you know we can kind of talk until no one has anything else to add about that question and then we'll move on to the next one. So, is there, are there any questions before we start?

S: I do have one question.

PI: yes ma'am?

S: I wondered how you got interested in the Down syndrome population.

PI: Well I um (.2) well that's a long story! ((laughter)) I'm just kidding, I uh, for the past I guess about 6 years I have taught adapted PE. So my focus has always been physical activity, physical fitness, you know just for all populations, all children with special needs. So I've work with kids of all abilities, and (.1) um recently in my doctoral program of study my focus has really just been healthy lifestyle living and obesity prevention within the whole family. And um (.1) I'm sure we will get to it today, but you know children with Down syndrome have a tendency toward obesity. You know of course not all of them and there just really isn't a lot of research that is out there that (.2) states oh is it because of Down syndrome or because of the family, and no one has really looked at kind of the family component. So that's what I wanted to do. Just talk to parents and just look at the impact of the family. Everybody just kind of points the finger at Down syndrome and there are a lot of physiological tendencies which I'm sure you know you all know well more than I do but yeah (.1) so I love children of all abilities and I think that's how I gravitated towards this topic. And with a dissertation it has to be very specified and I can't look at parents who have children with Down syndrome and Autism it has to be as focal, as focused as can be. So that is how I gravitated to looking at differences between siblings.

S: Okay great.

Folder B 01/08 – 10m18s/19m46s

PI: I will begin with question 1, and I do have a tendency to ah (.2) to speak quickly so if at any time I am saying something too fast just let me know and I will repeat it or slow it down okay?

K, V, S: Okay, great.

PI: So number 1 (.2) do you feel the physical activity habits of your children, with and without Down syndrome are similar or different? And how? (.2) And let's talk about what impacts those behaviors. (.2)

V: Um, I can start. All my kids are very close in age so you would think they would have similar (.1) um activity levels, but they don't. My daughter with Down syndrome definitely isn't as active as the other two [you know. The other 2 are definitely like outside exploring more and doing that kind of stuff and I think it's just more her personality ((child with DS)) versus necessarily having Down syndrome. ¹

PI: [okay

K: I'll go next, whoops I'm sorry V were you done?

V: Yup that's okay.

K: Um, it's K and uh I have 3 boys also very close in age and ah Aidan ((child with Down syndrome)) is just as active the 3 of them as the other 2. Um physically active so (.1). They all get outside and they play football, they play baseball, they play soccer, uh my only (.2) so they're both, all 3 of them are very very physically active. Now, the only drawback with Aidan ((child with Down syndrome)) that I would say is related to related to him having Down syndrome is that Aidan has (.1) like we have had him on teams (.1) but of course Logan and Carson, my oldest and youngest play on organized sports and we have had Aidan on team sports but he gets very um (.1) distracted. You know? He'll, he'll wanta play for like 5 minutes and then he'll just like sit down or it's (.2) just very hard for him to play (.1) organized sports.=

V: Yeah, and I can add to that too because you know Lily ((child with Down syndrome)) has been in and out of () classes as well and she does get tired quicker than the other kids. And I don't think it's that she's not interested in what's going on but she will sit down you know instead of stand up and wait in line with the other kids. She'll sit down and wait in line.

K: Yeah, and for Aidan ((child with DS)), I don't think he's tired I just think he's distracted or you know during the backyard play it their playing with friends he knows everyone, everyone kind of knows him and I think there's just a higher comfort level there. And when he's playing organized sports he doesn't know the other team and he doesn't, he just gets, he loses interest very quickly. =

PI:=okay.

(.3)

S: Okay this is S, and I would say Ben ((child with DS)) loves sports, he loves physical activity, he loves anything having to do with a ball. He has 4 older brothers and an athletic sister he has opportunities to be active; however, (.1) because he doesn't have um (.1) a network of friends outside the family like my other children do he probably is not as physically active so if he doesn't have someone to do something with he'll watch a movie or play a video game or do something more sedate. Uh he is in the adapted PE program once a week (.1) at the local college, he absolutely loves that. We tried him on a basketball team but well it was just drills, and he loved it the evening he went but he didn't want to go back because it made him too tired!

PI: ((laughs)) Okay.

S: So um (.1) But when we hike or do things like that he ((Ben)) loves to go with us so.

K: Yeah, Aidan he does gymnastics once a week and he has a one on one. So (.1) it is it is an organized program .hh but it's just him. It's the coach (.1) and him and he adores him. He adores it. Now eventually I'll move him into like a smaller class, just kids and then I'll move him into like a bigger class. But we'll see how that goes, but for now he's been doing that for about 6 to 8 months and just loves it. So.

PI: Okay, and so just looking at differences between your other children, you know it sounds like a lot of motivation and really interest level is kind of the primary difference or the primary motivator.

V: Yeah and sometimes () anything that Lily is doing she sometimes needs a purpose (.1) and if they're just doing things like drills (.1) um we were in a track and field class summer and she, she loves to run, so I thought she would love it but she didn't and it was too drill oriented and it just didn't have a purpose for her and I think she lost interest for that reason.

S: I think for Ben it's more social and if there are people doing it ah (.3) that he knows or that he's related to, or he's not interested.

K: Oh yeah, that's Aidan too. He's very, it is a social aspect and the comfort level so. When he is playing and he knows every, all the players (.1) he's good. But the organized sports just really doesn't seem to work for him.

(.2)

PI: Okay well great. And then anything else uh (.2) would you all like to share about any other differences as far as age of your children's interest or have you noticed maybe when your other children were the same age as um, obviously Lily is the oldest but you know Ben and Aidan ((children with Down syndrome)) are the youngest and in the middle have you noticed kind of a difference you know maybe in that their siblings were more active or less active at that age?

(.3)

K: Um, I would say that Aidan ((child with Down syndrome)) is comparable. Of course he walked later then um the other children so I think that his development absolutely affected his, the age of his development um affected his ability to participate but you know (.1) now that he is 10 he's just as active (.2) um as the other 2. I mean I would say just as active and um probably just as coordinated and talented as um as a typical child his age I mean he can (.2) you know he can catch the ball and he can, he bats and he plays football he scores on soccer I mean he definitely um is physically coordinated. And he gets that from his father not his mother because I am definitely not coordinated.

PI: Okay.

S: Well I would say that Ben is less active than his siblings when they were 11. Because they would hop on a bike or go run or walk over to a neighbor's house, house in the other neighborhood and um Ben doesn't have that. And they might walk down to the store to get something to eat and you know Ben will do that if one of his older siblings is doing that but because of a lack of a peer group in the area (.2) he's probably less active.

PI: Okay.

K: And I would say for Aidan, he's, he does do the things that his brothers do because they are so close in age. So, like Aidan, Logan's friends' consider Aidan one of their friends. Aidan considers himself a part of Logan's group and Carson's group and Carson considers (.1) you know Aidan doesn't have a (.1) a group of friends. But what he does, he's friendly with his brothers' friends and I think the fact that they are so close in age, that's what give him a quote, peer group. So he'll, he will go outside and play. Because 9 times out of 10 Logan's goin outside to play or Carson's going outside to play and they always go together=

PI:=Right. And V and S, you all have a little bit more of an age difference between your children.

S: Yeah, uh the next oldest child is almost 5 years older so when he was younger he would include Ben more when he was out playing in the yard. But now that the older kids are now in their teens and 20's, Ben's kind of left behind more.

PI: Right.

V: And mine are still really close, I kind of joke that I have triplets now because they are all at that 3 to 4 year old development level so they do play together a lot. But their too young necessarily to have peer groups or a group of friends and stuff.

PI: And they're at that age where you get to decide their peer group, right?

V: Right.

PI: well unless you all have something to share more about this and obviously if you think of something later when we're discussing other questions feel free to jump in. (.2) Otherwise we'll move on.

01/06 19m46s End.

02/06 0m of 11m 02s Start

PI: Alright we can (.1) move to the next question, which is very similar to the last question uh ((dog barking)) do you feel the eating habits of your children, with and without Down syndrome are similar or different and how? And what impacts those behaviors, so again when we talk about eating habits and feeding patterns kind of um you know the amount that they eat, how often they eat (.1), you know is it snacking is it meal times? Things of that things of that nature.

(.3)

V: Um, I can start again[all of my kids are very different in their eating habits, I have the spectrum um. My youngest, my 3 year old my boy, he's um (.1) he's a meal time, snack time, like on time, you know clears his plate (.1) kind of kid. I don't know if that's cause he's a boy ((laughs)), boys tend to eat better than the girls do (.1) um my middle child, Olivia, my girl, she is a snacker, she just wants to eat little bits all day long and is horrible at meal time, she just wants to take 3 bites and go (.2). And Lily ((child with DS)) is um (.2) is hard to necessarily put in a category or describe. She's had um (.1)

feeding issues, which I'm sure you have similar stories but when she was a baby she would gag a lot and uh and it always turned out to be medical so at that point, we had her tonsils out he adenoids out and the gagging stopped. And it was time to move on to more solid food and it turned out she had a blockage in her intestine (.1), and that was at (.1) she was right at 2 years old that she had surgery and we got that fixed, but it took her up to a year to trust food again because it made her feel so yucky. Um so a whole year then of not really having an eating habit other than wanting to eat yogurt. So (.2) at this point she's gone through a lot, she actually just had another surgery a year ago on her intestine. (.2) They had to go back in and fix it again so (.2) she never developed that mistrust of food again but its only been like I said a year (.1) since her intestines have been fixed so (.1) and being at school also I think she's definitely (.1) on a meal-snack (.1) routine? [PI: [okay hm, hm with their schedule?]

V((continues)): Right, and she is fairly good at (.1) she's good at, I mean all my kids are good at stopping when they are full and um maybe not necessarily eating as much as they should at each meal or snack but (.1) I think it's more important that they stop when they're full, especially Lily ((child with DS)) so hh. with the whole obesity issues.²

PI: Right and you said stopping when their full, is that something that you all discuss or do you think that's just something they've naturally learned?

V: You know (.1) I think it's both. Especially, they're all kind of in this phase where they're like, what's healthy? What's not healthy? Like they keep asking, every food that's in front of them. Is this healthy or is this not healthy? Uh, my little guy, he's little and petite and he's got a small man complex ((laughs)) so he needs to eat more and um if I think he needs to eat more and he's not if he's too distracted I'll say you know you're going to get big and strong if you eat this so um he feels (.1) we did it enough that now he's started to feel that he had to clear his plate so he could get big and strong. So now we've recently started talking about stopping when you're full because I don't want him to get into bad habits.

PI: Okay (.2)

V: yeah, that's really it. Alright, K or S?

S: Um, okay well (.1) Ben ((child with DS)) had (.1) a blockage in the small intestine at birth and had surgery when he was 7 days old. Uh I then when he started to be a little older and was interested in food, I started to try to give him these vitamins that were supposed to be specifically for children with Down syndrome and they were supposed to oh I don't know help them with all kinds of things. All kinds of promises that I'm now skeptical of any way ((laughs)) I would crush them up and put them in food. And then it became, it started this battle over food and um[it didn't really last very long (.1) but he would fight me tooth and nail and I would ya know, who says that kids with Down syndrome have low muscle tone=this kids really strong! ((laughs))

PI:

[okay

PI: And what were the fights about, him just not eating them? ((Vitamins))

S: I would try to crush it and put it in foods and he, he would not want anything to do with it=

PI: =oh okay=

S: Which I was trying to force it into him, which now I regret but it's anyway (.1) I don't know if that really started our battle of the wills over food but um (.2) He now, well now we're long down the road but (.1) he's always had a aversion to certain textures of food. So um (.1) I know you don't want to know a lot about fruits and veggies but he doesn't touch them. And um so I try to, when we all have dinner you know we try to all sit down together, except during baseball season! =

Group: =(laughs)=³

S: =But I try to always have something on the table that he'll eat (.1) even if it's just bread and butter. And I do not make him eat everything on his plate because I just think it would be futile. But anyway so=

V: Pick your battles right?

S: Yeah! You have to pick your battles. So you know I've tried to sneak foods into smoothies which will give him more of a healthful diet. So, I don't know if I'm answering your question?

PI: No, that's perfect and again that's the great thing about this forum is that there are no right or wrong answers, you know you all have the stories that people need to hear and learn from. That's kind of why I chose focus groups because it is so open and um you don't always know what you're looking for and so sometimes things just come about so (.2) you guys are doing great so. K do you have something you would like to share?

K: Um well Aidan ((child with DS)) is uh the opposite=

PI: =opposite of your other kids?

K: Yes, we actually call him the Viking, because the boy is (.1) he's very, very good eater. Of my 3 children he probably eats the most. He does not have aversion to pretty much anything, he loves fruits, he loves vegetables um ((tape cut out)) he's always asking for seconds. We um don't know, he's 10 years old and he wears a size (.1) 8 (.1) slim. So he uh, he my husband is very lean as are my other 2 children so clearly they have a good metabolism.⁴ But ya know Aidan's always been he's never had any type of feeding issue (.2) He was ya know constipated when he was younger and we had to do miralax in his baby cereal and what not but he has never and he doesn't like now you know it's very interesting he does not like candy and he is not a big fan of chocolate or um (.1) or you know cakes or (.1) anything like that=

V: =Lily's ((child with DS)) the same way, I call her my health food junkie=

PI: =(laughs)=

K:=Yeah he's ((child with DS)) very healthy I mean his only vice is (.1) ah soda.

PI: Now is that similar or different from your other children?

K: No my other kids, we don't really have soda in the house and um (.1) but he just (.1) uh you know from as long as I can remember that has just been you know his (.2) like to potty train him (.1) we used (.1) soda. And for good behavior, it's soda. He just loves soda.

PI: Okay.

K: But for the most part he drinks um .hh you know that's only for a special treat so for the most part he drinks uh Sunny D or (.1) water (.1) or milk of ice tea um (.1) and soda is really the um special treat. But again, he's a really, a really good eater and I remember being ya know at some point I did have some concerns because you do um (.1) see like older kids with Down syndrome that tend to be heavier But for Aidan he's just so active. And um, I think his body just needs that .hh a fuel. And the more active he is, the more he'll eat. Like you know we went to Disneyworld and we were just going from dawn to dusk and um he was eating (.1) you know 4 and 5 meals a day. Basically, to maintain the energy level.

PI: [right.

PI: And so it sounds like that's typical of your whole family?

K: Yeah, no my oldest is very picky (.1) he also burns a lot of energy but he's very picky you know he has a lot of small portions, we're not a clean the plate type of people um (.1) we'll just say eat til you're full. And he's ((child without DS)) always, I am full I am full. Or he'll just like take 2 bites, take 2 bites. Um, so he's a little on the pickier side and then the youngest is (.2) he'll try anything.

(.2)

PI: Okay, great. And V did you have something you wanted to jump in with?

V: No I was just agreeing Lily's ((child with DS)) the same way I call her my health food junkie. She would rather have an apple than a cookie.

PI: Well, that's wonderful.

V: (Yeah it's a good problem) Yeah, my middle child is my junk food junkie. She could live off candy and potato chips for sure.

(.2)

K: You know Aidan ((child with DS)) does like something salty, yeah like chips and pretzels (.1) and soda are basically his junk food=

PI:=vices?=
K:=Yeah, his vices. But that's really it, like he loves broccoli I mean he loves fruit he (.1) he does really good eating.

PI: Okay.

PI: Okay.

02/ 06 End – 11m2s

03/06 Start 0 of 19m19s

PI: Alright, going back to physical activity habits .hh how do you feel your personal physical activity habits impact your children and your family?

(.5)

K: I'll go.

PI: Okay.

K: I think I um, it's not my influence at all because I am I do go to the gym I do workout but I am more a I love to read so I think my however I think though the primary influence on my children's physical activity is their father. And then specifically on Aidan ((child with DS)) is his brothers so (.1) um I think I am physically active because I will get out there and play football with the kids or I'll jump on the trampoline so I think I am, but I think predominantly it would be my husband's influence and not necessarily mine.

PI: And do you think that's because of a similar gender? Or just you know personalities?

K: I think it's similar gender and personalities my husband was very active growing up and uh my oldest is very athletic, Logan's above average athletic too so (.1) like he was um an all-star on baseball and he's 12 but he plays on a youth 14 soccer team and he does swimming (.2) he's just very all, all around above average athlete. So I think that has a lot to do with and you know my husband was the same way just an above average athlete so I think it just trickles down (.2) type of theory. I'm (K) active, but I'm not an athlete by any stretch of the imagination.

PI: Okay, great. Thanks for sharing.

(.2)

S: Um, I'll go. This is S. Both my husband and I are physically active (.1) um as is all of our kids so (.1) um so Ben ((child with DS)) just consequently follows suit. And all, well let me think all almost all of the kids at some time in their life have participated in organized sports. Most of them, well more than half of them still are. But um Ben is not ((laughs)).

PI: It's okay.=

S:=(laughs) And I've kind of been waiting for him to mature a little because if he doesn't like what's going on then he'll just sit right down and (.1) ya know not move! So, but um he's pretty active and he's very um he's what 11 and um he's also in an 8 slim.

(.2)

V: Um (.1) my husband and I were both very athletic and I think that definitely helps but unfortunately neither my husband or I are as active and we'd like to be. However, like if we decide to go out in the backyard and kick the ball around, the other 2 ((children without DS)) are definitely very excited and are the first ones out there where Lily ((child with DS)) (.1) it just depends on what mood she's in. She's not necessarily that motivated by that and just sometimes she wants to sit down and watch a movie or play with her baby doll instead of taking that motivation of us being outside together um (.1) so (.2) I definitely (.1) schedule her more for activity time whether it be you know her gymnastics classes or things like that (.2) and we have plans after this next baby is born to have that gym membership at the YMCA over here and actually she'll ((child with DS)) be old

enough to do activities with me in the gym so (.1) yeah with her I definitely would need to plan more she's not motivated, I guess at all. She just goes by her own drummer so.

PI: And V since you brought up different types of um (.1) what I'll call support for activity what types of support do you all give to you children to encourage these habits? And it can be organized sports and you know it can be just basic physical activity, and it can be walking or playing outside. Have you guys noticed different types of support that you may give to some children uh, like V you said that Lily ((child with DS)) needs a little more organization or motivation. Have you guys noticed differences in support for activity?

(.4)

PI: And I can give another example if you all need um=

S: =Well I could answer that, its S.

PI: Okay go ahead.

S: And um yeah if Ben's ((child with DS)) been sitting in the house too much I'll say come on let's go jump on the trampoline or come on let's go over to the bike path and take a walk or so. And I didn't have to do that too much with my older kids so

PI: Okay.

S: That would be the difference.

K: Yeah, it's K. I would say I do that with um with uh Aidan as well, but I do that for all the kids (.1) Like they'll be sittin inside and I'll be like guys, what are you doin it's a beautiful day go outside! And they're like NO we don't wanta go outside we wanta play video games or we wanta watch a movie and I'll say no it's too pretty of a day and I'll say ya know go outside for at least an hour (.1) and then you can come back so uh that is pretty much (.1) or if the kids are riding bikes now Aidan is not coordinated enough to ride a bike and quite frankly we really haven't worked that hard with it and that's my goal for next year uh (.1) like if the kids are all riding bikes and Aidan and I'll take a walk (.2) with the dog. Or he'll go on his scooter, uh the kids'll all be on their bikes, Aidan'll be on his scooter and I'll walk with the dog so then he can kind of still participate and go.

PI: So then you all go as a whole family?

K: Yeah, so the kids'll go you know it'll be a group of kids in the neighborhood it'll be my 2 kids and a group of kids from the neighborhood and they'll wanta go for a bike ride and then so Logan'll come in a say Mommy we're all going for a bike ride (.2) um but Aidan wants to come. And I'll say okay so then I'll get the dog and then all the kids will just ride their bikes and then Aidan will just be on his scooter. And then I'll just go just kind of to keep an eye on them.⁵

PI: Okay, in case he's a little bit further behind the other kiddos?

K: Exactly.

PI: Okay.

V: Yeah I agree, I definitely need to activate Lily more than the other kids. The other kids just kind of do it on their own and again with them being so close in age I think they're starting to get Lily motivated to do more things but you know being cold outside now they just run circles around the house sometimes! And they'll chase each other, and she ((child with DS)) will jump up and join in that right away. So I'm starting to see that her siblings will be more of a motivator for her and hope that once she does develop that peer group that her peers will be but as far as my husband and I, we're definitely not motivators for her.

PI: Oh really?

V: Yeah, she ((child with DS)) doesn't I mean I can try to entice her with any kind of activity um (.2) and if she doesn't want to she (.1) won't. Unless if I go to Bounce Town or something!

PI: Okay, so you're still kind of looking for that trigger or that motivator?

V: Yeah. Which is again I think just her personality because it's across the board whether it's schoolwork or (.1) anything even just getting dressed in the morning. Like hhh we haven't there isn't necessarily a motivator yet.

PI: Right. (.5) Okay anyone else?

((phone rings in background))

(5 second silence)

PI: Are we all still here?

K, V, S: Yup, we're all here. Yes.

PI: Alright.

K: AIDAN, I just got a call from school Aidan's sick and needs to be picked up.

PI: Oh no.

K: And so I am um frantically trying to uh make arrangements to get him and I just got one of my friends to go get him so.

PI: Oh, okay. Well if you need to so you don't need to take a break or come back?

K: Nope I'm good. I'm fine.

PI: Okay well wonderful, aren't you a multi-tasker!

Group: ((laughs))

PI: Well okay ladies let's move on uh to the next one, so ((clears throat) excuse me, how do you feel about your own personal eating habits or feeding patterns and how do you feel they impact your children? And your family? So we were talking about activity of your own and now your own personal eating habits or eating patterns. (.3) So for an example um if you are a snacker you know we talked about different vices you know if you have that (.2) snacking sweet tooth you know will you eat it in front of them or do

you try and hide that from them? Just to give an example it doesn't have to be anything like that. But how do you feel (.2) uh those impact your children and family?

V: I uh I'm a sweet (.2) breakfast person um so up until probably recently I've tried to hide it from them um (.2) again it's a choosing your battles thing with a 2 and 3 year old it's hard for them to understand uh it's getting to the point now that I can say I'm mommy and ((laughs)) and I can have my vices! And so far that's worked for them. You know occasionally we'll break the rules for them and we'll have a donut for breakfast in the morning or something and it's more of a treat of them. So they'll definitely question it and you know they're at that age too where they question everything so hh I (.2) I don't know that it affects that because their still okay with their cheerios in the morning (.2) um before school. So (.2) that's kind of my answer for my influence.

PI: Okay.

K: It's K, I think for me we eat um (.2) we are definitely snackers and we my husband is definitely a nightly snacker before bed so the kids have all developed that habit they all have a drink before bed with their father. And then with my um personal influence I am um an emotional eater and this last past year has been very difficult, emotionally for me and um I have gained (.2) probably about 35 pounds and the children are um (.2) they're very much aware of the emotional situation they're very much aware that now I'm watching because I uh and now the kids are very much aware of how mommy is eating and making better choices so if, if my husband's influence is probably the snacking at night and then my influence just within this last year has been I have made some um and they didn't mine was mostly snacking at night too but they mostly just snack with their father not me um (.2) and just making you know I stay at home and the kids are at school so they don't really see the choices that I'm making but they've seen the end result. (.2) And so now they're um (.2) you know like they'll say um mommy you're watching what you eat don't have cake or um (.2)[oreo. So then that's kind of been (.2) I would say my personal influence on them that they um while they definitely didn't see me eating and putting on the weight. They've seen the end result and the fact that I'm happy and now (.1) that the emotional business has kind of settled down and I'm getting back in the game. Now they've realized that you know I'm making healthier choices, I'm watching my portion control so that is probably what my primary influence is on them.

PI: [almost helping?

PI: Okay, K thank you for sharing that.

V: Yeah, and if I could add too that just made me think of my husband is also an evening snacker hhh and the kids have kind of picked up that habit. Um (.2) except Lily, she's the only one that doesn't jump on the band wagon necessarily. The other 2 are instant if they see Daddy with a snack they have to have one too.

PI: And do you think it's related to kind of related to the socialization of hanging out with Dad? Or do you think it's more uh routine? Or they're hungry and they want that yummy snack?

K, V: I think, it's. Oh good ahead ((simultaneous))

V: For me it's a lot of it's the socialization and um also probably the hunger, you know they're also at that age where they kind of need those multiple meals throughout the day or every couple of hours they're still hungry so=⁶

PI: =Right.

K: Yeah, I would say the same thing for me it's a combination of I do think that they're hungry but I think and just as much I do think it's snacking with their father (.1) cause they all get their sna which is basically either um cereal or goldfish so all of them get cups of cereal or goldfish and a drink and they um go upstairs, watch TV with my husband have their little snack and then they'll kind of venture out. So you know one'll come downstairs with me maybe one'll go and read but it's definitely a routine I think it's combination of emulating their father, the routine, and they're hungry.

PI: Okay.

(.3)

S: Okay um at our house (.2) it seems like somebody is eating all the time!

PI: Okay! Well you have several folks at your house, right?

S: Yeah, um right especially males. You know the teenage, twentysomething males, um (.2) they eat a lot! You should see the grocery bill! ((Laughs)) so we have 3 meal times but you know not everybody is here of course during the middle of the day but probably 3 snack times! [So and um (.2) as far as the way my husband and I eat .hh my husband has he has some bad habits! He has a pick-up truck and I see what he eats when he's not at home! And you know I don't ever bring that stuff into the house. But you know like snickers bar and stuff like that so I'm really into healthful eating (.2) and so I really try to make the meals nutritious and even the snack food I try to make as nutritious as possible so what they get here is fairly good for you. And uh what they eat at other places, I don't know! Maybe that's why my husband sneaks snickers bars!! I'm not sure ((laughs))=

PI: [Right!

PI: =And you can just tell by the wrappers in his car? Is that what you mean?

S: Yes! Yeah but let's see as far as been goes he (.2) nibbles throughout the day because (.1) he probably didn't eat what I packed in his lunch so he comes home quite hungry but um so (.1) that's about what it's like at our house. Consequently the dishes are never always clean!

(.2)

K: Yeah I feel like I'm always cleaning the kitchen! That's how it is at our house, we have breakfast, lunch, and dinner and we'll have like on the weekends we'll have you know pancakes or eggs or bacon um (.2) then during the week the kids'll probably have

either eggs, pancakes, or cereal and then we have lunch and then we have a good dinner. But the kids are they'll definitely snack between breakfast and lunch, they'll snack between lunch and dinner and then they'll have a snack after dinner. I feel like I'm always cleaning up the kitchen, period.

Group: ((laughs))

PI: K, do your kiddos go to school they're not homeschooled right?

K: No, they go to school.

PI: So do you pack their lunches for them or do they buy lunch at school?

(.2)

K: No they have um their lunches are packed. So they usually get turkey (.2) and Aidan's now on this peanut butter thing. He's discovered peanut butter. So he'll have peanut butter and then they'll usually have a fruit. Aidan'll have a peanut butter sandwich (.2) a fruit like a apple banana or grape .hh and then like a goldfish or a potato chip. And he usually does eat, uh he's been known sometimes we'll pack his lunch he always gets pizza at lunch if they're serving pizza he gets pizza at lunch and we (.2) put money on his account but sometimes we'll forget and so we'll send his lunch in and he'll eat his lunch AND get a pizza=

PI: And how do you feel about that? =

K: = What's that? =

PI: And how do you feel about that?

K: Yeah he's fine yeah Aidan he's just (.2) hungry. And so I, uh I if he says I'm hungry (.2) then I get him something to eat. Like, I because he pretty much is. You know like I said we call him the Viking and he um like we'll go to this um (.2) Outback Steakhouse or a steakhouse and Carson and Logan'll get the children's portion of ribs, Aidan'll get the adult portion of ribs and eat the whole thing.

PI: And so you said, you feel that he's gotten pretty, pretty good at being able to tell (.2) when he's hungry or when he's not hungry?

K: Oh yeah! Absolutely. Like when he's done he'll ask for seconds and then so if I give him like a full portion as a second and you know if he's not hungry he'll leave half of it on the plate. And you know a lot of the time if he asks for seconds I'll give him like half of the portion or I'll give him just like a couple more bites and he'll say either okay I'm finished or can I have some more? And so then I'll give him a couple more bites but he knows when he's full I think he definitely recognizes that.

(.5)

PI: Okay, great. S or V did you have anything that you would like to add about that?

(.2)

S: No not that I can think of.

V: Yeah, I don't think so either.

PI: And S if I can interject just because you have several um, several more kids (.2) it's 7 total right?

S: Uh huh.

PI: Did you notice the difference in the desire to have a packed lunch or buy lunch at school you know I've heard some moms say that your kiddos know if a lunch gets pack they know it's going to be a little healthier. But if I buys lunch at school it's going to change what I'm eating. Did you notice a difference in your kids (.2) as far as that?

S: Well, Ben goes to a small private school a small Christian school and they don't have a kitchen so he gets his lunch packed every day. So it doesn't really apply. Well then we'll move on.

END 03/06 19m19s

START 04/06 0 of 11m20s

PI: The next is how do you feel physical activity impacts the quality time your family spends together? Do you notice that uh you spend more time more quality time being active or being inactive um (.2) ya know how do you all feel about that?

(.3)

K: I'm sorry uh ((PI)), I had to go outside and get Aidan (.2) could you just repeat the questions?=
PI: =No problem, sure. I said, how do you feel physical activity and this can be organized or just regular activity that your family spends together? So um (.2) do you spend more time being active together or er more time being less active together? Or do you recognize that quality time can be spent being active together?

(.2)

V: I think for us it's seasonal ((laughs))=

PI: =absolutely!

V: You know obviously when its warmer out it's a lot easier to be active together but we do try it (.1) and in the colder weather times we'll do different things like um do the open gym at the gymnastics park or go to Bounce Town and do things like that. Um .hh to keep us going um so I think really it's just a combination.

(.2)

PI: Okay.

K: And I would have to say for us its fifty fifty. I think to as a family we spend um ya know fifty percent of the time being physically active whether it's playing outside in the backyard or goin for walks, bike rides, and then the other fifty percent we'll snuggle up and watch a movie or we'll snuggle up and read books or uh watch TV (.2) so for us I think it's pretty fifty fifty.

PI: Okay.

S: I would agree with that. And it is seasonal[Right like what V I
believe said. Uh we in the winter do a lot of snowboarding or cross country skiing unfortunately Ben ((child with DS)) isn't there yet. So uh we're working on that but that's kind of an unfortunate thing though because you know we like to do things where as many of us as possible can be together at the same time so that's been a little bit of a hindrance, but he's almost 12 and he's more open to trying new things uh so (.2) we hope to get him out on skis again this winter.

K: [yeah for us its seasonal
PI: Okay, and S you said that he's not there but that he's almost there whenever you all want to go out and you want to have as many members of the family present as possible .hhh have you noticed that you'll still do those activities and then maybe you'll kind of branch out and mom will take some kiddos and dad will take some kiddos, have you noticed anything like that (.2) during activity?=
S: =Um (.2) well yeah that's what we (.2) well last winter was the first time I think that was the first winter that Ben even attempted to go out on skis, so I would go up the hill with the older kids and my husband would stay down on the bunny slope with Ben. And I imagine we'll try that again this year if we ever get any snow ((laughs))
K: Yeah I would say that we do the same things cuz we have a timeshare and um in the Poconos (.2) and what we have done is we have gone tubing um as oppose to going skiing because Aidan isn't quite there yet. But for that matter neither is Carson or Logan ((siblings without DS)) but then if we do have instances where there is something that Aidan just physically can't do, then Dan'll take Logan and Carson and I'll take Aidan or Dan'll take Aidan and I'll take Logan and Carson.
PI: Okay, so either changing the activity to include everyone or branching off (.2) according to ability?
K: Yes!
PI: Okay, and V what about you?
V: Um I think being seasonal and my kids are just still young enough that they don't want to be out in the cold more than 10 minutes (.1) and just walking through 6 inches of snow is a challenge for them [so we're not necessarily at the sledding stage so I think that just makes us even more seasonal. And just like I said at this point I call them my triplets so they're abilities, physically are all kind of the same um (.2) so we don't necessarily have to modify anything or any of our activities.
PI: [right.
PI: Okay, and if you all decide you want to be active as a family and obviously you, V, being about to give birth some of the activities may not work but if you do want take the triplets as you call them out and be active as a family, what sorts of things would you do?
V: Um well like this last year we started riding bikes and some with training wheels. So we'll go out and ride bikes for a little bit or we'll go out and kick the ball around the yard or (.2) go to the park. We go to the park often and usually we still do stroller to the park I don't make them walk all the way there and all the way back. They're starting to get to the point where they can walk there but need to sit on the way home because they wear themselves out hh. Um, the parks probably our most frequent activity, physical activity.
PI: Okay. And ladies anything else to share about quality time and activity within your family?
K: And I would just have to say that when my kids were younger (.2) when the kids were V's age the park, that's what we did too. We did a lot of stroller to the park, like Logan

would maybe ride his scooter, Carson and Aidan would be in the stroller and then gradually as um as they got older and Aidan got more coordinated then we started doing a lot more then we started being a lot more physically active. But in the um when they were younger ya know again with the cold they couldn't handle the cold so they're definitely wasn't near as much physical activity as there is now.

PI: And you all obviously the part of the country that you live in, weather is a big deal. Have you all thought of difference ways for everyone to be active inside or kind of alternative winter type activities that you can participate in? Or is that something that you all think about?

V: Um, at our house we have a decent sized unfinished basement, so I'll bring in we have their tricycles down there and they'll slide down there and get they go crazy downstairs! And that isn't necessarily a family activity but it allows them to get out their energy=

PI: Absolutely, that's great.

V: Yeah, um other than that we (.2) as schedules permit it's hard. You know we usually do our um gymnastics classes and dance classes and things like that over the winter. Um, again it's not a family activity but that's how we try to keep the kids active when it's cold.

PI: Okay.

K: We do a lot like not so much now but definitely when they were younger (.2) our mall has like a kid's um like playground area so I would in the winter time I would take the kids up there and they would play on the um they could play in that play area for like 2 hours and then we would just walk around the mall and then maybe get ice cream or something like that um and then they too will play they'll play in our garage a lot, they'll play like soccer or hockey um in the garage. And then they'll also (.2) we have like a felt soccer ball so they'll play upstairs in the hallway and then we too have an open gymnastics area er um facility so we'll do that (.2) that's how we try to um maintain some level of activity you know even when it's cold.

PI: Okay, so it sounds like a lot of you pending the weather you have to be kind of proactive in getting them to be up and moving. Would you all agree?

S: Yeah

K, V: Yes, definitely.

PI: Definitely?

V: Well not necessarily at my house because they (.2) our house is set up where they can run a circle and like I said before they play (.2) different chasing games[and monster games and things like that where they're running around the house and um=

PI: [okay.

PI:=they may not need you?=
V:=even when they're probably not supposed to be ((laughs)) and things like that so

PI: Okay.

V: I think they still stay active on their own obviously they would rather be outside.

((background noise))

PI: Okay, and S what about your kiddos?

S: Uh, well you know now that they are older it's different but my son John, the one who's next oldest to Ben will play what they call knee hockey in the living room with little goals and things like that. It's not a lot of physical activity but they're moving! But when we get snow we have a little hill in the yard that Ben and either myself or a friend or one of his brother's'll take him out on hhh and in the basement we have ping pong but ya know our house is not real big so there's not a lot for them to do inside and we don't have a garage. So yeah I definitely have to be creative. Fortunately at school they go outside everyday unless it's I don't know twenty below zero or something. So he gets exercise there fortunately.

PI: Okay. Alright, S and since you do have kind of the comparisons with more children when when the older ones were younger (.2) have you noticed kind of a difference in the level of creativity that you have to provide? Or the level of motivation between the kids?

S: Um yeah (.2) when the older kids were younger I used to home school for fifteen years and we used to actually play nerf ball games in the living room. We just painted the ceiling there used to be a ya know like a couple hundred tracks from balls on the ceiling ((laughs)). So yeah um they would run around the house more and definitely be more active um but now since Ben at times is almost like an only child I have to be more involved in getting him active. Which I'm not always as good at as I should be.

PI: Okay. Well great ladies, anything else on that particular topic?

Group: No, nope.

END 04/06 11m20s

START 05/06 0 of 10m08s

PI: How do you all feel um about the promotion of healthy eating habits or healthy eating practices related to quality time (.2) within your family? So for example uh (.1) you know you wanta have a day that the family spends together, so let's all plan the menu and help each other cook. Have you guys all thought about something a like that related to quality time and=

K:=We do that. This is K. We do that and um what we do is a on Saturdays and Sundays the kids, well it's more driven again by my husband but so on Sundays we'll watch football I'll usually read a book ((laughs)) and they'll watch football and alternate between like commercials or games and they'll go outside and play and then they'll come back inside but our Sunday ritual is um (.2) a salad bar? So (.) we go to the store and we go um get all the makings for a salad and then um we set it up on our kitchen table and then they will pretty much make um their own um salad (.2) and that is like their favorite they're just thrilled to death to do it! Which just cracks me up cuz you know most people are doing like chicken wings and um[
Yeah! But they wanted to do um they wanted to do a salad bar so that's what we do on Sundays. I mean Carson and Aidan, they'll put everything in their salad. They'll put it all. Logan, who's the oldest is just

pretty much lettuce and carrots. Ha Yes that is our we definitely do um and then we'll plan nights out you know like where do you want to go out to eat and we'll try to figure out what we all want and come up with a compromise and uh or we'll plan a day to go uh to the park and then after the park we'll go get something to eat. Or the dog park, so we'll take the dog to the park and then get something to eat. Yeah like that kind a thing. Cuz there's a pizza place right there, so we definitely do do that.

PI: [oh that's wonderful

PI: Okay, thanks for sharing. S or V?

(.2)

S: Okay, well (.2) a lot of our time together as a family is uh based around food.

((laughs)) um guys get really excited about (.2) eating! =

PI:=you must be a good cook with 7 children? =

S: ((laughs)) Uh yeah! Well large quantities =

K:=Excuse me S, do all your kids live at home?

S: No. Um (.2) let's see. Right now I have 4 at home, 1 at college who's just like an hour and half away so he comes home occasionally. Uh, my 1 married daughter's only 10 minutes away so she and her husband come over often. My other married daughter's 2 hours away so I don't see her as much but when we all get together there's usually the hub of the activity is in the kitchen! =

PI:=okay.

S: Uh, just about all my kids know how to cook. Except, well I'd say for Ben. And I've often tried to include him in making cookies or things like that but he mostly just wants to eat them!

PI: Okay ((laughs))

S: Yeah he is excited about doing the cookie cutter cookies after school today!

PI: Kind of a fun holiday treat?

S: Yeah!

(.2)

PI: Okay, and V what about you? Do you cook with all of your little triplets?

V: Um hh ((laughs)) occasionally.

PI: Okay.

V: I, I want to and would like to do more but I'm kind of a neat freak. Especially when I'm cooking (.1) by the time the cookies are in the oven I want the kitchen to be clean. So I struggle with that in my own personality so we don't do it as often as I would like to. But we (.1) so I try to include them um on and off (.1) with preparing the food, um they definitely help me set the table and things like that for dinner which they are very excited about doing (.1) just being involved with that process. They definitely enjoy it. And a wanta do it with me (.2) um (.2) =

PI: What about =

V: =Again I think with them being younger we haven't quite gotten to that stage of (.1) including them[in meal decisions and things like that.

PI: [right.

PI: And is that something that you uh would like to encourage once they get older?

V: Oh absolutely.

PI: Okay.

V: Yeah, partially because then I don't have to think about it! ((laughs))

PI: Ha, ha there you go!

V: But hhh definitely.

PI: And since, and I know that you all kind of shared that most of your children are pretty well able to you know recognize when they're full or when they're hungry um but do any of you have any specific I guess you can call them food rules, like you know as far as snacking? Like you have to ask mom or um you know seconds are okay as long as you have eaten all your different portions. Do any of you have any type of family food rules? (.2) And they may be you know direct or indirect you know something that is just kind of understood or is it it may be something that you actually enforce.

(.3)

V: Yeah at my house (.2) I do (.2) especially since my middle child ((child without DS)) is very picky and doesn't necessarily like to eat the healthy foods. Um (.2) she has to (.2) take certain bites of things if she tells me she doesn't like it, she still has to take a couple bites of it (.2) Cause one I know she likes it! =

PI: =Just to try it?

V: Yeah! I just know she wants more of something else. So we do do things like that like that. Like if er um like for lunch sometimes we'll have hotdogs and carrots and she'll finish her hot dog and maybe even want more hot dog but she hasn't touched her carrots so she has to er take so many bits or eat so many carrots before she can have more of something else.

PI: Okay.

K: Yeah I have to say for us it's like um when I'm cooking so let's say dinner is like a half hour away (.2) er you know any 1 of them could come up to me and say can I have um some pretzels or can I get an ice cream sandwich or and I'll say you know no, not before dinner. .hh Um the other thing is that they'll wanta have a drink. They'll want to get their drink and I'll say no you have to wait for dinner and then we also have um you have to try it rule. You have to have at least 2 or 3 bites and try it and then um ((phone rings in background)) we um well that's more so for my oldest who is picky, like he'll have to try it because he'll say oh I don't like it I just want to have cereal for dinner. And I'll say no you know you have to try it. Um (.2) and then um and that's pretty much and that's pretty much it for our house.

PI: Okay.

K: <speaking to food rules>. No snacks before dinner and no drinking before dinner, right before dinner. And then you have to try you have to try it.

PI: And when you say drinking, do you just mean something other than water?

K: Yeah! They'll come up and be like and I'll be cooking and I'll have all their drinks set up and ya know I'll have their plates set out and (.1) I'll have the drinks all ready to go and put on the table and they'll be like can I take my drink over um (.1) while I'm watchin TV? Or ya know I'm thirsty and I'll say no. Because what ends up happening is they'll drink their whole drink and then (.2) they're not hungry.

PI: Right. (.2) Okay.

V: I think the only other thing in our house is um (.2) .hh not total rigidity but we have a rigid schedule (.2) like snack time is at 2. Um in the afternoon and then otherwise they'll want a eat at (.2) 4. And we have dinner at 5 so kind of the time that we eat (.2) is a (.) rule in our house.

PI: Right, okay (.2) And S what about your family? And you can kind of think back to maybe when all of the kids were at home. Ya know it doesn't have to be right now immediate.

S: Right, um (.2) well (.2) I don't remember any of them being as picky as Ben ((child with DS)). So with Ben (.2) if there's something that I know he won't like gag on I do push it but if he's reluctant I will insist that he take like 4 or 5 bites and I threaten him that if he doesn't he doesn't get his ice cream ((said with laughter)) before bed but um you know and that way we have found that he actually does like some more food that he didn't think he liked by ya know kind of forcing that he does try something new. But he does have a (.2) he does occasionally gag on some foods so, the textural thing I don't push a lot because I uh (.2) it's not pleasant to gag on foods. =

PI: =Yeah absolutely!

S: Yeah.

PI: Okay, well if no one else has anything to add on that (.2) we'll go ahead and move on to the next question.

END 05/06 10m8s

START 06/06 36m0s

PI: Would you consider your family to be a physically active and healthy family? And what factors impact uh whether you all are or not?

(7.0) ((phone rings))

V: I would say that we are an active family um (1.0) we do our best to eat healthy um you know don't totally restrict ourselves[I think I mentioned before that my husband and I are not as active as we would like to be just because of our work schedules and stuff like that which hopefully as the kids get older we'll uh be able to do a (.2) little bit more for ourselves uh (.2) in that arena. But in general (.2) we are definitely a healthy active family.

PI: [right

PI: Okay and you said just mostly related to work schedules and (.2) .hh and the kids being younger (.2) kind of are what impacts whether you are ((active)) on kind of a daily basis?

V: Right. (.2) It's very important to us.

PI: Alright.

V: It's a priority for us.⁷

(2.0)

K: And I'd have to say that for us we to are very um (.1) I would say that we are um a healthy um active family. I think there's probably families out there that are healthier than ours because ya know we don't do organic or we don't do, well we do do some fresh vegetables when they're in season but for the most part we do the canned vegetables or the frozen (.) but I would on average that we are um healthy and probably a little bit above average as far as activity goes.

PI: Okay.

(3.0)

S: Um, I would say that our family is also (.1) ya know quite active. Somebody's playing basketball or hockey or baseball or something. Almost o I don't know at least 4 days a week. Um (.2) I just about never sit down until about 10 o'clock at night! In fact I'm very active.

V: That's probably my activity level too.

PI: Yeah? It doesn't have to be organized activity, like going to the gym.

S: Well I do actually walk or workout here in the living room but um, yeah we're all pretty health conscious I would say so uh (.2) and as far as average hh I guess as far as the average American we're probably more health, health conscious then a lot of Americans are but ya know I'm not saying that in a prideful way ((laughs)) ya know I'm just sayin it (.2)

PI: Honestly?

S: Yeah! We're not couch potatoes is what I mean.⁸

K: And we're probably half and half. We're probably half couch potatoes and half active. Because we do like to snuggle and we'll watch like on a Saturday if it raining out or if it's snowing we'll (.1) bring all the blankets into the living room and we'll do just like a movie marathon or my kids thank God like to read so we'll all climb up into my bed. And get under the covers and we'll just all like read for 2 or 3 hours and get snacks and then go back to read. So I'd say for us we're probably fifty fifty. But the kids are definitely, definitely active.

PI: Okay so it seems very well balanced?

K: Yeah I think we have it pretty well balanced.

PI: Okay.

(2.)

S: I would just add that one of the worst things that's come along for activity are video games!⁹

PI: Absolutely

All: ((laughs))

S: And um boys seem to be worse about the video games than girls. And I kind of wish they had never come into my house but they were introduced by one of my older sons [But yeah, I'm not a big fan.

PI: uh huh[

PI: [Since you brought it up do you have any rules about video gaming?

K: [See and that's interesting

(2.)

S: Um well after a while when I notice they haven't moved ((laughs)) in an hour or more. I'm like okay, you're done!

K: See that's interesting because my kids never um didn't really get into video games, we have them but they'll play (.2) like I know their friends like particularly Logan who's 12, you know their friends'll sit there for hours and play. Now my kids, they'll play for like ya know a half hour or 40 minutes (.2) but then they'll get up and go outside and then they'll come back in and they'll play a little. But they don't sit and have the marathon sessions that I know most kids his age, particularly Logan ((phones rings)) they do do that. But Logan, Aidan, and Carson, they'll play for like maybe a half hour 40 minutes but it's almost like they get restless. They'll go outside and play and then they'll come back.

PI: And then V what about video games in your household?

V: Well, we're not quite old enough for video games, I mean they have their Leapster. Which they enjoy (.2) maybe (.2) not even once a week to play that. I think the TV is our biggest vice in that arena. Which I personally go through phases of laying down some rules and restricting time frames and stuff and other times its kind of free will! ((laughs))

PI: And do you think that is kind of related to their behavior? The more often you see them at the TV, the more restrictive you may be?

(3.)

V: hh um no I think it's just more my own schedule and just what's going on in my life it's like uh choosing your battles. And if I have a lot of stuff I need to get done (.2) I just let the TV be on. Also they're at that age where in 20 minutes they're off and playing. [

And then they'll play for 20 minutes and come back for an hour and watch some TV. And it's just I think the (.2) the smaller attention span.

PI: Yeah[

PI: Right.

V: But Lily ((child with DS)) will definitely sit in front of the TV the longest. So she loves her movies where the other 2 won't sit as long, but then that can be an age thing too.

S: Yeah, same with Ben. He's very visual and he loves watching movies.

PI: Moreso than your compared to your other children?

S: Yes, definitely.

PI: And K what about you? Have you noticed a difference in that Aidan likes to watch TV a little more than Logan and Carson?

K: No. They're pretty much equal.

PI: Oh really okay.

K: Yeah, they'll uh. Like they'll sit and watch it for a little bit. Like um they come home from school typically around 3:30 (.2) and they have a half hour to do whatever they want and then I start making dinner and then they do their homework. So in that half hour, like sometimes they'll sit and watch TV for 10 minutes and then they'll go outside and jump on the trampoline or they'll play soccer. Um so but they're um it usually ends up being like 15 minutes of a TV show and then they'll go outside and play. And Aidan ((child with DS)) doesn't watch any more or any less I would have to say if anything he watches less TV than the other 2 because what I find is he if we're all sitting down watching TV he'll get up and grab a book and he'll just read a book like at the kitchen table. Or he'll go up to his room and read a book, so I would have to say if anything he watches a little less because he is either reading a book or um a lot of times he'll go out in the driveway and shoot baskets by himself, rather than watch TV. ((phone rings))

PI: Right. It sounds what I'm hearing it sounds like uh I mean the main factor is personality really?

V: I would agree with that.

K: Yeah, I think for Aidan that's probably true.

S: I was gonna say um Ben, when he comes home from school he's totally wiped out so I just allow him some quote unquote down time. Just to go sit and watch something, but he has had a history of sleep apnea and he has had trouble with his thyroid. So in that respect he's a little more vulnerable to becoming tired than my other kids. Because I don't know how well he's sleeping. And the hypothyroid is being treated but still I just allow him to go chill for a while and then I have him do his homework.

V, S: ()

V: I'm sorry. I do the same thing with Lily when she comes home because she gets tired after school and she's only in first grade so. The all day thing is new and so I do allow her the down time. She um, we recently went dairy free with her diet and um she's sleeping better she's behaving better just all these things have improved in her life over the best few months and I noticed it's probably because she is sleeping better. I mean she'll get home from school and she's not tired. She doesn't even request that down time but I do I just allow it.

(2.0)

PI: Okay, so you've seen positives just from making that small dietary change?

V: Oh yeah, huge.

PI: Are you all gluten and casein free or just casein?

V: Yeah, just dairy.

PI: Okay.

K: I think for Aidan, Aidan's been gone to a full day program since he was 3, so for him (.2) I (.2) I'm sure when he was 3 and 4 and 5 you know going to that full day program like when he was 3 he came home and took a nap. And then when he was 4 that was the pre-k all day program and if I remember correctly he would come home and take a nap. And then at 5 ya know he already had 2 years of a full day program under his belt. So he um he transitioned um (.2) a lot transitioned probably a lot better and quicker since he was learning to conserve his energy or he was just by routine. So he really doesn't um, and now he's in 5th grade so he doesn't really need that he needs more of a running around burning off that energy kind of thing more than, down time. But I think that has a lot to do with history of going to school.[so

PI: [right.

PI: And I know a K you spoke a little bit about kind of barriers to being active or being healthy (.1) um were related to your work schedule. Did anyone else have anything they want to share? As far as maybe barriers that you are aware of that a (.2) you may be trying to control or maybe it's something that you're not trying to control, that kind of inhibit you or your whole family from being active or healthy?

(3.0)

K: Uh Kelly that was V (.2) because[I'm actually looking for a job=

PI: [oh I'm sorry

V:=It's fine.

K: For us, I would say the biggest um barriers to being both healthy and active is our activities. So um Logan plays on 2 soccer teams and he has practices, Carson plays on 1 soccer team and he has practice and Aidan does (.2) um gymnastics. I volunteer (.1) at our school, my husband volunteers at a baseball and what I find ends up happening is that some nights they're coming home from school and we need to be somewhere at 5 or 5:30 so in those cases (.2) particularly like uh especially if it's like a Monday night, I know McDonald's has dollar happy meals on Monday nights. So if we're runnin if we have to be somewhere at 5 on a Monday, the kids are gonna get home at 3:30 they have down time until 4 a lot of times we'll be um a lot of times we'll be driving through that drivethru=

PI: =So it sounds like its scheduling and affordability?

K: yeah! So affordability. And it's easy and as far as time is concerned and ya know this is what I was especially doing when I was working and ya know my husband has a job that is very (.2) I mean sometimes we don't know if he's coming home at night or when

he's coming home at night so ya know, I have to get all 3 children where they need to go, get their homework done. Get the children, ya know (.2) get dinner. So if there is any barrier to us being active and um healthy, it's probably because of our activity and schedule. And we are not nearly as healthy. Now the one thing, I absolutely did recognize that and I have started using the crock pot a lot more because we were doing a lot of um fast foods and we were doing a lot of like cereal or (.2) breakfast for dinner. Particularly, September to November is really busy for us so I started doing a lot of um cooking with the crock pot to kind of offset that um, ya know to try and stay healthy with the eating.=

PI: =And also help you plan? =

K:=Exactly. And that was especially true when I was working
(.2)

PI: Okay, and S what about you? Any barriers that you all have and maybe its barriers that you have recognized and have already overcome.

S: Uh well (.2) for the last several years I have been helping my sister take care of my mother who has Alzheimer's so I have my mom here 4 out of the 5 week days so (.2) when Ben comes home I also have my mom. So sometimes it's hard for me to go (.2) do things with him. In the summer for instance, there were days I wanted to take him out to the small lake nearby for swimming (.2) but because of my mom she couldn't have physically gotten down to the water.

So[that has been a bit of a hindrance to (.2) ya know doing more things with him.

PI:[Right

PI: And what about, will your other children help out and maybe be proactive and take Ben places or do different things to get him active?

S: They do a fair amount at work and they're busy with their own lives and they are they love him dearly and so they are great with him. But sadly ya know since my daughters aren't here they were really the ones that would take him a lot of places. But, they're not here!

PI: Right. Okay. And V I know you shared a little bit earlier but is there anything that you would like to add? Maybe barriers that you've already recognized? You seem to be kind of a big planner with things.

V: Yeah I am ((laughs))

PI: Yeah, that's great! I meant that as a compliment.

V: I'm a super planner. Probably the only other big thing I could think of (.2) is just finances and budgeting like over the winter time I like to have them in more classes. Gymnastics and dance class and things like that. But um hh but affordability is not necessarily there, to do that.

PI: And so do you have any plans to maybe be creative at home or model different things for them at home since you know since financially it's just not there?

V: Right. (.2) Um, (.2) ya know it's challenging as a parent to balance everything. So I go through phases (.2) where the focus is more on academic type stuff or then the focus ends up being on physical activity or things like that um so (.2) and again being seasonal obviously it's easier to be more creative to think of things to do during the summer (.2) or when it's warmer outside. So it probably just depends on what my focus is at the time. Yeah what I feel like we go through the phases, we get through an academic phase and I'm like we're really lacking in our activity so we'll start focusing on that. ¹⁰

PI: Right.

(1.5)

K: I remember doing that to when they were younger. Like I would be like oh my gosh, I'd get those books the activity books. Like the pre-K big book or the first grade big book and we'd sit at the table and we'd um do those books and we'd do play-doh or we'd do um (.2) cooking and then I'd be like wow when was the last time I did that with the kids I haven't done that with the kids in a while I need to create some memories! ((laughs)) So then for week we'd be like slammin out the (.2) play-doh and the painting and all this and then I'd just get exhausted and then it's always a mess! And I'm like V ya know I do like things a little neater, then messier. And I'd be like Okay guys, outside! And they're like let's do play-doh again and I'm like Nope, let's go outside!

PI: Right.

V: Yeah, we do that a lot to and I try to do a lot of craft type thins with them.

S: Well Kelly I was thinking of another barrier in our lives is that we live in the country well it's a village removed from a Ithaca, New York which is kind of a unique small city because there's a couple universities there so there's a lot of things culturally there. But for me to take Ben to say (.2) gymnastics class would be 30 to 35 miles roundtrip=

PI: =Wow.

S: And also because it's a small area (.2) there's not a an active Down syndrome group. I mean my husband and I started a Down syndrome group, but there's hardly any children (.2) around here with Down syndrome=

PI: =Right.

S: So I know some of the larger cities, both 50 miles away from us have a lot of activities for children with Down syndrome, which I really wish Ben could be more involved in but[so yeah. So geographically, that's a barrier for us to having him more active in classes and things.

PI: [just the distance?

V: Yeah, we have our um GG's playhouse is the group that we go to all the time and they have a once a month dance class a once a month pre special Olympics uh class with various play groups that we, we frequently go to.

PI: Okay.

K: Yeah I know for me that's a big concern for me with Aidan as he gets older because um ya know right now um Logan and Carson and Aidan are really good buddies and Logan takes Aidan a lot of places and definitely includes him in his peer group and his peer group has grown up with Aidan so they're very welcoming and accepting but there's definitely gonna come a point where they're ((brothers without DS)) gonna want to be able to do their own things. And me to I also live in a smaller area and I worry very much um about his um (.2) ya know the barrier then becoming um lack of peer group. And GG's playhouse in Chicago is wonderful, I've been there. And they do a lot for, for specifically children with Down syndrome. And here in Salisbury, ya know we just don't have that. Ya know and I'm originally from Philadelphia, and Philadelphia has a lot of ya know where they do things as a group (.2) for different children of all ages. Ya know they'll do dinner groups or everyone will go to the movies or they'll go bowling and we um we just don't have that here in Salisbury. And the other thing we don't have, we do have a lot of children with Down syndrome though[But they're all girls! There are no boys.

PI: [Okay.

PI: And that so that, do you think they're maybe more focused on ((other things like)) crafts or academics and not so much on activity?

K: Yes! Yeah so there's gonna be, like I know all the mom's with the girls all have them in a dance class. They all have them doing cheerleading, so the girls are all and I'm sure as they'll get older ya know the girls go to um the girls always include Aidan. He goes to all the girls' birthday parties and they just adore him. But ya know now that they're 10, they're starting to do the little boy girl thing. Now before they were all just, they were all friends and they didn't really notice differences. But now the girls we'll be like I'm sitting next to Aidan! No I'm sitting next to him!

((all laugh))

K: And so um[Yeah! But that's one thing I do worry about as he gets older that he, whereas the girls (.2) are all gonna have good girlfriends. Have peers that have Down syndrome. Whereas Aidan (.2) he's gonna have good girlfriends, but he's not gonna have ya know any friends (.2) that are boys.

PI: [so socially that's great.

(2.0)

PI: And do you worry about that socially or developmentally, ya know what is your specific worry?

K: Mostly socially. Like I can see a lot of these girls like as they grow up, I could see them getting jobs in the same area I could see them moving in with each other ya know with a house parent.

PI: Okay, so from a more functional perspective?

K: Yeah, I could see them being independent and being dependent on each other. Ya know some of the girls are fairly um, some of them are high functioning. So I could see them getting an apartment with a house parent, etcetera. Ya know taking the bus to work, etcetera ya know going bowling or doing this. But for Aidan (.2) and he'll be included

with those girls I think absolutely but I really would have liked to have had (.2) more boys.
(1.5)

PI: Okay (1.0) well um ladies I don't want to keep you too much longer you all have I'm sure a busy day planned. But I just had one more question (.2) and ya know I think we spoke a little bit about it and (1.0) we spoke about how a lot of children with Down syndrome have a tendency towards overweight or obesity and I know that is not something that any of you all have dealt with or really mentioned that has gone on, but I was just curious if that concern is or has been in the back of your mind? And if that concern may impact how you discourage or encourage activity or how you may change eating habits? Have you all ever thought about that?

V: Yeah, absolutely. It's always in the back of our mind, which is one of the reasons why uh once I start going to the gym I want to bring her ((child with DS)) with me. Just to start creating those (.2) life habits[of keeping physically active and healthy.

PI: [Yeah.

PI: And so the concern is more so for Lily ((child with DS)) rather than Olivia ((child without DS))?

V: Yeah, like I said being healthy is definitely a priority in our family. But the things we've discussed like the lack of motivation and things like that I don't see as much in Lily even as a 4 and 5 year old, she should be active constantly. That and (.2) just the challenges she will have cognitively just dealing with life in general. I want her to have that up front, healthy habits, so it's just there and it's not something she has to think about.

PI: Okay, great. And K or S have you all that about that?

K: Well for me, for our family, my husband, my husband's father is very big and my husband's 2 sisters have also battled with weight. One of them had gastric bypass surgery. She was like 5'2, 5'3 and weighed almost 350 to 400 pounds so she definitely I mean he ((husband)) has a history of weight issues in his family. And I have a definite, I have that as well. I have more emotional eating, and my sisters and even my brother, my mother definite emotional eaters. So we've kind of gone back and forth with our weight as well as a family. So for this fam, so for our kids that has always been more in the forefront of our minds um because of our family history. We also have a family history of Diabetes, so um for us it's really about healthy eating, it's really always been about healthy eating and sitting together as a family at 5:30. Ya know providing healthy snacks and um absolutely being physically active. And making good choices. Like for example we don't, like my sister will never take her kids to McDonald's. They never eat anything that's not organic, that's not us. I mean we have Oreo's in the house, we have chocolate chip cookies in the house, but it's more or less trying to teach them to eat in

moderation, make good choices, and that's always definitely been in the forefront of our minds because of our family history.¹¹

PI: Right, so you think more so your family history rather than (.2) having a child with Down syndrome?

(1.5)

K: Right, the Down syndrome (.1) I kind of felt like (.2) ya know I definitely thought about it when he was first born and then the next couple years I definitely thought about it. But for me, I guess my novice research and novice conclusion was that a couple years ago or really kind of back in the day especially with kids with Down syndrome and the low tone, I don't think there was a clear understanding of low tone and physical activity. So I think what ended up happening back in the day was that because children with Down syndrome were typically born with low tone I don't think physical activity was encouraged because I think a lot of parents didn't fully understand low tone, a lot of doctors maybe didn't understand low tone. So I think parents of children with Down syndrome were discouraged (.2) from having their children be physically active because of the low tone also because of the neck instability [so I think that back in the day and it's why you see a lot of older and young adults that are heavy that have Down syndrome is because there wasn't a good understanding of the (.2) the low tone, the neck instability. And really what children with Down syndrome are capable of!¹² So what I kind of came to the conclusion, I figured for us, we were gonna get Aidan's neck checked which we did (.2) and we were just going to have him and encourage him to do just what we would encourage Logan or Caron to do. And ya know whatever he could do, he could do and whatever he couldn't do, he wouldn't. But we never said Aidan can't jump on the trampoline or Aidan can't go outside to play, ya know he might get hurt or he can't do this. So definitely in the beginning I did kind of look into it and it was a concern of mine but I do think that that was the thinking before and this is the thinking now.

PI: [absolutely

PI: Right. And K if you did notice, and not only with Aidan but with Logan or Caron, notice a weight change (.2) and you wanted to be proactive would you gravitate towards targeting eating habits or gravitate toward targeting activity, just if you had to what would you initially try to change?

K: It would probably be, be the eating habits because they're just, their physical activity I think is totally fine. And ((laughs)) I think if anything's gonna go it's gonna be the eating habits. Ya know if they're gonna start, maybe, ya know Logan's only 12 but maybe as he gets older he might get more into the video games. And he might be ya know sitting in front of the TV more with his friends and just snacking and he might just be sitting there. And I think for its Logan I think it's, well for Logan Aidan and Caron I think it would be eating habits, before physical activity.

PI: Okay, great well thank you for sharing K. And S or V did you have anything else you wanted to add. We talked about that concern in the back of your mind and how that may have impacted your family?

(3.0)

S: Oh well, let's see. I guess from the beginning when I found out that Ben had Down syndrome I decided to do all I could to make him as healthy as possible. I nursed him longer than the other babies, and I've tried to give him really good food. And he's as active, an active child, ya know even when he watching a movie or playing a video game he's on his feet ya know hoppin' around. So if anything I would be concerned because he's underweight. He has no body fat, one time his pediatrician wanted to put him on hormones, but I was like no we're not doin that=

PI: =Yeah, good for you.

S: Yeah, so I don't worry about obesity. I do try to keep him active because it also affects his well-being and the brain and the whole bit, so. It's not hard to keep him active but I do have to encourage it occasionally when the weather's bad.

PI: Right, and so you kind of recognize the psychological benefits of activity as well?

S: Definitely!

PI: Thank you. And V what about you? Anything you would like to add about your family after hearing K and S's comments?

(2.0)

V: Um, I mean just overall health. I mean everything goes hand in hand, your eating habits, your activity habits. Your physical and mental well-being for sure. In a former life I was a personal trainer so (.2) I have a lot of knowledge in how all that works together so it's not one thing or the other for sure. (1.5) I don't think there's anything I can think of that I can add. Well one thing Lily does that is kind of funny I hadn't been able to mention it, is that every morning while we're waiting for the bus. We're outside for like 10 minutes and she does sprints up and down the driveway ((laughs))[
Yeah, she does sprints up and down the driveway so.

PI:

[oh wonderful!

PI: And do you think that's something she learned? Where did she learn that from?

V: She just decided it was fun! All by herself to, because her brother and sister are already on their bus off to preschool so we're hangin out there by herself and she just does sprints in the driveway! It's funny.

(2.0)

PI: Well ladies, that concludes all of my questions that I specifically wanted to ask you all. Thank you so much for sharing all of your comments. Is there anything that you all would like to comment about or add something else related to the topic maybe something else that you were hoping I might (.2) hit on (.2) that I didn't?

V,K,S: Nope, I don't think so.

End of questioning.

END – 06/06 36m0s

***Disclaimers, question about member checks* off tape**

Annotations

¹ Mother states there are clear differences in her children's physical activity levels, she attributes those differences to personality and level of interest. Her child with DS is the least active

² Mention is made here that all her children should stop eating when they are full but an extra comment is made saying especially the child with DS, "with the whole obesity issues."

³ Sometimes it seems what is on the table (food - see the whole transcript) is not as important as the entire family being there eating together

⁴ Makes the comment despite as much as he eats, her son (without DS) is thin (similar to family history) and concludes that he must have a good metabolism

⁵ This Mom will go with her children so that her child with DS can be physically active with his brothers' friends, and not negatively impact the peer group and the child with DS gets to participate and be active.

⁶ Task: This mom recognizes the social aspect of even snacking, that Dad models the habit and the children follow and they may or may not be hungry but the social aspect is a big motivator. Coded as enjoyment

⁷ When this mother was asked about what impacts their level of activity she states "it's important to us" WOW.

⁸ Equates the average American as being a couch potatoe.

⁹ Feels very strongly that video games negatively impact amount of physical activity

¹⁰ Phases of health. So a connection is made here that the priority at that time directly impacts the aspect of family that is encouraged (i.e., activity, academics) or how that time is spent. There was another comment somewhere from another mom similar to this. "making memories of healthy eating, physical activity..."

¹¹ Because of this family's tendency toward obesity, they are choosing to provide healthy options, without restricting the not so healthy options. The goal is to teach them the habits "to eat in moderation" rather than forcing them

¹² Very well thought out rationale for why this mother almost worries more about the family history of weight rather than the DS-related weight component. There was an initial concern, but she researched it and from that came to her own conclusions that she should not set limitations on her child with DS differently than the others.

Transcript, Interview Kenna

Interview via Skype

Start 01/02 0 of 46m08s

Principal Investigator (PI): Okay, alright. Let's begin. So again I appreciate your time and um ya know all that you are giving up to sit and talk with me. So the recorder is on, if at any time you need to get up or take a break feel free to do so, it's absolutely informal. The session will last about 90 minutes. The purpose of my dissertation is to explore the development of physical activity and eating habits among families who have multiple children including one with Down syndrome, from the perspective um of mothers. And the target of exploration will be the potential relationships between parent modeling and physical activity levels and eating patterns (.1) between, between siblings um between your children. And different family perceptions of barriers to some of those lifestyle habits. And so when I speak about feeding pattern differences kind of I want to talk more about um practices ya know parenting practices rather than types of foods. So ya know the introduction of foods or maybe food rules that you have, or maybe restrictions of certain foods or snacking is only allowed at certain times, or clean your plate type of philosophies. So rather things like that ya know the practices, rather than we have broccoli, we have carrots. Does that kind of make sense?

K: Yeah, yeah.

PI: And um (.2) yeah, so that's about it. So let's start. Why don't you tell me how many kids you have, what are their ages, what are their names, I know you may have sent that in an email but just so we can talk specifically about each one of them, if you don't mind.

K: Okay. My oldest daughter, her name is McKenzie do you want me to spell that?

PI: No, you're fine.

K: Okay, and she's 11.

PI: 11, okay.

K: And then my youngest daughter is Avery and she's 7. And she has Down syndrome.

PI: 7, okay. And you have 2?

K: Yes.

PI: Okay, alright wonderful .So let's begin with the first question. Okay how do you feel the physical activity habits of your children differ? (.2) And what impacts those habits?

K: Um (.2) hhh (3.0) I feel like, I think Avery ((child with DS)), my youngest is probably a little more active than the older one just because she is younger and she doesn't have the attention span to sit and do things for longer periods of time. Whereas McKenzie ((child without DS)) can sit and watch an entire movie or ya know if I let her, she would watch TV all day long.

PI: Yeah?

K: Yeah, so I have to turn the TV off for mostly McKenzie, ya know Avery she, she gets bored of a show or a TV, movie or something. So she'll get bored and get up, she loves to

be doing things outside and she's very active[She's, I call her my gross motor queen!]
[Yeah because she's just, there's not (.2) delay as far as gross motors skills. She's really just good at it all. Ya know she can scale a wall and she's good at climbing, ya know we have a play structure outback and she'll go just play on her own or she tries to get her sister to come outside with her. Whereas Kenzie could just stay inside all day and watch TV.¹

PI: [okay.

[oh Yeah? ((laughs))

PI: Okay, and so how does McKenzie react (.2) when Avery wants her to come outside?

K: Um, ya know (.2) sometimes she will and sometimes she won't ya know it depends on if she's in the middle of something. Especially like a movie that maybe she's recorded that she's been waiting for or um ya know if it's something that she's pretty interested in she'll say yeah (.2) in just a little bit. And then she'll come outside. (.2) Or I push her outside!

PI: Okay, well great. So more um do you think a difference because of age or a difference because of personality?

K: I think just personality. Avery's just more (.2) active, she likes to go places. Ya know she's always ready to go. No matter the time, day or night. And Kenzie, she a homebody. And she likes to be at home and stay inside and just ya know, be a homebody.

PI: So that's just her preference?

K: Yeah.

PI: So now, the next questions which is a very similar one um but this one is how do you feel the eating habits or the eating patterns of your children differ and what impacts those habits? So eating patterns (.2) maybe the amount that they eat or whether they can tell if they're full or not (.2) to stop eating. Things like that.

K: I think again McKenzie, ya know she's going, she's approaching the teenage years and she .hh we have to really watch the amount that she eats [because she, she eats really fast. Ya know. She'll eat super fast and we'll try to get her to slow down and drink water or your milk in between, ya know set your fork down in between bites um ya know she asks for seconds or thirds, we say well finish up what you were drinking at first and then wait a few minutes and then you can go back and get more. Whereas Avery, she's a snacker. She would prefer to snack all day long and (1.5) that would be just right up her alley.² ((laughs))

PI: [okay

K: I think the hormones for McKenzie definitely impacts the amount that she eats. Uh, and her preference really is to have a lot of sweets. And so we've had to put some restrictions, on that=

PI:=Okay.

K: Uh, and Avery, her favorite food is chicken and rice! That's what she wants, she would eat that all the time, 3 meals a day, she would snack on that. Um (.2) and she's not, she doesn't like a lot of junk food or sweets especially.

PI: Okay, and McKenzie does?

K: Hm, uh ((affirming)). Yeah. Avery's more about, she'll eat a lot of fruits and vegetables, but she does like um she likes (.2) um carbs. Like she'll have crackers, or pretzels or things like that so.

PI: Okay, and since you brought it up you said that um you have kind of put some restrictions maybe on McKenzie ((child without DS)) just cause you've noticed she's knockin' on that adolescent door and is your concern, is it for health, is it for weight or what is kind of the motivation behind putting those restrictions.

(3.0)

K: Health and weight. She's mentioned to me like do you think I've got a little bit of a belly? She's kind of getting to that age where's she's concerned about her body and she's not overweight, her body mass index is (.2) good. It's below that cut off line so we don't really have to worry about her but we have to, we have to stay on top of it ya know. (1.5) So the restrictions that we have put on her have been that (.2) she gets desserts on weekend, that's it=

PI:=Okay.

K: Monday through .hh Thursday ya know, it's just her meals and that's it. And if she wants something kind of sweet then she I give her an apple er a piece of fruit or something like that.³

PI: Okay, so now Avery does not have that same type of restriction or=

K:=She doesn't, because she doesn't ever ask for dessert.

PI: Okay.

K: Ya know she'll say she's hungry, but that means I want something, something substantial to eat. Like she doesn't every ask for ice cream or candy or cookies or anything like that. Whereas McKenzie would.

PI: Yeah, she can kind of self-regulate a little bit more?

K: hh I don't know if it's self-regulation it's just a preference.

PI: Okay.

K: Ya know, she just doesn't like that stuff. And if we go out for ice cream, she likes sorbet. That's, that's what she prefers.

(1.)

PI: Okay (1.5) Okay good alright. Well moving on to the next one. How do you feel your personal physical activity habits impact your children, impact the girls, and then your whole family, the 4 of you?

K: Um hhh (1.5) Well I probably, I think McKenzie's like me in that I'm kind of a home body. Um and Avery's more like Brian, he's always ready to go and ya know always

willing to do something. He likes to stay real active. Um so, it's ya know but I do get myself to go out and we go on bike rides and hiking in the park. And I don't know if you're aware but Chico has (.2) one of the ((1.5 pause connection lost)) world's largest city parks and so[and the park is huge and so we get to use that a lot. And we live close enough so we just hop on our bikes and just ride from our house um, so we try to do that [all 4 of us, yes. Yeah, I have a trail-a-bike for Avery so she um gets on the back of my bike so I don't know how much pedaling she's doing sometimes I swear she's not doing any at all! ((laughs))

PI: [oh really
[all 4 of you?

PI: And you said a trail-a-bike, is it kind of like a tandem?

K: It is. It attaches to the back of my bike and it has one wheel in the back and then so she has a handle bar and she pedals as well.

PI: Okay.

K: So, she could sit back and do absolutely nothing and I would be pulling her the whole way, which (.2) has happened sometimes. And I have this little rear view mirror where I can see her and I'll say pedal faster! Ya know and she'll get going a little bit and then sometimes we'll get off our bikes and she wants to walk and she'll even run while we ride ((connection poor)) () so she's much more active. But I think that we are fairly active as a family but we definitely have room to grow.

PI: Okay and do you notice any um I know McKenzie's a little bit older and so as they get into adolescence their interests change. But do you notice Avery's level of activity right now being different then what McKenzie's was at her age?

K: I think so. Like I said I think their personality's are so, ya know Avery's always willing to get up and go and do something and McKenzie, it really depends on what it is ya know?

PI: Okay.

K: Yeah, if it's something that's interesting to her she'll go do it. But otherwise she's like 'nah, I'll just stay right her.

PI: ((laughs)) (1.5) So very politely?

K: Yeah

PI: So what have you noticed since there is that level of interest difference have you noticed that your encouragement or the types of support you provide to encourage them, are different? Since maybe one likes it a little more. So and when I mean support I mean maybe signing them up for classes or buying them equipment or being active with them? (1.0) Do you notice a difference between the 2 girls?

K: Um, well just like for Avery, things that we might buy her are things that we can do outside. Like a little T-ball set or a soccer ball or she has a little basketball hoop and things like that. So things that I would buy her would be things for outside whereas McKenzie it might be ya know clothes and books and things like that.

PI: Okay. But, so if you were to try and encourage McKenzie for physical activity and whether that's organized (.1) or whether it's just some type of independent exercise, what types of support would you give her since her interests are a little bit different?

K: She is interested in soccer. So (.2) she's been playing since she was about 6 or 7 um=
PI:=okay.

K: So whatever it is that she's interested in, we'll encourage as much as possible and so that means that like her Dad is the coach () ((possible connection lose)) has been assistant coach he's been the coach the last 2 seasons. So I think that, that really encourages her to ya know keep going with that.

PI: Because she sees him there?

K: Oh she loves it, oh she loves that he's the coach that's just the best thing. That Dad, that Dad is the coach. And then we, Avery and I'll go to the games and we'll sit and we'll watch her play and encourage her in that regard. Um, we also (.1) the girls and I all dance hula. So we (.2)=

PI:=Okay, and what is that?=
K: Pardon me?

PI: Hula, what is hula?

K: Hula dancing? Yeah, Hawaiian dancing.
PI: Oh, okay!

K: Yeah, ((laughs)) my girls are um Hawaiian. They're Polynesian.

PI: Oh, okay!

K: So yeah, we started them both when they were 4 and 5 years old. So, that's a regular practice ya know once a week=
PI: =how wonderful! This is something they do with you instructing them or they go somewhere?

K: Uh, we all go somewhere
PI: Oh fun.

K: ((connection lost)) () class that we all take together. And it was in () them seeing me and then they'll all do it with me. And so we do lots of performances. Ya know especially at retirement homes and birthday parties and weddings and corporate parties or whatever. We do a little performance and they hire us so.

PI: So it's active, but it's something that you all enjoy?

K: Yes, yes. That's I think that's how I encourage them. Like doing things that are a lot of fun like say going on bike rides and going hiking and a ya know hula (.2) soccer and Avery does swimming and McKenzie does soccer.

(1.5)
PI: Okay, wonderful. So um and this next question and you kind of already answered it, ya know how do you feel physical activity the quality time that you all spend together? Er do you recognize that quality time can be spent by being active?

K: Yes! That's a much higher quality than sitting watching a movie together! ((laughs))⁴
PI: yeah!

K: Yeah, we'll go (1.0) also our housing area has a big playground in the middle of it so we'll go to the playground and let the girls play and walk the dog and do all kinds of stuff like that. And I feel like that's really important and that's what we like to do as a family, it's ya know go bike riding and playing at the playground and ya know (.2) I love hula dancing so

PI: Okay, well I'm so, I'm intrigued by this now ((laughs))

K: It's a good bonding experience for all of us.

PI: Absolutely. Well and you know I'm in Texas so we don't have a great deal of hula dancing, so I'm sure it's more common in California.

K: Yeah, I guess.

PI: That's really interesting. So now kind of transitioning back to eating habits and different feeding patterns how do you feel your eating habits and patterns of eating impact your children? And so just to give an example um ya know maybe you snack at night and so maybe sometimes you don't want to snack in front of them because you don't want to encourage or discourage that. Or maybe you're careful of what you snack at night. And it may not, it could be something positive that you want to model but how do you feel your habits impact them?

K: Um, well if I'm gonna have ice cream or something like that I'll wait til after they go to bed.

PI: Really?

K: ((laughs)) I fight that part!

PI: And is that from past experience or is that something you just kind of wanta hide from them?

K: Um no because McKenzie will say well you're having ice cream, so why can't I have ice cream? Because I'll show her a pint of ice cream and say, this for me is going to last 4 times! Whereas for her it would be 1 or 2! [Um so yeah and I'll show her I'll have a little bit of ice cream and I'll show her the top of it, now this is how much I've eaten that's 1 serving for me =

PI: [1 or 2, yeah.

PI:=yeah!

K: So the rest will go and I'll have a little bit more tomorrow and a couple more nights after that. So she's noticed and she um she thinks it's not really fair and she'll say things like you're o well you're um shoving it in my face or something like that. So I said well okay so I just have my little bit of ice cream when you're in bed. Um but I think that ((connection lost)) () ya know we also have some that we want to encourage um (.2) both kids is that we ah juice. We've been juicing for probably 2 years. Raw fruits and vegetables. And so especially my husband and I do it every day for lunch, that's our lunch, to have about an 8 ounce, 8 to 12 ounce glass of juice and um so then on the weekends we'll make it bigger we'll throw in an extra apple or orange to make it sweeter

and then I encourage them to have some too. Especially like if she's gonna do a soccer game, we're like this is fuel ya know this is gonna make you have a great game, and so we'll give her um (.2) they probably have I'd say 6 to 8 ounces of juice on a weekend. So I'm trying to encourage them to have more fruits and vegetables (1.0) um and they see us doing it so.

PI: And so that's worked for you guys, they see you and so then they want to do it.

K: Hm huh ((affirming))

PI: Okay, and so since you've mentioned that McKenzie you know may want to have those extra snacks have you guys imposed any types of restrictions or rules on you know snacking or you know portions or having seconds or maybe they have to ask mom before they want something?

K: They do need to ask me before they want anything. Both of them do. Because that's just, I don't want them running and grabbing, because ya know they run and grab unhealthy snacks.⁵ And not that we have a ton in the house, but anything that we've got they'll go for it so yeah they need to talk to me before, yeah can I have this to eat or can I have that? Um the restriction I told you about the dessert for McKenzie is only on the weekends, Friday, Saturday or Sunday. And for Avery ((child with DS)), she really wants to snack right before dinner.[Yeah she always wants to eat, so like 3:30 or 4 o'clock and we eat early, we eat at 5 o'clock um ya know 3:30, 4 o'clock she wants a bunch of snacks and I try to hold her off as much as possible (.2) or give her something that's not gonna fill her up. So that she'll eat dinner, and then if she doesn't eat dinner then ya know we hold it for awhile and then if she asks for a snack later, then we give her, her dinner.

PI: [Oh really?

PI: Okay. (1.0) Okay great and so do you guys talk about kind of the concept of feeling full or ya know recognizing hunger within yourselves. Is that something that as a family you guys have ever focused on?

K: Um we have in the regard that um we've talked to both of them in the regard of well maybe you're just thirsty? So let's try some water first and see if ya know if that will fill you up. And ya know we're able to explain it to McKenzie more in that sometimes your brain doesn't know the difference between thirst and hunger, so you might reach for the water first=

PI:=right=

K: =for Avery we just give her something to drink and we just say here drink this and then I'll go fix you a snack and so she'll be drinking that while we prepare something for her to eat and um (.2) ya know we've talked to McKenzie also that it takes your brain awhile before your stomach to tell that's it's full for it to understand that ya know I'm full. And so that's why ya know when she asks for seconds we'll say you need to finish what you're drinking and we're gonna wait 5 or 10 minutes and then you can have

seconds. And usually when we ask her to wait she won't go for it for another serving or helping.

PI: Okay.

K: And for Avery, we (.1) ya know we've told her you've had enough to eat you couldn't possibly be hungry, cause you just ate all this. Um and ya know let's go do something or let's go get a drink of water or (.2) ya know anything like that. So it's hard to kind of rationalize that kind of stuff with her and try and explain all that stuff with her so we're probably a little more um ya know demanding of her in that respect.

PI: Okay, and how does she I mean does she respond well or does she respond, okay Mom and Dad said that's it, that's it.

(1.5)

K: Um, sometimes she gets upset she goes no, no I'm hungry. And I'll say Avery you just had pretzels and you had a mango and ya know you couldn't possibly be hungry and she'll say I'm hungry, I'm hungry and so then I usually just try to distract her with something. Ya know, well let's play this game or some let's sit down and we'll do this puzzle er ya know let's play with this ball or let's play this game (.2) and so sometimes she'll buy it and sometimes she'll continue to insist that she's hungry ((laughs)).

PI: ((laughs)) Okay, great. Okay let me see, we're just moving right along. Let me make sure we are hitting all these points (2.0) so I don't think we um hhh how do you guys feel about um physical activity and quality time and have you guys thought about how physical activity could be quality spent together?

K: That's usually what we do as far as when we spend time, on the weekends we usually do something together and it's usually something active.

PI: Okay.

K: But ya know sitting around the house and watching a movie or even um well once in a while we'll do like a family game night and that's pulling all the games out of the cabinet and doing one right after another after another. So once in a while we'll do that but usually it's going somewhere and doing something ya know Chico's a fairly small community and so we have a lot of community activities, so it might even just be ya know walking around town doing whatever is the activity downtown or but usually it's kind of going to the park and doing some hiking or biking or ya know walking or something.

PI: Yeah, that's pretty common for you?

K: Yeah. I think that's, that's how we think of physical activity. Yeah, family time is more physical rather than just sitting around.⁶

PI: Okay, so then similarly how about um ya know quality time related to eating habits or eating patterns? Do you all look at that as being an option, so for instance going out to dinner or planning the meal together?

K: Um (.2) I think that's important too (.2) because I think it sets good examples for the kids. Ya know on how to eat, how to prepare the food, ya know what types of things are healthy. So ya know once in a while Brian and the girls will make a big meal for me. So they'll go from the planning phase, to the shopping, to cooking and cleaning but we do family dinners every night so. I'd say there's maybe 2 nights a month where we don't sit down and have dinner as a family together and I think that for us is just kind of checking in our day. So I see that ya know family meals are pretty important as quality time as well.

PI: And so you said those 2 nights that you don't sit down together, what would prevent you guys from sitting down as a family?

K:Um (4.5) I'm trying to think (2.5) maybe if we were going to someone else's house for something, like a party or something, um hhh let's see (2.5) and sometimes like McKenzie might have a sleepover and so then maybe Avery, Brian, and I would just I don't know maybe we would go rent a movie and we would let her have dinner in front of the TV once in awhile.

(1.5)

PI: So I know some moms have talked about scheduling, ya know we're taking this child to this activity or Dad has to go here and so scheduling can be uh and issue. Do you see something like that, that prevents you all?

K: hhh, uh not as much we don't do a lot of stuff in the evening. I know with Avery's speech, it's gone a little later the last few weeks so that might be, yeah. So that might be one ((connection lost)) (night a week) that a we've had some issues with that. But that's only, but yeah maybe 1 of those times during the month might be a scheduling issue.

PI: Okay, so how do you plan for that? Do you make a lunch prior or do you plan to grab some food, some fast food on the way? How do you plan for that?

K: We don't, we don't usually do fast food. We would, what I would do would be to do like a leftover or I would throw something in the crockpot or um (1.5) yeah those are the usually we would try to run home really quick and just eat some food kind of quick and change clothes and go to the next activity.

PI: Okay.

K: No I wouldn't do, we wouldn't go out to dinner because that's gonna take too long and we don't grab fast food. (1.0) The only time we grab fast food is if we're traveling and ya know there's not a lot of options.

PI: Okay, very nice. So and you've spoken that you feel your family is a very physically active family, you know you've given several examples, have you noticed I know we spoke a little about activity differences within the girls, um have you noticed that if you decide to do an activity within the family (.2) are you able to all do it together? Or

sometimes does ability kind of make you branch off and maybe Mom goes with Avery or Dad goes with McKenzie. Have you noticed maybe a specific activity or anything like that where you have to do that?

K: Both.

PI: Both, okay.

K: Both, yeah. We try if we're gonna do something that's like fun family time, we try, well we do we make it to where we can all do it together. Cause that's just not, I mean you can't have family time without everybody, so[Like I said, we've adapted things where we put the trail-a-bike on the back of my bike and if we would go to something like running um we've done that in the past where we'll go for a walk and we might run for a bit. Ya know we're not runners by any means, um but we have this (vital) course where you can stop and you do exercise in between [so we do that once in awhile um and so what we do is we'll take the jogging stroller with us so that if Avery gets tired, she fatigues a little bit easier than everybody else, um if she gets tired she can just hop in the jogging stroller and rest for a little bit and then we can push her and keep going but if she doesn't want to stop then we'll just push the stroller, empty so, we try to do adaptations as we can.

PI:

[Yeah!

[Yeah.

PI: Rather than branching off?

K: Right, and but ya know if it's something um McKenzie and Brian going to soccer, I might take Avery and she and I would go play on the playground while McKenzie and her Dad'll do soccer. So we'll do both.

PI: Okay (2.5) so I know you said you guys are a pretty healthy family and gave the example of the juicing and all that. But do you notice any factors or any barriers that you guys do see, so maybe either seasons or times in life when you are not as active or what you would consider to be healthy. Can you think of any barriers for you?

K: Well, Chico we have a lot of cold, cold weather and it rains a lot up here. Not like Southern California, I mean we can go for like a week at a time where we can't, where it's just raining. So what we've done is we got that Wii System and we got, I told them the stipulation for me was that it had to be a moving game because I'm, I was kind of anti-video game. I think kids are doing this and you know you can't, reach em so[so we'll have to get all the moving games. So we got a couple of the ones with the mats like they're outdoor adventure where you have to run and jump up and do think like that and we have the dancing one and then we have the zumba and (1.5) I forget there's another outdoor activity one that we got for Christmas so we're gonna start on that one. So that might be something that, the weather would make it something difficult for us to get out so we went ahead and got a video game that will kind of help us to get moving at least.

PI:

sure[

PI: Okay, so you have that alternative built-in in case that barrier presents itself.

(1.5)

K: I'm sorry could you repeat that.

PI: I said you have that alternative kind of there if the barrier does present itself.

K: Right, right. And then in the summer time we've got extreme heat. 100 plus, so we just try to um we've joined a gym to where they have I don't know 5 pools or something like that. So in the summer time it's a lot of swimming. So we keep the kids in the pool a ton.

PI: Okay, and will you and your husband swim also?

K: Yeah, usually if we can go together, we'll take turns. So I'll hop in at the lanes and just ya know do as many laps as I can do again ya know I'm not a ((connection lost 2.0)) great swimmer so I hold on to that little board and ya know he'll take some turns, so if we're both together we'll do that. And if it's just me usually I'll get in the water with them for a little while and its just kind of playing around, ya know it's nothing. I don't consider it a ton of exercise for me, but I do for the girls.

PI: But like you said you feel it's important to model that.

K: Hm, hmm ((affirming)).

PI: Okay, great. (2.0) Let me see (1.0) so um and I know that we haven't mentioned this at all and this may not be something that your family kind of um has dealt with or will deal with in the future. I know McKenzie's kind of at that adolescent age where she does worry about her weight or kind of ya know has made some comments and I'm sure it's not news to you that children with Down syndrome are prone to overweight or obesity and um have you noticed kind of that concern in the back of your mind? And maybe that is a motivator, or you encourage activity or healthy eating habits because of that concern.

K: Yeah, yeah I mean Avery (already has some weight issues) and um we decided (1.0) when she was born and we knew about those issues and so that it was gonna be important for us to um stay active and to do active things and that's why we did we joined the gym and like I said we got her into swimming and she has juvenile arthritis so that presents a huge, actually I should have talked about that, a huge barrier with working out when she is having episodes with that she doesn't really wanta (.2) move.

PI: Right if it's inflamed.

K: Yeah, she doesn't want to walk or anything. So um, yeah we try to um, we put her into swimming because we thought that would be good to get her joints going and hopefully help out with her arthritis. She does it all year long. (1.0) And she's about ready to join a team. And we want to get her into Special Olympics, eventually. So we're trying to encourage it because it's something that she's good at, it's something she enjoys, it's good for her body and her health issues and then we try to be as active as we can. I think like I said, there is always room to grow but I think that we would like to continue to work a little harder. Like I said we joined a gym this last year and we're trying to get out

and do more of that. And taking the girls with us and ya know sometime what they'll do is they'll stay in the daycare for awhile and then we'll work out and then we'll grab them and then all together as a family we'll all go swimming.

PI: Okay, so then are they aware kind of that you have that pre-time where you and Dad and getting your workout and you come and get them are they, are you guys vocal about that? Or have you had any conversations about that?

K: yeah, yeah they know they're in the daycare just because we're trying to work out a little bit.

PI: Okay.

K: And then like I said sometimes it might be ya know, Dad swimming with the girls and I'll jump in the pool and go do laps and then okay now it's your turn so they're seeing us go from one to the other. And then at home, I've done the zumba one with the girls and ya know they think it's fun to wear the little belt that keeps track of your movements and so um they'll do that one with me and it's been awhile since we've done that because that's usually more of a winter activity so just kind of starting to get into the zumba thing again. They'll do it with me and they see me doing it.

PI: And you made a comment that you and your husband kind of decided that, let's make them active or let's you know be active as a family. Now is that kind of because of a familial history, ya know a history within your family overweight or obesity or because [of Down syndrome?

K:

[Down syndrome.

K: That was specifically because of the Down syndrome. We knew that she was gonna have potential for a weight issues and so we knew that we had to step it up.

PI: Okay.

K: As far as that went.

PI: Right.

K: Also, with the with the diet, we just make sure that we're conscientious, like I said Avery's just not a sweets kid so that just worked out in our favor. But ya know portion control and we've been I don't know cognizant recently about instead of giving her a bag of pita chips or a bag of pretzels is to um put them in a bowl. Which she doesn't like, but she's getting used to. So just try to keep in mind portion control and we'll tell her you know you can't have the whole bag because you don't need to eat that much.

PI: Yeah.

K: Ya know this is enough for you to eat. And this is enough and you're not you won't be hungry after you eat this.

PI: Right.

K: So portion control is another thing that we've had to work on with Avery as far as the snacks go.

PI: Okay, so more portion control with Avery and then kind of monitoring the sweets with McKenzie? Would you say that's[okay=

K: [hmm hm ((affirming))⁷

K:=Yeah. And then activity level with both of them.

PI: With both of them, okay. And so if ya know if down the line you did have a weight concern for one or both of them would your primary target be to change eating habits or to change activity levels?

K: Both.

PI: Both, okay.

(1.5)

K: Yeah, I know for awhile, for awhile there I was doing that kind it's called sneaky chef?

PI: Okay.

K: Where, I don't know if you're aware of that?

PI: Just adding in vegetables here and there.

K: Yeah, I would, yeah you puree them and then you hide them in lasagna or there's one, I made McKenzie spinach and blueberry brownies and she oh can I have more? It's like sure!

((Laughs))

PI: I've never heard of those!

K: What?

PI: I've never heard of that one, I'll have to try it.

K: Yeah, she liked it. But now she's, she's suspicious. McKenzie is. I'll say here's some orange juice and she'll go well what else is this? Is there a carrot in there? Yeah, it's just 1 carrot ((laughs)) and Avery just doesn't, ya know she doesn't even care.

PI: Yeah.

K: If it tastes good, she'll eat it or drink it. Ya know, a snack for her might be a cup of peas. I mean that's okay for her.

PI: Okay, wow and so she's okay with that?

K: Yeah she loves fruits and vegetables and that's one of the things I first offer is when she asks for a snack I'll say well would you like a pear or have a mango or an apple or um apple sauce or um peas and then if she keeps saying no no no no, last resort is something like pita chips or pretzels or um popcorn, the low calorie popcorn is another one. Those are her big snacks. Pita chips, pretzels and popcorn. Those are the things she just loves.

PI: Okay, very cool. Well let me see (1.0) I think we have just about gotten through all the questions that I had originally planned.

K: Okay.

(3.0)

PI: And I think that is. Now um and we kind of talked about several different things is there (.1) ya know anything you can think of broadly that you would like to share, maybe

something that you were hoping I might ask about whenever you heard the topic. Something that you would just like to broadly share, something that you feel people should know about related to (.2) eating habits between siblings, when one has Down syndrome or er within the family kind of healthy environment?

K: Um, I think that when I said I like talking about food[we've just done a lot of research. I think it was April of 2010 I was diagnosed with breast cancer and I've spent the last year and a half doing a ton of treatments and um (.2) surgeries and I still have reconstruction going on.=

PI: [yeah

PI:=Wow

K: I still have 2 more small office procedures, so (1.0)

PI: So is the cancer gone? Are you considered cancer free yet?

K: Yes, I'm cancer free, cancer [free for over a year, but um ya know that's kind of inspired me

PI: [wonderful

to do a ton of research about food and it's inspired me to work on taking a lot of um chemicals out of our meals and the food that I prepare. It's really encouraged me to do a lot more from scratch and it's encouraged me to not eat at places like when I said fast food, we just don't do that. And we've never been a big fast food family anyway, but now it's even more so. And if we're driving or if we're traveling, we'll still try to stop at a sit down restaurant. Instead of you know going to, we don't eat at McDonald's, period. That's evil! ((laughs)) but we might go to Carl's Jr. or something like that and that's ya know if we're really in a bind. So I think my health issues and then I think Avery ((child with DS)). Ya know it all started with Avery and her health issues and we've even looked at maybe taking Gluten out of her diet and just trying to you know mess around with our diets and see if we can live a little healthier lifestyle based on what we put in our bodies. So that's, I think all of these health issues between all of us and my husband was having these migraines and we've noticed that when he was on the South Beach Diet he didn't have these migraines so what was not in there that's in our regular diet that's causing these migraines. So I've done, like I said we've made a lot of changes in the last couple of years to our diets, and the juicing has been one of them and I felt like we really need to add a lot more fruits and vegetables ya know I feel like that's the best thing we can do for, for us and so I think the girls have had a lot of encouragement in that regard. When they see us eating well and making these changes and we talk about, McKenzie um she doesn't wanta ever eat fast food. So, and instead of calling it McDonald's she calls it McFatties! ((laughs)) So yeah she did her science fair project on um hamburgers and ya know, the McDonald's hamburger didn't grow mold and why was that ya know?=-

PI:=Right, if it doesn't go bad, it's not food!

K: No! Because of all the um, preservatives and um even formaldehyde in there, and that's pretty bad.

PI: Absolutely!

K: And so Mc Avery will still, she'll still ask for McDonald's and it's been years since we've been there but she'll still ask for it.

PI: Because it's so visual!

K: yeah, the marketing I think is just so good! Yeah, I mean my hats off to the marketing department at McDonald's but um ya know she'll still ask for it but I think a lot of it for her was because we went to the play place and she got to play while she was there. Yeah, and Avery's not always as aware of what we're doing or the changes that we're making in our diets. And if she does ask for McDonald's I'll say no we don't eat there, that's yucky food, that's not good for you. So we'll explain it to her in a way that she understands, but ya know she doesn't really comprehend that it's full of all these chemicals and it's bad for my body, but those are some of the major oh I don't know things that are encouraging us to keep making those changes.

PI: Right, and so the lifestyle change seems more focused on health rather than weight or something like that.

K: Yeah, that's not I mean I don't think that, I mean the weights important but I think it's really just about putting good foods in your body and whole foods and we do a lot of organic stuff which is easy in California and it's easy in Northern California because we're surrounded by fields so we have a ton of farmer's markets we have a lot of local stuff. We have like 5 farmer's markets a week! I mean it's crazy.

PI: Wow.

K: Yeah, so we do a lot of that stuff. And Avery likes going to the farmer's market and ((lost connection)) () she'll go and grab a carrot and ya know pick out some fresh honey or whatever so (.2) she enjoys that stuff and she understands and we are getting good food and we're juicing and she likes to help us juice and so it's kind of like a family play day. And she'll know that, that's what we do. Ya know we juice and we get our good healthy foods and so that's important to all of us, and it really isn't as much about the weight but ya know, being active and having good exercise and eating good food so ya know um one is not more important than the other.

PI: Right, there kind of all interchangeable?

K: Right. Well, Ms. K I appreciate your time and I think that really is all the questions that I have and I appreciate your description of everything. Do you have any questions?

01/02 Stop 46m08s

02/02 Start 1m30s of 2m28s

K: We give her healthy foods and we try to keep her as active as possible and we'll keep pushing that as much as we can but ya know, and we just do the best we can.

Or seconds or whatever and you know putting your fork down and talking, so we'll make sure that we are modeling all this stuff as we sit down for dinner ya know with Avery she might just be eating and so we'll ask her you know how was your day what did you do and make it more social and so she has time to realize that she is full and she doesn't ya know need anymore.

PI: So mealtime is multipurpose, it's not just for food it's for building family relationships?

K: yeah, checking in. Yeah, we've read the studies about meal times and how it keeps them out of gangs, drugs, school[right and when it was a little more difficult we would ask open ended questions like what was the best thing about your day today and what was the worst thing? Yeah, so even then Avery was participating. And we're always open to new suggestions and new things⁸ and yeah so I'm interested to see some good stuff that comes out of this that can help us too!

PI: [opens up communications

Tape Stopped 2m28s

Annotations

¹ Age difference could also be an influential factor, but this mom states that her child with DS is more active than her child without DS. Her reason why the difference seems related to one child's interest in sedentary activity (i.e., TV).

² This mother appears to monitor and restrict the eating habits of her child without DS more so than her child with DS. At this point it has not been said whether this child has a potential weight issue, but the mom seems concerned because she is in her early teenage years and she eats really fast

³ Restrictions were placed on food after mom noticed that her daughter without DS was getting into the teenage years, asking about the size of her 'belly' and that she ate fast, despite having a 'normal' BMI. There are no restrictions on the daughter with DS because she does not even ask for dessert

⁴ Very strong statement. I think another mother has said this as well that being physically active together is much higher quality than being sedentary together.

⁵ The reason for requiring them to ask when getting a snack is because Mom wants to make sure they don't eat unhealthy snacks, insinuating that they would grab unhealthy ones on their own.

⁶ quality time is higher when spent being active than sedentary

⁷ Child with Down syndrome = restriction/portion control; child without Down syndrome = monitoring of sweets

⁸ Puts great emphasis on the interaction that happens at the dinner table between parents and children. She's very educated and has clearly researched this. She terms the interaction as 'checking in'

Transcript, Interview Eva

Interview via Skype

01/02 0m of 33m56s

Principal Investigator (PI): Okay, so the audio recording equipment is already in place, if you need to take a break or leave the room at anytime please feel free to do so the session will last about 90 minutes ah the purpose of my dissertation is to explore the development (.1) of physical activity and eating habits among families who have multiple children including one with Down syndrome, from the perspective of mothers. Uh the target of exploration will be the potential relationships between parent modeling, physical activity levels, and feeding pattern differences between siblings and perceptions of family barriers to healthy lifestyles habits. And when I speak about feeding pattern differences I mean to include practices so rather than types of food uh I would want to discuss like the introduction of new foods or restriction of foods (.1) or having food rules (.2) cleaning your plate philosophies so things like that (.2) not so much the fruits and veggies.

E: Okay.

PI: Um (1.0) let's see (1.0) so I have about um 13 questions

E: She just came to see you again ((laughs, Julie [E's daughter] came on the computer screen to say hello))

PI: ((laughs)) okay, I have about 13 questions or say and um ya know it's kind of free and open discussion so if we want to stay a little big longer on one question that's great or if we want to move on to the next one that's great. So, it's absolutely flexible like that so.

E: Alright.

PI: ((clears throat)) Alright, Ms. E I will begin are you all ready? Do you have any questions?

E: Uh, no I'm good.

PI: Okay, my dear the first one (.1) is how do you feel the physical activity habits of your children are similar or different? And what impacts those behaviors?
(2.5)

E: Um, Julie ((child with DS)) is a high energy girl (.2) truly. ((background laughter)) I know you heard that, but she is not as likely to get up and do physical things. Uh my son ((child without DS)), plays a lot of sports and likes to get out and do stuff, she would rather (.2) be on facebook. And I really don't hh probably make her get out as much as I probably should, she's very trim uh well you can see that! ((laughs))¹

PI: Yes! She is yeah.

E: And she participates in Special Olympics every season (1.5) but uh she doesn't really like to go and do stuff and truthfully I don't make her a lot. So I'm gonna say that hopefully, truthfully. Um (1.5) And probably part of it is to that he ((child without DS)) is

playing at a level that she is not. And she of course is older so she doesn't always want to play however she can do it, and ((he)) wants to be with his buddies down the street which I totally understand[and I want him out there playing so I'm kind of mostly fine with that

PI: [right

((background Julie's is asking questions and wants to participate))

((in the background))

Julie (To E): Mom, hey Kelly, Kelly

E: (To Julie): Jules, come here and talk to Kelly if you want, come here and do it () oh okay you want to do your own Skype, you have at that. Oh my golly we have created a monster ((laughs))

PI: ((laughs)) That's okay!

E: It's actually, this may be kind of a cool thing for her. Um, did I answer everything?

PI: Absolutely and if I could just branch off you had made a comment about maybe you don't encourage her ((child with DS)) as much, do you think that you have encouraged him ((child without DS)) a little bit more?

E: .hhh no I just don't hold her feet to the fire and she doesn't really want a do it and unless I then am out there making her do it (.2) it's probably not going to happen. I honestly and this'll just tell her as my failings as a mother and a human being is that I'm busy and I get home from work and want to work on dinner or work on whatever[so if I'm not in it, then it's not happening and I don't necessarily want to do it my own self so (.2) that's me just telling the truth.=

PI: [okay [yeah

PI:=right. Yeah, absolutely. But if you were to go out=

E:=it's not like I don't want her ((child with DS)) (.2) to do it <physical activity> but she is honestly (1.0) not interested[I probably allow her to get out of it (.2) because we're so thankful that she's trim and very uh physically capable in her own way. So we've been really lucky. There's a lot of children with Down syndrome that are very chubby=

PI: [yeah

PI:=right.

E: And she's not. She only weighs 75 pounds. I mean she's not very big.

PI: yeah.

E: She's like in girls (1.5) she's like a girls 12 or an extra extra small in a junior.

PI: right and she's 16.

E: Yeah she's a little one

PI: right, so there's no concern (.1) for her weight?

E: Not at this point ((laughs)) she's echoing me in the background ((speaking about her daughter standing behind her)) No, not at this point and we put her in track for Special Olympics and softball and whatever dance and cheerleading but (.1) that's not every day. (1.0)

PI: So do you think the the lack of concern impacts how much you encourage her?

E: Probably, it does at this point in life and the fact that we're just a busy little family and her mother ((speaking in 3rd person)) (.1) doesn't exercise enough her own self. That's part of it too is me. Less about my son and more about me.

PI: Right, (.1) if you were to go and do it though, do the activity or whatever would she follow, easily?

E: No. She would fuss but I'm still the mother I still run this railroad=

PI:=absolutely!

E: Yeah, so she would go cause I would (.1) make her. And my son can't make her cause she'll just be so obnoxious to him that he'll just give up. Cause he tries, he wishes she'd play more that she will and she's laughing cause she's listening to everything I'm saying[she knows that he will beg her to play and she won't do it.

PI: yeah[

PI: what about, what about your husband? Does she=

E:=he will definitely engage her more cause he's definitely more athletic and more interested in doing athletic stuff than I am. So when he's home, he travels a lot but when he's home he'll definitely do stuff but he still he coaches Stephen ((child without DS)) in basketball and stuff so (.1) he's still more to take () but he will make her do something. He can. I'm more likely to dance in the kitchen with her, we were dancing yesterday mornin getting ready to go to school and I'm like we must look like the biggest knuckleheads ((laughs)) so

PI: Well that's activity.

E: It's like 6 in the morning and we're dancing in the kitchen and (1.0)

PI: Well dancing is activity.

E: Yeah! Dancing counts, see I'm more likely to do that ya know then I am to go and try to play basketball which I pretty well stink at.

PI: Yes, but if you look at activity as more (.1) movement, including dancing[would that kind of change the amount of activity that you think guys do?

E: [yeah

E: Um, it does. It won't change it a huge amount but yes cause it's pretty, it's not set it's fairly impromptu. But she likes to dance and I do too. So I'm totally open to that.

PI: Okay.

E: So the good Lord skipped over me with athleticism ((laughs)) but I can dance! I have rhythm thankfully.

PI: Okay, so you can have a little dance party in the living room?

E: Yeah!

(1.5)

PI: Well that sounds like fun. Okay, well we'll go ahead and move on to the next one but again feel free to come back to this one if, if you'd like too[so a similar format to the last one. How do you feel the eating habits and feeding patterns of your children are similar or different? And so just to give an example um you could speak to pickiness (.1) or you could speak to uh having a sweet tooth.

E: [okay
 E: Okay, um Kelly this will be probably the single most unusual answer you are gonna get I will bet from anybody you interview=
 PI:=okay=
 E: because I have a really bizarre little family (.1) food (.1) group of people. I'm the only one that can eat regular, in this family. My husband's a diabetic so he mostly eats pretty regularly, my son has horrendous food allergies, he is terribly allergic to milk, eggs, and peanuts.
 PI: Okay.
 E: So we are very careful how we .hh prepare food here and what foods we do and I cook so all of us can eat I don't fix stuff for him and then stuff for the rest of us. I cook[for us ya know as a family. So we took those things out of our food, when he was 6 months old he was diagnosed um (.2) but Julie on the other hand ((laughs)) can you hear her?
 PI: [right
 PI: I can, absolutely.
 E: She's like their talkin about me! Um (1.0) Julie when she was born had a really severe heart defect, and I'm not sure how many other families will have something like that too[a lot of kids with Down syndrome have a heart defect, almost 50%. But because of her heart defect (.1) ((speaking to Julie)) What sweetie? Cut it? ((laughs)) ((speaking to PI)) Because of her heart defect, she was on an NG feeding tube. It was in the nose[and hhh down the throat to the stomach, for 12 months=
 PI: yeah absolutely[
 [wow
 PI:=oh for 12 months, wow.
 E: Yeah. 12 months and (.2) the deal is I really believe that the doctors and the nurses really were so un-used to children with her, her severity of heart defect surviving that it never occurred to them (.1) the absolute terrible situation that was being created as a result of the NG tube being down her for 12 months. That's a long time.
 PI: Yeah, absolutely.
 E: And it's a horrendous thing to do to anybody. I don't even know how, thinking about it now, we just didn't know. We as new parents did not know what we were doing to her. Uh and the interest of saving her but once she got through the really big one, she has had 2 heart surgeries and once she got through the really big one we should have just yanked that tube and honestly put in a stomach uh=
 PI:=a GI tube or something?
 E: Yeah, but we just didn't know and they didn't know. I don't blame my husband and me because we just didn't (1.0)
 PI: You didn't know.
 E: Yeah. And I think they just weren't used to people like Jules, making it. So they, really, honestly, should have done that sooner, but long story short that created a horrendous problem for us in that once we did pull the tube and figured out that we needed to put in a stomach tube, which she had for 8 years. A feeding tube in her stomach

um she didn't want to eat by mouth. She didn't want, if you would get near her (.1) with food (.1) if you would even get to her lips she would throw up. She would throw up I kid you not, fifteen times a day[per hour. And uh, so my Lord this dog is gonna make me crazy right now. Um, so as a result of that Julie was fed with a feeding tube for 8 years so we finally went to and we tried and tried and tried and we did all kinds of therapy and we could just not get over the hump cause she, it was just so bad. And I really did not, like she would cry so much and all the therapists would tell me about force and just getting her to do stuff and little by little but it was so that I didn't want to do it cause (.1) I didn't want to make her cry, she'd already been through so much I didn't want to make her cry anymore, I'd had enough of my kid having a hard time so I didn't, and I'm not a trained OT so

(1.0)

PI: [yeah

PI: Yeah.

E: So we ended up going to children's hospital in Cincinnati when she was 8 years old and we spent a summer living there and we went for therapy 3 times a day[and they, by the end of the summer she was eating by mouth. So.=

PI: [wow

PI:=That's amazing=

E:=It was oh I cannot tell you that place is such a blessing, they have a Down syndrome clinic in there and they are just touch notch, on the ball. That facility is just extraordinary! If you ever (.2)=

PI:=and so this is in Chicago?

E: No in shCincinnati.

PI: Cincinnati, okay I'm familiar with the one in Boston but not Cincinnati okay.

E: Well this place and John's Hopkins has an excellent clinic and a lot of people on the parent, Ups and Downs list talk about Hopkins but and I've not dealt with Hopkins but gee whiz Cincinnati is just, we just actually went there for another full blown eval and that is a fabulous place if you ever are giving anybody advice that live anywhere close I mean Cincinnati reaches the Midwest all the way over to the East coast it's not that far=

PI:=Yeah=

E: I mean it's doable so anyways so, as a result of her being a kid with severe feeding issues for such a long time, she does not eat sweets, at all, she's not interested[it's not like I want to talk her into it but I offer her dessert when I have dessert and she absolutely does not wish to have it[so I'm thankful for that. I think that's really (.1) good, cause I know some kids are big sweet, dessert people um (.1) she (.1) is a picky eater in some respects (.1) because of all that (.1) and but she also likes to eat now and she's every year getting better, like just cause she was 8 and ate by mouth that just meant that we're no longer using the tube it was years before and we're still introducing new foods to her um because she doesn't (.1) like certain textures in her mouth=

PI: [hm hm

[yeah

PI:=right.

E: Um, but she ((laughs)) she's eating pasta, ((describing her daughter Julie's actions)) she must have gotten in the refrigerator, she's walkin around and I think she wants you to know that she's eating the pasta but she's only eating one strand at a time, walking around behind me. But what Julie basically would absolutely live on if I would let her (.1) pasta, shrimp, cheese uh anything else Jules ((turning and looking to her daughter)) corn.

PI: Corn? Oh okay.

E: She loves those foods so much! And almost any kind of seafood and bread. So (.1) if I'd let her live in the land of starch ((laughs)) that would be fine with her!

PI: ((Laughs)) okay.

E: But um (.1) I don't ! (1.0) She ((child with DS)) likes vegetables, and she'll eat them okay but she doesn't go after them. And uh (.2) I yeah she'll eat fruits but not so much, so sometimes I just cut them up really small and I just tell her she can't get up until they're done.

PI: Okay.

E: But that's, she's not very good at eating fruit, but vegetables she's pretty, she'll do reasonably well, with vegetables. Green beans er peas er a little bit of salad and stuff but she doesn't like everything. (.1) And I think it's a texture thing.

PI: Right, and so you said you will monitor a little bit (.1) saying you have to eat a certain amount?

E: Yeah because in order for her ((child with DS)) to get the vitamins in those foods!

PI: Absolutely².

E: The rest of us love fruit. I mean we love it so (.1) yeah we have fruit a lot in my house ((laughs)) hhh=

PI:=and do you guys=

E:=(talking about Julie behind her)) oh she's just so painfully shy!

PI: Right! Where does she get that from? ((laughs))

E: I know!

PI: So have you guys um, oh what was I gonna say (.1) have you um and I forgot it so we'll just move on to the next one ((laughs))

E: Well let me tell you this=

PI:=Yeah go ahead=

E:=she only drinks water she doesn't like anything else to drink and I, we have never been able to convince her to milk or () uh so she just drinks water and I really don't care because this kid has been through a war more than once.

PI: Right.

E: So water, I'm pretty much fine with that.

PI: Yeah, so since everything did start out with a feeding tube did you guys ever talk about feeling full or (.1) anything kind of like that kind of words like that?

E: Yeah, she'll absolutely tell you she's hungry or she's full. She's mostly hungry. She'll tell me that always, if I have to do homework it's I'm hungry ((speaking to what Jules would say)) or if she has to do chores, I'm hungry. Feed me, she's learned that! That ya know if she says she's hungry I'll usually fix her something, because I don't want her to be hungry.

PI: Right.

E: ((to Julie)) Alright, enough Jules. ((to PI)) And she's not always hungry because she just wants to get out of stuff, she's good at that.

PI: Okay. So you think she ((child with DS)) can tell the difference?

E: I absolutely think she can. And I think sometimes depending on what she wants to be doing rather than what we're doing she'll say she's full, because she wants to leave the table and go get on the computer. I think she's not always telling the truth and I think the same with the 'I'm hungry' to get out of having to do her chores.

PI: Okay and do you think that's something Stephen ((child without DS)) does as well<recognizing that he's full and not just saying it to get out of something>?

E: uh (1.0)

PI: Or has done?

E: He's not as likely to do it cause (1.0) he's easier to tell that if he (1.0) like I know how much he normally eats so, it's easier to tell if (.1) I don't think that's accurate ((speaking to his amount of food intake)). He loves to eat, so he's not one to leave the table too soon.

PI: Or if it's something that you fix that he doesn't want to eat, he wouldn't say I'm full?

E: yeah, if I fix something he doesn't want to eat. Yeah he'll eat just a little, cause he knows I'm not gonna fix anything else, he'll say I'm just gonna be done for tonight. And 'I know I'm not getting any snacks' cause he's not. I'm just done ((stating that's what her son would say)). And that's okay. Ya know? I might fix something that he doesn't love and that's okay, once in awhile we'll ya know try something new (.1) and it might be a hit but I'm not going to cook a second meal!

PI: So you're not a short order cook?

E: I'm just not. And I think that parents make a huge mistake when they indulge that, ya know my mom, her parents just had no money and they had 8 kids and lived in this sweet little house, but it was little. And you know what? They all grew up to be amazing good eaters and ya know everything sit down. And not picky, they ate their vegetables, and there was just not fussing and I think you know you don't fuss when you don't have a choice. And we're so indulged, all of us, including me that because there's just so much more money in the United States then when my mom was growing up that, it's a negative.

PI: Right.

E: So, I don't want to indulge that anymore than I possibly (.1) have to. So I try to, I'm sure I fail some. But I don't fix a second meal, ever! That never happens, so (1.0) ya know. Eat or don't eat! You'll be fine til tomorrow.

PI: Right, and they'll eventually eat.

E: Yeah, he will!

PI: Especially if he realizes that's the rule.

E: yeah, and that's how I feel about it. And if there's something that he really just doesn't like, okay! My mom made baked steak once every 2 weeks and I absolutely detested it! And I still can't stand it, and I never make it trust me. My husband wishes I did, but I don't! I can't stand baked steak. And it was an absolute staple of my table, growing up but whatever. I ate everything but the baked steak () ((laughs))

PI: And you said your husband does travel a little bit but whenever you guys do eat, do you all eat as a family at the table or in front of the TV?

E: No, not in front of the TV. Only on special nights. Once in a while or if he's away and I'm ((laughs)) honestly tired I'll fix the meal and I'll tell the kids we can sit in here and relax a little bit. But most of the time we eat at the table because that's how I like it. (1.0) And I think we should be together as much as possible. ((background to Julie)) ()
Yeah, no you're not calling anybody at this hour. Yes, alright you can skype in a little bit.

PI: Alright my dear, let's move on to the next one and I know you spoke about it a second ago, but how do you feel your personal physical activity habits impact your children and your family?

E: Uh, they do less than they would do, honestly because of that cause yeah (.1) that's one of the things about me that's definitely not my shining star moment as a mom. That's probably if I were going to say the list of things about me that ((background to Jules)) honey that's enough don't do that please ((to PI)) Um, that would probably be at the top of the list of things that I should be doing more about uh (.1) certainly for my own self and health much less encouraging my kids. So, yeah, that's probably my number one negative. Other than not being patient enough some times. That might be number one.³

PI: and what do you think about the activity habits of your husband and uh his impact on your kiddos and the family?

E: Uh, well my son loves it! That my husband'll do whatever, play basketball, throw the foot-I mean I'll do some things, but Jim'll do all of it. They golf together, they throw the foot-I'll throw the football. I can actually throw a football reasonably well, for a certain distance ((laughs)) I mean I can throw a spiral, I'm kind of proud of myself=

PI: =Yeah. That's pretty difficult=

E: =Yeah! Ya know I was happy the first time that happened to me, but I mean I'll play Ping-Pong, but Jim'll do it almost every time. And I'll do it sometimes. Cause we have a Ping-Pong table downstairs and I just, I don't know whatever it's just who I am, I always have been, but it's not necessarily the best thing to be and I say that because sometimes it's definitely a negative for my son and I uh I've even said to him, ya know it's not that I don't necessarily want to play with you but I can tell you when I was a kid, my parents would say I wonder where E is? Oh wherever she is she has a book, because that was me.

PI: Yeah, and everybody has their own interest.

E: Well and I just don't take to things that well, that are (.1) athletic in that regard so I'm sure that's part of it is that I'm not that good at it. So I never really pursued it. It just is what it is.

PI: Right, absolutely.

E: Yeah, but it doesn't make the kid happy. Cause, ya know, he ((child without DS)) does like to do stuff, a lot. And he doesn't always have a playmate there so he wants Mom to do it. So, ya know, sometimes I do sometimes I don't. Probably 75, 25. That'd be a fair estimate.

End of transcribed information 26m21s

[off topic conversation]

End 01/02 33m56s of 33m56s

Start 02/02 0 of 33m27s

PI: And that's what is so great about talking to moms, because you are passionate about your kids and you get so much more than just ya know, the 12 questions.

((laughter)) ()

[off topic conversation not transcribed]

PI: Alright, let me look at the next question (1.0). Okay, similar to the last one and they're all similarly formatted .hh how do you feel your personal eating habits or feeding patterns, impact your children and your family? So, I'll give you an example, if an when you snack do you snack in front of them or do you wait til they go to bed?

E: Okay (1.0) definitely my son, and I'm sure if Julie had not had a feeding tube she would be more like us but she's really not in this regard, but I don't think it's so much the fact that she has Down syndrome as it is that she had a feeding tube for so long but he ((child without DS)) definitely snacks. Both of us, Jim is really uh he likes chips and he likes sweets and uh I don't care about chips nearly as much but I definitely like sweets. But um, so yes our son is a lot like us. And I think the fact that I do what I do, definitely encouraged that in him. And I bake because I can't always find stuff that he can have, but I like to bake and uh he likes fun and I could never find cookies, chocolate chip cookies and stuff that Stephen could have, but I can make them. ((referring to the previously mentioned food allergies of her son)) Because you can buy chocolate chips that are real, that don't have milk in them and that's what I do I buy the kind that doesn't have milk[and I make all that stuff myself. So, and I don't make it all the time but yeah. Definitely my family snacks, and I do not hide and snack. I mean they know and so and no there's nothing that, that their not aware of!

PI: dark chocolate?]

PI: Okay, next have you ever thought about physical activity as it relates to quality time (1.0) within your family or do you feel that your family spends quality physical activity time together?

E: Um, we absolutely do not spend enough quality time in a physical way together (.1) because when we do do it, it's really good. So, you would say to your self, gee E

((sounds out name slowly)) the fact that that's really good you would think that would encourage you to do more um but it really doesn't. I'm just telling you the absolute truth=
PI:=absolutely, thank you.

E: And the fact that it doesn't, some of that is just (.1) me, some of that is (.1) after I work all day I want to come home and like get everybody a snack and cause my kids get home, we all get home about the same time (.1) and, and everybody's hungry and I usually want a little bit of time to sort of, some of my friends call it de-fragging. But I want a little bit of that decompression time. Because I am intensively working (.1) with kids all day long and I am teaching reading, working with very small groups, it's very direct, explicit instruction, all day long. And I (.1) love it and I mean I absolutely love the job, I love the kids, I am happy to go to work every single day. And then, I need an amount of time in between=

PI:=right.

E: Which doesn't necessarily happen because my kids get home and they're ready to talk, which I want to hear it, it's a shame I can't come home an hour earlier. I just want to like (.1) yeah, chill out for a little bit. And then probably we should go do something but usually I don't, usually Stephen goes down the street and hooks up with a friend or the friend comes up here. And Julie just really really really wants to get on facebook. Because after she's been at school all day long she wants to go home and stare at them! ((laughs)) And she really doesn't want to go do anything else, so I would have to totally make her. And I, I usually have stuff to do.

PI: right.

E: And none of those are really excuses I'm just tell you how our day is.

PI: Yeah.

E: And so you mentioned when you guys go and do stuff together it's really good, so what do you mean by that?

E: Like we'll go downstairs sometimes and play Ping Pong and we just have a big old time. And so you would think well you'll want to do that every day and it's not that I don't want to do that and have fun and giggle and laugh ((laughs)), I really like to sit down and watch a taped, I DVR everything I watch, everything I watch I DVR.⁴

PI: right, I don't know how we lived without it!

E: I don't like commercials, so I'm like clicker, clicker, clicker. And Stephen and I have several things that we really like to watch together I like that, with him that we watch, like I wait and I don't watch them without him[Yeah I like that we like to do that. Uh and ya know it's just, the day. It's dinner, it's homework, the kids have evening activities and then boom[it's time to go to bed and then get up and do it again. So the window of shared time to do that isn't huge and a lot of times I let it slip away. Just like a dandelion, puff and it's gone, so (.1) because my son would totally do it every time I said a thing he would be game, ya know no pun intended ((laughs)) and Julie, I could make her do it. She would do it for awhile, we get her to play Ping Pong

sometimes and it's pretty fun to see her cause, she's pretty hysterically funny[playing Ping Pong.

PI: [Yeah, what do you guys watch?

[right

[yeah

PI: So what I'm hearing, it sounds like, are you still there?[Okay I thought I lost you for a second=

E: [Hm mm ((affirms))

E:=say it again

PI: So what it sounds like is scheduling and business a main barrier for being active together?

E: And, and me. I mean I'm part of it too cause like the mom who's really likes to be up doing stuff all the time, she would come home and do that. Because that would be the way that she de-fragged.

PI: Right

((background noise)) E: oh that's my computer singing to you. ((laughs)) So yeah, it's me, how I am plus the schedule.

PI: Okay.

E: because you know at the end of the day some of that is just purely excuse because other moms would not let that moment go by (1.0) and I do.

PI: Well, I appreciate you know your honesty.

E: Oh, well hello, you make time for what you want to make time for, to some degree.

PI: Absolutely.

E: To some degree you do, even if it's 20 minutes.

PI: Right.

E: And I think that's what I forget is that I can do it for 20 and be done and everybody could be happy and I guess I always feel like I need to give them 2 hours when I should just do it for 20=

PI:=right.

E: But honestly .hhh if I even do it for 20 it's like (.1) my son ((child without DS)) for instance wants it to never be over[and I know that he's gonna keep begging, so sometimes I just don't want to start it because I don't want, I wish 20 could be good enough but that's what I have to give but (.1) cause I hate to say no and when he's begging it's hard to say no ()

PI: [yeah

E: Yeah, he really likes to play stuff, he really does.

PI: And he's 19 right?

E: No he's 13.

PI: Oh 13, okay I don't know why I was writing down=

E:=No 13, he's little. He's ((child without DS)) not little, he's physically a, a good sized kid but he's (.1) startin to get a little bit tall and he's a sturdily built kid. He's not super big but he definitely takes after my mom's brothers, in his build, they were kind of big

guys that played football, he definitely takes after them ((background conversation)).
What? Oh she's telling you that her brother is coming to high school with her next year.

PI ((to Julie)): Great! Julie are you excited about that?

E: Are you excited? That he's coming? Yes, she said.

(2.0)

PI: Okay, alrighty my dear this one is similar to the last one, as they all are, how do you feel the promotion of healthy eating, impacts the quality time your family spends together. So for an example would be um (.1) if you all planned a meal together that ya know had lots of fruits and vegetables and you guys all did that together that could be an example of quality time. Have you ever thought about how you could spend quality time making healthy meals or talking about healthy eating together?

E: No, you know what I haven't. That's a really good idea. I really don't think that I have. I try to create meals that are representative of all the (.1) types of foods that we're supposed to be eating at every meal um but no I really haven't thought about involving them in those discussions and in the, I mean they cook with me some but (.1) I do the absolute best with, but 98% of it 95% of it, but yeah that's a really good idea, I hadn't thought about that. To be perfectly honest, but that seems to me to be a great thing to help teach your kids for the future when you're not right there telling them what to do. When they have to think for themselves.

PI: Well and that's not my idea I stole it from someone else so don't think I'm the one that thought of it ((laughs)). But you said they do cook with you right?

E: Say it again?

PI: They do cook with you sometimes?

E: Yeah, she does more than he does. Yeah she likes to cook, she gets in there and does a throw down. She'll watch the food network and stuff, I mean I'll get up some mornings and you can't imagine what my kitchen looks like when she gets up before me for more than like 20 minutes ((laughs)) ((Julie in the background – I heard that!)) ((laughs))

E: Last Saturday she got up pretty early and got an entire jar of Italian seasoning went all over a bunch of cut up bananas and different things, she goes look what I made you. I said good, you will start first ((laughs)) no you go first ((laughs)) I said there is no way! [off topic conversation]

PI: Alright, now I know you spoke of this a little but, would you consider your family to be physically active and or healthy, ya know you can talk about them separately, healthy eating versus physical activity and what factors impact whether you guys are?

E: Um, obviously Julie ((child with DS)) is the trimmest of the 4 of us, it's not that she eats the absolute healthiest food,⁵ because Jim (husband)) and Stephen ((child without DS)) and I eat better with vegetables and fruit than Julie ((child with DS)) does. Part of that may be her body structure and her heart may be impacting that, ya know she have (.1) well maybe she has a really killer metabolism. It's hard to say. Stephen ((child without DS)) (.1) plays a good amount of sports and is active so I think he's probably the

healthiest, and Jim ((husband)) can keep up with him most of the time in basketball so (.1) he might be next and I'm probably the one that's the least, because I do the least amount of physical activity [But I try to eat pretty healthy, I absolutely love (1.0) just love, we all love food. I mean food tastes good. I like to cook, I like to eat, I am absolutely a stress eater (1.) which uh, I wish I weren't. But I have been since she was born and I have not kicked it yet. And I have tried I will tell you (1.0) 6 or 8 or 10 different ways to try to (1.0) I mean everything from the (1.0) uh I got this book on the pray down to weight down, ya know where you pray about whole thing to weight watchers to whatever you order over the TV and it comes in a box in the mail I forget what it's called. =

PI: [Yeah

PI:=nutrisystem?

E: Yeah, the one where all those famous people are all skinny now. Yeah, I've tried it. I've definitely done everything. But probably the reality is that until I can find a way to stop feeling stressed and then immediately going to the cabinet, the other is not going to work (.1) cause it hasn't, unfortunately nothing's really worked and I would definitely like it to but so then I guess that's my answer. Julie, then Stephen, then Jim, and then me. In terms of who's the healthiest.

((background))

PI: Do you notice that you encourage or support Stephen or Julie differently as far as getting them to be more active? (1.0) And I can give you an example, ya know types of support could be just verbal encouragement or um taking them to the sports team or participating with them

E: Well (.1) I'm gonna answer that, I'm gonna answer that a little bit in 2 ways. I will drive either of them to whatever they have and I do it all the time so that makes no difference to me I (.1) whatever you have I, I'll take you to it. I will work my schedule in ways that I will take one to something, leave him or her, go to the next one, drop off then go back and get the other. I mean I will do whatever I need to do to get them to their activities.

PI: Yeah.

E: That makes no difference. Um, as far as just verbally encouraging activity, I am way more like to say to Stephen you go ahead, it's a gorgeous day outside then I am to make Julie do it. Honestly for several reasons, she just flat out cannot be sent outside without supervision because if some good lookin boy drove by, she would try to go with him and I'd never see her again. And B she doesn't really want to, but again like I said earlier somebody has to kind of make her do it. And probably C there has to be something people are willing to do and play that she could do or play and that's often, again without someone like me, that's not going to happen[because kids want to play at their level and not her level.

PI: [right

PI: Okay, so what about gender or age differences? Do you feel that maybe he's more active because he's a boy or because he's younger? Or do you think it's ability?

E: I think he, no I really think it's because he doesn't have Down syndrome. Because I think there are a lot of girls like ((my)) niece who's very active and plays a lot of sports and stuff and I don't think it's gender at all.

PI: Right.

E: Although I do think that boys tend to be in lots of ways more active but I also think that trend is shifting and there have been more and more sports for girls to play. Growing up there were like 2 things are girls to play, basketball and volleyball and softball I guess and maybe track so I guess 4, but we didn't have a lot[Now it's like everything the boys have the girls have, except football. Pretty much, I'm trying to think if there's anything that we don't have that they have. But there really isn't anything. I really think its Julie hhh because she is who she is and she doesn't want to do it.

PI: [right

PI: And so would lack of opportunity be kind of an option, there's not as many programs=

E:=Yeah I think so, yes I think that would be fair.

PI: Not as many programs for her.

E: Yes

PI: And then Special Olympics is only offered one time of year right? In the spring?

E: Well it's offered every season, but they don't practice that much

PI: Yeah.

E: Like volleyball, when she ((child with DS)) was in season for volleyball it was twice a week for an hour. Um but then that's it. Like Stephen ((child without DS)) might go to basketball practice for an hour an a half or 2 hours and then he'll also shoot around here, we have a basketball hoop and stuff and so he'll hook up with his friends and do some more. And for Julie, that's it. She goes and they do it and then she's done.

(2.0)

PI: Okay , so let's see (2.0) okay so I know we spoke a little bit about this already and I appreciate you know your transparency when you said that maybe if you were more likely to do things then they would as well so um do you, how do feel about health being a priority with you and how do you feel that you guys kind of uh (.1) ya know maintain that priority or how does your family relate to that role? So if it is a high priority do you make one or do you not. How do you feel about (.1) uh how much you make it a priority and then whether it is a priority? Does that, does that make sense?

E: yeah, I just need to think about it for a minute.

PI: Okay, take your time.

(8.0)

E: Uh, I think (2.0) I think that the parents, whatever the parents make the priority directly impacts the children, obviously because it's what we would choose to give our time and attention to so I uh I do care a lot about my kids being healthy. I've spent, I've been in 8 hospitals with Julie, and I care about their physical health and I know, I've said this earlier and I'll repeat it again I probably won't say it right but I hope you'll get it, I'm resting on there not my laurels, but on the fact that Julie's pretty stinkin healthy (.1)

without a whole lot of physical intervention from me and I'll just kind of allow that. And I'm sort of lucky, cause if she were chubby I would do something because I just don't want that for her. I don't want her to be chubby, she might get chubby later on but at this point in life, I think it would be bad for her heart and I don't want that.⁶ And as for my son, you know he's at the age now where I can't keep up with him in terms of his basketball abilities and he used to have me race him to the car from ya know the store of something and for years I could beat him[now I'm at the point where I absolutely cannot beat him. But if I had been someone who was more interested in doing physical things I, I, I know that your studying the part with the family and the families with the kids with Down syndrome but the greater impact would have been on him. If I would have done more with him, it would have been a much better positive impact on him as opposed to her. Purely by just luck that she's so um physically small and very capable despite the fact that she was sick for a long long time and I mean her legs were laid out like a frog in the hospital bed for months and months and months, so to try to get her legs to come back in to be able to use them. Her gait is wide and it's not as wide as it used to be and she has done a lot of physical therapy but (1.0) she does pretty well, even with all her medical negatives she has found a way to make it work. She's not the fastest runner in Special Olympics, ever, she never gets the gold, um she could care less. She goes across the finish line and whoooo ((cheering sounds)) 1st or 4th, it makes no difference to her.

PI: ((laughs))

PI: If only we could get excited about something like that, right?

E: I kid you not it's just pure joy to watch her!

PI: Oh yeah, I've coached it before I just love it!

E: And ya know I have people every year at the state meet who say to me, I can't wait to see her. I look for her every year.

PI: Yeah?

E: That's pretty fabulous to get to be the mom of that kid! The one they're all lookin for. Because she really is sort of atypical even in the land of Down syndrome, she's just really really a positive, energetic, enthusiastic and people like that. Ya know people like enthusiasm and it makes us feel, everybody likes that. I like that[She likes it! We're lucky she has such a nice personality, given her (1.0) early years. Cause they were very, very tough. And she's just a tough kid. She just tough, and a fighter and whatever so. But I know that Stephen ((child without DS)) would definitely benefitted and to this day if I were to, cause I'm the one around, my husband like I said travels quite a bit, and I was a stay at home mom for 12 years and I was there. And if I were an athletic person I'm sure he, I mean he is an athletic person, but he would have been more athletic if he had a different mother. Truth, to be perfectly honest because he likes it he takes to it, he has a great golf swing he hits a baseball, he's able to throw a football man he's able to do all kinds a stuff and um he's (.1) definitely built that way. He would have benefitted from having me be like, like that. So just goof with, even at an earlier age (.1) cause I didn't

know, I just didn't know some of that back then and ya know I would have started some things earlier but I didn't know, I just didn't know.

PI:

[of course

PI: And you made a comment about um ya know there's not a weight concern with either of them and so=

E:=He ((child without DS)) has a little bit of one, but I think he'll be fine. Because he's spent several months not really in a sport which it's the first time in his whole life and ya know xbox has become kind of a big thing and there has been too much of that. So, now we're back into a number of things and I think that'll take care of itself, ya know even though it's the winter time coming I think it'll be okay. But he (.1) he's built sturdy, but he could definitely put it on if he's not careful.

PI: And do you have any rules about the xbox or time limits or anything like that?

E: Ya know, ((laughs)) I have at different times had different rules and uh I need a better rule than what I have, I don't let him do it all the time but he probably does it too much. I do say okay, you've been on that for a solid, you're done, I don't want to see it on again. But do I say that every day? No, so. Probably there should be, like I've even tried to do things to have both my kids earn computer time and its, my consistency is not always a strength for me. Because I (.1) I forget! Or I get busy, and I just forget! To pay attention to every little detail is challenging.

PI: Right! And a mom's the hardest job in the world.

E: And everyday it's a different schedule so it's not like I can just say you can have this from 5 to 6, it's not like I can set that because every day they have something different. And they both do, so. It's a little tricky and part of that's just I don't know I don't have that organized well enough I guess.

(2.0)

PI: Right. So if um obviously you said right now with Julie ((child with DS)) there is not that concern so if one day in the near future in the far future you notice there may be a weight concern, um I guess what would you do specifically? Would you decide to change some of the eating habits or would you decide to change some of the activity levels?

E: I probably would do the eating habits first, and either put something away because we have definitely indulged her, mostly because she's been so underweight and we've been more worried about getting some weight on her. We've let her eat kind of whatever she wants, we're just so glad Stephen used to be really really skinny because with his food allergies and trying to get enough food in him was really hard, with both the kids. And now we've gotten really good at being able to live with his food allergies and I can cook, I can make literally almost anything that anybody else eats I can tweak the recipes[I really can. I can, again, not everything but I can get pretty close. I haven't figured out how to make a meringue ((laughs)) but I don't really care cause I don't care too much about meringue! So yeah, I would probably change what food she gets first and then try to think through what to do for the physical activity, because I don't know 100% of what

I would do. I would definitely spend time, I would do way more for my children than I would do for myself. Because that I can control, much more easily.

PI: good for you[

PI: And again I know this isn't something that you guys have dealt with and some of the other moms have kind of, I'm going to kind of use their terminology whenever we talk about it, um ya know some of the moms who do have kiddos that have, that may be overweight or have a little bit more weight on them and they've talked about how some moms have attributed that she's overweight because she has Down syndrome and then some moms have said well she's overweight because we have a family history of it and that's why I'm aware of it. Have you ever thought about that or do you have anything to add about that?

E: Uh with regard to both my kids or just Jules?

PI: Both. I'm interested in both, so not just Julie.

(1.5)

E: Well, uh Jim's ((husband)) side of the family, my sister in law is really trim and she isn't very uh tall and my mother in law when she was younger she was, she's not, you don't look at her and go oh my golly she's so big, but she's very short, she's like 5 feet tall. And she weighed like 90 pounds when she was giving birth, she weighed like 105 when she gave birth to Jim, she was a tiny lady and now she's, she's almost 75 years old and she doesn't do a whole lot of physical activity [um at this stage of life and she has some knee issues so she has, she's a little bit of a pear shaped lady. But I think Julie ((child with DS)) probably, like her feet look like Jim's side of the family! ((laughs)) So I think she kind of takes after the fact that Jim's mom and Jim's sister are very trim, if not currently, at one time. And for a long time, even Jim's mom was. Even when I got to be in the family, she was still fairly trim and so I think that it is genetic and I think it's her heart. I'm not sure her heart can tolerate a whole lot of extra weight and I don't really know that. And I think her metabolism is probably pretty good. I really think that's probably part of it. Stephen ((child without DS)) definitely looks like a Woodtrain, which is my mom's maiden name. I had 5 uncles and they were big, and their bones were big and some were trim but they were big men. And it will be interesting to see when he goes through puberty how tall he gets because he definitely takes after that side. And I have big bones and even before I put on this weight, I was not the thin shouldered whatever, I was built like my uncles. And I mean I was a 10, 12. 12's kind of my normal, and I'm not currently but whatever. And so I think my son is like me in that instance and not only that but he has the propensity if he sits around, to put on some pounds. But I've noticed that his looks, look like my uncles. And his feet look like my side of the family. So I definitely think there's a genetic component to it and lack of physical activity. Because kids used to come home and they'd run outside and now half the kids are doing something else or there's nobody to play with and then there's this XBOX!

PI: [yeah

END 02/02 33m27s of 33m27s

Skype stopped and closing remarks and member checks questions completed via telephone and were not audio recorded.

Annotations

¹ Mention is made that she does not encourage physical activity as much as she probably should with her daughter, but there is not a sense of worry 'becuase she is thin.' I feel this comment is made only about the daughter because the son is more physically active.

² Food monitoring for the purpose of health

³ Verbalizes that if she could change something it would be her level of activity for the purpose of encouraging her health and the health of her children.

First parenting change code - search for 'I should' to find more using text search

⁴ She states that activity is fun and she should do that every day, but the assumption is that she has a greater interest or just gravitates more toward the sedentary activity (e.g., TV)

⁵ When asked about health, this mother answers with each person individually rather than the family as a whole. Note that a reference is yet again made that being thin equates to health even in the absence of healthy eating.

⁶ Thin is compared to being healthy, or the absence of overweight is referenced.

Transcript, Interview Stacy

Transcript Interview in person

01/01 0m of 18m21s

Principal Investigator (PI): Let me begin by reading all of my assurances so that we are all legal and ethical. The audio recording equipment is on and if at any time you need to get up and take a break please feel free to do so. The session will last about 90 minutes or so. Uh the purpose of my dissertation is to explore the development of physical activity and eating habits among family who have multiple children, including one with Down syndrome from the perspective of the mothers. The target of exploration will be the potential relationships between parent modeling, physical activity levels, feeding pattern differences between siblings, and perceptions of family barriers to healthy lifestyle habits. And when I speak about feeding pattern differences I mean um like parenting practices related to health, so rather than types of foods uh for instance the introduction of new foods, restriction or control, rules about food uh rules about cleaning your plate or philosophies like that so (.1) um not so much fruits and vegetables but how they are introduced[Yeah, habits, absolutely.

S: [habits

PI: Alrighty, so I will (.1) there's about 10, we have 11 questions (.1) and so we'll just go through them 1 by 1 and if ya know we'll just talk about them until we're done and we can move on to the next one but if at any time we want to go back to one that's that's great to it's totally informal. So, alrighty Mrs. S I will read the first one. So, how do you feel the physical activity habits of your children are similar or different? And what impacts those behaviors?

S: Well (.1) first of all each one's an individual (1.0) but I made sure that they were all exposed to the possibility, like (.1) a movement program and Luther ((child with DS)) of course at TWU ((speaking to a university Adapted Physical Education program that he participated in)) and they each had their own interests. Both of my boys are interested in baseball, basketball and Lauren (.2) did gymnastics and so did Lisa (.2) and Lucy did soccer. So we kept did, I tried to keep them well-rounded and (.2) interested. And with Luther we tried different things (.2) we tried soccer and he sat down in the middle of the field! ((laughs)) He did! Yes=

PI:=And before we start too much will you all their names and their ages, just go right down the list so I have it written down?

S: Lucas 33, Lauren is 31, Lisa 28, Lynn he'll be 27 soon, so 26, um and Luther is 21 and Lucy (.2) is 18.

PI: Alright, I and I did not realize they were all Ls. And where did the Ls come from?

S: ((laughs)) nowhere in particular!

PI: Oh, okay.

S: We just got started and had to keep it going ((laughs))

PI: So you said the main thing is just keeping them interested in something?

S: Yeah. We just wanted to keep them (active) and their dad liked to play baseball and he was interested in sports and he played basketball for while when he was in college, intramurals too so. We just kind of naturally flowed into it.

PI: Right.

S: And then all the opportunities <physical activity based> that were available here.

PI: Do you mean for specifically with Luther? Or just for everyone?

S: Just for everyone. For all of them, with the program at UNT and then the program at TWU and and then a we had the YMCA for baseball and basketball and (.2) then later little league. So it was just ya know, and now Lucas has got his boys that are interested to

PI: Interested in sports too?

S: Yes. They're interested in sports too. And our biggest thing has been bicycling. When, Lucas ((oldest child without DS)) goes to Colorado, he takes his bike with him because his father-in-law loves to go around and Colorado's got lots of trails.

PI: Absolutely.

S: And he loves to bike and hike and so does Lisa and Lauren does too. Lucy (.2) would, if she has someone to do it with. So they're all into it.

PI: Yeah and so you mentioned interest. So if some of them didn't have the interest would you do something to kind of get them interested in a different type of sport or activity?

S: There was a time when I would drop Lucas off at one field, drop the girls off at gymnastics and drop Lynn off at another field and hhhh then go pick them up ((laughs)) and then (.2) with Luther, I also took him to TWU. So it got to where we were (.2) I was running a pretty good bus service!

PI: ((laughs)) Absolutely. And so you said Luther did not, he did not enjoy soccer?

S: No

PI: And so did you just do in one year?

S: Well he, he's (ended up with the shirt) and then we tried the um there was a special needs baseball ya know there was the the was it the city baseball league? Denton boys baseball and there was a guy at that time that was putting together and special needs (.1) group and it was enough for 2 teams.

PI: Oh okay.

S: And, we tried. The dads worked with them, but Luther (.1) could hit the ball. But he wouldn't field it! He'd just watch the ball go by ((laughs and motions with hands))

PI: ((laughs))

S: So, ya know and that was the end of that! And then he tried golf, a friend at church had worked with him for awhile and then, Luther was doing real good, he could straight shot that thing, I mean he's got a great throwing arm, I mean you gotta look out

PI: Yeah! I've seen him throw!

S: yeah, he's got a great throwing arm but he's just () and they need a lot of motivation.¹

PI: Absolutely. And so what is his ((child with DS)) favorite thing to do in general? Not specifically activity.

S: Sit and listen to music.

PI: Listen to music?

S: The same 3 songs, over (.1) and over and over 24 hours a day.

PI: Yeah?

S: ((nods head in affirmation)) I got him a laptop, just for him to look at his pictures, watch his movies, and listen to music. Because he likes, he likes to dance

PI: He likes to dance, okay.

S: And last year when they had the talent show, after one of the teachers said I wish we had put him in the dance class so he could have performed.

PI: Yeah!

S: But we didn't. But if he could do some dance classes, (we could probably pay to have it done), he would thoroughly enjoy it. I've been sending him to camp, Camp Summit and he loves, he loved it. Because he did horseback riding when he was little over at a (.1) Riding Unlimited in Argyle on 407 (.1) He went out there for oh I don't know 2 years. And did the hippotherapy.

PI: And he really enjoyed it?

S: Yeah, he did really good. He's fall asleep right on the horse! Cause you know they'll lay them down on their stomach (.1) or on their back and or just drape em over. He'd be sittin there with his head bobbin, just (.1) asleep!

PI: I guess it's just the calming nature of the horses huh?

S: But that's what <horseback riding> strengthened him ((pointing to abdominals)). He had no muscle tone=

PI: =okay. So core strength from the horseback riding

S: Yeah because he never used those muscles. Yeah I think it was 2 years, 2 or 3

PI: In what middle school or the beginning of high school? Younger?

S: No, it was preschool=

PI: =Oh, he was young=

S: He was 2, until he cause he was going to () in Keller (2.0)

PI: Okay. Did any of the others kiddos do the horseback riding?

S: No

PI: So what the program specific for kids with special needs?

S: Yeah, it was for kids with special needs. I can't think of her name the therapist, the PT (1.5) I can't think of her name right now. (1.5) She worked with him.

PI: And I know there are several hippotherapy places around (.1) Denton County.

S: Yeah and there's that riding places down in (.1) Corinth

PI: Hm hh ((affirming)) right next to Crownover

S: Evidently free, whereas we were going to keep going with this place but it was 100 buck a month. So, when he got to be a certain age (.1) we just quit.

PI: Because of finances or lack of [enjoyment. Okay, finances

S: [yeah

S: Yeah, finances. Yeah, because it did him good. He'd ride and then he'd go into the PT room and do some leg work in there. So he had a lot of home visits when he was little. Because he wasn't at school, we did home school. They so, the OT and the PT both came here

PI: They would just come here yeah.

S: And you've seen the videos of Luther ((referring to assessment videos from the university Adapted Physical Education program))

PI: I have. Ok, well good. Well let's go ahead and move to the next question, which is very similar. How do you feel the eating habits or your feeding patterns for your children are similar or different, and what impacts those behaviors?

S: (1.5) Well, when all the older ones when they were little, Lucas had a bunch of food allergies real bad so we did a lot of () and natural stuff, so we got to where we didn't we didn't prepared, pre (.1) pared[Yes! I made everything from scratch, even making my bread. So they learned a good dietary habits which (1.5) the oldest one hasn't but the other 3 have carried on. And Luther's picky and Lucy never got it so she's my Betty Crocker box mix food kid.

PI: [processed?

PI: Oh okay.

S: But no we had very good, I tried to keep sugar out of the house as much as possible and stuff like that (.1) so it was very (1.5) now the feeding patterns of course you know Luther had trouble, he had to learn to eat because of the lack of tone and feeling ((motions toward the throat)) (.1) so that's

PI: His transition from soft food to hard food, was is ya know several years behind the other kids or=

S: =Um yeah we all had to learn () And with soft food he did fine with of course and but the solid food we had to work with and I'd tell them I'd go ((motion to throat exaggerating movements)) to make him chew. And his OT, I can't remember her name but she would have him move the food around in his mouth so he'd have to learn to use his tongue. But to this day he still kind a eats like a bird ((movements with necks))

PI: really?

S: Yes ((laughs)) He'll just drop it down his throat and swallows it

PI: so because of that <DS related eating issues>do you give him certain foods [or make any changes[

S: [nope

[nope

S: No dietary changes, it's like (.1) you're in this family and you're eating what we are. It's kind of like my son and his wife and what they're doing with their kids. Everybody's gonna do what they need to do[But Luther is picky, he won't eat fruits, he will (.1) but when he was real little, I'd give him apple sauce and he'd turn red as a beat.

PI: [right

PI: Oh really, so do you think there's an allergy

S: I don't know if it was an allergy or if it was the ascorbic acid, cause you get that (.1) what they call the Niacin flush[(.1) if you get too much so that could have been it but now I don't know. (.1) Raw apple, stuff like that he was fine (.1) but processed, apple sauce would do it and not only that but we went blueberry pickin (.1) and go home with this grocery bag filled with blueberries so we were all just sittin there ((motioning with hands an eating motion)) and he was too. And then (.1) he was all red again, so there's something (.1) in the fruit. So now he very rarely touches it, but if I give it in a can he likes it. If I get those little single tubs of peaches for him to take with his lunch and stuff he'll eat it. And vegetables, picky about what he eats (.1) He won't eat baked potatoes unless you take the skins off for him (.1) for him! But otherwise he pretty much, he's a pasta guy he loves (.1) pasta[and he will eat. You order (and he will eat it all). That's another reason I'm putting him in a home ((referring to after Luther graduates he will move to an assisted living facility, S mentioned this before the tape started, he's eating us out of the house)) ((laughs)), no but he's got a healthy appetite, but it's a very (.1) limited one, whereas the rest of them, Lynn is, well he's worked with a trainer, and he's been getting into like the South Beach Diet and staying away from the carbs as much as possible so he's, he's gotten into that. Lucy, Lisa's getting there of course with liking the bake and everything (.1) it's a little hard, of course she had to learn the gluten free baking=

PI: [yeah

[he loves pasta, okay

PI:=oh she does gluten free baking?

S: Well she hasn't learned it yet, but she could and uh Lauren worked in restaurants for years, good restaurants, so she's into (.1) hhh expensive meals=

PI:=expensive meals? ((laughs))

S: ((laughs)) Yeah, so (1.0)

PI: When you say expensive do you mean healthier? Or just expensive?

S: 5 star restaurant type food, yeah cause she worked in, she worked in several in DC, so she was working and serving ((motions with hands) (1.0)

PI: Famous people?

S: Yes. Newt Gingrich, ya know she worked at the Capital Grill (1.0) for awhile, and then she worked at some other places, where (.1) the night we went to eat at the place she working uh Rush, Rush Limbaugh was there[Yeah, so it was all (.1) that caliber of people that she worked with so you know what the food was like. (1.0) And a

so she's got high dollar taste ((smiles)). But uh yeah they've all (.1) been taught (.1) to eat healthy. Whether or not they do (.1) that's their problem!

PI: [oh really?

PI: Alright, and what about snacking and things like that have you noticed a difference in uh like the amount of snacking or how often=

S:=well, like I said some of them were trying to do healthy (.1) I don't know what Lucas and his family does anymore, cause I'm not around them. Lucy's (.1) definitely (.1) over the counter getting whatever and Luther (.1) he doesn't like sweets he won't eat sweets. Even for his birthday you have to force him to eat a piece of birthday cake[

Yeah, so he's just not into (.1) the sugar stuff and I think that's why he's so, stays slim cause you know Down's children have a tendency to (.1) be heavy and he's always been, course his Dad's 6'5 and skinny as a rail so he's inherited a little bit but uh he's just not into sweets. He likes, I'll give him the emergen-C drinks so he'll drink=

PI: [oh really?

PI: =Emergency what?

S: Emergen-C (.1) have you ever heard of it?

PI: No.

S: It's a powder it's a phizzy powder, loaded with vitamin C and usually B complex and uh it's good for cold's and stuff like that and so when he gets home from school I'll mix him up a glass of Emergen-C and uh (1.0) he's the antioxidants and all that stuff too=

PI:=oh, okay

S: So (.1) it's a little box and there's packets. Phizzy packets

PI: Okay, and it's all natural it's just like vitamins?

S: Well there's some sugar in there, but it's a good, good booster cause it's got a lot of electrolytes in it, a well balance of the potassium

PI: So the benefits of Gatorade, without all the sugar?

S: Yes. And a lot (.1) more interesting flavors, more interesting flavors ((laughs))

PI: Natural, not the artificial ones?

S: Right.

PI: well since, and I was gonna wait to do this uh at the end but since you brought it up uh we can talk about it now. Um you know you mentioned that children with Down syndrome have tendency towards being overweight or obese (.1) and I'm sure you know seeing Luther's classmates or you know seeing kiddos who are like that, and that's kind of the main purpose of this is to just bring about discussion about ya know family habits versus (.1) the tendency that children with Down's have towards being overweight and um (.1) is it they're overweight because of Down syndrome or because of family habits and family history.

S: I think that some of it, I know we had Luther's thyroid tested (.1) early, you know because they tend to have an underactive thyroid, which is a lot of the cause of the weight problem (.1) and so far, he's staying in the normal range=

PI:=okay.

S: Which I don't know (.1) I'm sure that has a lot to do with it plus the thalamus[and you know everything that affects digestion, absorption, and all of that he seems to do real well. When he was little (1.0) he did he always had a bit of a problem with low motility in the bowel (1.0) and but he never had the heart problem and he never had the problems with the bowels like some of them do and you know he's had a (.1) bilateral hernia when he was little. But other than that (.1) ya know, he's done (1.0) really well (1.0) and I never had any of them immunized (they didn't go to public school)

PI: absolutely[

PI: Okay. So he ((Luther)) hasn't had some of the more severe problems that some of the kiddos have had ((speaking about other children with DS))?

S: And when he was born, he was born at home, he was breech (1.)

PI: were all of your kids born at home?

S: 4 of the 6, the first 2 were born at the hospital. He ((Luther)) was so weak ya know his chin just fell on his chest, no (.1) frontal muscle tone. And that's part of the reason for the hippotherapy. But he always did really uh you know, I mean he, he never cried, I'd have to wake him up to get him to eat, cause he would sleep for 24 hours if I let him. He still would if I let him ((laughs))

(2.5)

PI: Okay. Well alrighty, now, number 3, going back to Mom, how do you feel your personal physical activity habits impact your children and your family?

((phone rings))

END 01/02 18m41s

START 02/02 0 m of 42m42s

PI: Okay alright, so this question is about your personal physical activity habits and how that impacts your children and your family?

S: I am not really active, but like I said I've kept them active and had them, what I and when I was in high school even after I got my driver's license my favorite thing was bike riding, biking and so I guess that kind of (.1) passed on. But I've been too busy, when we were running the business, schooling, and raising the kids, I didn't have a lot of time for that for a lot of activity but I kept them in the activity so that's really how it impacted my kids and my husband likes to do stuff and he did some sports and he'd get out with the kids once in awhile. When Lucy, Lucy was playin soccer at the end of the year the last day of the season, they have a family day and parents could participate and he'd get out there and play soccer with her I thought he was gonna

() but he'd get out there.

PI: Oh yeah?

S: Yeah. He'd participate and try to get Lucy to play basketball but by the time she got into it, she was too old.

PI: And Lucy, she's into track right?

S: She ((child without DS)) does, running. But she's not, she's not competitive, and she has a bum knee and we're thinking she might have torn the meniscus[so she has a bum knee. And the same way with my oldest one. The other 2 girls were in gymnastics til they got too tall to do it. Well and Lisa dropped out because she wanted to do, we couldn't do gymnastics and piano lessons both so she opted out for piano. But she's still stayed very active and the thing is that when I was pregnant L Lisa I did aerobics, it was a maternity class and we did aerobics and she's the happiest one of the bunch! So

PI:

[oh okay

PI: I guess she felt it in the womb.

S: I think so and she says, thank you mom and she's into cause she likes to bake and stuff so she does, you know milled the flour the whole natural everything and she's always done that and when she went to work at the ski lodge in Winter Park of course it's Bisquick and all that kind of stuff but she managed to talk the guy into letting her do a little bit of stuff, naturally, and she'd fix meals for them for the lodge and a (2.5) they wanted seconds ((laughs)) yeah

PI: ((laughs)) cause it tastes better

S: ((nods head in affirmation))

PI: Okay and so you mentioned you know keeping them in sports and I know mentioned transportation and driving them around, what other ways would you kind of encourage them or get to stay into activities?

S: Well, they all like to ride bikes and when until Lucas got his driver's license we lived on this side of town ((motions to one side with hands)) and all of his friends lived on this side of town ((motions to other side)) well I felt like, he was always cautious so I'd let him but he didn't have a bike but a friend loaned him a bike. He would bike (.1) everywhere. And the rest of them, just, just developed from there.

PI: Followed suit?

S: Exactly. Cause now they've got bikes and it's the 500 dollar bikes

PI: Oh wow.

S: yeah for doing stuff. Lisa's got her bike with her, I don't know if she's using it now if she's had time to use it, but she's got her bike. And Lauren has a bike, Lucy has a, well it's not a real expensive bike but she has a bike.

PI: Right.

S: And then when our car was down, I rode the bike to work.

PI: yeah.

S: And ya know, and stuff like that is pretty much how (1.0)

PI: so you just modeled it?

S: Modeled it and then um like I said when Lucas goes to Colorado when they go to Colorado to visit his inlaws uh (1.0) they got Lucas and Jessica got married in January and then that May, Russell got transferred, he works for FedEx he got transferred to

Colorado which was 11 years ago and got into all (.1) what Colorado has to offer them, hiking and the biking and the skiing, the whole bit and so that has kept Lucas active when they go on their, he doesn't have a lot of time here because he's, he manages a Sprouts store

PI: Oh he does, oh okay.

S: The new one down by TCU.

PI: Okay, so they live close?

S: ((nods in affirmation)) bout an hour away, which we still don't see them very much because they're busy, we're busy. But yeah. So they've all stayed active and Lynn's been the one who said, if I wasn't in the Marine's and the service he's says I'd think I'd be a (1.0) he'd work in a gym (1.0) because he's really got into it, workin out and eatin right. And Lisa's pretty much the same way, Lauren's a little not quite as much but she does have a bike she does do the stuff she's just not as, active as the other 2, and Lucy, when they're all here they all have their bikes, she goes with them

PI: So if they're all together, that'll encourage some of the ones that maybe don't do it as much individually

S: Right

PI: So have you guys ever tried to go out all together as a family?

S: We've never all had bikes at the same time ((laughs))

PI: Right, well I know you've mentioned hiking have you guys ever tried to all go hiking together? I know you said=

S: Hm hm ((shakes head no)) I went out to California to see Lynn in September and he says well Mom what do you want to do and I said I just want to go hiking and I hadn't been hiking in 30 something years[I had a ball! 8 miles worth! =

PI: [yeah

PI: =Right oh very nice. Okay

S: And he says oh there's another mountain up there and we'll climb () ((laughs))

PI: Yeah!

S: () ((conversation too quite to hear))

PI: So what about the whole L((last name)) clan?

S: No we've never gone as a group

PI: Right, because of logistics, because there are so many of you all or what?

(1.5)

S: Partly plus yeah, everybody's with a big family, pretty soon everybody's pretty scattered and we didn't look, we used to do camping too and I think since I've been married I've gone camping twice and just uh, the other thing the other activity that Lisa and Lynn did was, was dancing=

PI: =Okay.

S: Because one of Lynn's buddy's got it going here in town for a (2.0) swing dancing.

And Lucy has done that=

PI: =Oh fun!

S: And Lucy hasn't done it lately, but she used to go swing dancing

PI: And would Luther ever partake in this or=

S: =He's never gone. When he lived out in the (commission) when we lived out in Argyle they had a big gymnasium there and they'd have parties. And I taught him how to dance, he knows how to dance, he's got some moves I don't care for =

PI: =like partner dance?

S: Both, both. He can, he can do, the mild form of the jitterbug and stuff like that and uh (1.0) he can waltz but he loves to dance and he leads the Sunday school class in their music and he's got a gal at school that (1.5) and now he's got some moves that (1.0) we wished he didn't have.

PI: Okay, so he's learned some suggestive moves that you don't care for?

S: Yeah. ((laughs)) I don't know where he learned it.

PI: ((laughs)) from the television?

S: From classmates.

PI: And so what about the television, do you guys spend a lot of time together in sedentary activities? Kind of sitting and watching TV together?

S: We used to have a family night, TV but Luther won't sit with us.

PI: Really?

S: Yeah.

PI: If you guys are all sitting=

S: =even if it were one of his movies, he's got all these movies a whole shelf full. He's become very much a loner. But we have had family nights and (1.5) the kids were always into table games. They play um (2.0) (dutch blues) and uh (1.5) Taboo you know a lot of mind, thinker games

PI: Right, rather than the watching TV

S: The kids have had great friends to run around with and they'd get together and do stuff like that. One night we had a party at the other house and we had a Bunko party[and uh all kinds of stuff like that or they do uh what do ya call it where you act out=

PI: [oh fun

PI: =charades?

S: Charades and then there's the other, Pictionary's another they like to do and stuff like that. Not Arlo's ((father/husband)) not a table game person and I'm more the one, the thinker, spelling and stuff like that and I can't think of what the one game is (1.0)

PI: Scrabble?

S: Yeah we do scrabble and then there's another one where you do (1.0) and I can't think of what it's called but you, you spin the dial and it picks a letter and then you have questions and all the answers have the be the[Yes Scatagories, I love that one. Cause I love stuff like that, whereas Lucas is not to good at that um I think that Lynn and Lisa would be, I don't know about Lucy cause we hadn't done it that much with her. But that would be my favorite game, that and uh scrabble.

PI: [Scatagories?

PI: So would Luther participate at all? Or just kind a=
S:=he'd sit and watch even if it was over his head. But he had one game it was called, a memory game and it's (1.0) 4 different sets of pictures and it's, it's kind a like concentration cause you turn them all over so you can't see all the cards and then there's 4 different sets of pictures and each person is working a picture and then, but you have to do them in sequence, so you learn sequencing and you have to learn memory cause it's like playing concentration. You turn it over and if it doesn't match you have to turn it back[yeah so that and then when you complete your set (1.1) you tell the story [of what the pictures are and what's going on so that's all he's done pretty much, we've never gone any further
PI: [right and then you have to remember where it is

[oh okay

PI: So is that a 1 person game or is there=
S:=there's 4, as many as 4 can play.

PI: Okay, well good. (1.0) Well alrighty my dear, moving on to the next one (.1) how you do you feel your personal eating habits or feeling patterns impact your children and your family? So similar to the last one. And I have an examples, so if you are a snacker do you choose to snack in front of them or do you choose to wait until they do to bed?

S: It varies. Not usually when they were all home, since we homeschooled, with snacking it was everybody. And then as they got to where they were older it got to where the stuff was there and then they snacked when they wanted (1.5) It's only been the last couple of years that I've been a snacker (1.0) cause I, well my favorite is popcorn! But like I said Luther's not a snacker at all. The other kids are, and it varies sometimes its like just fruit and stuff like that. Sometimes it might be a granola bar (.1) and if Lisa's around (.1) it's baking cookies and stuff like that (1.5) or not at all. We've gotten to where the eating habits are where you don't chow down 3 times a day, it's more like you kind of graze all day, which is healthier!

PI: Absolutely, so when all the kids were here did you have food rules. And I know a lot of times with big families, there's not as much food or you have to go shopping more often.

S: hhh You know I've got the kids trained, where they didn't snack a lot.

PI: And so what do you mean by trained?

S: We just didn't, we ate and then we were busy! And we ate! Whereas my grandkids are like granny, granny ((motions with hands like wanting something))

PI: So its about nourishment rather than (.1) habit²

S: Yeah.

PI: And so do you think your grandkids kind of learned something a little bit different?

S: Definitely.

PI: Okay so what do you mean? How is it different? Can you elaborate?

S: Well they constantly come in wanting something to eat. And we never had that food in the house. Or if we did, well I always had nuts and stuff like that available. Lynn will raid the pantry, and there was always stuff there. I didn't necessarily eat it[some good some bad

PI: [right

PI: So you don't think that the grandkids have learned or you don't think the grandkids are coming to you because they're hungry?

S: ((shakes head no)) I think a lot of its habit.

PI: Its habit, just habit.

S: Yeah I think some of its habit. Plus (.1) she keeps the pantry stocked with (1.5) cheetos and (1.5)=

PI: =junk?

S: Yes. Junk food junkies

PI: ((laughs)) right and so your kiddos didn't have the option or didn't learn that, it's a habit

((S nods in affirmation))

PI: Did you guys ever have the conversation about hunger, feeling full or we eat to=

S: =I guess I kind of set the pace for eating, which good or bad, cause I'm not a (.1) big eater and I'm normally not a grazer. And in the mornings I'm not, now in the afternoon for a pick up I'll often eat something and now I've gotten to where it's like stuffed celery with almond nut butter and stuff like that

PI: Right.

S: Which, again the kids are all gone and we've always had cookies and stuff inside the house (1.0) and for a while we were even doing goat's milk because Lisa goat sat for a friend and she loves goats. And when they were gone she'd bring some of the milk home and all the fresh eggs, cause I grew up on (.1) fresh eggs, fresh milk, and mom would buy a side of beef and a side of pork and a side of lamb and so our freezer was always stocked and then mostly frozen vegetables, Grandma had a little bit of a garden. So I just tried to pass on as much as I could to the kids and I think I did a pretty good job<referring to healthy eating habits>

PI: yeah, absolutely

S: Or their workin on it anyway ((laughs)) it's their turn, I'm done!

()

(1.5)

PI: Exactly, alrighty and we spoke about this a little bit so if you don't have anything extra to add it's fine, number 6 but how ((do)) you feel that physical activity impacts the quality time that you guys spend together? Or have you thought about physical activity kind of uh being spent (.1) as quality time?

S: I don't think we ever looked at it that way a lot of it for us cause (.1) Arlo's ((husband)) a worker and a lot of times that was the physical activity (1.0) us doing (.1) work=

PI:=okay

S: Like, if we'd a been here when the kids were little ((referring to their current property which S mentioned off tape that they had not lived in while the kids were young)) they'd be out there raking and cutting down trees branches and stuff like that. Uh so as far as that (.1) there really wasn't a lot

PI: So if you had to um I guess paint a picture of how you guys would spend quality time together, what would that look like?

S: Movie

PI: A movie?

S: If possible, so once in a while or maybe playing a game but most of the time it's either movies or nothing. Cause we were around one another so much with home schooling that we needed the (.1) to get away

PI: Right

S: ((laughs)) We needed a break!

(1.0)

PI: Okay, and the next one how do you feel the promotion of healthy eating impacts the quality time your family spends together?

S: We had good times at the table and it was (.1) most of the time fairly healthy food, I tried to promote that and our family's always been one though and Grandma Larson was that way too it's (.1) eat, get done, get away from the table.

PI: Okay.

S: Ya know, clean up your plate, but then get away from the table=

PI:=right, okay

S: She was a pusher and we were never people to lolli-gag if you will, it was get done and get out.

PI:Right. So did you have any rules about seconds or having seconds?

S: It was on the table and you ate til you were full ((smiles))

PI: Okay ((laughs))

S: You weren't forced to (.1) you know, if you took it you ate it³

(1.0)

PI: Right, and what if you guys were sitting down at the table and one of the kiddos said that they didn't like this, what would that look like?

S: Well, we'd usually just let it go because there was usually enough of everything else that they could still get full, my goal was to keep them full

PI: Right.

S: And we would do new foods and now with Lucas, now the one thing I can say with him managing a store, when he was little I always had fresh fruit and they do keep that in the house as well ((speaking about her oldest sons' house)) I don't know how balanced it is, but at least its there (.1) And I haven't done as much with fruit (1.0) in the later years um (1.0)

PI: Just because you said that Luther doesn't like it?

S: Luther doesn't like it and (1.0) Lucy ((motions with head turn and hand gestures indicating nothing)) everything, ya know?

((tape stopped, Luther comes in to the room))

PI: So what if you guys were all sitting down to eat and Lucy or Luther said that they wanted something else? I think some other mom's coined the term like short order cook. So if the family is eating this, would you make a separate meal for one of the other kids?

S: No. No I don't. Arlo's Mom used to always put peanut butter and jelly on the table so if they didn't want to eat dinner they had that=

PI: =Really, and how do you feel about that?

S: I don't think it's right because it's teaching them well there's always an alternative. We had no alternatives, now if they were still hungry when we were done eating they could go raid the pantry or whatever but no (.1) what's on the table is on the table

PI: Right. So what about, and I know most of your kids are older and this is kind of a new fad I guess, but menu planning? There's a lot of talk nowadays about having all the kids in the kitchen and all the kids going to the grocery store together, what do you think about that?

S: I wish I'd a done it! I'll put it that way, I never did because I'm not a planner that's been my uh an () all along because I'll just walk in the kitchen and think okay what am I'm gonna throw together[] and I never really trained the kids to cook (.1) Lauren didn't like to and now Lisa did and what I did for Lisa (.1) is ya know those spiral bound 6 notecards ya know? We got one of those and she started cutting them out and putting in recipes and so she had her own little first cook book, all her own (.1) And she liked that we did that and it was part of homeschooling and she liked to cook and be in the kitchen whereas the rest of them didn't until much later and now Lucas, grills and the whole bit[] but growing up? No ((laughs)) Dad didn't do it so he didn't do it. And he still can't ((referring to Arlo)) um Lauren, hated to cook (.1) Lucy hates to cook but Lauren is a great cook. She doesn't like to but when she does she does an awesome job and () likes to cook when he comes home we have a good time (.1)

PI: [yeah

[right

PI: Yeah.

S: But I'm not an organizer, I'm not an administrator so I was never one to push I kind of more or less just did it myself

(1.0)

PI: Cause somebody had to do it

S: Yeah, pretty much pretty much ((Laughs))

PI: Okay, alrighty. And we've we may have spoken about this before (.1) but how physically active and healthy would you consider your family to be? And we're on number 8 and what factors impact that?

S: Well other than me and Arlo and Luther they're all very pretty active (1.0) Lucy still goes and plays volleyball and stuff like that and she was on the college (.1) football team and stuff like that so she's still, she needs to be more active (.1) all of them are (.1) and Lucas included when he gets a chance he goes and rides the bike trails down in Fort Worth and down there and uh Luther doesn't. Like he'll say Saturday tomorrow morning Mom what are you gonna do? I'll say I'm gonna do this this and this and I said what are you gonna do? .hhh Listen to music ((smiles, laughs)) And Arlo is just as busy out here ((motions to the big backyard)) And we try to engage Luther and the only time he'll help outside is if I'm working and I say okay Luther come on and we have raked and bagged leaves until we're blue in the face and we get a system going=

PI:=Right.

S: Other than that hh (1.0)

PI: so he would only, Luther would only do it if you were with him

((S nods head in affirmation))

PI: But he wouldn't do it with your husband?

((S nods head no))

PI: And why do you think that is?

S: Perfectionism.

PI: Perfectionism, okay. On your husband's part?

((S nods head in affirmation))

PI: Okay and so with you, you'll get the system going and kind of get Luther motivated a little more?

S: Huh uh ((affirmation)) I mean it's, it's seldom but (1.0) the problem is for Luther and this is why I want to get him in a home is there's just always been too much going on here and people to take the time and me included to sit back and really work with him

PI: Right

S: So that's been the biggest bugaboo in our life. And I feel like if he was in a home they would keep going=

PI:=and he would have to do it?

S: Yes, he would have chores and he used to (1.0) clean his room, he'd vacuum it, swiffer it, he'd get home from school and everyday=

PI:=oh yeah?

S: And then he went to camp and he came back from camp, and he had that week of one on one (1.0) with Scott, Scott's his greatest friend in the world but he came home and I think, the depression and he hasn't done anything

PI: oh really, and that was this past summer?

S: this was 2 summers ago

PI: is this, was this like a camp counselor or just a buddy that he met at camp?

S: it was his counselor at Camp Summit, and uh he's been to camp twice since, the one time he had Scott for the weekend camp and then Spring Break, he had that's when UNT had a bunch of students volunteer to work the camp and he had the guy from there (1.0) and then this past summer he went and he went the first weekend in December he went to camp again and he got Scott! And uh cause Scott's lookin for work but (1.0) uh (1.0) he just shut down (1.0) and he will do the work I have to coax him a little bit more, one day I was busy cleaning and 'Mom what are you doing?' I'm doing this I'm doing that and so I said (.1) why don't you clean your room? And he says, nah I don't want to do that. (I said) that's fine and so I go back about my business and next thing I knew I heard the vacuum cleaner going ((smiles))

PI: Okay ((laughs))

S: And he folds the laundry for me or we'll do it together and (.1) but his job now is at um this sports place over by Guyer and (.1) he's cleaning

PI: Oh okay it's the new uh it's like sports acceleration place right?

((S nods in affirmation))

((off topic conversation not transcribed))

S: Anyway they like him there, they had cake for him for his birthday, but he's learned to do a little bit more cleaning and he came home one day and I said something about oh this bathroom needs to be cleaned (and he cleaned it!) [so I know he's learning to do stuff

PI: [oh really?

PI: so is it volunteer-based now or are they paying him anything?

S: Right now he's in the work study (.1) the job corp program at the high school he has a job coach that goes over there with him but I'm thinking I might see if there's some way, I don't want to be the job coach [but if I can find somebody that could take him through the summer and let him keep working

PI: [right

PI: Right, so he can get used to that routine, absolutely.

S: And then I think they could hire him there later on

PI: Absolutely

S: but ya know it takes like 30 minutes to get over there but it would help me get out of the house because I'm gonna go crazy here ((laughs)) I am already

PI: ((laughs))

S: Anyhow. Enough of that. That's just kind of where that's at

PI: Alright, I think we did speak and kind of have gone back and forth but barriers do you feel your family faces related to being physically active or do you see any barriers for your family? (.1) And that could be each individually or the family as a whole.

S: Individually just attitudes um (3.5) and that's a lot of it

PI: Attitudes?

S: And you know with a teenager ((speaking about her younger daughter)) they're like I wanta do what I want no matter what so and you know she quit doin stuff (1.0) so I think she was kind of setting the tone and we're glad she done ((whispers very low)) because there was a lot of stress. (1.0) But I think physical activity and the healthy eating, I think the barriers mainly has been attitude. (1.0) And ya know I don't know how it is with you but sometimes you experiment with foods that you () don't want to eat anymore. But and that hasn't been that often but I think that would basically be it

PI: Okay

S: Just like I said Arlo grew up on a farm (.1) I grew up (1.0) Mom always fed us everything because she was young during World War II in England and Scotland and there were times when they didn't have (.1) any food

PI: Right

S: And so her whole attitude, ya know (.1) affected that. So we (1.0) we ate well (1.5)

PI : you eat what you have and food is for nourishment

S: Hm hm ((nods in affirmation)) and so that's kind of the way that I grew up and I think Arlo did too but being from farm country and all (.1) it was again a (1.0) different perspective

PI: Right.

S: And his mom made their bread and it was white bread, she always called wheat bread brown bread but she (.1) she did baking and stuff too and she liked to bake so but they just got it a little bit differently (.1) they got the high card angle

PI: Right

S: (And we got the other angle)

PI: And from what it sounds like, being a healthy family is definitely a priority[for you guys so how do you feel you guys kind of uh (.1) your role measures up to that priority so um if you kind of had to evaluate ya know, it's this much of a priority (1.0) have we met that?

S: hm hm ((affirming))

S: Well we were so consistent I was then ((referring to the older children)), I'm not now I'm too tired to be consistent! But we were consistent for a long time, I think til the 2 mid kids as we call them, that's Lynn and Lisa went away to college and then things kind of (.1) I was burnt out (1.0) but I was just consistent whether they like it or not. I kept sugar out of the house and stuff like that and it was just a consistency that um I guess you could say in a way it was a priority and then it became habit.

PI: Right, it became a habit. So it made it easy?

S: Hm mh ((affirming))

PI: Okay and I know you have mentioned, I don't think any of the kids has ever had a weight issue, so there's never been a concern about weight or anything like that=

S: =Right=

PI: =and um, if there was or if there would be in the future I know all of the kids are kind of grown up now but=

S: =well Lisa remarked about that when she went away to college and I was reading this article about 15 you know you put on these 15 pounds[the freshman 15 because you're getting if you're eating in the cafeteria you're getting a lot of carbs and she said Mom, I gotta do something. So she quit.

PI: [the freshman 15

PI: She quit what?

S: Eating in the cafeteria

PI: oh okay

S: And started fixing more of her own stuff and she was, she was an RA as well and she was working out at the gym and she joined the track team and all that, but she changed it. Lynn did too, they had a better choices at VMI ((referring to Lynn's college))[they had a good cafeteria at least what we saw when we visited. And then Lauren did too but as she's gotten older ya know your body, your metabolism changes and she's had to battle it a little bit more. And Arlo's Dad tends, tended to be on the heavy side[on the chunky side and most of the family's big boned, his one sister's six foot tall and then Lucy of course, is just not that much shy of being six foot, she's long and lean and right now she is tall and lean and Sandra was too and now she's ((shakes head)) Sandra and Jan, his 2 sisters ((S's sister-in-laws)) (.1) the 3 of them look like they don't belong in the same family they're like this and he's like this ((hand gestures, insinuating and Arlo is much thinner than his sisters))

PI: [I'm sure

[alright

PI: so if the kids were to come to you or you were to notice kind of a weight concern what would you recommend, would you recommend changing eating or would you recommend activity? Or=

S: =both

PI: Both, okay.

S: Like with Lucy, she's (.1) a lot of carbs and I said ya know Lucy you tend to be like your father and you've got a big derriere and 'Mom you don't need to tell me that' ((laughs)) and we talked about the weight thing and she's, she's self-conscious of it (1.0) but she's startin to now that she's moved out and having to buy her own food she's tending more towards the salads and drinks water and eats vegetables instead of (1.0) the junk

PI: Oh okay. So in that conversation with her would it be basically about weight or would you talk about general health?

S: I think I would probably go to general health, because I'm still I've come to the conclusion that I have a gluten sensitivity, so I try to stay away from it so I said well you know the thing that puts all this on is the sugar and the carbs and stuff like that so I said if you can avoid that and move more (.1) this way (.1) you'll feel better. And they've even noticed since I lost 13, 13 pounds and doing just, just that I've had more energy so just, they uh they pick up on it from me too. (.1) I've tried to be an example so I may have or not ((smiles, laughs))

PI: ((laughs))

S: Once in awhile they'll come back and say thank you mom

PI: Er you said one day? Or once in awhile they will?

S: once in while they will

(1.5)

PI: Right and that is (.1) all of the questions and I know we spoke a little bit about it and if there's (anything) you wanta add you know we talked about this and you said a little bit about your husband's family history with weight and I know Luther, he doesn't have any weight issues (1.0) and do you think it's, maybe he's not one of the kiddos that leans towards your husbands' side or do you think it's because of lifestyle habits? That kind of=

S:=I think it's probably a little bit of both because he is built like his Dad, because you know he's tall for a Down's child[and I mean he weighed 8'8 when he was born so he was a big baby (1.0) I think that's a lot of it, like I said he's not an eater, I mean we have to force him to drink water and=

PI: [he is, absolutely

PI:=and do you think that's something that he's learned? Or that him, because I've ya know a lot of moms'll say they almost have to stop their kiddos from eating. Ya know? Er especially their, children that have Down syndrome.

S: Well and you look at him and you look at Audrey? I don't know if you her?=
PI:=I do know her ((referring to a classmate of Luther's who has Down syndrome and is obese))

PI:=I do know her ((referring to a classmate of Luther's who has Down syndrome and is obese))

S: And she likes her sweets⁴

PI: And I don't know their family well to know=

S: Oh her Dad's a doctor, he's a plastic surgeon

PI: oh really

S: And I know, I can't remember what her mom's name is I can never remember it, but she's concerned about Audrey's weight and she has to watch her, they've had to take food away from her (.1) now (.1)

PI: And so have you ever kind of thought about the differences between them as far an environment?

S: I think that could be some of it but she they have another child that has some, some learning difficulties=

PI: =learning difficulties okay=

S:=as well, but I try to still have him eat properly I tried to make sure I pushed the protein and with all that kind of stuff in my pregnancies, stayed on the high end of a good diet (.1) (2.5) Not every Mom I think (1.0) does that (1.0) and I mean I just did a lot of things ((laughs)) and sometimes I think out of stupidity or not knowing or=

PI:=while you were pregnant?

S: Yeah or just, just I tried to do what, if you will, what I felt comes naturally (1.0) I guess that's why I had all the kids at home

PI: ((laughs)) absolutely

S: Um, but even in the hospitals I never had any ((referring to her first 2 births)) medication or any kind of, it was still natural it was just in a hospital environment but .hhh I've just always been (1.5) not intentionally just have been a naturalist[ya know I was into homeopathy, I did homeopathy with the kids when they were little (.1) if they got sick they got homeopathic medicine, very little aspirin to this day the kids don't even like to take aspirin or an ibuprofen unless they absolutely have to (2.5) and I think that's been it I mean if you think about all the junk that's out there, but I was a stickler on that, Arlo used to call me the jungle doctor ((laughs))[Jungle doctor!

PI: [hmm h ((nods))

[the what?

PI: So if you had, if you had um any advice for moms of ya know kids of all abilities, kids without Down syndrome, kids with Down syndrome as far as healthy what would you recommend or what would you suggest since you know you're kids are older and on their way out?

S: Well first of all, in talking I would just tell them to really have a good diet before=

PI:=Right. Before?

S: Before pregnancy and especially during (.1) and my biggest thing is don't let the kids (get off) thinkin, get them, make them try things even if they don't want to. I did a lot of more limited with Lucas, my first one, mainly because I was learning but we did get into the fruits and stuff and with the rest of them I just started branching out now I have to admit that there are some foods that I don't like that I definitely wouldn't serve. But they know they're there!

PI: Right.

S: I mean there's what 90 some different vegetables and our list of vegetables is very limited and again I've got trying to serve Dad too and we'll keep it good that way. But yeah I would (.1) the most important thing you would, the most important thing you can do for your family is feed them properly and even one of the most important things (2.5) second to knowing the Lord.

PI: Right.

S: They need the spiritual food first, then the physical

PI: Right, well that is all of my questions.

S: Okay.

PI: Do you have anything kind of related to the topic that you were maybe hoping that I would ask or do you think there's something=

S:=no, cause I hadn't really, I don't even remember what your questionnaire was, I remember it was long ((laughs)) but my biggest thing is I would love to see more going on again at TWU in programs

PI: Right

S: I think I'd have the energy now to start, ya know, of course Luther's so much older. But they need some programs, I don't want to see the programs disappear. And I know UNT used to have one and I don't know if they still do but they had a program over there working with parents of autistic children (.1) to teach them how to handle them, to teach them what to do and what not to do and you know that is the biggest part of the teaching. When Luther was born, he was born at home and Dr. McGee came to the house, if you can believe that he made a home visit and he confirmed that is was Trisomy 21.

PI: And so how long after he was born did you find out? Immediately or I've heard some folks say it was a day?

S: We knew that day, the midwives knew right way, they picked up on it right away because he definitely has the markings, the hands and the extra skin at the neck and things with the feet. Plus just being, although his Apgar was good but just being, the floppy head and just different things

PI: Right.

S: Then we went to see the doctor, but he had never worked with families and kids with Down syndrome, so I was the student and the teacher and I've always been one of those people to say let's look at the challenge and so I started reading up and I called the Down Syndrome Guild and he was born in the morning and that afternoon I called the Guild and I think ya know we've got something we have to deal with and I can vaguely remember we were out in California and they were talking about someone who have the Mongoloid daughter

PI: I know, and it's terrible but that was the term

S: That was the term

PI: Right, and in doing this research I've had to go back to original research and even books from just the 1960's and the terms are just terrible.

S: I know, but so I can remember that and I just got okay, what are we going to have to do. And Kelly, the midwife that was the first one and she was just really good and she was like well you know there's this possibility and that possibility and the one thing that Dr. McGee said and by then I was into natural medicine and he's says well you've got a Down syndrome child so I'm going to be seeing you a lot and I thought (.1) not if I have anything to do about it you won't! I think we went to the doctor may twice that year. He had to have a hernia removed and he's had a lot of tubes in his ears, he had the measles,

mumps, and the chicken pox and he had a 30% hearing loss and we had to have his eyes done because he had amblyopia, strabismus 2 or 3 times.

PI: So do you feel the lack of stress from having the babies at home is less?

S: Yes! And you both recover fast from having the baby at home, you're more relaxed you're not being woken up all the time by nurses.

PI: Right!

TAPE STOPPE 02/02 42m43s

Disclaimers and permission to assist with 'member checks' were completed off tape

Annotations

¹ She mentions 'they need a lot of motivation' they meaning children with Down syndrome? Through the context that assumption would be fair

² Food is for nourishment, referring to the fact that 'nowadays' many children and adults just eat to eat, rather than eating for nourishment.

³ Since the primary goal was to instill the good/healthy eating habits on her children, I don't think she worried as much about having food rules because she took the time to think about how the modeling of habits from would positively benefit her children.

⁴ I think a lot is being inferred in this statement. In talking with S about her son with DS's lack of weight issues and the how and why around it, she brings up a girl in her son's class who also has DS, but is extremely obese. She does not give a reason just yet of why she feels like this girl has weight issues and her son does not, but I feel she has brought it up to demonstrate that yes some children with DS are obese and some are not.

APPENDIX F

Researcher Reflexive Journal

Reflexive Journal, Focus Group A

During transcription I reflected on the focus group. I was very nervous at the opening and closing parts of the focus group, but really felt like I was able to be my natural self quickly on. The participants all seemed very open and honest and almost excited to be present. Prior to recording, one mom said she loves doing this “sharing information.” I am very aware of my tendency to use closed ended questions, filler words, and speak more quickly than is necessary. I recall being conscious of these things during the focus group and also conscious of being an active listener so as to meaningfully engage the participants during the discussion. I feel this is why I did not take any notes during the focus groups.

During questions 1, I did not differentiate clearly between types of physical activity. This could be a potential future area of target. By type of physical activity I mean, organized, less organized, intense physical tasks.

Potential future question: Do moms see the physical activity intensity differences in terms of health benefit differences? My comments throughout this focus group were very directional, in that when comments were made about being active or practicing healthy eating habits I praised them. While when comments were made regarding inactivity or fast food, I seemed indifferent. As I transcribe the data and familiarize myself with the context, I notice missed chances for probing the topics further. This is why it is so important to transcribe after each interview. A mom mentioned time for physical activity was limited because her son with Down syndrome is slow to transition. She attributed his

slow behaviors because of the Down syndrome. Then another mom mentioned that her daughter, who does not have Down syndrome, was similarly slow when transitioning to different tasks. Both children are close in age, potentially the 'slow' barrier to activity or transitioning is related to age, developmental period, or personality. Rather than the child being slow 'because of the DS.' I do not think this discussion was fully explored.

Reflexive Journal, Focus group B

I was less nervous during this Skype session for the reason that the group video was not available. This was not expected, but it made me worry less about appearance or eye contact and I could focus solely on the sound of my voice and wording of questions. Thus, I feel it gave me more freedom to fully without any regard for my body language. A full capacity for listening. While the second interview on 12-13, which was a one-on-one interview with K did have a video. I feel that my natural progression of questioning may not have been as smooth and I was conscious to maintain eye contact throughout the interview. This was not an issue during the focus group via Skype.

The challenge to not ‘counsel’ or ‘guide’ parents related to their comments or questions has been very difficult. But since I am aware that guidance and counseling is not the focus of this exploration I feel it made it easier not to give in. And I may not have been successful in completely holding back my own personal beliefs, I feel I tried my best. However, there were times in some of the interviews where there was a question which I have been in the position to answer, based on my profession or knowledge (i.e., something related to APE) gained from reading other researcher’s results. So I am aware of the line between gaining information, gathering knowledge about a topic I’m interested in and helping the interviews based on the topic. If I were to have provided advice or ‘answers’ to the discussion this may have changed the dynamic of the group or could have possibly changed how participants answered future questions. I am aware of

this very grey line. And I may have reached it; however, I do not feel that it was crossed up to this point (i.e., 2 focus groups and 1 interview complete).

In reading other interview results (i.e., from other studies) I realize the mention and even the understanding of physical fitness is not common among mothers. Weight loss and physical activity are commonly mentioned, but fitness is rarely mentioned. Why is this? Lack of knowledge, understanding or lack of importance? This idea was not fully explored and may not be relevant to purpose of this particular study.

As I transcribe I realize many instances where I might have missed some very rich data if I had just explored a little bit further (FG 1, S, L, M 08/08) I think time was a factor, not wanting to go too far past the '90 minute mark.' However, that is the reason for the potential follow-up interview.

I should have explored L's comment when she stated (8m,39s A 08/08) that she is interested to see how that plays out? Related to her husband not being active during the week and doing very little on the weekends. What did she mean? Plays out with his health, family health, impact on family? Does she plan on attempting change. Ask Lisa: is this a conscious choice between you and your husband or just an unspoken rule

Reflexive Journal, Interview Kenna

Immediate thoughts are how the questioning in this interview sounds so much more clear and direct. There are few filler words and examples and direct the conversation a certain way. I asked specific, open-ended questions and then paused to wait for her answer. I wonder if this was because this was my first one-on-one interview rather than focus group?

A note has been made that parents from this current or previous interviews may have been comparing their children at the current stages rather than thinking back and comparing their children's physical activity levels during the same ages (i.e., Jon was 7, Kate was 7). So that may have made some of the parents' interpretations of the kids' habits a bit inaccurate. This could be a potential area of follow-up.

Question formatting: Thing about the physical activity levels of your children throughout their life stages. What have been the physical activity level differences when you compare them at similar ages? However, 10 minutes into this interview I asked this very question! The preparation or lead-in to some of the more personal questions (i.e., weight issue and children or family) can often be wordy. I think this shows my hesitation to ask about this content, my understanding that it is a sensitive topic, or my own inexperience as an interviewer.

Reflexive Journal, Interview Eva

Initial response after completing the interview and now transcribing is that I liked her very much. She was extremely transparent and clear about her own personal weight struggles and did not hesitate to share any of them. E seemed to be such a good story teller that when listening back to the tape it seems there are many missed changes of places where I could have explored a little more or specifically asked about habits between her 2 children. But her stories were so captivating!

I felt myself becoming more of an observer in this interview rather than the interviewer. I should have asked her what do you think about the level of interest for activities between your 2 children, what does she attribute these differences too? Why does she encourage her son to be active more than her daughter? Does she measure health by weight or the absence of overweight? A note should be made that on page 13, why do you think you could have had such a stronger impact on your son rather than the level of activity for your daughter? Later this comment was addressed.

Reflexive Journal, Interview Stacey

Comments and conclusions can be made that there is awareness that stronger efforts were made – regarding health for the older children. In that in this household, with multiple children (6) efforts to encourage health were greater as the mother was younger, and with the first few children. Comments were also made that the children have learned some healthy habits on their own and that the mother is very glad about that, as she feels strongly and their health. But again, the absence of noticeable weight issues may have been a factor in the ‘lack of worry’ regarding the encouragement or the ability to be ‘content’ with the eating habits of the younger children even though they are probably not as good as the older children. So there appears to be a combination of tiredness from the mother (i.e., related to the parenting of 6 children) and the notion that the absence of excess weight equates to health. This combination may lead to less restriction of food encouragement to change eating habits that may not be ‘as healthy.’ She is very introspective, she makes the comment on page 15 that health was a priority and then...it just became a habit.

Reflexive Journal, Summary Points

It seems as though the mothers whose children with Down syndrome had feeding issues (i.e., stereotypical to DS) are almost thrilled that their child is eating by mouth 'normally' and that there may be less of a focus on what is being eaten because they are just thrilled with the normalcy that they are eating by mouth! Not shakes or through tubes, etcetera.

Several missed changes to further explore the eating habits between siblings. I think the mothers were more focused with their comments related to their children with DS. So the questions or instructions may not have been as clear regarding the need or desire for information about all children. Not just about the child with DS, but all children. There were differences between siblings not at all related to Down syndrome.

I'm realizing the potential limitations of the data in that not only did the participants self-select, but they are all members of an education type discussion board or group. They are all educated. But not one of the children with Down syndrome is obese, only one mom mentioned her son might be a little overweight. But all others have not had to deal with weight issues. However, half of the mothers did mention concern for overweight among both children because of family history, not Down syndrome.