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## Parents of Children with Significant Disabilities Describe Their Children's Eating Habits: A Phenomenological Study

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### Abstract

This qualitative phenomenological study, through interviews, aimed to understand the experiences of parents of children with significant multiple disabilities about their children's eating habits. Review of literature indicated disparities in health between people with significant disabilities (SD) that include intellectual disabilities (ID), intellectual/developmental disabilities (IDD), or multiple impairments (MI) and people who are typically developing. People with significant disabilities are at a higher risk for obesity, future weight gain, underweight and/or malnutrition, adherence to a less-healthy diet, and problem behaviors during meal time. Semi-structured initial and follow-up interviews used general questions to gather data, which were subsequently coded and examined for themes across participants. Five themes emerged from the interviews and were compared to findings in the literature. This study included some unique characteristics: detailed descriptions of the children's eating habits, family experiences around these habits, and what habits are going well for the children.

### Keywords

Significant Disabilities, Eating Habits, Qualitative Research

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In 2007, when faced with the question of what we should eat for optimum health, food journalist and author Michael Pollan answered, "Eat food. Not too much. Mostly Plants." A recent focus on diet is largely due to the obesity level in U.S. adults at 36.5% of the population and children ages 2 to 17 at 17% (NCHS, 2016). Increasing attention focuses on dietary habits of children as obesity becomes a widespread health concern, especially in terms of costs for outpatient treatments, prescription drugs, and emergency room visits (Neufeld, 2016; Trasande & Chatterjee, 2009). Health of children with intellectual disability (ID), multiple impairments (MI), or intellectual/developmental disabilities (IDD), warrants special attention because of further complications with health compared to the typical population (Gibson, Temple, Anholt, & Gaul, 2011; Krahn & Fox, 2014; Stewart et al., 2009).

### Government Dietary Recommendations

The debate about improving health in our nation centers around the modern "Western" diet of highly processed, salty, sugary, high-fat foods combined with sedentary lifestyles (Jinks, Cotton, & Rylance, 2011). To counter this common diet, the Academy of Nutrition and Dietetics (AND), in conjunction with the U.S. Department of Agriculture (USDA) and the Department of Health and Human Services (HHS), developed health guidelines for adults and children (AND, 2018; Office of Disease Prevention and Health Promotion, 2018). The AND and the U.S. governmental agencies recommend most people build their diet around fresh vegetables and fruit, whole grains and products, and low fat or fat free dairy, along with lean meats, beans, eggs, and nuts. Refined grains are recommended to make up less than 50 percent of grain products consumed daily. Additionally, it is recommended that foods with fewer nutrients make up leftover calories only after all nutrition needs are met by consuming the

foods meant to constitute the majority of a diet. (Academy of Nutrition and Dietetics (AND), 2015, 2018).

The government guidelines recommend limiting sodium intake by eating unsalted and low salt versions of nuts and snacks, as well as limiting deli meats such as bacon, sausage, hot dogs, pepperoni, and lunch meats (USDA, 2016). The guidelines also recommend avoiding added sugar in the form of sodas, punch drinks, many popular “fun” cereals targeted towards children, flavored/sweetened yogurts, cakes, pies, and cookies (AND, 2016b).

Processed foods are also a source of confusion for many. Processed foods are any foods that have a combination of ingredients, and/or alter the whole components of food prior to sale or consumption (AND, 2016c). Many people correctly view cookies, potato chips, and fast food as processed; however, organic breads, soups, and trail mix are also processed foods (AND, 2016c). How to tell the better choices from ones to avoid? The AND (2016c) lists the following as examples of good choices that make healthy eating easier and are minimally processed: bagged lettuces, cut vegetables and roasted nuts, canned tomatoes, frozen fruit and vegetables, and canned tuna. They list the following examples as moderately processed, to eat in moderation: foods with ingredients added for flavor and texture (sweeteners, spices, oils, colors and preservatives) including jarred pasta sauce, salad dressing, yogurt and baking mixes. Finally, they list the following examples as highly processed and to be cautious of, due to large amounts of added sugar, fat, and sodium: crackers, granola, deli meat, candy, donuts, fast food, frozen microwave dinners, pizza, and chips. The AND advises when choosing processed foods to go for those with more fiber and protein and less saturated fat, sugar and salt (AND, 2016c).

### **Health and Diet of Children with Significant Disabilities**

The American Association on Intellectual and Developmental Disabilities (AAIDD) defines ID as a combination of significant deficits in both intellectual functioning (reasoning, learning, problem solving) and adaptive behavior, resulting in an IQ score of 70 to 75 or lower and manifesting prior to age 18 years. Some individuals with ID have comorbid conditions such as cerebral palsy, epilepsy, communication disorders, and other conditions, identified as MI. When individuals have developmental disabilities, such as autism, as well as intellectual disabilities, they are commonly referred to as having IDD (AAIDD, 2013). A broad term for diagnoses such as ID, IDD, and MI is significant disabilities (SD).

Health disparities, such as higher obesity rates, poorer diet, lower rates of exercise, and sedentary lifestyle, are evident between individuals with significant disabilities and those who are typically developing (Grumstrup & Demchak, 2017; Humphries, Traci, & Seekins, 2009; Reeve, Ashe, Farias, & Gostin, 2014). Current concerns with obesity-related health issues for individuals with SD necessitates research into what the problems are and what is being done to address them.

The literature related to obesity and children and adolescents with SD indicates they are more likely to be obese than the general population (Rimmer, Yamaki, Davis Lowery, Wang, & Vogel, 2010; Salaun & Berthouze-Aranda, 2011). Obesity is defined as a body mass index (BMI) of 30 or higher, calculated by weight in kilograms divided by the square of height in meters (CDC, 2016). Obesity is linked to risk for further conditions including diabetes, hypertension, high cholesterol, cardiovascular disease, stroke, arthritis, and certain cancers (NCHS, 2016). Obesity in individuals with SD raises the risk of related health conditions as well as shorter life span, future weight gain, and lower quality of life (Pett et al., 2013; Reilly & Kelly, 2011). Obesity-related conditions may create further struggles for those with an already challenging condition, such as SD (Begarie, Maiano, Ninot, & Azema, 2009). Other research indicates that some disability groups are associated with high BMIs: autism, spina bifida with co-occurring ID, and Down syndrome (Rimmer et al., 2010).

In contrast, some individuals with SD require diet intervention but are not overweight, with a significant number considered underweight (Maaskant, Van Knijff-Raeven, Van Schrojenstein Lantman-de Valk, & Veenstra, 2009). Some studies also show a tendency for people with SD to be malnourished, lacking sufficient nutrients to maintain optimum function (Franssen, Maaskant, & van Schrojenstein Lantman-de Valk, 2011), whether they are over or under-weight. (Meijers et al., 2009). Many individuals are at risk for nutrient deficiencies, caused by feeding/oral motor difficulties, narrow food preferences, frequent choking episodes, dental issues, food allergies, specialized diets, and medication side effects that influence diet or metabolism speed and efficiency (Gibson et al., 2011).

Of further importance to the topic of health for individuals with significant disabilities is nutrition and food choice, as diet is widely assumed to have a role in obesity (Caton et al., 2012). Some research suggests that individuals with SD adhere to a less healthy diet over a healthy one (McGuire, Daly, & Smyth, 2007), and that these issues often persist into adulthood (Fodstad & Matson, 2008). It has also been proposed that individuals with ID have limitations in understanding healthy food choices and nutrition (George, Shacter, & Johnson, 2011). However, Jobling and Cuskelly (2006) suggested that knowledge about what constitutes a healthy diet may not be the issue in this population; that the individuals can describe or show what constitutes healthy eating, but preference dictates what they actually eat.

Other research has focused on problem behaviors during mealtime, such as in the following examples. Several assessment studies indicate a need for intervention to increase food flexibility in those with ID and IDD (Keen, 2008; Koegel et al., 2012). A response to this need occurred through single case research design (SCRD) studies attempting to address this issue. Some studies focused on increasing the variety of food the child would eat (Gentry & Luiselli, 2008; Knox, Rue, Wildenger, Lamb, & Luiselli, 2012; Koegel et al., 2012). Others focused on increasing independence at meal time for children who were prompt dependent or had limited independent feeding skills (Bailey & Angell, 2005; Qvarfordt, Engerström, & Eliasson, 2009). Another study addressed both issues of prompt dependence and limited independent self-feeding skills (Kadey, Roane, Diaz, & Mellow, 2013).

It is clear that researchers have responded to questions about what the problem is (e.g., health disparities in SD), and what can be done about it. Interventions were primarily implemented in SCRDs, which are important in addressing specific and targeted behaviors for low incidence populations (Horner et al., 2005; Kratochwill et al., 2013; Wolery & Dunlap, 2001). However, such studies are not designed to provide in-depth knowledge of individual experiences with an emphasis on how or why certain phenomena occur.

### **Purpose**

The purpose of this qualitative study was to seek in-depth descriptions of individual eating habits of children with SD from the perspective of parents. Our research was guided by the following questions: What do the children reportedly prefer to eat? What foods do they refuse? How do food preference and refusal relate to AND (2016a, 2016b, 2016c, 2018) recommendations? Are the diets of the children with SD different from others in the household? How have parents responded to food refusals and eating differences? This study could address gaps in the existing literature and contribute to an understanding of the eating habits of children with SD.

### **Method**

This is a phenomenological study, aiming to understand the lived experiences (Rossman & Rallis, 2017) of parents of children with significant disabilities, specifically MI

about their children's diets. Interviews describe, in detail, the parents' experiences with their children's dietary habits. Each interview was analyzed through thematic analysis of phenomenological meaning categorization, specifically using Moustakas' (1994) modified van Kaam method to develop insights from the perspectives of those involved (Koch, 1995; Rossman & Rallis, 2017).

### **Researcher Background, Context, and Positionality**

One of the researchers, Brianna, has 9 years' experience working with students with significant disabilities, specifically those with IDD. Brianna was a teacher in a self-contained program at the high school level, then a consulting teacher specializing in students from this population district-wide. Brianna made many health changes and improvements within the last 5 years, so holds the view that diet and exercise are instrumental to health outcomes. Furthermore, based on her experiences with parent concerns and her prior research, she believes children with SD are at higher risk for poor diet, decreased exercise, and their effects.

The second researcher, MaryAnn, has been a professor teaching courses and conducting research in the area of severe disabilities for over 30 years. Additionally, she has been the director of a statewide technical assistance project funded by the U.S. Department of Education, Office of Special Education for nearly 30 years. This project, the Nevada Dual Sensory Impairment Project, provides consultation and training to families and service providers who have children with impairments in both vision and hearing. Through this work, she has had extensive experiences and developed relationships with families of children with SD that include sensory impairments.

It should be noted that we co-authored a narrative literature review outlining current issues in obesity, nutrition, and intervention for people with significant disabilities (Grumstrup & Demchak, 2017).

### **Participants**

This study was approved by the Institutional Review Board at our university. The study was exempt from federal regulations in accordance with the requirements of the Code of Federal Regulations on the Protection of Human Subjects.

We each recruited participants by electronic flyer to various groups affiliated with parents of children with SD, such as Down Syndrome Network of Northern Nevada, Easter Seals, Cerebral Palsy Network, and other family collaboration and advocacy networks known to one or both of us. Additionally, as was also permitted by IRB approval, families known personally by either of us received the same flyer. The only criterion for inclusion were that parents must have a child with ID, IDD, or MI (ID paired with another diagnosed condition (e.g., autism, cerebral palsy, epilepsy, sensory impairments, genetic conditions)).

Consent to participate was defined in the IRB application for this study as participants contacting either or both researchers if interested, and subsequently assenting to answer interview questions. All participants were given a consent and information letter, but no signed forms were required as participants were adult parents. Eleven parents initially contacted the researchers with interest in participating. One potential participant had a child who did not meet the disability criteria for the study; three others ultimately did not schedule interviews. Seven parents completed the interview process for this study; three of these parents were personally known to Brianna while three others were known to MaryAnn. One participant who completed the interview was ultimately eliminated because it was determined that the child did not meet inclusion criteria of having ID, IDD, or MI. This child was diagnosed as having autism spectrum disorder with no evidence of accompanying ID. The study ultimately included six

parent participants of seven children. One child, Grizz, was substantially younger than the other children represented in this study; however, his parent's interview responses were included as Grizz and his parent met the study's inclusion criteria and we had not included age ranges in those criteria. This parent has several children with disabilities, including those who were adolescents or young adults, and she chose to focus on Grizz; it was by chance that all but one child was an adolescent or young adult. Table 1 shows participant demographics, child strengths/interests, and interview type. For the purposes of this study all of the participants' children are referred to as "children" throughout the results and discussion, even though six of the children are adolescents or young adults.

Table 1  
*Participant Demographics*

Participant	Type of Interview	Child's Name/Gender	Child's Age	Child's Disability & Related Conditions	Child's Strengths/Interests
Dana	Phone	Amber, Female	28	ID, vision and hearing impairments, chromosomal abnormality	Happy and self-sufficient, enjoys video games, Disney, and walks
Rita	Email	Grizz, Male	6	ID, drug effects, cleft palate, heart condition, autism	Likes iPad, flags, balloons, YouTube videos, jeeps, hummers, is funny
Alice	Email	Kiki, Female	17	ID, chromosomal abnormality, vision and hearing impairments, low muscle tone, health impairments (Crohn's disease)	Likes music, online videos, dancing, great sense of humor, strong "street smarts"
Elizabeth	Email	Matthew, Male	22	ID, ASD, seizure disorder	Ability to laugh at himself, good at puzzles, Legos, board games, likes baseball, movies, and summer camp
Bill	Email	David, Male	23	ID, ASD, PDD, hip dysplasia, carpal tunnel, scoliosis, hypotonia	Loves people unconditionally, empathetic, connection with animals, enjoys baseball, jets, trains, cartoon video clips
Sara	Email	Emma, Female	30	ID, had a genetic syndrome, skeletal malformations, ASD characteristics, OCD	Remarkable knowledge of sports statistics, gold medal in bowling (Special Olympics), enjoys concerts, rock music, and sports
	Email	Aiden, Male	23	ID, had a genetic syndrome, skeletal malformations, ASD characteristics, OCD	Good at multitasking with technology, knowledge of meteorology, enjoys video games, tracking weather, bowling in Special Olympics (also recently won a gold medal)

## **Data Collection**

We sought detailed information about the individual family experiences of participants, and also description of diet and eating habits from which we could develop themes to compare to the literature for children with SD. Therefore, we designed questions to be open-ended. Semi-structured interviews with general questions and follow up questions informed this study. The interview protocol of 15 initial questions is included in the appendix. Further follow up questions were asked as they arose naturally and as needed for clarification of parent responses and varied due to the individual answers given. There were two or three interviews for each participant. An initial interview provided the bulk of the data with a second interview to ask further questions. A few participants required a brief, third follow-up to clarify information. All participants reviewed final transcripts for accuracy. Interviews were conducted by phone or email based on participant choice. The rationale for allowing this choice was that parents of children with SD lead very busy, complex lives and we wanted participation to be convenient (increasing the likelihood a parent would commit to the study). One participant chose her initial interview to be over the phone, with the interview recorded on a digital audio recorder. We both were present during this interview, which lasted approximately 21 minutes. Follow up for this interview was conducted over email. The remaining 6 parents chose email format and answered our interview questions at their convenience. Transcript review occurred via email for all participants.

## **Data Analysis**

Moustakas' (1994) modified van Kaam method of analysis was utilized. This method allowed the grouping of similar topics and refinement of these groupings to show relationships between the experiences described by different participants (Anthony & Weide, 2015). This method was chosen because of clear directions for implementation but openness to adaptation. Additionally, the method lent itself to exploration of experiences and letting themes emerge naturally, reinforcing the notion that those who have experienced phenomena are the ones who should communicate that experience (Anderson & Eppard, 1998; Mapp, 2008; Mpuang, Mukhopadhyay, & Malatsi, 2015).

The Moustakas (1994) van Kaam method generally consists of seven steps for analyzing qualitative data:

1. Preliminarily group elements (ideas) by giving initial codes.
2. Eliminate or exclude redundancies while noting repetitions of ideas.
3. Relate different codes to each other for possible compatibility (combine codes).
4. Present categories with evidence in the participants' own words and validate categories with two or more people judging their validation.
5. Determine potential themes across participants from the categories.
6. Meaningfully relate themes within and across participants to determine compatibility to the phenomena of study. Are individual ideas expressed by the majority of the sample, and compatible with the final themes on the whole?
7. Reflect on the themes in the participants' own words and synthesize findings into essence of the experience

The email interviews were in written form, serving as the transcriptions. The single phone interview was recorded on a mobile device, downloaded as a voice file onto a computer, then



transcribed by Brianna using oTranscribe, chosen because it is an open-source and web-based program. Transcripts were saved electronically on the university's approved file storage and sharing system for research and sensitive data; names were changed to pseudonyms chosen by each participant (or chosen by the researchers if directed to do so by participants) to ensure anonymity. Thematic analysis through phenomenological meaning categorization was implemented for each interview by identifying codes, categories, and themes (Rossman & Rallis, 2017).

A code was defined as a single word or short phrase that assigned an attribute to portions of one's data (Rossman & Ralis, 2017). Each separate transcript was analyzed coded by idea or phrase for each response at the point when the statements changed to a new idea (e.g., the point where a participant changed from talking about one interest of their child, to a completely different one). It was possible to have two sentences with one code, or one sentence with three different codes, as the sentence could contain responses representing multiple, different ideas (e.g., food particularity, resistance to change, and high intake food choices).

Categories were defined as groupings of codes that all represented similar characteristics in one's data (Rossman & Rallis, 2017). Similar codes in our data were placed into categories; subsequently categories were reviewed to determine if any should be combined.

Finally, a theme was described as a declaration of the pattern interpreted within or across categories (Rossman & Rallis, 2017). Our themes emerged by reviewing the categories. The first transcript was analyzed, categorized and themed before moving onto the second to begin the process again. The second was analyzed, categorized, and themed before moving onto the third, and so forth. The researchers returned to transcripts where analysis was complete to reanalyze as new codes emerged. Categories were compared across participants, with themes emerging holistically across participants.

### **Trustworthiness and Credibility of Data**

Several actions contributed to the trustworthiness of the data analysis. All data were preserved to establish an audit trail. Initial and follow up interview transcripts were dated to indicate collection timeline, and also doubled as evidence that data were gathered across time and not in a single "shot," which is important to making claims in qualitative research (Rossman & Rallis, 2017). All revisions and versions of data code, category, and theme keys were kept in the same secure (locked with no public access) location as the coded transcripts.

All participants were requested to review transcripts for accuracy. Additionally, we made an attempt at triangulation of data through collaborative analysis of transcripts. Discussion of disagreements occurred for codes, categories, and/or themes until 100 percent consensus was reached. Though the researchers could not be inside the participants' minds, they could search for evidence of participant perspective (Rossman & Rallis, 2017), with the knowledge that researcher experiences and perspectives could influence interpretations of statements. The goal of the Husserlian phenomenological study is understanding someone's lived experiences while attempting to avoid influencing experiential descriptions and suspend one's own preconceptions (Mapp, 2008; Parahoo, 2006). The awareness that multiple perspectives can differ and that it may be impossible to suspend all beliefs and biases strengthens reliability of qualitative research and is referred to as researcher reflexivity (Rossman & Rallis, 2017; Saldaña, 2015).

Qualitative inquiry is systematic and rigorous when researchers are explicit about their purposes and clear about their perspectives (in this case, through the review of literature). Recognizing that researchers reflect on their own meaning of participant behaviors, and that

participants may do the same with the researcher, helps to address reliability and validity of a study (Saldaña, 2015).

Finally, attempts were made to establish usefulness of the study by providing detailed theoretical (literature review, researcher background) and methodological descriptions. We described participants and their situations with the hope that readers can make their own determination about whether these results would be useful with similar participants.

## Results

When the data were organized, they were grouped into five major themes. All appeared repeatedly, to varying amounts, in most or all interviews. All foods discussed in this section were determined to be recommended high intake foods, recommended moderate intake foods, and foods to limit or avoid, according to guidelines by the AND (2018, 2016c). A theme related to various types and levels of participation in physical activity was an incidental finding in that the focus of the study and initial interview questions was on eating habits. The five themes are as follows:

1. Variety of foods (including those recommended for high, moderate, and low intake).
2. Food particularity, preferences, and inflexibility
3. Health conditions impacting eating routines
4. Family mealtime adaptations
5. Variation in engagement with physical activity

### Variety of Foods

Our review of literature revealed prior research consensus that many people with significant disabilities are affected by malnutrition and poor nutrition choices. In contrast, our interviews found that most target children ate a variety of foods, many of which are recommended for high amount of consumption (frequently, three or more times per day) by the AND (2016a, 2016c). However, our target children also often ate foods recommended for limited intake (less than every day), and some recommended for moderate intake (sometimes, once or twice per day). The AND (2018) asserts that “A healthy eating plan that includes all foods is possible.” We agree that variety refers to eating a range of foods, from healthy to less healthy, but chosen for needs, preference or pleasure, consistent with recommendations for all Americans.

**Foods recommended for high consumption.** Some foods are recommended to be eaten frequently or sometimes by AND, and most of the children in the study liked and consumed a number of these foods. Alice reported, for example, that her daughter, Kiki likes a variety of high-intake foods: “We do smoothies with veggies and green apple (no skins), brown rice or pasta, chicken mostly grilled, cubed, boiled or lightly seasoned, fish (salmon, shrimp, or halibut) ...eggs...bananas.” From this statement, it is clear Kiki likes to eat fruit, vegetables, whole grains and lean proteins, all of which are widely recommended as building blocks to a healthy diet.

**Foods recommended for moderate consumption.** Foods recommended for moderate intake by the AND (2018, 2016c) appeared repeatedly across interviews. According to Bill, David eats a lot of starchy foods, including “pancakes, English muffins, sourdough bread, tortillas, spaghetti...white rice.” When asked for clarification during follow up, Bill confirmed

that David would not eat whole grain versions of any starch or grain foods. As stated previously in the literature review, refined grains are recommended by AND (2015) to be less than half of total daily grain consumption. Other participants reported frequency of these moderate intake foods, mostly in the form of refined grains or starches, as well other processed foods combining multiple food groups such as tacos, sandwiches, and spaghetti. The variety within this subgroup of foods contributes to our view of the overall variety in the children's diets.

**Foods recommended for limited consumption.** Although high intake foods were mentioned most frequently during our interviews, limited intake foods were also very common across all participants' children. As noted previously, AND recommends these types of foods make up a small percentage of calories per day or week, for example as leftover calories after a variety of nutritious foods are consumed and dietary needs met. Rita said that Grizz loves "Pop Tarts...ham, bologna, mozzarella sticks...French fries and hash browns." Due to sodium and sugar content, foods such as these constitute those that should be eaten less often. However, less healthy foods comprise a varied percentage of the whole diet and contribute to variety in food choices.

### **Food Preferences, Particularity, and Inflexibility**

Though the children in this study eat a somewhat varied diet across the AND's "recommended" spectrum, there was still strong indication of narrow food interests or preferences. Some children were reportedly particular about food textures.

Regarding her two children, Sara said, "Textures of food, such as meats, hot and cold foods or anything hard such as carrots or most vegetables, they would not eat." She added, "My children have come a long way regarding eating, however; there are still many things that they dislike." Since texture or food temperature preferences could indicate higher levels of particularity, this quote illustrates such particularity observed by parents.

Also related to restrictive eating patterns, parents described broad groups of foods their children refuse. Rita reported that "Grizz stays within his safe foods (listed as noodles, cheese, apples, grapes, oatmeal, eggs sometimes, pop tarts, some meat). Never straying too far from his home food base...he is not adventuresome in the eating department." Rita's statements represent inflexible behaviors and choice around food.

Furthermore, three of the target children consumed very limited or no fresh fruits and/or vegetables. It was reported that David will only eat corn on the cob and Matthew, even though he is 22 years old, will only eat fruit or vegetables in baby food form. Rita indicated that Grizz likes "apples and grapes," but no vegetables. Not only do these statements give evidence to the general theme of food particularity, they also show that some of the children in the study could have greater dietary variety if they did not refuse entire food groups.

### **Health Conditions Impacting Eating Routines**

We found that many of the children in the study have various health conditions that affect their food choices or eating habits. This was consistent with the literature on those with SD and nutrition complications due to various dietary needs and physical conditions (Gibson et al., 2011; Stewart et al., 2009). For example, Grizz requires tube feedings and special dietary formulas. Sara says, regarding Aiden and Emma (who both have the same genetic syndrome), "When they were young, they both had a difficult time with food. Due to their condition, swallowing and chewing was difficult and eating became more of a necessity than a pleasurable experience for them."

Kiki has Crohn's disease and requires a restrictive diet to reduce its symptoms. Alice continued to explain Kiki's digestive difficulties:

Lately, she goes in waves of eating and not eating. Since the Crohn's affects your entire body from mouth to anus there are times when she won't eat because she is in pain. Then when she is feeling better she will tend to eat too much! Then there are the times when she eats (regular amount) and when she bears down to poop she ends up throwing up all of her meal. Then she won't eat right away; but when she finally eats, she will gorge herself since she is so hungry. It really is a vicious circle!

The AND asserts that all foods have room in a healthy diet. However, these statements do not consider needs inherent to some children with SD. Some have physical conditions that prohibit or limit certain foods. The combination of medical conditions and personal preferences that restrict diets create complex barriers when encouraging children to eat a variety of nutritious foods.

### **Family Mealtime Adaptations**

Parents in our study reported attempting to change some of their children's eating habits, as well as developing strategies to address the dietary challenges their children have. According to Elizabeth, she will make a separate meal for Matthew if he does not like what they are eating. She also stated, "I would love to see him eat fresh vegetables. He won't even try most of the vegetables but at least he's polite as he's refusing to do it, 'No thank you' over and over."

Other reported strategies included repeated attempts to introduce foods (with mixed levels of acceptance by the children), allowing the child to choose from what is made, and the whole family changing their diet to only eat what the child can eat (due to medical needs). It appears that families face a number of challenges in feeding their children a varied diet. The strategies discussed by different participants seemed tailored to the needs of the child, while attempting to fit those needs into the family routine.

### **Variation in Engagement with Physical Activity**

Diet and exercise are widely assumed interdependent in increasing and maintaining health. Despite sedentary lifestyles being a problem reported in the literature (Jinks, Cotton & Rylance, 2011), we had a serendipitous finding related to the children in our study participating in a wide range of physical activities. Parents described most children as enjoying and participating in at least one sport or physical activity with two of the children getting regular exercise. This frequent physical activity is contradictory to research that children with SD live sedentary lifestyles or have low levels of physical activity compared to peers (Grumstrup & Demchak, 2017; Humphries, Traci, & Seekins, 2009; Reeve et al., 2014). Rita reported that Grizz likes his "bike, basketball, and will walk a full mile." Amber "walks every day and tries to be active," according to Dana.

Though the remaining children were reported to enjoy physical activities, these were seasonal or limited. Bill said David "enjoys playing Wii, especially baseball and bowling games. He plays baseball in the Challenger Little League senior division." Kiki goes to dance class once per week and swims seasonally. Two other children compete in Special Olympics. If physical activity is seasonal or sporadic in nature, it is difficult to establish a consistent routine in which to gain frequent exercise. Though parents freely shared with us the activities

their children enjoy or participate in, low frequency of exercise was reported as a concern by some.

Elizabeth said, “My concerns are that with the fast food and sweet tooth he has he will continue to put on weight. Other than walking he doesn’t get much exercise.” Elizabeth’s statement conveys concern for lack of exercise due to Matthew’s preference for sugary foods coupled with low opportunity and/or interest to be physical. Other parents blamed complications created by medical issues in the children getting adequate exercise. The variety of statements made about children’s physical activity illustrates a variety of reasons special needs can contribute to levels of exercise.

## Discussion

It was evident that children with SD in this study are unique individuals not without challenges. Parents worried if physical activities their children enjoy are enough. Many of the foods the children like should be limited according to the AND. Many of the foods recommended for high intake by AND were lacking in these children’s diets. Results consistent with other findings include overweight/obesity (Rimmer et al., 2010; Salaun & Berthouze-Aranda, 2011) and underweight and malnutrition (Franssen et al., 2011; Maaskant et al., 2009). However, our results yielded a less common finding: individuals with ID do exhibit some desirable health behaviors, similar to findings in a review on successful health initiatives by Heller, McCubbin, Drum, & Peterson (2011).

Rimmer et al. (2010), Salaun and Berthouze-Aranda (2011), and Grumstrup and Demchak (2017) reported that children and adolescents with SD were more likely to be overweight or obese than their typical peers. Three children in this study were reportedly overweight or obese. Matthew and Amber are overweight, and Emma is in the obese range of BMI.

Additionally, our results supported Franssen et al. (2011) who found that many individuals with SD are malnourished and/or underweight, and Gibson et al. (2011) who described eating challenges due to oral motor difficulties. In our study, Aiden has a history of being underweight and deficient in many nutrients because he struggles with oral motor strength and sensitivity to textures. Additionally, even though David is at a healthy weight, Bill expressed concern over the amount of nutrients David is getting and stated that he requires supplements. Grizz requires a supplemental formula and tube feedings to ensure he is getting adequate nutrients.

Gibson et al. (2011) and Heller et al. (2011) discussed the barriers to health that people with SD face, such as limited knowledge, narrow diet preferences, medication side effects, and oral motor difficulties. Narrow food preferences and refusal behaviors, such as some displayed by children in our study, are commonly reported in the literature pertaining to children with disabilities (Gentry & Luiselli, 2008; Keen, 2008; Knox et al., 2012; Koegel et al., 2012). Narrow food preferences can contribute to reduced amounts of healthful foods in the diet, a possible reason why those with SD are reported so frequently to have dietary issues. Our study found narrow diets with most participants’ children, often reportedly related to textures. Emma and Aiden also have motor difficulties from their physical conditions and Kiki has a restricted diet due to Crohn’s.

Our study included many statements from participants about involvement with their children’s diets. However, results indicated that despite parent assistance, the children did not always reduce unhealthy habits or add healthy ones. David and Matthew are reportedly eating the same foods they have their entire lives, refusing new foods. Several published studies suggested that diet and weight of people with SD can be influenced by parent or caregiver intervention and remaining in the family home (Fodstad & Matson, 2008; George, Shacter, &

Johnson, 2011; Hamilton, Hankey, Miller, Boyle, & Melville, 2007). In contrast to this literature, parents of both David and Matthew were reportedly unsuccessful in attempts to modify their children's diet toward more healthy choices. Elizabeth was able to encourage her children to eat more foods over time, but this was a slow process and Emma and Aiden still refuse many foods.

Parents report continuing attempts to add new foods or encourage the children to taste different things. For example, Alice reported that Kiki was able to overcome some textural aversions to foods with occupational therapy, but still dislikes certain food consistencies. Grizz was reported to refuse most new foods; however, due to his age, he still has plenty of time for his parents to continue attempts at trying new foods. The aforementioned literature on parent involvement in habit change, as well as experiences such as Sara's (Aiden and Emma both eat more foods than when they were younger) may predict that further encouragement from parents could expand Grizz's acceptance of new foods.

Although there was much agreement between our results and the literature, this study revealed unique insights. We identified resistance to change as an additional barrier to those documented in the research. Five of the participants reported that their children were resistant to change to varying degrees, though Emma and Aiden both changed their diets somewhat to include greater variety and Kiki overcame some issues with textures before being diagnosed with Crohn's.

There were also themes indicating strong health habits that refuted literature on children with SD. For example, the theme of food variety did not align with past findings. Our participants' children face many barriers to healthy diets and lifestyle, but some healthy habits emerged repeatedly. Nutritious "frequently recommended" foods and opportunities for physical activity were prominent enough that two themes featured what was going well. Amber was unique in that she reportedly eats virtually all foods offered to her.

The prominent theme about physical activity was also unique. The literature on physical activity for individuals with significant disabilities indicates that they exercise less than typically developing peers and amount of activity declines as children move from adolescence into adulthood (Shields, Dodd, & Abblitt, 2009). Furthermore, reduced opportunities for activity are reported as problematic in the research (Casey, Rasmussen, MacKenzie, & Glenn, 2010). We found that all children in the study participated in and enjoyed at least one physical activity. Some were active regularly, which is not consistent with messages throughout the literature. However, our findings were consistent with Shields et al. (2009) that older children and adults are not getting as much exercise as the younger children. Also, most children participated in seasonal, limited, or inconsistent exercise and had a variety of reasons for not getting more. These possible reasons include low interest, possible lack of opportunity, low mobility, or health conditions that create illness.

## **Limitations**

Possible limitations for this study include sample size and homogenous demographics of participants. The choice given to participants to interview over email is also a limitation. It is possible that we did not get the amount of information if someone had to type it versus the ease of speaking it. However, we felt that the email option was appropriate because parents of children with disabilities (and all parents) lead very busy lives. In addition, participants may have felt comfortable writing their answers, reflecting on them, and editing before submitting. However, editing the information before we saw it could also be a limitation of the study in that participants might have eliminated relevant information for any number of reasons (e.g., fear of being judged or viewed negatively).

In addition, there is a risk of familiarity bias and skewed interpretation of results, as we knew all participants. Some researchers suggest that it is important in qualitative research to balance trust and relationship-building with ability to limit judgement in interpretation of data (Rossman & Rallis, 2017; Shenton, 2004; Silverman, 2000). In our study, it was possible that we subconsciously wanted to find positive statements in the interviews because we cared about the participants and their children. Multiple attempts to contact parents with whom we did not have a personal relationship were made, but largely unsuccessful.

## Implications

The studies about what is working in health interventions for people with SD reviewed in Heller et al. (2011), were conducted in 2009 and before, leaving a nine-year gap prior to the present study. This presents a time period lacking information about individuals with significant disabilities who are leading healthy lifestyles. Furthermore, that review focused largely on quantitative research. Our study is important because it describes diets of individuals with significant disabilities and family experiences in detail. It provides new information about why some children have certain eating behaviors, how parents feel about the eating habits, and at what health habits their children are succeeding. We also uncovered important insight into mealtime adaptations and strategies developed by the participants in response to their experience with their children's diets. It appears they perceived the children's habits as needing improvement and so accordingly attempted to make changes while still meeting the needs of the family.

Overall, our results support suggestions that individuals with significant disabilities have distinct diet and eating behaviors from the general population (Bailey & Angell, 2005). Although mealtime issues are not included in the definition of ID, IDD, or MI, these problems continue to be documented in the literature. Findings from this study, like Fodstad and Matson (2008), suggest that eating problems persist into adulthood and should be a major area of concern due to widely established links between diet and overall health. It is evident from our study, that parent intervention in habits they consider problematic does not always yield change.

More research is needed to explore experiences with health behaviors from the perspective of adults with disabilities. A phenomenological study that interviews adults within the population of those with significant disabilities could be valuable. Would descriptions of eating and exercise habits from the individual's perspective provide additional insights? Furthermore, quantitative research with a larger sample size could be conducted with adults with significant disabilities to explore prevalence of mealtime or diet issues. Larger quantitative studies, such as survey designs or comparative work between different groups could yield a more accurate picture of a population.

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