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The Experiences of the Parents of Children Undergoing Occupational Therapy Intervention for the Occupation of Feeding

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The Experiences of the Parents of Children Undergoing Occupational Therapy Intervention for the Occupation of Feeding

Presented in Partial Fulfillment of the
Requirements for the Degree of
Doctor of Occupational Therapy

Eastern Kentucky University
College of Health Sciences
Department of Occupational Science and Occupational Therapy

Michael A. Coldiron MS, OTR/L
2016

EASTERN KENTUCKY UNIVERSITY COLLEGE OF HEALTH SCIENCES

DEPARTMENT OF OCCUPATIONAL SCIENCE AND OCCUPATIONAL THERAPY

This project, written by Michael A. Coldiron MS, OTR/L, under direction of Dr. Colleen Schneck, Faculty Mentor, and approved by members of the project committee, has been presented and accepted in partial fulfillment of requirements for the degree of

DOCTOR OF OCCUPATIONAL THERAPY CAPSTONE COMMITTEE

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EASTERN KENTUCKY UNIVERSITY COLLEGE OF HEALTH SCIENCES DEPARTMENT OF OCCUPATIONAL SCIENCE AND OCCUPATIONAL THERAPY

Certification

We hereby certify that this capstone project, submitted by Michael A. Coldiron, MS, OTR/L, conforms to acceptable standards and is fully adequate in scope and quality to fulfill the project requirement for the Doctor of Occupational Therapy degree.

Approved:

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Executive Summary

Occupational therapy practitioners practice under the values of client-centered care and cultural sensitivity. This valuates the role of the occupational therapy practitioner in pediatric feeding intervention pertaining to diverse diets. The problem is that there is a lack of research into the experiences of individuals who consume a diverse diet as they undergo occupational therapy intervention for the occupations of feeding and eating. The purpose of this study was to enable individuals with diverse diets to self-report these experiences. Participants were questioned on the challenges they encountered and detailed questions regarding the types of experiences they face. The study was built upon the principles of the People, Environment, Occupation (PEO) model. Through the use of qualitative methodology in a two-subject case study, the researcher was able to document the experiences identified by participants. Data collection included semi-structured interview, video documentation, and audio documentation. Results indicate recurring themes in participants' experiences. Findings indicate trends, which the occupational therapy practitioner should address in the assessment and treatment of individuals with feeding and eating issues.

Acknowledgments

I would like to submit a special thanks to all of my friends and family who have long supported my passion. To the faculty and staff of Eastern Kentucky University’s Department of Occupational Science and Occupational Therapy, I would like to express my appreciation for your genuine approach to a challenging and rewarding educational program.

EASTERN KENTUCKY UNIVERSITY
COLLEGE OF HEALTH SCIENCES
DEPARTMENT OF OCCUPATIONAL SCIENCE AND OCCUPATIONAL THERAPY

CERTIFICATION OF AUTHORSHIP

Submitted to: Colleen Schneck
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Title of Submission: The Experiences of the Parents of Children Undergoing Occupational Therapy Intervention for the Occupation of Feeding

Certification of Authorship: I hereby certify that I am the author of this document and that any assistance I received in its preparation is fully acknowledged and disclosed in the document. I have also cited all sources from which I obtained data, ideas, or words that are copied directly or paraphrased in the document. Sources are properly credited according to accepted standards for professional publications. I also certify that this paper was prepared by me for this purpose.

Student's Signature: Michael A Coldiron

Date of Submission: 5-10-16

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Section One: Nature of Project and Problem Identification

There is a specific need for individuals with dietary restrictions to receive improved feeding therapy care from occupational therapy practitioners. Before it is possible to improve occupational therapy service delivery, the diversity of occupational therapy clientele must be understood, ensuring that the diversity of their diets is included.

Families with children consuming restricted diets are on the rise, with 25%-35% toddlers being described by their parents as “picky eaters” (Leung, Sauve, & Marchand, 2012). Dietary diversity can be the result of personal choice or medical mandate. It is explained as the “proportion of children within 6–23 months of age who receive foods from four or more food groups of the seven food groups” (Beyene et al., 2015). Furthermore, dietary diversity score (DDS) is a measure developed to quantify dietary diversity by summing number of foods consumed from each of 9 food groups (Drimie et al., 2013).

The Diagnostic Statistical Manual – 5th edition includes a diagnosis of Avoidant/Restrictive Food Intake Disorder (ARFID) to better categorize those children reported to be “picky”, and those who fit in no other previous food-related disorder, including anorexia nervosa and/or bulimia nervosa (Fisher et al., 2014). Families are being encouraged to experiment with removal of a potential allergen from their child’s diet, and some professionals even regard experimental exclusion of potential allergens to be an “intervention” when working with children with autism spectrum disorder (Warren et al., 2011). This phenomenon is not supported by research into the experiences of the family. Families are being directed in therapeutic feeding interventions that include recommended foods, strategies for meal presentation, behavioral structures, and sensory integration techniques, which may present challenges to occupational engagement, yet there is a lack of research into the experiences of these families.

Applying feeding program interventions is often difficult for therapists and families as they are limited in their understanding of diversity, including the reasons for the dietary restriction, and clients may be limited in progress as a result (Campinha-Bacote, 2009).

As called to do by the American Occupational Therapy Association (AOTA), occupational therapists should be focused on maximizing the access that diverse individuals have to quality occupational therapy services (AOTA, 2007). Failing to respond to this disconnect in feeding therapy service provision fits the description of an occupational injustice (Wolf et al., 2010). Therefore, this study aimed to identify and document the experiences of families of dietary diversity undergoing occupational therapy intervention for the occupations of feeding/eating.

Problem Statement

There is limited research into the experiences of individuals with diverse diets undergoing occupational therapy intervention for the occupation of feeding. Increasing occupational therapy practitioners' understanding of this diversity will increase the success toward therapeutic feeding goals (Kavle et.al., 2015).

The foods that people eat, how they eat them, and when/why they eat them are important details in creation of a client's occupational profile and treatment plan. With limited research into challenges that are being experienced by individuals of dietary diversity, this problem continues to grow.

Purpose of the Project

The purpose of this capstone project was to explore and document the experiences of individuals with a restricted diet as they undergo occupational therapy intervention for feeding challenges. This was to be accomplished through clear and specific documentation of their experiences as reported and observed by one occupational therapy practitioner and the parents of children who consume a restricted diet. By identifying their experiences, improvement can be made in occupational therapy practitioners' understanding of dietary diversity and its impact on the occupations of feeding and eating for children with special needs and their families.

Project Objectives

The objectives of this capstone project were:

1) Describe the experiences of two therapist- caregiver-child triads, where the child was consuming a diverse diet, to understand the impact of the occupational therapist's recommendations on the family's experiences and the occupations of feeding and eating.

2) Identify the similarities within participants' experiences.

Theoretical Framework

This capstone project was designed to operate upon the principles of the Person Environment Occupation (PEO) Model (Law et. al, 1996). Within this model, the therapeutic interventions are tailored to meet the needs of the overlap of these three domains. The person incorporates diversity. The environment considers the context in which the occupation is to occur (i.e. medical dietary restrictions, where the occupation is occurring, the emotional state of the parents of the children). The environment is exceptionally important within a qualitative study as the context impacts the data collected. The occupation, of course, is feeding. The blending of these three components provides a snapshot of each participant and how they engage in their lives, allowing a thorough understanding of their diversity.

Significance of the Study

The findings of this capstone project, including specific trends in the experiences of the participants, can be used to begin to improve the implementation of occupational therapy intervention for feeding therapy.

Great feeding programs and interventions are in existence, such as the Sequential Oral Sensory program (Toomey & Ross, 2011) and the TR-eat model (Elliot & Clawson, 2010), that serve to increase the quantity of foods consumed by each child. There remains, however, an implicit need for these interventions to be customized to meet the needs of diverse individuals, hence increasing successful outcomes. In one study, this attempt at customization of interventions was labeled Trials of Improved Practices (Kavle et al., 2015). Healthcare outcomes in regard to occupational therapy are a measure of the successful interventions that create positive change toward the goals of the client. Creating an increase in the effectiveness of these interventions will promote greater healthcare outcomes. As more and more diverse individuals are arriving in the United States of America, more and more clients with diverse diets are arising. The delivery of healthcare services is mandated to move ahead of this trend in demographics, preparing it for providing necessary healthcare services at the highest level of efficiency and quality.

Healthcare policy is the facet of healthcare implementation that is most impacted by this capstone project. Healthcare policy, as well as the American Occupational Therapy Association's Centennial Vision, calls for ethical treatment of all people in need of healthcare services. It also calls for the respect of diversity in implementing these necessary healthcare procedures.

The significance of this study lies within its direct ties to the AOTA's Centennial Vision for Occupational Therapy. Within this vision, therapists are called to provide evidence-based care that is rooted in occupation, driven by the client, and that understands and respects diversity. More specifically, this study served to maximize the number of clients who benefit from feeding therapy by empowering occupational therapists to identify with the experiences of their diverse clientele.

Project Overview

In summary, this study served to increase the quality of occupational therapy service delivery by documenting the experiences of families with restricted diets engaged in feeding intervention. By learning to better understand the experiences of diverse individuals, occupational therapy practitioners are exercising cultural sensitivity. Therapists, clients, and their families must all realize the importance of exploring the experiences of the clientele in developing skills in respect for diversity, the definition of health, and therapists' adherence to the responsibility to be the best practitioners they can be.

Section Two: Review of the Literature

A literature review was completed to identify the quality and quantity of research pertaining to the topic of pediatric occupational therapy intervention, specifically the need for sensitivity to dietary diversity, the role of the occupational therapist, the experiences of the families engaged, and the methods of occupational therapy intervention. What began with broad searches of more than fifty online databases became detailed, succinct searches using specific terminology including the terms “picky, feeding, dietary diversity, selective diet, and restrictive diet”, exploring more targeted databases which included healthcare journals and therapeutic journals. Four themes emerged from the literature review: Defining dietary diversity, recognizing a need for increased sensitivity to dietary diversity, identification of specific feeding interventions used in occupational therapy intervention, and a review of feeding-related clinical diagnoses. These four themes focused the capstone project from a broad and general attempt at increasing cultural competence among occupational therapy practitioners (Campinha-Bacote, 2009). The four themes of the literature review identified the need for a fifth theme to explore *how* families are experiencing occupational therapy feeding intervention, which became the focus of this capstone project.

Defining Dietary Diversity

Dietary diversity is defined in this capstone project as a form of diversity that is sometimes the result of a cultural choice while other times the result of medical needs, such as Diabetes, Crohn’s, or food allergies. Though picky eating is reported to be on the rise (Leung, Sauve, & Marchand, 2012), there is a lack of a consistent operational definition of “picky eating”, which limits the ability of researchers to measure this phenomenon (Boquin et.al, 2014). Food selectivity, as it is termed in another study, is defined as “the term used to describe children who eat an unusually limited variety and/or amount of foods” (Cronin et.al. 2009). The literature review identified another definition of food selectivity, which was defined as the consumption of a narrow diet that is nutritionally inadequate (Field, Garland, & Williams, 2003). Other perspectives identified in the literature review included a definition of dietary diversity as the “proportion of children within 6–23 months of age who receive foods from four or more food groups of the seven food groups” (Beyene et al., 2015), referring to the necessity for children to consume a diverse variety and volume of foods. There is a plethora of terminology to describe a limited oral intake of nutrition and a lack of a consistent operational definition of the phenomenon. There is a need for occupational therapy practitioners to actively develop sensitivity to the dietary diversity of their clientele.

Recognizing a Need for Increased Sensitivity to Diversity

The American Occupational Therapy Association calls occupational therapy practitioners to be focused on maximizing the access that diverse individuals have to quality occupational therapy services (AOTA, 2007). In doing so, it is necessary to recognize any challenges that inhibit diverse individuals from accessing quality healthcare services (Franklin & Rodgers, 2003). Adis (2004) writes that culture defines health, explaining that not all individuals possess the same definition of health. This idea is repeated in Flaskerud’s statement “culture offers individuals a repertoire of beliefs” (2007). Occupational therapy practitioners need to focus their energy into understanding the definition of health for each client they engage.

It is also important to recognize the possibility of experienced challenges in the form of access to health promotion programs. Bermudez and Tucker (2004) identify personal challenges among a population of diverse elders that limited their engagement in nutrition programs. The authors call for professionals to educate themselves and their peers/staff in order to better recognize experienced challenges and increase cultural sensitivity. Bomela (2009) explains how country of dwelling, number of people in the household, wealth, birth weight, age, maternal education, number of children <5 years of age, and source of drinking water were strong predictors of child nutritional status, highlighting the complexity with which one's diversity can impact their wellbeing. This enables occupational therapy practitioners to understand the depth and complexity of the diversity of their clientele. Engaging healthcare students and practitioners in an educational program targeting increased cultural sensitivity is effective in maximizing their understanding of the need of cultural sensitivity (Trujillo, 2009), a theory which can apply to the occupational therapy practitioner. The United States healthcare system is following a path toward quality health care that aims to be safe, efficient, effective, timely, patient-centered, and equitable, however it must be acknowledged that disparities in health care persist and are a clear sign of inequality in quality (Betancourt, Corbett, & Bondaryk, 2014). Failing to explore the experiences of clients, particularly in feeding therapy service provision, fits the description of an occupational injustice (Wolf et al., 2010).

Identification of Specific Feeding Interventions used in Occupational Therapy Intervention

The role of the occupational therapy practitioner in interventions addressing the occupation of feeding varies. One systematic review identified the role of the occupational therapist in thirty-four different studies (Tsu-Hsin & Tien-Ni, 2013) with the occupational therapist engaging the client in varying forms of intervention including swallow studies, oral motor training, and tube weaning (Trabi et.al., 2010). Despite this broad scope of practice, the use of the occupational therapy practitioner in feeding and swallowing intervention has decreased over the last two years (Paul & D'Amico, 2013). Occupational therapy practitioners are engaging pediatric clients with restrictive diets in interventions targeting sensory regulation to target the olfactory, visual, gustatory, tactile, and auditory systems (Daubs & Toronto, n.d.) as well as interventions targeting changes in behavioral responses to the presentation of non-preferred foods (Elliot & Clawson, 2010). These two models of intervention were the focus of the literature review.

The Tr-Eat model (Elliot & Clawson, 2010) utilizes approaches of behavioral analysis aiming to minimize and eradicate the behavioral responses of children when presented non-preferred foods. Elopement and escape behaviors are minimized, and positive behaviors such as remaining at the table or consuming a non-preferred food are rewarded. Other behaviors that are present in many children with autism spectrum disorder include rocking, throwing items, resisting sitting at the table, and presenting frequent tantrums (Crowe et.al., 2010). Occupational therapists may also improve the sensory integration and oral oversensitivity in children with ADHD and oppositional behaviours (Ghanizadeh, 2013). The Sequential Oral Sensory program (Toomey & Ross,

2011) utilizes sensory-integration techniques to desensitize and regulate the sensory processing systems of children. The olfactory, tactile, proprioceptive, vestibular, visual, auditory, and gustatory systems are targeted in pre-meal and meal-based activities that serve to regulate each sensory system. The complexity of the sensory processing system as related to feeding and eating is evident as a study lists reported limitations to food consumption among children with autism which included food color, temperature, and packaging (Crowe et.al., 2010). Oral processing skills are promoted through systematic desensitization as experiencing tastes and textures and encouraging fun with food are effective in desensitization (Harding et.al., 2010). Daubs and Toronto (n.d.) reiterate the effectiveness of regulation of the sensory processing system to increase the consumption of non-preferred foods.

Review of Feeding-Related Clinical Diagnoses

Dietary diversity is present among many populations of children engaged in occupational therapy intervention and in many forms. While many children are outgrowing their feeding problems, feeding issues persist in 3-10% of children (Lukens & Silverman, 2014). One group of individuals of dietary diversity are those diagnosed with Avoidant/Restrictive Food Intake Disorder (ARFID). The DSM-V (American Psychiatric Association, 2013) included Avoidant/Restrictive Food Intake Disorder, a diagnosis encompassing children with a pattern of food refusal and/or severe food refusal. Though a small percentage of pediatric clients with restrictive feeding disorders meet the criteria for ARFID, it provides an understanding of children who do not present with anorexia nervosa or bulimia nervosa (Norris et.al. 2014). ARFID diagnostic criteria include significant weight loss (or faltering growth), nutritional deficiency, dependence on enteral feeding or oral supplements, and a marked interference of psychosocial function (American Psychiatric Association, 2013). The implications of ARFID reach far beyond food consumption, potentially presenting limitations in school functioning and socialization (Eating Disorders Review, 2014).

Another group of individuals of dietary diversity are those with Autism Spectrum Disorder (ASD). Approximately 1 in 68 children are diagnosed with Autism Spectrum Disorder (Autism Speaks, 2014). Children with ASD are slightly more likely to present with restrictive feeding than their typically developing siblings (Martins, et.al. 2008). Children with Autism Spectrum Disorder often present with dysregulated sensory development that can impact their ability to consume appropriate quantities and qualities of food (Luisier et.al. 2015). Behavioral responses (gagging, elopement, etc.) to the child's non-preferred foods can also limit appropriate oral intake of foods (Elliot & Clawson, 2010). One study explains how a dysregulated sensory processing system of a child with Autism Spectrum Disorder can contribute to behavioral responses that limit appropriate food intake (Smith, 2016). Some children with Autism Spectrum Disorder are presenting major challenges for their parents (i.e. a child who will only eat one specific brand of white bread, gags upon the sight of a non-preferred food, or who refuses a food based upon other visual characteristics or smell) (Martins, et.al. 2008). There is no evidence to suggest that children with ASD are refusing the same foods, rather the foods they are refusing are varying (Martins et.al. 2008). Crowe, et.al. (2010) continue that 84% of children with autism participating in their study prefer certain foods, but the reasons for their food preference vary. 38% of the children, for example, limited their intake based on food texture, however temperature, color, and packaging are all reported as barriers to consumption of non-preferred foods that were not reported by all participants. Another study reported that more children with ASD were picky eaters, mouthed nonfood items, resisted new foods, limited foods based on textures, had problems with gagging, had difficulty eating at regular restaurants or at school, resisted sitting at the table, and threw or dumped food (Crowe et.al., 2010). Children with Autism Spectrum Disorder and children with a diagnosis of Avoidant/Restrictive Food Intake Disorder are benefitting from skilled occupational therapy intervention to correct these feeding concerns.

This review of the literature identifies adequate research into the number of consumed foods required to be considered diverse, specific intervention strategies used in occupational therapy feeding therapy, and a plethora of definitions of dietary diversity. The literature review was completed to identify *how* clients are experiencing these components of occupational therapy intervention. Little is known about the experiences of families with children of dietary diversity as they engage in occupational therapy intervention to address the occupations of feeding and eating.

Section Three: Methods

Project Design

This was a two-subject, qualitative case study. A qualitative case study was selected as the purpose was to identify *how* diverse individuals are experiencing occupational therapy intervention, and because the researcher planned to change no behaviors among the parents (Baxter & Jack, 2008). This qualitative case study was exploratory in nature, that is, the experiences of the participants have no specific set of outcomes (Baxter & Jack, 2008). The completion of the study in the clinical setting might impact the behavior or level of engagement of the child, however this is not an outcome measure for this study. This study was approved by the Eastern Kentucky University Institutional Review Board (Appendix A) and all participants signed informed consent (Appendix B).

The purpose was to describe the experiences of two therapist- caregiver-child triads, in which the child is consuming a restrictive diet, to better understand the impact of the therapist's recommendations on the family's experiences regarding the occupations of feeding and eating. The case study of two therapist-caregiver-child triads began with the researcher immersing himself in the culture of families with children practicing a restrictive diet to determine, via observation and formal interview, the experiences of diverse individuals in feeding interventions as led by an occupational therapist. Immersion (Creswell, 2014) refers to the surrounding of oneself in the culture of other people for the purpose of understanding their experiences. Immersion in this study occurred in the clinical context as it enabled the researcher to subjectively collect the reported experiences of the family as they engaged in the occupation of feeding with the child, using only the foods provided from each household. The study occurred in three phases.

Phase one, completed during the first week of the study, included an initial survey completed by the parents of the participating children. The survey (Appendix C) included 10 questions.

The second phase, completed during the second and third weeks of the study, was the observation phase. During the observation phase, videos and audio recordings documented the occupation of feeding in the clinical context. Each participant was video recorded for one session, ranging from thirty to forty minutes, and each participant was audio recorded during a second feeding intervention of the same duration. During this phase, the researcher observed and analyzed transcriptions of the behavior and verbal responses of both children and parents as they engaged in feeding intervention in the clinical context.

During the third phase, week four of the study, parents were then given the opportunity to self-report their experiences, thoughts, and concerns. This information was collected via semi-structured interview (Appendix D) that was audio recorded, and the findings were then transcribed, coded, and reported. The formal interview contained eleven questions.

The data was coded based upon methods for early-stage data analysis in qualitative research (Glaser & Laudel, 2013). It began by linking raw data to the research question. To do so, the researcher analyzed the data through the lens of empathy and attempt to understand the experiences of the participants. This raw data was documented in a coding draft (Appendix E). The data was then categorized into sections including *emotions* (frustration, social concerns), *resources* (time, money), and *activities* (grocery shopping, dining out, and school engagement). From these categorized statements, patterns were identified in the participants' responses. These patterns were labeled and used as codes for analyzing the data. Some codes were included without trending or patterning as they were believed by the researcher to be critical information regarding the findings of the study.

The qualitative validity of the capstone project is maximized through the use of the following strategies, as recommended by Creswell (2014). Clarifying the bias of the researcher creates an air of honesty among readers. Spending prolonged time in the field, immersion, allowed the researcher to develop an in-depth understanding of the problem(s). In an effort to further ensure the reliability of the capstone project, the researcher also checked transcripts to identify obvious errors, identify any drifts in the meaning of codes, and cross-checked codes that are created by different people (Creswell, 2014).

Overseen by the Institutional Review Board (IRB) of Eastern Kentucky University, the ethics of this study were of the utmost importance. Participants were identified only with a single letter to protect their privacy. Data collected via technology were immediately uploaded to a two-password computer data filing system and deleted from the device with which the data was collected. All pertinent files, field-notes, consent forms, and data collections were kept in a locked filing cabinet in a locked office. No other individual other than the researcher had access to the keys.

Setting

The setting was an outpatient pediatric clinic in Somerset, Kentucky, where families bring their children on a weekly basis to engage in occupational therapy to address the occupation of feeding. The study was implemented in this private practice, as the practices' caseload was conducive to the selection of appropriate participants. The clinic serves as the outpatient center from which feeding intervention is tailored. Therapists within this outpatient clinic are not licensed to conduct in-home occupational therapy visits, so the clinical context was selected. The therapist directed the interventions as caregivers sat nearby. Therapy was completed in a quiet room with the door fully closed to limit auditory distractions. Visual schedules and visual timers were used to structure the demands of the feeding intervention. Foods used during feeding interventions were prepared and brought from the home of the participants. Individual portions of each food were plated and water was provided yet with controlled access. The researcher, who is a partner in the practice, holds periodic meetings with the practice's second partner to discuss the roles of program development, research, and professional development. These meetings reflect mentorship, which is a tool by which the researcher can identify barriers to success and develop skills in self-evaluation (Baker, 2011). The practice accept clients who private pay as well as those who are backed by managed care organizations and Kentucky Medicaid products. Therapy sessions for the participants were billed to their respective insurance providers.

Identification of Participants

In addition to active engagement in a feeding program, the child must possess dietary diversity in the form of a restrictive diet, either by medical mandate or personal choice. Diversity is present among these clients in the form of food allergy, family/cultural food choice, sensory processing challenges, and/or behavioral challenges. Clients currently receiving nutrition through tube feedings, as well as children less than three years of age were excluded. There was no maximum age for participating in this study. The children and parents in this study were specifically selected as they present with restricted and diverse diets and are attending outpatient occupational therapy sessions to address their occupations of feeding and eating. Parents engaged alongside the occupational therapist in structured feeding interventions targeting the performance of the child. In these treatment sessions, the children were seated in pediatric-sized chairs at a table facing a bare wall to decrease visual distractions.

The study was limited to two subjects as this facilitated a thorough collection of data over the four-week duration of the study. Including more than two participating families with only one researcher might decrease the depth and breadth of the data collected. The researcher is a full-time occupational therapy practitioner carrying a full caseload of 35 pediatric clients, including the cases of both participating families. This might produce bias. The data for this study was collected during regular operating business hours. There were five fully eligible families who were not solicited to participate. Neither child nor their parents had geographical diversity. They resided in a small city in southern Kentucky with a population of roughly 18,000. They both attended public school, and one of two children received special education services in his school. Both children consumed a diverse diet secondary to medical mandate, and one of two children also consumed a diverse diet secondary to his family's choice to consume a diet heavy in organic health foods free of potential toxins such as high-fructose corn syrup, complex carbohydrates, and saturated fats.

Participants

The first of the two participating children is called J. He is a six-year-old boy who has been diagnosed with Autism Spectrum Disorder. He was originally referred for occupational therapy intervention for feeding concerns by his pediatrician at age five. He has been in occupational therapy intervention for three months at the time of the study. At the time of the initial evaluation, he only consumed proteins with breading, which included fish sticks, country fried steak, and sausage biscuits from a particular restaurant. He consumed minimal fruits, no vegetables, and drank sugary juices between meals. Gastrointestinal insufficiencies were ruled out by a gastroenterologist. His treatment plan is written to address behavioral responses to non-preferred foods, as well as sensory integration strategies to systematically desensitize to the non-preferred characteristics of nutritious foods. His mother, who completed all surveys and interviews related to this capstone project, brought him to each appointment and reports his progress in the natural context.

The second participating child is called I. He is a nine-year-old boy. He has two formal diagnoses, including autism spectrum disorder and generalized weakness. He was referred for occupational therapy intervention to address feeding concerns by his pediatrician at the request of his parents. He has been in ongoing occupational therapy intervention for two months and three weeks at this time. Upon beginning occupational therapy treatment, he consumed only one vegetable (corn), one fruit (applesauce), and consumed only two proteins (chicken and turkey). His treatment plan is written to decrease maladaptive behaviors (emotional outbursts) when presented non-preferred foods, increase oral motor skills, and systematically desensitize to visual and olfactory processing concerns. His mother and father alternate bringing I to his ongoing occupational therapy appointments. His mother completed the phase 1 survey and his father completed the phase 3 semi-structured interview.

Ethical Considerations

Dietary restrictions are sometimes the result of a cultural choice while other times they are medically necessary. Using popular intervention strategies can be difficult for therapists and families as they are limited in their understanding of the culture or feeding program, and are limited in progress as a result (Campinha-Bacote, 2009). This is an occupational injustice (Wolf et. al., 2010). From an ethical standpoint, it was important to avoid stereotypes in selecting participants. Furthermore, it was important to include clients with a clinical disorder that demands an altered diet or those who are choosing modified diets for health benefits. These participants were assured that the goal is to create inclusion and understanding of their culture, disability, or lifestyle choice, not further separate them on this basis.

Outcome Measures

Outcomes were measured by the parents’ reporting of their experiences and the observations made by the researcher as related to the child’s diet. Comments directly from each child were not included in the findings of this study as they are not experiential in nature, dialoguing only about the intervention process in that moment rather than the reflective nature of the parents' reporting of their experiences. Methods of data collection included self-completed surveys by the parents of each participating child to capture, in writing, their feelings regarding their engagement in the occupation of feeding, audiotaped formal interviews to document the experiences of the caregivers, and video/audio recorded therapy sessions to document the experiences of the children engaged in the occupation of feeding in the clinical context.

Summary

The overarching goal of this study was to document the experiences of individuals of dietary diversity as they are guided through the feeding intervention process by their occupational therapist. Through the careful collection and evaluation of data, the researcher was able to effectively document experiences as reported by the participants regarding the occupations of feeding and eating. Adhering to the Occupational Therapy Code of Ethics set forth by the American Occupational Therapy Association requires that practitioners incorporate culturally-sensitive behaviors into their client-centered practice. Beginning with an awareness of the their own cultural competence, the findings of this study may be used to aid occupational therapy practitioner's attempts to eradicate barriers to appropriate occupational engagement in feeding and eating. Participants provided candid information regarding the experiences they encounter in daily occupations surrounding feeding and eating, but also in socializing and leisure occupations. Findings indicate similarities in the responses of the participants, reflecting the possibility of experiences that may be shared by others.

Section Four: Results and Discussion

Results

The researcher transcribed and coded all interviews, recordings, and videos, as well as referenced field notes to document the experiences of each participant. The codes (Appendix F) enabled the emergence of four themes, which were shared experiences among the participants. The four themes included: *meal planning*, *difficulty dining out, difficulty with school lunches*, and *increased frustration surround the occupation of feeding*.

Meal planning is a challenging experience for the participants because they are required to provide forethought into what they prepare. In school, the parents are not present to ensure their children are eating appropriately, and there is concern that the children will not consume appropriate nutrients required for school engagement. J's mother continues that it is challenging to prepare two meals for her family – one for J and one for the rest of the family: *"It's difficult to plan meals because I always have to cook something different or make sure that he pre-eats."* I's father reports *"The hardest part is planning meals."*

Dining out is a challenging experience for I's family as they find it difficult to complete their occupational therapy practitioner's pre-meal activities in public places. Their therapist recommends movement-based activities providing proprioceptive input prior to engagement in structured mealtime, as well as oral motor/oral desensitization protocols that require sterile objects and/or the client's finger to enter his mouth. Dining out is also reported to be challenging, as parents do not always have the opportunity to choose where the occupation of feeding will occur. School field trips, for example, have been challenging for J as he is not currently able to consume any foods from two field-trip locations this school year. J's mother explains: *"They took a field trip and went to [ice cream restaurant] as a class and he doesn't participate in that type of stuff because he doesn't eat ice cream. The same, they had gone on a field trip and stopped at [pizza restaurant] but he doesn't eat pizza, so um, you know, it's been difficult in those types of situations."* Indicating similar challenges in dining out, I's father explains: "*When you're going out to eat it's hard to get – you know – we can't do exercises. It's harder a little bit, at times, but when you're home it goes better."*

The third theme is increased frustration surrounding the occupation of feeding. Feeding requires increased thought, planning, scheduling, and structuring meal times. The social implications of a restricted diet are also contributing to increased frustration. I's father reports that before beginning occupational therapy intervention, the family experienced less frustration because they simply prepared one meal for the whole family whether or not I would eat. He writes: *"It's frustrating. [My wife] is cooking dinners all the time and you know, before, we didn't make a difference of what she made." J's mother continues: "At home it's not as bad, though I do have to cook differently for him than the rest of the family."*

The fourth theme is difficulty regarding school lunches. As indicated in a previous study, children with autism spectrum disorder presented challenges eating at regular restaurants or at school and resisted sitting at the table (Crowe, et.al., 2010). Parents are not present with their child in school. They can only pack for lunch what the child will eat. They can't present non-preferred foods in the school setting as their children may simply not eat. I's father explained: "*I make his lunches but I make the same thing. For* *lunch, you have a short period of time and you need to give him what he will eat."* J's mother continued: "*Anywhere we go, we eat before we go or I pack food for him so he has something to eat."*

Not all experiences, however, were shared. Other important experiences that were reported by only one participant included *Social Engagement, Grocery Shopping, and Cost*. Both participating families appear to experience some phenomenon differently. The parent of J, for example, reported that her family is severely impacted by the social implications of her son's dietary diversity: *"It's hard in social type situations. At home it's not as difficult, though I do have to cook differently for him than the rest of the family. Socially it's difficult because we have to take food with us wherever we go."* On the contrary, I's father reported that his family experiences no social repercussions as a result of their son's dietary diversity: *"Neither one of us let other people dictate or bother us. We like who we are and we don't really care what other people think about that. You know, if we go somewhere, we're not going to say, "He's a picky eater". We'll find something. I'm not going to label him and [make you] abide by those things…"*

Experiences reported by only one participating family are also critical to developing a better understanding of the experiences of the clientele. Considering grocery shopping illustrates the challenging experiences that one participant encountered. K: "*We have to go specific places. The things he likes best, you have to get in different places. The chicken he likes we have to go to Wal-Mart to buy but the fish sticks he likes are from Kroger. So we have to go to multiple places to get the things he eats the best."* Similarly, cost is an important challenge experienced by the participants. The costs of the foods the child will eat are important to consider as the family has very few other options. K:

"*Price wise - his country fried steaks - Josh this weekend was like; these are 9 dollars a bag! But they were only 6 when we started buying them.*"

Discussion

This diversity in the experiences of participants validates the concept that not all people experience interventions in the same way. Furthermore, occupational therapy practitioners must be sensitive to this diversity as they complete occupational profiles and establish plans of care. This study supported that there are similarities and differences in the experiences of the participating families as they undergo occupational therapy intervention for the occupation of feeding and eating. The findings of this study coincide with the notion that a better understanding of the experiences of clients with diverse diets will increase success toward occupational therapy outcomes (Pangborn et.al., 2013). Crowe et.al. (2010) similarly reported, "Knowledge of these early differences can help pediatric therapists to assess feeding issues and plan interventions", further indicating the need for a better understanding of dietary diversity by occupational therapy practitioners.

The researcher was able to draw objective conclusions from the study that were not reported by the child or their parent. When conducting interviews at the end of the third phase of the study, the researcher recognized frequent nervous laughter demonstrated by one participating mother. Field notes during this phase of the study indicate the researcher detecting anxiety and coping mechanisms regarding the occupation of feeding. During the second phase of the study, the data collection phase, the researcher documented in field notes specific behaviors (i.e. nervous laughter, fidgeting) in both parent and child.

At the start of the study, there were findings that the researcher hypothesized. These included more intrinsic, emotional experiences including social challenges, isolation, stress, and frustration. Increased stress on parents decreases success toward occupational goals (Didehbani et. al., 2011). Intrinsic/emotional experiences were reported in the form of stress/frustration by both participating families in this study, indicating a need to minimize the stress and frustration of the clientele by better understanding what they are experiencing as they undergo occupational therapy intervention. Other expected findings were the challenges in implementing feeding therapy home programs outside of the therapy clinic. The outpatient clinic appears to provide structure to mealtime to which children respond well. This structure in not always possible in the natural context as participants reported responsibilities and extra-curricular activities inhibited their ability to adhere to the feeding program.

Other findings were unexpected by the researcher. Meal-planning is one example. As transcribed, one participant reported: “It’s difficult to plan meals because I always have to cook something different or make sure that he pre-eats.” The second participant responded similarly: “The hardest part is planning meals.” The challenge in planning multiple meals is something that is not commonly experienced by individuals consuming ‘typical’ diets but is common among the parents of these participating children. Coinciding with the idea of Pangborn et al., (2013), knowledge of these experiences *before* engagement in occupational therapy intervention may facilitate a higher level of outcome attainment.

Another unexpected finding was the relationship of the occupational therapy practitioner’s recommendations for structuring mealtime in the natural context and increased frustration on the part of the family. I’s father explained how the family, although relieved to understand the scientific reasons for his feeding, is experiencing frustration as they attempt to improve I’s ability to engage in the occupation. There is a specific need for improved feeding therapy care from occupational therapists. As indicated in the literature, inclusion of Restrictive/Avoidant Food Intake Disorder in the DSM-5 may enable greater education among healthcare practitioners regarding the complexity of feeding challenges. In doing so, healthcare practitioners will be able to provide a higher quality of care (Fisher et al., 2014). The unexpected findings of this study are arguably the most valuable pieces of data collected in this study as they provide insight into disparities that are not commonly considered among individuals experiencing these occupations differently than the participants.

Verification of Data and Limitations

The qualitative nature of data collection in this study allowed a healthy, intimate view of the occupations of feeding and eating through the lens of the participants. The small sample size and role of the researcher as the primary occupational therapist working with the participants created a simplicity and familiarity with which the participants appeared comfortable. Attendance among the participants to weekly outpatient occupational therapy appointments was also a strength of this study, allowing consistency and continuity in regard to data collection. The use of technology, which included video recording and audio recording, strengthened the quality of the data collected as they allowed the technology to be placed inconspicuously. This minimized the level of distraction for the participants. Both participants were ongoing feeding clients, and this study was used as a cross-section of their engagement in a comprehensive feeding program. The validity of the study was strengthened by crosschecking codes, researcher immersion, and identification of bias. Triangulation was used as observation combined with semi-structured interview transcriptions, as well as referencing of field notes in data collection (Carter et al., 2014). Rich, thick description occurred in a full description of setting, context, and participants (Davis, 1991).

The study was also limited by its small sample size. Two participants, both presenting dietary diversity in regard to food selectivity, were included. No other families were solicited to participate in this study despite the adequate number of appropriate participants. Clients with more severe feeding conditions (impaired swallow, tubes) were excluded. This may generate the exclusion of experiences that are experienced by families who did not participate in this study. An additional limitation of the study was the responsiveness of participating families in returning documentation. The researcher collected some data via take-home surveys, which were not returned in a timely manner by either participant – one of which failing to return the document at all. It is arguable that the researcher, also serving the role of the primary and ongoing occupational therapist for the participants, was a limitation. The participants were all comfortable with the therapist, and the possibility exists that their engagement reflected this level of rapport. The possibility of bias is present in this capstone project as the researcher has a longstanding professional focus on individuals with restrictive diets and occupational therapy feeding intervention. It is possible that the researcher was overly compassionate or leading interviews with specific questions regarding minor details in the day-to-day experiences of the participants. It is important to consider that the researcher is a coowner of the practice, all research and feeding therapy session were billed for, and the researcher selected the clients/families, all of which might facilitate continued bias.

Implications for Practice, Health Care Outcomes, Healthcare Delivery, and Healthcare Policy

It is possible that trends in participants' experiences are commonplace for families with diverse diets. As many experiences were shared among the two participants in this study, it is rational to assume that other families of children with diverse diets experience them as well.

It is known that increasing cultural competence makes better client-centered occupational therapy practitioners. Several tools have been discussed that help to accomplish this goal. It is recommended that each occupational therapy practitioner implement a culturally sensitive conversation into each occupational profile that he or she creates. When used as a tool in the initial evaluation, it could promote a higher quality of outcome attainment.

Health is not an objective measure. It is a measurement of one's experiences, which no two people are bound to experience in the same way. It is important to remember that as occupational therapy practitioners create healthcare outcomes for their clients, they are sensitive to what "health" means to their culture. Diversity in regard to one's diet is a great example. If a goal is written for a client to eat a soft, steamed vegetable, yet that client is of a culture excluding steamed vegetables, the client has been set up for failure.

The delivery of healthcare systems is in need of further education regarding dietary diversity and cultural competence. As intake paperwork is completed, and occupational profiles are conducted, it is of the utmost importance that occupational therapy practitioners are sensitive to the uniqueness of the client. A diverse diet is but one example of the many differences among two seemingly similar people.

All business owners, hospital administrators, and each professional there between need to recognize the importance of analyzing the experiences of individuals of dietary diversity. Pediatricians are rating a child’s diet in part on the consumption of fruits and vegetables. This, in and of itself, is not a problem. The problem arises when pediatricians are assuming that their patients and families are consuming what they deem a ‘typical’ diet. On the local, state, regional, national, and international levels, it is critically important that policy-makers are sensitive to the dietary diversity of the population. Schools, hospitals, daycares, and restaurants need to be well prepared to serve *all* patrons, regardless of their diversity. Business leaders would not condone refusing service based solely upon clothes, their skin, or their language, so why would they be refused the opportunity to engage in meaningful, impactful occupations because of their diet? To better serve all individuals of society, community leaders need to compassionately study their experiences to better understand how to remain sensitive to their needs.

Future Research

This study serves as the foundation for future studies, which could aid in eradicating disparities among individuals of dietary diversity. It is recommended that future researchers address the limitations of this study to strengthen the validity and reliability of their own studies. Individuals of dietary diversity, as well as the discipline of occupational therapy, will benefit from research that identifies effective strategies for circumventing or eradicating challenges that are identified in the experiences of the participants of this study.

Future researchers will also benefit from carefully executing a high-rapport study with a greater population of participants. A broader selection of inclusion criteria will allow participants who are experiencing disparities with feeding tubes, tracheotomies, or structural swallow impairments to engage in the study. This could also include several researchers collecting data in several contexts.

Future researchers should distribute surveys and interview forms to a greater number of individuals facilitating the collection of more generalizable data. Data should also be collected in the natural context, as full immersion is not possible in the clinical context. Furthermore, the interviews conducted with participants should include an interview with the children to capture any self-reported experiences they might add.

Conclusion

Diverse diets are on the rise. More parents are reporting that their children are "picky eaters" than ever before. A child with a diverse diet, however, is no less qualified to receive the highest quality occupational therapy intervention. Parents of children with diverse diets, when given the opportunity, are verbalizing similar experiences, some of them challenging. These challenges, including social instability, meal planning, grocery shopping, and cost, are impacting not only the occupational engagement of the children but also that of the parents. Occupational therapy separates itself from other disciplines upon its ability to understand the intrinsic factors related to health and wellbeing as practitioners strive to provide client-centered care. Occupational therapy practitioners invest time, energy, and resources into identification of client factors that impact occupational performance and dietary diversity should be no different. This study provides a small glimpse into the challenges experienced by a family with a diverse diet, the next step is to eliminate as many of these challenges as possible.

References

American Psychiatric Association, DSM 5 Task Force. (2013). DSM-5: Diagnostic and statistical manual of mental disorders (5th ed.). Arlington, VA: American Psychiatric Publishing.

Autism Speaks, (2014). Annual report 2014. Retrieved from https://www.autismspeaks.org/sites/default/files/docs/annual_report_9-11.pdf

Avoidant/Restrictive Food Intake Disorder. (2014). *Eating Disorders Review*, *25*(2), 2.

AOTA. (2007). *The road to the centennial vision*. Retrieved from http://www.aota.org/vision

Baker, C. (2011). 10 Strategies for encouraging workplace mentoring programs. Retrieved from http://www.brighthub.com/office/human-resources/articles/114295.aspx

Baxter, P., & Jack, S. (2008). Qualitative case study methodology: Study design and implementation for novice researchers. *Qualitative Report*, *13*(4), 544-559.

Betancourt, JR., Corbett, J., Bondaryk, MR. (2014). Addressing disparities and achieving equity. *Chest*, *145*(1): 143-148. doi:10.1378/chest.13-0634

Boquin, M. M., Moskowitz, H. R., Donovan, S. M., & Lee, S. (2014). Defining perceptions of picky eating obtained through focus groups and conjoint analysis. *Journal of Sensory Studies*, *29*(2), 126-138. doi:10.1111/joss.12088

Campinha-Bacote, J. (2009). A culturally competent model of care for african americans. *Urologic Nursing*, *29*(1), 49-54.

Carter, N., Bryant-Lukosius, D., DiCenso, A., Blythe, J., & Neville, A. J. (2014). The use of triangulation in qualitative research. *Oncology Nursing Forum*, *41*(5), 545-547

3p. doi:10.1188/14.ONF.545-547

Creswell, J. W. (2014). *Research design: Qualitative, quantitative, and mixed methods approach*. Thousand Oaks, CA: SAGE Publications, Inc.

Cronin, A., Poe, S., & Ruscello, D. (2009). Team intervention in food selectivity in a medically complex child in rural Appalachia. *Occupational Therapy In Health Care*, *23*(3), 207-225 19p. doi:10.1080/07380570902976767

Crowe, T. K., McClain, C., Osbourne, P., Provost, B., & Skipper, B. (2010). Mealtime behaviors of preschool children: Comparison of children with autism spectrum disorder and children with typical development. *Physical & Occupational Therapy in Pediatrics, 30*(3). doi:10.3109/01942631003757669

Davis, D. S. (1991). Rich cases. The ethics of thick description. *The Hastings Center Report*, *21*(4), 12-17.

Didehbani, N., Kelly, K., Austin, L., & Wiechmann, A. (2011). Role of parental stress on pediatric feeding disorders. *Children's Health Care*, *40*(2), 85-100. doi:10.1080/02739615.2011.564557

Elliott, C. & Clawson, E. (2010). The TR-eat model. *Pediatric Feeding and Dysphagia Newsletter*, *10*(4), 1-6.

Field, D., Garland, M., & Williams, K. (2003). Correlates of specific childhood feeding problems.Journal of Pediatrics and Child Health,39,299–304.

Fisher, M., Rosen, D., Ornstein, R., Mammel, K., Katzman, D., Rome, E., Walsh, B. (2014). Characteristics of restrictive/avoidant food intake disorder in children and adolescents: A "new disorder" in DSM-5. *Journal of Adolescent Health*, *55*(1), 49-52. http://dx.doi.org/10.1016/j.jadohealth.2013.11.013

Franklin, L., & Rodger, S. (2003). Parents' perspectives on feeding medically compromised children: implications for occupational therapy. *Australian Occupational Therapy Journal*, *50*(3), 137-147.

Ghanizadeh, A. (2013). Parents reported oral sensory sensitivity processing and food preference in ADHD. *Journal of Psychiatric & Mental Health Nursing, 20*(5), 426-432 7p. doi:10.1111/j.1365-2850.2011.01830.x

Glaser, J. & Laudel, G. (2013). Life with and without coding: Two methods for early-stage data analysis in qualitative research aiming at causal explanations. *Forum Qualitative Sozialforschung / Forum: Qualitative Social Research*, *14*(2), 1438-5627.

Harding, C., Faiman, A., & Wright, J. (2010). Evaluation of an intensive desensitisation, oral tolerance therapy and hunger provocation program for children who have had prolonged periods of tube feeds. *International Journal of Evidence-Based Healthcare (Wiley-Blackwell), 8*(4), 268-276 9p. doi:10.1111/j.1744-1609.2010.00184.x

Katie Daubs, Toronto, S. (n.d). Play with your food, therapist urges. *Toronto Star (Canada).*

Kavle, J. A., Mehanna, S., Saleh, G., Fouad, M. A., Ramzy, M., Hamed, D., Hassan, M., Khan, G. & Galloway, R. (2015), Exploring why junk foods are ‘essential’ foods and how culturally tailored recommendations improved feeding in Egyptian children. *Maternal & Child Nutrition, 11,* 346–370. doi: 10.1111/mcn.12165

Law, M., Cooper, B,. Strong, S., Stewart, D., Rigby, P. & Letts, L. 1996. The person-environment-occupation model: A transactive approach to occupational performance. *Canadian Journal of Occupational Therapy, 63*(1):9-23.

Leung, A. KC, S Sauve, R., & Marchand, V. (2012). The ‘picky eater’: The toddler or preschooler who does not eat. *Paediatric & Child Health, 17*(8), 455-57.

LHI Infographic Gallery. (2014, August 23). Retrieved August 23, 2014, from www.healthypeople.gov/2020/LHI/infographicGallery.aspx

Luisier, A., Petitpierre, G., Ferdenzi, C., Bérod, A. C., Giboreau, A., Rouby, C., & Bensafi, M. (2015). Odor perception in children with autism spectrum disorder and its relationship to food neophobia. *Frontiers in Psychology, 6*1-10. doi:10.3389/fpsyg.2015.01830

Lukens, C. T., & Silverman, A. H. (2014). Systematic review of psychological interventions for pediatric feeding problems. *Journal of Pediatric Psychology,* 39,903–917.

Martins, Y., Young, R., & Robson, D. (2008). Feeding and eating behaviors in children with autism and typically developing children. *Journal of Autism & Developmental Disorders, 38*(10), 1878-1887 10p.

Norris, M. L., Robinson, A., Obeid, N., Harrison, M., Spettigue, W., & Henderson, K. (2014). Exploring avoidant/restrictive food intake disorder in eating disordered patients: A descriptive study. *International Journal Of Eating Disorders*, *47*(5), 495-499

Pangborn, M. M., Borrero, C. W., & Borrero, J. C. (2013). Sequential application of caregiver training to implement pediatric feeding protocols. *Behavioral Interventions*, *28*(2), 107-130. doi:10.1002/bin.1356

Paul, S., & D'Amico, M. (2013). The role of occupational therapy in the management of feeding and swallowing disorders. *New Zealand Journal of Occupational Therapy*, *60*(2), 27-31.

Smith, J. A. (2016). Sensory processing as a predictor of feeding/eating behaviors in children with autism spectrum disorder. *Open Journal of Occupational Therapy (OJOT)*, *4*(2), 1-11 13p. doi:10.15453/2168-6408.1197

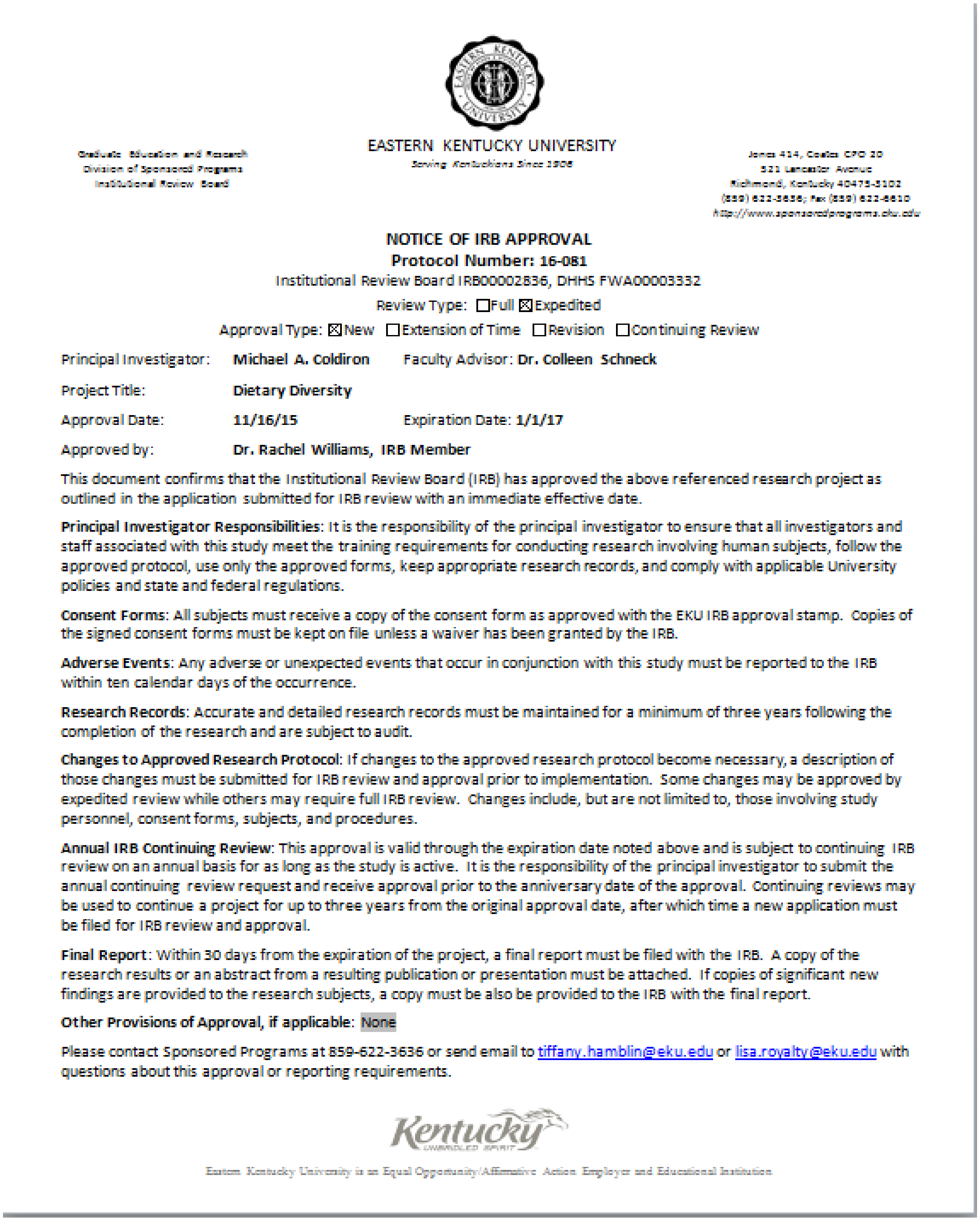
Toomey, K. A., & Ross, E. (2011). SOS Approach to Feeding. *Perspectives on Swallowing & Swallowing Disorders (Dysphagia)*, *20*(3), 82-87. doi:10.1044/sasd20.3.82

Trabi, T., Dunitz-Scheer, M., Kratky, E., Beckenbach, H.,& Scheer, P. (2010). Inpatient tube weaning in children with long-term feeding tube dependency: A retrospective analysis. Infant Mental Health Journal, 31,664–681.

Tsu-Hsin, H., & Tien-Ni, W. (2013). Systematic review of interventions used in or relevant to occupational therapy for children with feeding difficulties ages birth-5 years. *American Journal of Occupational Therapy*, *67*(4), 405-412. doi:10.5014/ajot.2013.004564

Wolf, L., Ripat, J., Davis, E., Becker, P., & MacSwiggan, J. (2010). Theory meets practice: Applying an occupational justice framework. *Occupational Therapy Now*, *12*(1), 15-18.

Appendix A



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NOTICE OF IRB APPROVAL
Protocol Number: 16-081
Institutional Review Board IRB00002836, DHHS FWA00003332

Review Type: ☐Full ☒Expedited

Approval Type: ☒New ☐Extension of Time ☐Revision ☐Continuing Review

Principal Investigator: **Michael A. Coldiron** Faculty Advisor: **Dr. Colleen Schneck**

Project Title: **Dietary Diversity**

Approval Date: **11/16/15** Expiration Date: **1/1/17**

Approved by: **Dr. Rachel Williams, IRB Member**

This document confirms that the Institutional Review Board (IRB) has approved the above referenced research project as outlined in the application submitted for IRB review with an immediate effective date.

Principal Investigator Responsibilities: It is the responsibility of the principal investigator to ensure that all investigators and staff associated with this study meet the training requirements for conducting research involving human subjects, follow the approved protocol, use only the approved forms, keep appropriate research records, and comply with applicable University policies and state and federal regulations.

Consent Forms: All subjects must receive a copy of the consent form as approved with the EKU IRB approval stamp. Copies of the signed consent forms must be kept on file unless a waiver has been granted by the IRB.

Adverse Events: Any adverse or unexpected events that occur in conjunction with this study must be reported to the IRB within ten calendar days of the occurrence.

Research Records: Accurate and detailed research records must be maintained for a minimum of three years following the completion of the research and are subject to audit.

Changes to Approved Research Protocol: If changes to the approved research protocol become necessary, a description of those changes must be submitted for IRB review and approval prior to implementation. Some changes may be approved by expedited review while others may require full IRB review. Changes include, but are not limited to, those involving study personnel, consent forms, subjects, and procedures.

Annual IRB Continuing Review: This approval is valid through the expiration date noted above and is subject to continuing IRB review on an annual basis for as long as the study is active. It is the responsibility of the principal investigator to submit the annual continuing review request and receive approval prior to the anniversary date of the approval. Continuing reviews may be used to continue a project for up to three years from the original approval date, after which time a new application must be filed for IRB review and approval.

Final Report: Within 30 days from the expiration of the project, a final report must be filed with the IRB. A copy of the research results or an abstract from a resulting publication or presentation must be attached. If copies of significant new findings are provided to the research subjects, a copy must be also be provided to the IRB with the final report.

Other Provisions of Approval, if applicable: None

Please contact Sponsored Programs at 859-622-3636 or send email to tiffany.hamblin@eku.edu or lisa.royalty@eku.edu with questions about this approval or reporting requirements.

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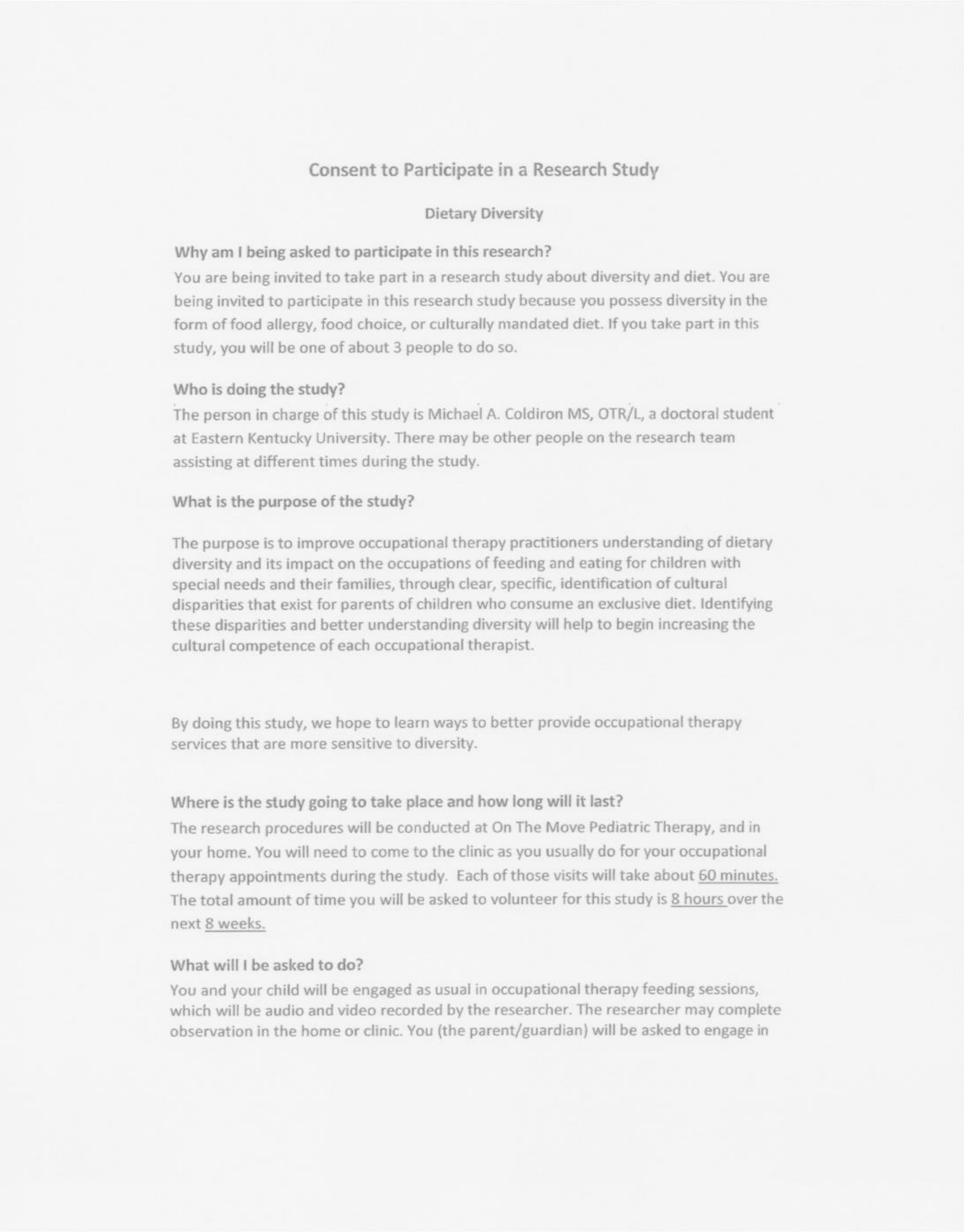
Appendix B



Consent to Participate in a Research Study

Dietary Diversity

Why am I being asked to participate in this research?

You are being invited to take part in a research study about diversity and diet. You are being invited to participate in this research study because you possess diversity in the form of food allergy, food choice, or culturally mandated diet. If you take part in this study, you will be one of about 3 people to do so.

Who is doing the study?

The person in charge of this study is Michael A. Coldiron MS, OTR/L, a doctoral student at Eastern Kentucky University. There may be other people on the research team assisting at different times during the study.

What is the purpose of the study?

The purpose is to improve occupational therapy practitioners understanding of dietary diversity and its impact on the occupations of feeding and eating for children with special needs and their families, through clear, specific, identification of cultural disparities that exist for parents of children who consume an exclusive diet. Identifying these disparities and better understanding diversity will help to begin increasing the cultural competence of each occupational therapist.

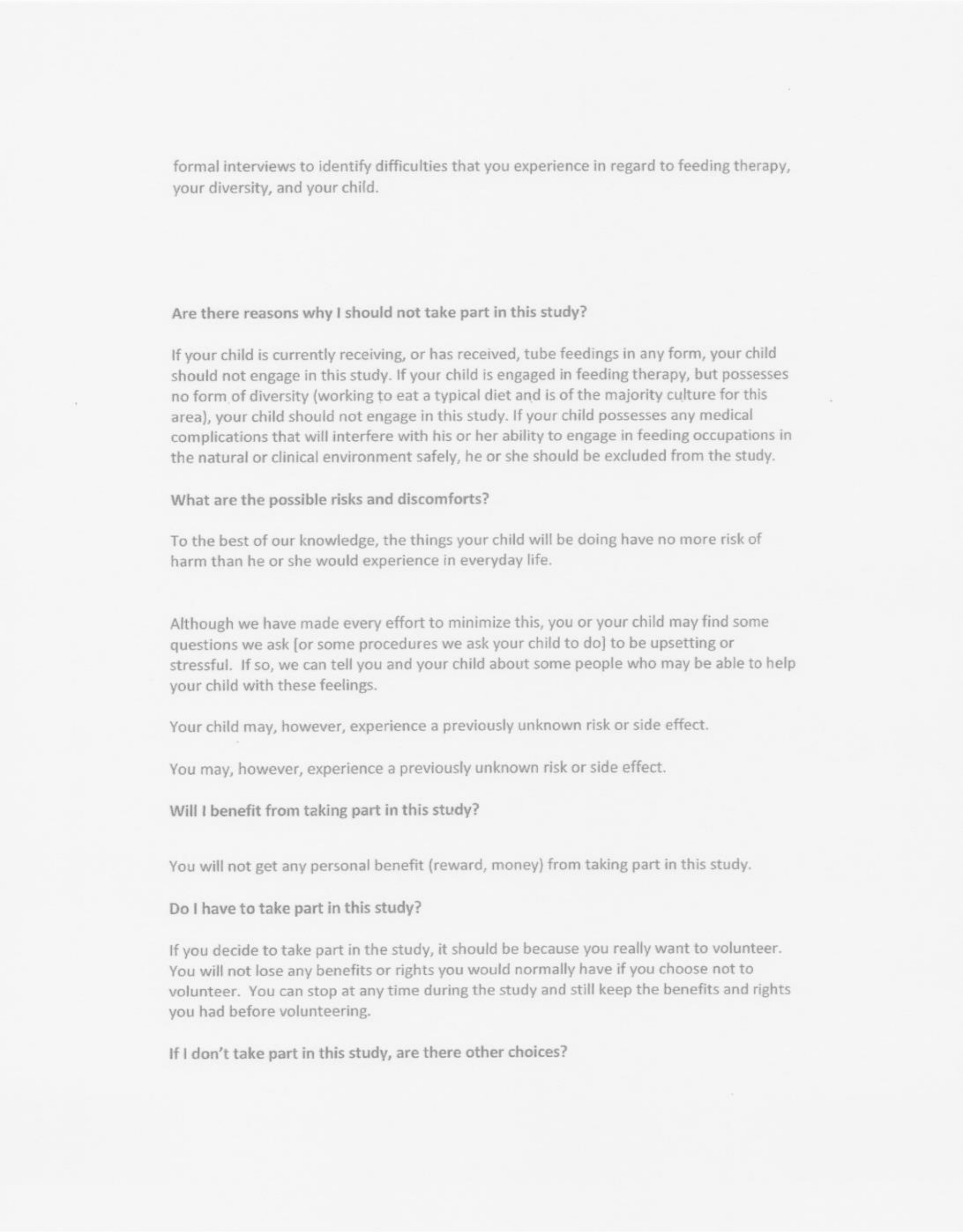
By doing this study, we hope to learn ways to better provide occupational therapy services that are more sensitive to diversity.

Where is the study going to take place and how long will it last?

The research procedures will be conducted at On The Move Pediatric Therapy, and in your home. You will need to come to the clinic as you usually do for your occupational therapy appointments during the study. Each of those visits will take about 60 minutes. The total amount of time you will be asked to volunteer for this study is 8 hours over the next 8 weeks.

What will I be asked to do?

You and your child will be engaged as usual in occupational therapy feeding sessions, which will be audio and video recorded by the researcher. The researcher may complete observation in the home or clinic. You (the parent/guardian) will be asked to engage in



formal interviews to identify difficulties that you experience in regard to feeding therapy, your diversity, and your child.

Are there reasons why I should not take part in this study?

If your child is currently receiving, or has received, tube feedings in any form, your child should not engage in this study. If your child is engaged in feeding therapy, but possesses no form of diversity (working to eat a typical diet and is of the majority culture for this area), your child should not engage in this study. If your child possesses any medical complications that will interfere with his or her ability to engage in feeding occupations in the natural or clinical environment safely, he or she should be excluded from the study.

What are the possible risks and discomforts?

To the best of our knowledge, the things your child will be doing have no more risk of harm than he or she would experience in everyday life.

Although we have made every effort to minimize this, you or your child may find some questions we ask [or some procedures we ask your child to do] to be upsetting or stressful. If so, we can tell you and your child about some people who may be able to help your child with these feelings.

Your child may, however, experience a previously unknown risk or side effect.

You may, however, experience a previously unknown risk or side effect.

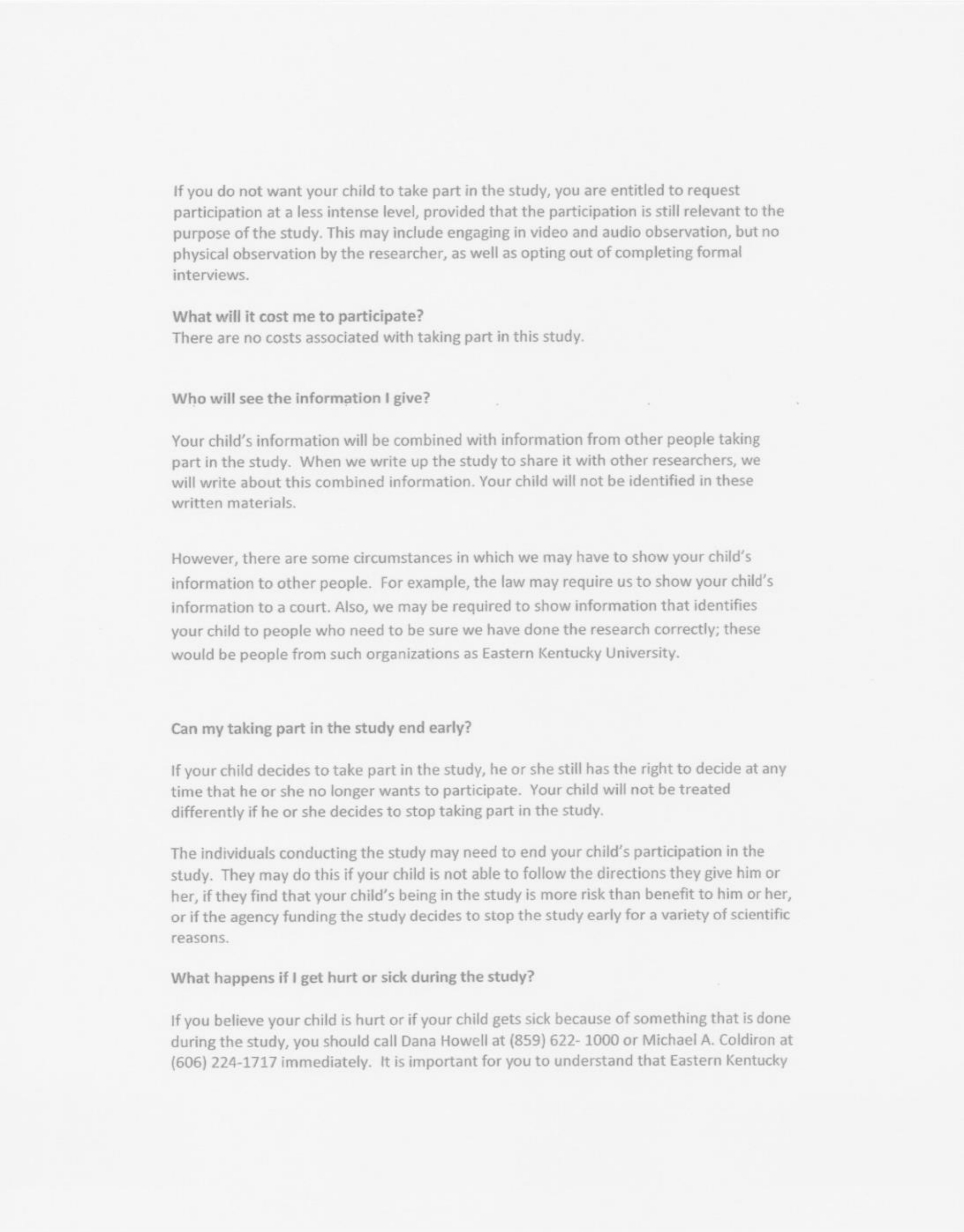
Will I benefit from taking part in this study?

You will not get any personal benefit (reward, money) from taking part in this study.

Do I have to take part in this study?

If you decide to take part in the study, it should be because you really want to volunteer. You will not lose any benefits or rights you would normally have if you choose not to volunteer. You can stop at any time during the study and still keep the benefits and rights you had before volunteering.

If I don't take part in this study, are there other choices?



If you do not want your child to take part in the study, you are entitled to request participation at a less intense level, provided that the participation is still relevant to the purpose of the study. This may include engaging in video and audio observation, but no physical observation by the researcher, as well as opting out of completing formal interviews.

What will it cost me to participate?
There are no costs associated with taking part in this study.

Who will see the information I give?

Your child's information will be combined with information from other people taking part in the study. When we write up the study to share it with other researchers, we will write about this combined information. Your child will not be identified in these written materials.

However, there are some circumstances in which we may have to show your child's information to other people. For example, the law may require us to show your child's information to a court. Also, we may be required to show information that identifies your child to people who need to be sure we have done the research correctly; these would be people from such organizations as Eastern Kentucky University.

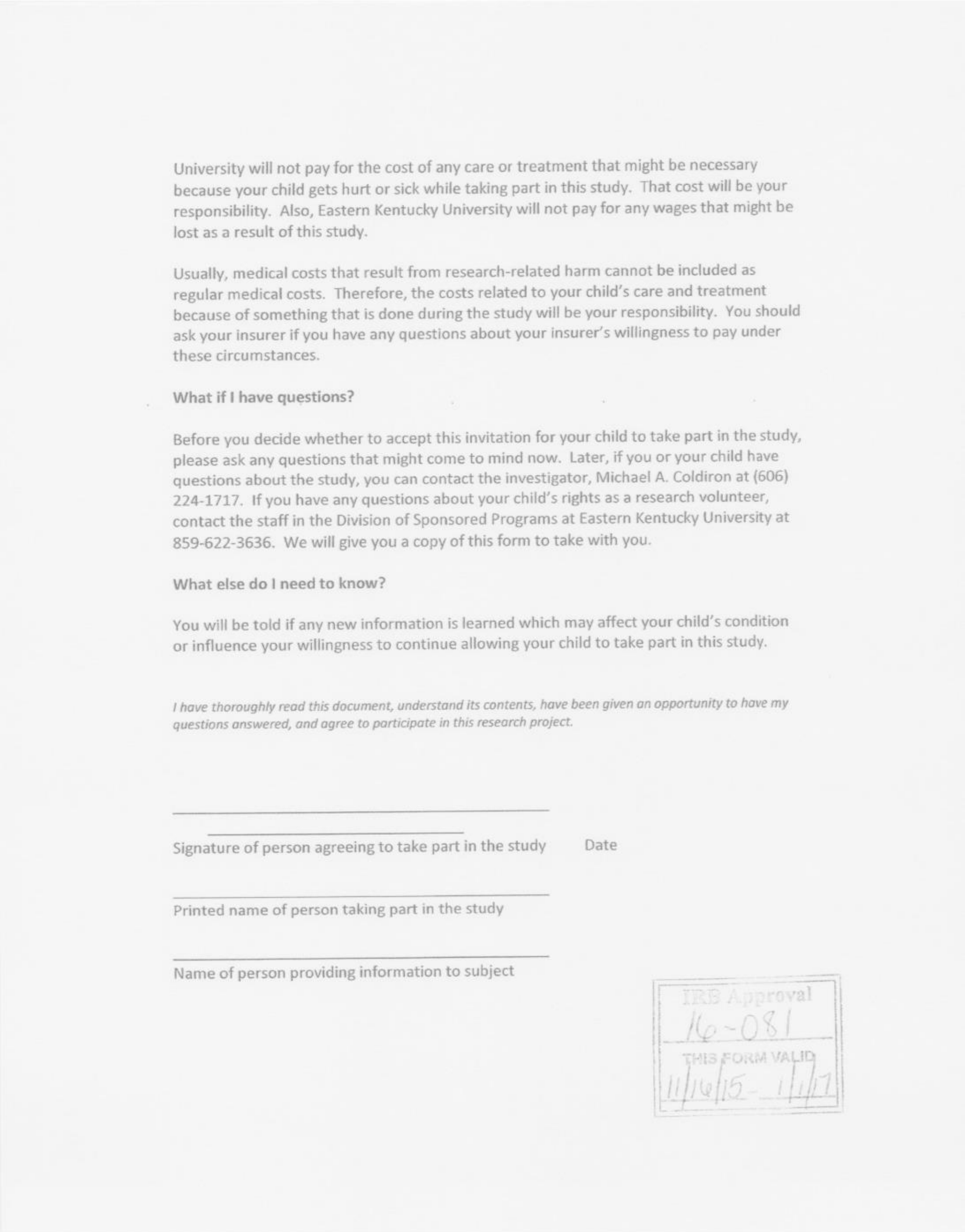
Can my taking part in the study end early?

If your child decides to take part in the study, he or she still has the right to decide at any time that he or she no longer wants to participate. Your child will not be treated differently if he or she decides to stop taking part in the study.

The individuals conducting the study may need to end your child's participation in the study. They may do this if your child is not able to follow the directions they give him or her, if they find that your child's being in the study is more risk than benefit to him or her, or if the agency funding the study decides to stop the study early for a variety of scientific reasons.

What happens if I get hurt or sick during the study?

If you believe your child is hurt or if your child gets sick because of something that is done during the study, you should call Dana Howell at (859) 622- 1000 or Michael A. Coldiron at (606) 224-1717 immediately. It is important for you to understand that Eastern Kentucky



University will not pay for the cost of any care or treatment that might be necessary because your child gets hurt or sick while taking part in this study. That cost will be your responsibility. Also, Eastern Kentucky University will not pay for any wages that might be lost as a result of this study.

Usually, medical costs that result from research-related harm cannot be included as regular medical costs. Therefore, the costs related to your child's care and treatment because of something that is done during the study will be your responsibility. You should ask your insurer if you have any questions about your insurer's willingness to pay under these circumstances.

What if I have questions?

Before you decide whether to accept this invitation for your child to take part in the study, please ask any questions that might come to mind now. Later, if you or your child have questions about the study, you can contact the investigator, Michael A. Coldiron at (606) 224-1717. If you have any questions about your child's rights as a research volunteer, contact the staff in the Division of Sponsored Programs at Eastern Kentucky University at 859-622-3636. We will give you a copy of this form to take with you.

What else do I need to know?

You will be told if any new information is learned which may affect your child's condition or influence your willingness to continue allowing your child to take part in this study.

I have thoroughly read this document, understand its contents, have been given an opportunity to have my questions answered, and agree to participate in this research project.

____ ________________________________

Signature of person agreeing to take part in the study Date

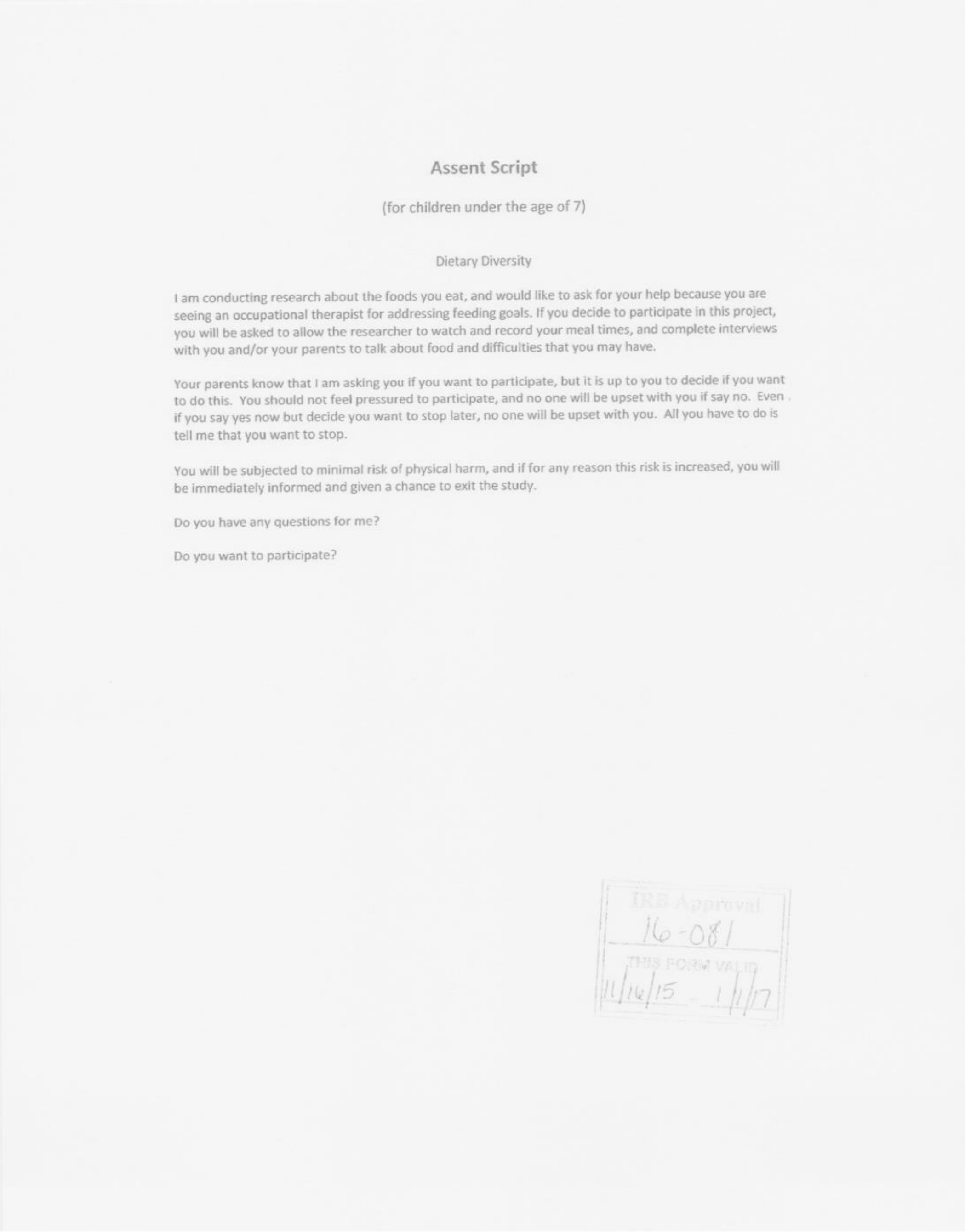
____

Printed name of person taking part in the study

____

Name of person providing information to subject

IRB Approval
16-081
THIS FORM VALID
11/16/15 - 1/1/17



Assent Script

(for children under the age of 7)

Dietary Diversity

I am conducting research about the foods you eat, and would like to ask for your help because you are seeing an occupational therapist for addressing feeding goals. If you decide to participate in this project, you will be asked to allow the researcher to watch and record your meal times, and complete interviews with you and/or your parents to talk about food and difficulties that you may have.

Your parents know that I am asking you if you want to participate, but it is up to you to decide if you want to do this. You should not feel pressured to participate, and no one will be upset with you if say no. Even if you say yes now but decide you want to stop later, no one will be upset with you. All you have to do is tell me that you want to stop.

You will be subjected to minimal risk of physical harm, and if for any reason this risk is increased, you will be immediately informed and given a chance to exit the study.

Do you have any questions for me?

Do you want to participate?

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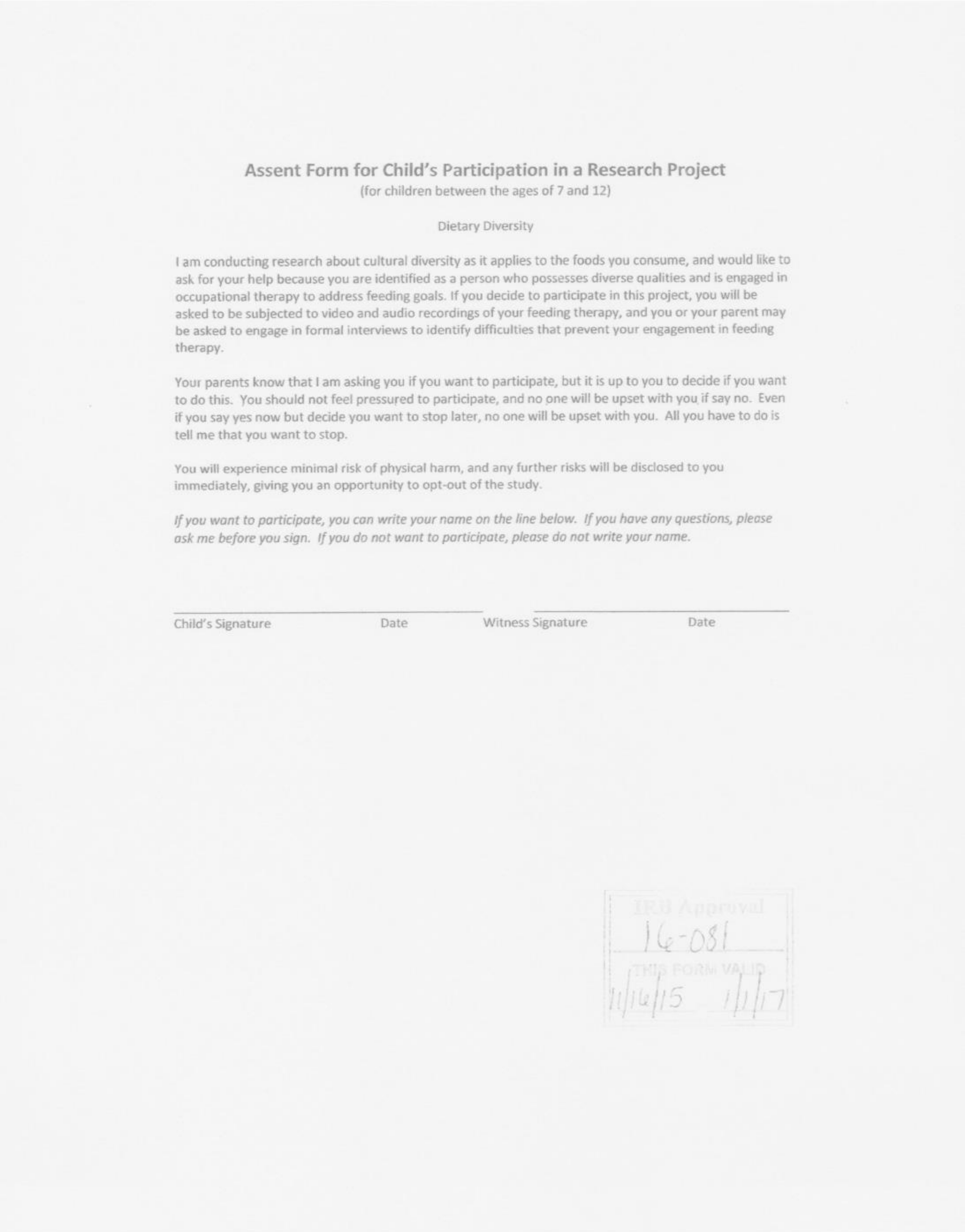


Assent Form for Child's Participation in a Research Project

(for children between the ages of 7 and 12)

Dietary Diversity

I am conducting research about cultural diversity as it applies to the foods you consume, and would like to ask for your help because you are identified as a person who possesses diverse qualities and is engaged in occupational therapy to address feeding goals. If you decide to participate in this project, you will be asked to be subjected to video and audio recordings of your feeding therapy, and you or your parent may be asked to engage in formal interviews to identify difficulties that prevent your engagement in feeding therapy.

Your parents know that I am asking you if you want to participate, but it is up to you to decide if you want to do this. You should not feel pressured to participate, and no one will be upset with you if say no. Even if you say yes now but decide you want to stop later, no one will be upset with you. All you have to do is tell me that you want to stop.

You will experience minimal risk of physical harm, and any further risks will be disclosed to you immediately, giving you an opportunity to opt-out of the study.

If you want to participate, you can write your name on the line below. If you have any questions, please ask me before you sign. If you do not want to participate, please do not write your name.

Child's Signature Date Witness Signature Date

IRB Approval
16-081
THIS FORM VALID
11/16/15 1/1/17

Appendix C

Dietary Diversity Survey

1. What are your child's dietary restrictions?	
2. What is it like to live with (a client with) a restricted diet?	
3. What is the most difficult thing for you in regard to your child's feeding and eating?	
4. How often do you encounter difficulties in feeding therapy strategies based upon diet restrictions?	
5. Is it difficult to grocery shop for foods that feeding therapists recommend to continue the interventions in the home?	
6. Would the use of thorough home programs (with consideration for diversity) make it easier to adhere to home programs outside of the clinic?	
7. How often are you given a written home program to take for use in the home?	1-Never 2-Once per two months 3- Once per month 4- Every other visit 5- Every visit
8. How difficult is it to grocery shop for foods that your child will eat?	1- Extremely difficult 2- Difficult

	3- Average 4- Easy 5- Very easy
9. Please rate how satisfied you are with your occupational therapist as they work with you toward your feeding goals.	1- Extremely dissatisfied 2- Dissatisfied 3- Indifferent 4- Satisfied 5- Extremely satisfied
10. Please rate your level of involvement in the therapeutic process with your occupational therapist.	1- Completely uninvolved 2- Uninvolved 3- Some involvement 4- Involved 5- Well involved (equally engaged with therapist)

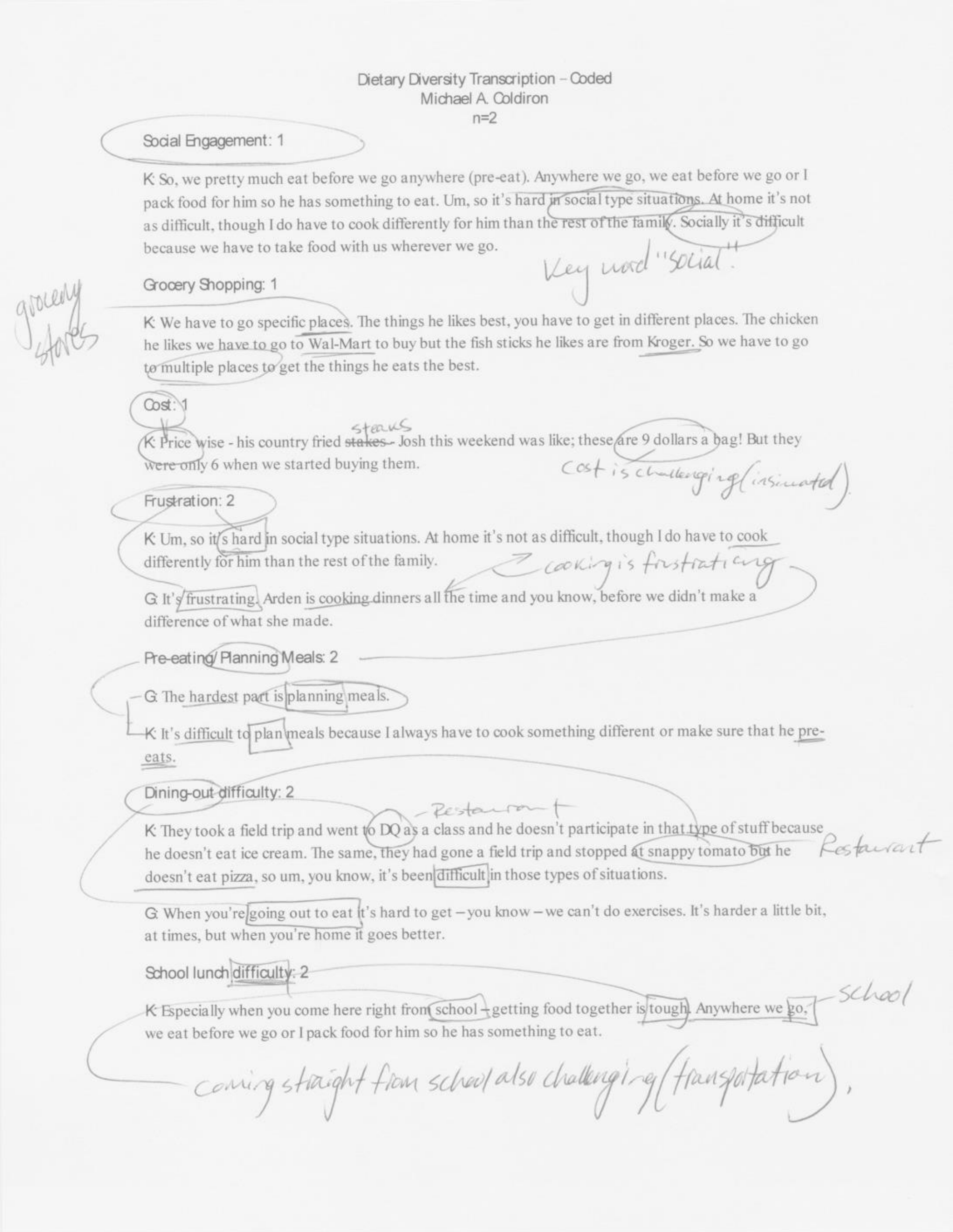
Appendix D

Dietary Diversity: Parent Interview

1) How are you? How are things going? Thank you for your time in regard to this study.
2) What are your child’s dietary restrictions?
3) What is it like to live with (a client with) a restricted diet?
4) Do you identify your child’s diet as diverse? Why or why not?
5) Do you ever feel isolated or restricted by others as a result of your family’s dietary customs?
6) What is the most difficult thing for you in regard to your child’s feeding and eating?
7) How often do you encounter difficulties in feeding therapy strategies based upon diet restrictions?

8) Do you feel that it is difficult to grocery shop for foods that your feeding therapist recommends to continue the interventions in the home?
9) What tools/strategies do you need to ensure carry over at home?
10) Do you think that parents of children with feeding difficulties find it difficult to implement therapy strategies in the home?
11) I would like to give you an opportunity to add any other thoughts, opinions, or concerns.
I would like to thank you again for your time and effort regarding this study.

Appendix E



Dietary Diversity Transcription – Coded
Michael A. Coldiron
n=2

Social Engagement: 1

K: So, we pretty much eat before we go anywhere (pre-eat). Anywhere we go, we eat before we go or I pack food for him so he has something to eat. Um, so it's hard in social type situations. At home it's not as difficult, though I do have to cook differently for him than the rest of the family. Socially it's difficult because we have to take food with us wherever we go.

Key word "social".

Grocery Shopping: 1

grocery stores

K: We have to go specific places. The things he likes best, you have to get in different places. The chicken he likes we have to go to Wal-Mart to buy but the fish sticks he likes are from Kroger. So we have to go to multiple places to get the things he eats the best.

Cost: 1

K: Price wise - his country fried ~~stakes~~ steaks - Josh this weekend was like; these are 9 dollars a bag! But they were only 6 when we started buying them.

Cost is challenging (insinuated).

Frustration: 2

K: Um, so it's hard in social type situations. At home it's not as difficult, though I do have to cook differently for him than the rest of the family.

cooking is frustrating

G: It's frustrating. Arden is cooking dinners all the time and you know, before we didn't make a difference of what she made.

Pre-eating/Planning Meals: 2

G: The hardest part is planning meals.

K: It's difficult to plan meals because I always have to cook something different or make sure that he pre-eats.

Dining-out difficulty: 2

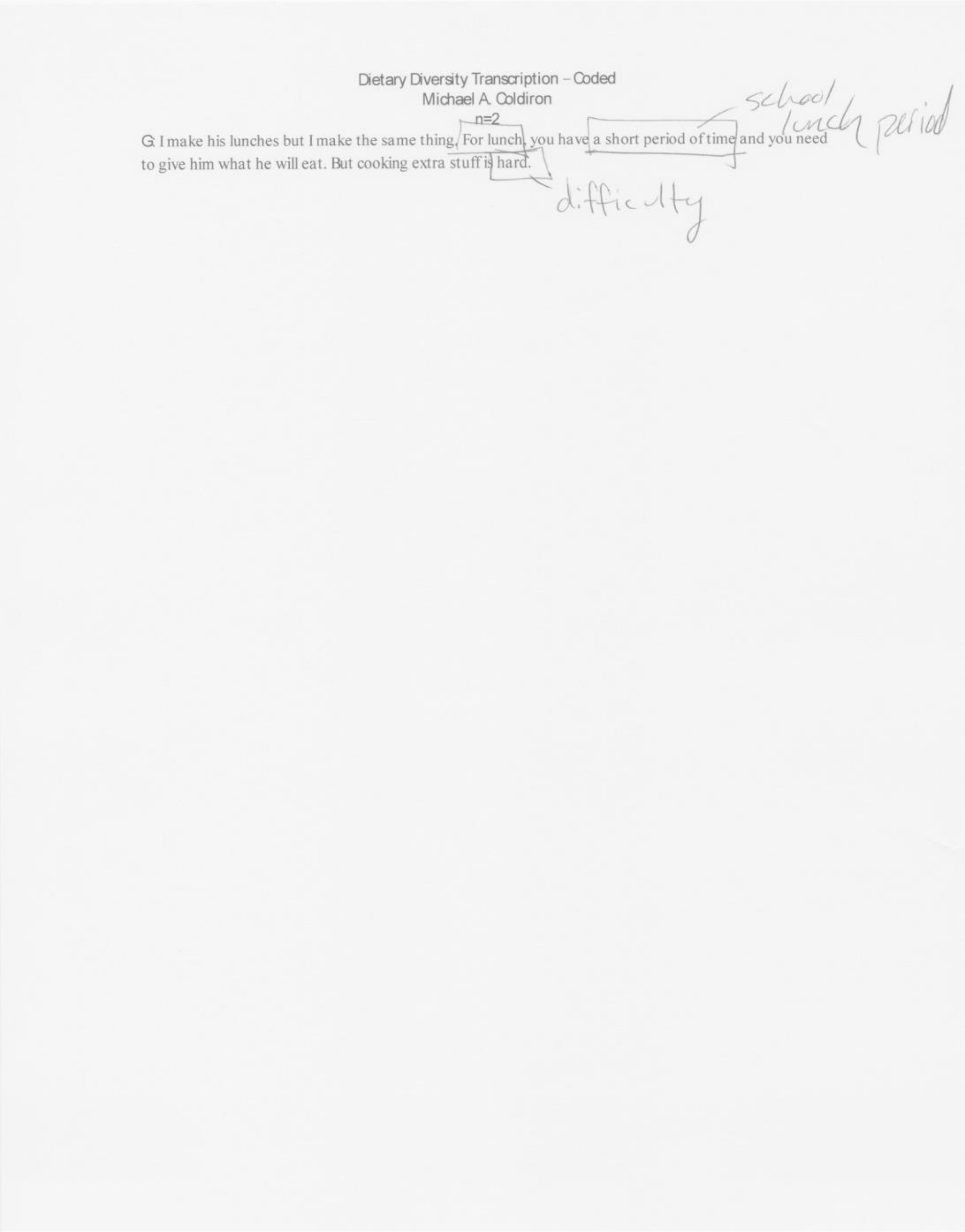
K: They took a field trip and went to DQ – Restaurant as a class and he doesn't participate in that type of stuff because he doesn't eat ice cream. The same, they had gone a field trip and stopped at snappy tomato but he doesn't eat pizza, so um, you know, it's been difficult in those types of situations. Restaurant

G: When you're going out to eat it's hard to get – you know – we can't do exercises. It's harder a little bit, at times, but when you're home it goes better.

School lunch difficulty: 2

K: Especially when you come here right from school – getting food together is tough. Anywhere we go, – school we eat before we go or I pack food for him so he has something to eat.

coming straight from school also challenging (transportation).



Dietary Diversity Transcription – Coded
Michael A. Coldiron
n=2

G: I make his lunches but I make the same thing. For lunch, you have a short period of time and you need to give him what he will eat. But cooking extra stuff is hard.

school lunch period

difficulty

Appendix F

Dietary Diversity Codes

"K" is the mother of Participant named "J"

G" is the father of Participant named "I"

Social Engagement: 1

K: *So, we pretty much eat before we go anywhere (pre-eat). Anywhere we go, we eat before we go or I pack food for him so he has something to eat. Um, so it's hard in social type situations. At home it's not as difficult, though I do have to cook differently for him than the rest of the family. Socially it's difficult because we have to take food with us wherever we go.*

Grocery Shopping: 1

K: *We have to go specific places. The things he likes best, you have to get in different places. The chicken he likes we have to go to Wal-Mart to buy but the fish sticks he likes are from Kroger. So we have to go to multiple places to get the things he eats the best.*

Cost: 1

K: *Price wise - his country fried stakes - Josh this weekend was like; these are 9 dollars a bag! But they were only 6 when we started buying them.*

Frustration: 2

K: *Um, so it's hard in social type situations. At home it's not as difficult, though I do have to cook differently for him than the rest of the family.*

G: *It's frustrating. Arden is cooking dinners all the time and you know, before we didn't make a difference of what she made.*

Pre-eating/Planning Meals: 2

G: *The hardest part is planning meals.*

K: *It's difficult to plan meals because I always have to cook something different or make sure that he pre-eats.*

Dining-out difficulty: 2

K: *They took a field trip and went to DQ as a class and he doesn't participate in that type of stuff because he doesn't eat ice cream. The same, they had gone a field trip and stopped at snappy tomato but he doesn't eat pizza, so um, you know, it's been difficult in those types of situations.*

G: *When you're going out to eat it's hard to get – you know – we can't do exercises. It's harder a little bit, at times, but when you're home it goes better.*

School lunch difficulty: 2

K: *Especially when you come here right from school – getting food together is tough. Anywhere we go, we eat before we go or I pack food for him so he has something to eat.*

G: *I make his lunches but I make the same thing. For lunch, you have a short period of time and you need to give him what he will eat. But cooking extra stuff is hard.*