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Exploring Parents' Experiences of Raising a Child with Sensorimotor Impairments and Expectations for Leisure Participation

Emily Eicher
Eastern Kentucky University

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By

Emily Eicher

Thesis Approved:

Camille Skubik-Peplaski
Chair, Advisory Committee

Shirley Peganoff O'Brien
Member, Advisory Committee

Anne Fleischer
Member, Advisory Committee

Dean, Graduate School

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By

Emily Eicher

Bachelor of Science in Kinesiology
Georgetown College
Georgetown, Kentucky
2014

Submitted to the Faculty of the Graduate School of
Eastern Kentucky University
in partial fulfillment of the requirements
for the degree of
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DEDICATION

This thesis is dedicated to my grandfather,

George Henry Eicher,

who inspires and supports

my thirst for learning.

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ABSTRACT

The objective of this phenomenological study was to explore parents' experiences and expectations of raising a child with sensorimotor impairments and how leisure pursuits impact their expectations of their children. The development and participation in leisure activities is different for these children and could affect the parents' hopes and dreams for their child's future. Six children between the ages of 5-8 years of age, with sensorimotor impairments, participated in a movement program that was held for eight sessions at an outpatient pediatric clinic to address praxis and sensory processing impairments. Six parent dyads were interviewed during the fifth, sixth, seventh, or eighth session of the program. Areas addressed in the semi-structured interviews included parenting challenges, school experiences, and sensorimotor impairments effect on child's leisure participation. Five themes emerged following the interviews, which were parenting expectations, school support, social participation, leisure participation, and ADLs for their children. Parents provided practitioners insight into their everyday lives and this information is essential for making occupational therapy services more family-centered.

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CHAPTER I

Introduction

The role of parenting is familiar in American culture. Parents help to nurture and develop their children into adulthood (Case-Smith & O'Brien, 2015). However, parenting a child with a disability may create significant concerns, altered expectations, and disruptions in family routines (Resch, et al., 2010). In order to incorporate family-centered care, addressing the family's needs and caregivers' feelings about their roles and routines are of great importance (Dunbar & Roberts, 2006). Parents can provide practitioners with insight into their family's everyday lives and insight into how services can encompass their expectations for their children. The objective of this phenomenological study was to explore parents' expectations and perceptions of raising their child as well as their perceptions of leisure pursuits for their children with sensorimotor impairments. An eight-session movement program for children with sensorimotor impairments was implemented to address poor praxis and sensory impairments. During the movement program, the parents of these children participated in a semi-structured interview in order to explore their expectations and perceptions of raising their child and how leisure pursuits impacted the parents' perceptions and expectations of their children. Understanding parent expectations and perceptions of their children with sensorimotor impairments is essential for making occupational therapy services more family-centered.

CHAPTER II

Literature Review

Parenting

In order to build a foundational understanding of parenting for this study, it was important to review and explore literature about parents' perception of their roles and occupations regarding child rearing. This assists in developing an occupational science foundation and lens to move forward into the study. In a phenomenological study conducted by Dunbar and Roberts (2006) researchers interviewed seven women between the ages of 24 and 42 years of age to understand their perceptions of mothering. The mothers in the study had children between the ages of 13 months to 18 years. Participants were asked questions to explore their occupational experiences regarding mothering, how those perceptions influence participation in occupations, and the differences involving mothering between older and younger mothers. These questions were addressed through interviews, participant journals, and authors' notes.

The results of the study displayed four major themes. First, the socio-cultural impact of mothering involved how society and culture influenced their occupational experiences. Family and culture influenced their perceptions, because many of the mothers expressed how their mothering occupations were influenced by how they were mothered. The next theme, activities and occupations of mothering, involved important occupational aspects that had attached meaning and influenced how activities were completed. The third theme, range of feelings, was based on a continuum of negative to positive feelings regarding mothering experiences. The researchers discovered that the younger mothers displayed more feelings of guilt and more demands than the older mothers. The last theme, role management, involved a description of how a mother managed her occupational roles in the family. Negative and positive factors were discussed regarding the mother's ability to manage her role.

Understanding a mother's occupational experiences adds to the occupational science understanding of mothering and the importance of including the mother within the evaluation and treatment of the child, which supports family-centered principles. Dunbar and Roberts (2006) state, "[Crucial factors that continue to limit occupational therapists' ability to engage in family centered practice (FCP)] is the continued notion that 'real treatment' only involves direct intervention with the child" (p. 71). Researchers discussed that in order to incorporate family-centered care, addressing the family's needs and caregivers' feelings about their roles and routines are of great importance.

Considering the mothers as clients as well as the children is a starting point to incorporating family-centered care. Dunbar and Roberts (2006) stated, "[O]ccupational therapists may [need to] begin to consider mothers as clients as well, as they listen to the mothers' occupational needs associated with the care of children with special needs. This may help to close the gap between idealized family-centered care and actual family-centered care, where families are considered as a whole" (p. 54-55). This article provides a thorough background to the proposed study because it discusses how therapists should address the family's needs and gain understanding of parents' feelings by treating them as the client along with the child.

Parenting Children With Disabilities

Another research study provides insights into a mother raising a child with a disability, which assists in building a stronger understanding of a mother's experiences regarding child rearing. Zibricky (2014) conducted an autoethnography on raising her child with a disability and developed four themes about her experiences. The four themes were judgment, predictability, disappointment, and fear of 'letting go.' In regards to judgment, the mother felt she was viewed through a critical lens by society and family members based on constructed ideologies shaped by the dominate culture she is living in. Predictability occurred as a theme because she needed order in her child's life in order for him to feel safe, and she needed order in her own life to face harsh unpredictable reactions in society. Disappointment occurred as a result of her experiences with community members, professionals, family members and friends. These individuals were shaped by the constructed ideologies of society. Lastly, the fear of 'letting go' was constructed as a result of her anxiety and fear of her child's transition into adulthood. She felt this way because she knew her son would have to navigate in a society shaped by constructed ideologies of what a person with a disability is. Overall, this provides insight into a mother's experience regarding the intersection between motherhood and disability and a parent's experience raising a child with a disability.

Another research study reviewed challenges experienced by parents of children with disabilities of various types. In a qualitative study conducted by Resch et al. (2010), 40 parents participated in a focus group in seven communities across a southwestern state in the United States. Parents that participated in the study cared for children with various types of disabilities (physical, developmental, or intellectual disabilities). A written interview guide was used by the moderator and was framed around the research questions which were: what are the principle stressors and challenges for parents of children with disabilities and what supports and services are identified by the parents as necessary for dealing with the stressors and challenges they face (Resch et al., 2010).

The results of the study displayed four major themes that influenced the parent's wellbeing: obtaining access to information and services, financial barriers to obtaining services, school and community inclusion, and family support. According to Resch et al. (2010) the parents illuminated that finding information and resources was a continuous process made more difficult by a complex service system that can be perceived as unhelpful. They also discovered that parent stress and wellbeing is associated with information, resources, and supports not being met to respond to their needs. Resch et al. (2010) suggests, "[T]hat researchers, service providers, and policy makers respect the singular perspective of parents by allowing them to be the experts on the 'realities of their daily lives'" (pp. 147). This idea supports the notion that parents should be integral components of providing services to children with disabilities. This research article supports the proposed study, because parent expectations and aspirations for leisure activities for their children, with sensorimotor impairments, should be studied and more understood.

Defining Sensorimotor Impairments

Sensorimotor impairments involve understanding how sensory processing and praxis work together. Sensorimotor impairment is not a clinical term, but is used to describe the difficulties of the children in the proposed study. Sensory integration can be defined as organizing information and sensations to give meaning to a task (Ayres, 1974). Poor sensory integration can greatly interfere with a child's ability to engage in everyday activities and learning because they have a limited ability to organize sensory information to focus on tasks with the appropriate responses (Schaaf, & Miller, 2005). Mailloux et al. (2011) explains that sensory integration difficulties can occur in different forms such as sensory modulation and praxis problems. Sensory modulation involves producing responses that are appropriate to sensory stimuli (Mailloux, et al., 2011). They also discuss that issues in sensory modulation occur when children are over-responsive or under-responsive to stimuli, which can result in sensory seeking or sensory avoiding behaviors. Praxis involves ideation, motor planning, and motor execution (Dunn, 1997). Praxis difficulties can be characterized as a child's inability to conceptualize, plan, and execute a motor activity (Dunn, 1997). Therefore, the children in the present study may have difficulties with sensory processing and motor planning working together effectively.

Meaning of Leisure for Children and Adolescents

Furthermore, understanding the meaning of leisure for children and adolescents with physical disabilities is important, because participation in leisure has been shown to have health benefits for children by enhancing their quality of life (Powrie, Kolehmainen, Turpin Ziviani, & Copley, 2015). Unfortunately, children and adolescents with physical disabilities spend less time engaging in leisure activities than their typically developing peers (Powrie et al.). Powrie et al. (2015) conducted a systematic evidence synthesis regarding the meaning of leisure participation for children and adolescents with physical disabilities. According to the results, the themes that emerged were: fun (the pleasure experienced from leisure); freedom of choice and from constraints; fulfillment (discovering, developing, and displaying potential); and friendship (social connectedness and belonging) (Powrie et al., 2015). The four themes resonate strongly with the self-determination theory (SDT), which involves addressing basic psychological needs in order to promote individual motivation and a sense of wellbeing (Powrie et al., 2015).

When interpreting the descriptive themes using the SDT, it suggests how leisure provides a way of meeting the psychological needs of children and adolescents with physical disabilities. The children and adolescents in the study were reporting that leisure activities were fun because they permitted them to experience freedom, fulfillment, and friendship (Powrie et al., 2015). However, the children and adolescent's social environment can restrict leisure participation; which highlights how practitioners can assist in altering the social context to improve the child's participation in leisure activities. It was also found that the children and adolescents use leisure to prove their abilities and worth as well as to overcome stigmas regarding their disability (Powrie et al., 2015). Therefore, these themes provide an understanding regarding the role of leisure in children and adolescent's lives. The proposed study aims to understand how a movement, leisure program could affect a parent's expectations and aspirations for improving their child's quality of life.

Children and Leisure

Another component integral to the proposed study is defining leisure for children ages 5-8 years old. Kohlemainen, Ramsay, McKee, Missiuna, Owen, & Francis (2015) define play/leisure as an activity occurring outside of the school day that is engaging and freely chosen by the child. In the study conducted by Kohlemainen et al. (2015), they discovered that participation in physical play is largely influenced by the families established rules, routines, and ways of engaging in leisure. This is important in regards to occupational therapy services because understanding how a family operates as a whole is essential for creating interventions that integrate existing routines in the family for carryover at home. One way of integrating family routines into intervention planning would be to consider family participation in play and leisure activities during assessments. This article supports the idea that understanding the family as a whole can improve the direction occupational therapists take when providing services to children with sensorimotor impairments to improve their engagement in activities of leisure.

Parent's Hopes for Outcomes in Occupational Therapy

Moreover, research has been conducted regarding parents' hopes for outcomes of occupational therapy using a sensory integration approach. Cohn, Kramer, Schub, & May-Benson (2014), conducted a qualitative study with 275 parents who were seeking services for their children at an occupational therapy clinic in the northeast United States that specialized in sensory integration interventions. The parents were asked to complete three open-ended questions on the intake forms in order to identify concerns and hopes regarding occupational therapy services for their children. According to the results, parents expressed four primary concerns or hopes regarding the outcome of their child's intervention outcome: self-regulation, skill development, social participation, and confidence.

Many parents had concerns regarding situations or experiences that often overwhelmed and caused their child to become disproportionately upset. Parents discussed how their child had difficulty connecting with their peers and feeling included. Many parents were also concerned about the ability of their child to accomplish motor tasks such as throwing or catching a ball, riding a bicycle, running, or tying their shoes. Lastly, the parents felt that their children linked their skill level to their self-confidence and one parent worried that her child's self-esteem dropped significantly in school. These themes are significant concerns for parents and are important to take into considerations when developing family-centered occupational therapy services. Furthermore, these themes are pertinent because they may affect a parent's concerns for their children's participation in leisure activities.

Identification of Performance Difficulties

Likewise, identification of performance difficulties also assists in making occupational therapy interventions more effective for children with sensory processing difficulties. Koenig & Rudney (2010), conducted a systematic review regarding performance difficulties in activities of daily living (ADLs), instrumental activities of daily living (IADLs), rest and sleep, education, work, play, leisure, and social participation.

According to their results, children who have difficulty processing and integrating sensory information demonstrated decreased quality and quantity of play skills and social participation. The children in the study also demonstrated more difficulty in motor tasks for ADLs and IADLs and children with tactile sensitivity had higher disturbances during sleep. Lastly, the children had lower participation in school activities, decreased academic achievement, and decreased attention. Koenig & Rudney (2010) state, "By addressing problems in sensory integration and processing, occupational therapy practitioners can have a direct impact on children's or adolescents' ability to engage in play, school, and functional ADLs" (p. 440). Addressing the underlying sensory issues can benefit the child's school experience. The current study can support the field of occupational therapy as the profession continues to move towards effective use of evidence-based practice.

Need for Evidence-Based Practice

Evidence-based practice is increasingly important in the occupational therapy profession. Schaaf (2015) explained that the Patient Protection and Affordable Care Act (ACA) of 2010 (Pub.L. 111-148) created an environment where practitioners need to use evidence-based practices to justify their interventions and deem them as efficient with scientific evidence. Therefore, utilizing supportive research for practitioners can assist in endorsing their intervention decisions.

One area in need of further research is developing an understanding of parent expectations and perceptions of raising a child with sensorimotor impairments in order to make therapy services more family-centered. Moreover, caregivers raising children with sensorimotor impairments experience different routines than caregivers of typically developing children (Kolehmainen et al., 2015). Specifically, caregivers must spend more time taking their children to therapy services and these children often do not have typical activities of leisure in the community to engage in (Resch et al., 2010). The development and participation in leisure activities is different for these children and could affect the parent's hopes and dreams for their child's future.

Parents can provide important details about their child to improve the intervention planning process of an occupational therapist. Incorporating the parents, and their concerns, into therapy services is integral for making therapy more effective (Case-Smith & O'Brien, 2015). Researchers discussed that in order to incorporate family-centered care, addressing the family's needs and caregivers' feelings about their roles and routines are of great importance (Dunbar & Roberts, 2006). Therefore, studying parents' perceptions and expectations regarding raising a child with a sensorimotor impairment and the child's participation in leisure activities could provide integral information on how to best provide services for children with sensorimotor impairments. The purpose of this phenomenological study was to explore parent's perceptions on raising a child with sensorimotor impairments as well as their perceptions of leisure pursuits for their child.

CHAPTER III

Journal Article Manuscript

Introduction

Evidence-based practice has become increasingly essential in the occupational therapy field. Schaaf (2015) explained that the Patient Protection and Affordable Care Act (ACA) of 2010 (Pub.L. 111-148) has created an environment where practitioners need to use evidence-based practices to justify interventions as efficient and scientific. Therefore, it is important that practitioners use supportive research in order to endorse their intervention decisions. One avenue in need of further research involves parent's experiences and expectations for a child with sensorimotor impairments. Considering a parent's experiences of raising a child with sensorimotor impairments and expectations of a leisure program is significant for the occupational therapy profession. Understanding a parent's perspective on their expectations and needs for their child will enable occupational therapists to provide interventions that are family-centered and can support the child's success in the community.

Family-centered interventions are an important aspect of occupational therapy when working with children. Fingerhut et al. (2013) discussed how therapists who work with children would use the term family-centered rather than client-centered because caregiver education and participation is integral for success with the children's interventions. Caregivers of children with disabilities can experience many obstacles, which is why research studies in this area are critical for the occupational therapy field in order to further understand caregiver experiences (Resch et al., 2010). They also explain that a parent has more influence on the wellbeing of the child than any other individual or healthcare provider.

Parents can also provide information on their child’s performance difficulties through explanations of their everyday routines, roles, and activities. Identification of performance difficulties can assist in making occupational therapy interventions more effective in children with sensory processing difficulties. Koenig & Rudney (2010), conducted a systematic review regarding performance difficulties in activities of daily living (ADLs), instrumental activities of daily living (IADLs), rest and sleep, education, work, play, leisure, and social participation. According to their results, children who have difficulty processing and integrating sensory information demonstrated decreased quality and quantity of play skills and social participation. They also demonstrated more difficulty in motor tasks for ADLs and IADLs and children with tactile sensitivity had higher disturbances during sleep. Lastly, the children had lower participation in school activities, decreased academic achievement, and decreased attention.

Koenig & Rudney (2010) state, “By addressing problems in sensory integration and processing, occupational therapy practitioners can have a direct impact on children’s or adolescents’ ability to engage in play, school, and functional ADLs” (p. 440). This adds to our foundation of understanding children with sensorimotor impairments. Researching the parent perspectives can increase occupational therapists’ understanding of how to incorporate family-centered and effective interventions. This supports a need for the current study. Also, researching how these issues impact a child’s ability to engage in activities moves the profession towards evidence-based practice.

Understanding parents’ expectations and perceptions can also help to identify how children and adolescents’ social environment can restrict leisure participation; which highlights how practitioners can assist in altering the social context to improve the child’s participation in leisure activities (Powrie et al., 2015). In a study by Powrie et al. (2015), researchers found that children and adolescents use leisure to prove their abilities and worth and to overcome stigmas regarding their disability (Powrie et al., 2015). Therefore, exploring a parent’s perspective regarding leisure restrictions in their children’s lives may assist therapists in improving the child’s participation in leisure activities.

Consequently, parents raising children with sensorimotor impairments experience different routines and accommodations than parents of typically developing children (Bernheimer, & Weisner, 2007). Specifically, parents may have disrupted routines as a result of taking their children to therapy services (Resch et al., 2010). These children often do not have typical activities of leisure in the community to engage in (Law, Anaby Imms, Teplicky, & Turner, 2015). Law, et al. (2015) explained, “A North American study found that 37% of children and youth with disabilities never took part in organized physical activities in the community as compared to only 10% among their typically developing peers” (As cited in Bedell et al., 2013, p. 106). Some of the factors contributing to less participation were environmental factors such as: physical environment, social, attitudinal, familial, and institutional (Law, et al., 2015). Therefore, the development and participation in leisure activities is different for these children and could affect the parent's hopes and dreams for their child's future.

Incorporating the parents, and their concerns, into therapy services is integral for making therapy more effective (Case-Smith & O'Brien, 2015). Therefore, studying parents' perceptions and expectations regarding raising a child with a sensorimotor impairment and the child's participation in leisure activities could provide integral information on how to best provide services for children with sensorimotor disorders. The purpose of this phenomenological study was to explore caregiver perceptions on raising a child as well as their perceptions of leisure pursuits for their children with sensorimotor impairments.

Method

Research Design

A transcendental phenomenological research design was used for this study, which was recommended in the literature to understand a common experience shared by individuals (Creswell, 2013). Epoche, or bracketing, was applied in order to set aside bias and take a fresh perspective on the experiences being studied (Creswell, 2013). The bracketing technique was implemented throughout the entire research process through reflexive journaling about personal preconceptions or biases.

Sampling

Convenience sampling was utilized for the research study. Parents in the study were required to have a child participating in a movement/leisure program conducted at a pediatric outpatient facility in the southeast region of the United States. In order for the children to be considered for the study, they had to be between the ages of 4-10 years old, have sensorimotor impairments, and currently be receiving therapy services for sensorimotor impairments. Child participants were excluded if they had an intellectual or neurological disorder. The six parent dyads were recruited through the use of flyers in a pediatric outpatient setting.

Procedure

The study was approved through an Institutional Review Board. Informed consent was documented verbally and through a written format preceding the interviews. Six parent dyads participated in a semi-structured interview lasting between 30-50 minutes. The participants were interviewed one time on the fifth, sixth, seventh, or eighth session of a movement program. Interviews took place in therapy rooms at the pediatric outpatient center. The principle investigator conducted four of the interviews and an occupational therapy student conducted the remaining two interviews.

Data Analysis

Data was secured by using pseudonyms on documents with participant names and all documents remained in a locked cabinet for protection of participants. Data was collected through audio-recorded, semi-structured interviews. Data was transcribed verbatim from the audio recordings by the principal investigator and the occupational therapy student assisting with the interviews. Describing, classifying, and interpreting the data was conducted through the use of phenomenological data analysis (Creswell, 2013). Creswell (2013) explains the steps as highlighting significant statements, sentences, or quotes, which is known as horizonalization (as cited in Moustakas, 1994).

The highlighted statements were then developed into clusters of meaning and consequentially themes. Ten categories were developed and narrowed into five themes to describe the nature of the phenomenon.

In order to ensure rigor, multiple strategies were put into place throughout the research process. To begin, reflexivity was conducted through journaling in order to set aside bias or preconceived notions about the topic being studied. The principle investigator, and the occupational therapy student who assisted in conducting the interviews, engaged in reflexive journaling or bracketing, about their biases during the interview process. The principal investigator also engaged in reflexive journaling while transcribing, coding, and theming the interviews in order to reduce the possibility of negating the results with bias. Peer debriefing also occurred between the principal investigator, occupational therapy student, and research instructor regarding the interviews and research process. Another strategy set into place to ensure rigor was developing an audit trail to report how decisions were made during the research experience. Lastly, member checking occurred with three of the participants to ensure the results accurately reflected their experience of raising a child with a sensorimotor impairment.

Results

All participants were parents of children with sensorimotor impairments aged 5-8 years old participating in movement program sessions. Five themes emerged regarding the lived experiences and expectations of the participants raising children with sensorimotor impairments. The themes included parenting expectations, school support, social participation, sensorimotor challenges impact on leisure participation, and activities of daily living (ADLs) challenges.

Parenting Expectations

All of the parents described expectations regarding consistency in routines for their children. Many of the children required structure in their day, and the parents expected to be more spontaneous with their daily routines than they felt they were allowed to be. They explained that their children with sensory concerns were often not flexible with their routines and could have a meltdown as a result of their routines being deviated. Additionally, all six of the parents discussed altered expectations regarding participation in activities. Many parents discussed how they didn't expect their child to be engaging in therapy while typically developing children were engaging in other activities and competitions. Phyllis described her altered expectation in the following reflection:

> *"I always expected to have activities with my child, dance class, soccer, basketball, some kind of physical activity. I didn't expect that to come in the form of physical therapy and occupational therapy."*

Their sensorimotor impairments appeared to play a large role in what the parent's expectations were for their child as well. Some parents discussed how they had expectations based on their child's milestones, not what other people might expect from a typically developing child. They also discussed having different expectations for physical movement due to sensorimotor impairments. Wendy reflects on her adapted expectations regarding physical movement for her child in school. She says:

> *"I'm not saying I want her to be on the jump rope team at her school… but I would like for her to at least be able to make it through gym class during jump rope for heart time without a meltdown because she can't physically do it."*

Parents also discussed how they didn't expect to have a child with a sensorimotor impairment and they felt unprepared for that experience. One parent discussed how she didn't expect to have a child that had to be carried through the grocery store because that experience was too stimulating for her. She felt unprepared to handle these sensorimotor situations. More specifically Georgia states:

> *"Nobody prepares you for, you know, sensory problems. And if you had a child that had like Spina Bifida, and you knew what to expect, and that was an obvious birth defect, an obvious disability, you could plan for it. But sensory problems don't present like a disability. And so you don't get a handbook with it, and you don't get recommendations… you sort of figure it out as you go and it makes it so much more difficult."*

Overall, the parents felt like their expectations for their children were different than what they envisioned raising a child would be like even when compared to their other children. The child's sensorimotor impairments created altered expectations for routines and activities, adapted expectations for physical movement, and expectations for parenting they were unprepared to meet because sensory issues were unfamiliar to them.

School Support

In this theme, all of the participants discussed how school supports impacted their children's learning. Two of the parents of children in preschool seemed pleased with the supports their child were given, but they felt their child had not really entered into the school system yet. One parent of an older child explained that the school was good at matching personalities to determine which teacher would best serve her child. The other parents felt they didn't receive any supports or the ones they did receive were not sufficient enough for addressing their children's needs. Some supports that were given to the children were sensory breaks; exercise balls, rulers, and move and sit cushions. Barbara reflected on the school supports her child receives and stated:

> *"They work with us to a certain extent, but I feel like they fail her by not giving her more."*

Some parents felt that they were receiving insufficient supports because their child didn't score low enough to qualify for certain services. One parent discussed how she asked to see her child's assessment scores because she was shocked that she didn't qualify for services. She expressed that she was surprised, because her child needed to be in the 8th or 9th percentile in handwriting to qualify for services and she felt that you would want to address this issue as early as possible. Wendy further elaborates:

> *"Apparently, you can't be able to write at all to qualify. And she wouldn't have scored that high if we hadn't been working on it outside. You are almost like Catch 22."*

Parents also felt that there was a lack of school support because the school was not educated regarding what the child needed to support their learning. One parent discussed how teachers didn't understand that her child needed movement to meet his sensory diet and that was more than just walking across the room. They also felt their children were capable of doing well if the supports were available, but the school was not willing to work with a child with sensory needs. Georgia provided a scenario regarding a lack of support from the school in the following reflection:

> *"In preschool she had a little Velcro patch underneath the table and she would sit and rub it to the point she would have blisters on her fingertips, but she would sit still and listen. The kindergarten teacher wouldn't do the Velcro patch for her unless she got an IEP. Chewing gum, same thing, even though it helps her calm down, so they are very unsupportive."*

Overall, parents discussed supports their child was provided, but the majority felt that the school could do more. Parents felt that their child did not meet the requirements for services, but they would not have scored that well if they had not been receiving outside help. Limitations to school support appeared to be a lack of school personnel's knowledge regarding children with sensorimotor impairments.

Social Participation

In this theme, all of the parents discussed how their child's sensorimotor impairments affected their child's social participation because of their skill level in motor activities. Through reflections, many parents felt their child was hesitant to engage in typical activities for fear of ridicule from their peers or from feeling left behind. Parents believed that motor deficits were to blame for this fear of being teased by their peers. Georgia states:

> *"Most of the time, where she has to learn a series of things or has to interact with her peers, it takes about 2-3 classes before she realizes [and states she isn't] good enough, and she doesn't want to go anymore. She's afraid of being made fun of."*

Parents also discussed how their child felt isolated from their peers as a result of their sensorimotor impairments. The parents felt that this occurred as a result of missing social cues. Parents expressed that they wanted their child to feel accepted by their peers regardless of their difficulties in motor tasks. Many times the child felt left out or left behind because they couldn't keep up. Yolanda states:

> *"So I think that when they are in something with typical kids who don't have motor planning issues and they see those kids gaining those skills quickly then they already feel left out or left behind."*

Social participation appeared to be an area that children feared as a result of their sensorimotor impairments. Their delays in motor skills inhibited their participation with their typically developing peers who were able to complete motor tasks. Consequently, they felt isolated as a result of their inability to keep up with their peers.

Sensorimotor Impairments Effect on Leisure

Sensorimotor concerns played a large role in the children's participation in leisure activities. Many parents stressed the importance of keeping their child active, but felt like many sports had an adverse effect on participation as a result of their child's sensorimotor concerns. Many children felt over-stimulated while engaging in a leisure activity or they felt like their ability to motor plan was not sufficient enough to engage in a sport. Teresa discussed how t-ball was over-stimulating through the following reflection:

> *"In t-ball he did not like the crowd. He didn't want to go in the dugout and if he did go he didn't want to stay in there. He would freeze when it was his turn to bat because he could see everyone behind it."*

Georgia felt that her child's lack of participation in leisure was largely sensory related as well. She stated:

> *"I know the team sports is 100% sensory. She doesn't like the interaction. She doesn't like people touching her. She doesn't like things being thrown at her. She doesn't like people running at her. Yea, the noise, the whistles! Whistles are like sensory kids demons. She hates them."*

Program adaptations in the movement/leisure program that their children were currently participating in played a large role in the child's success. The movement program implemented sensory needs for their children such as oral stimulation (blowing bubbles, chewing gum, eating sour candy), proprioceptive input (wall push-ups, exercise ball, contralateral extensions), vestibular stimulation (log rolls), and auditory stimulation (metronome, music). All of the parents discussed how the program supported their child's sensorimotor needs for participation and allowed them to be successful, which improved their self-esteem. Furthermore, providing sensory stimulation through auditory, proprioceptive, oral, and vestibular input appeared to benefit the children as well. Wendy stated:

> *"I'm actually surprised how well she did with the tap last night practicing, trying to keep up with the feet and the clicking of the metronome. She did better, really!"*

Leisure activities can be over-stimulating and prohibitive for a child with sensorimotor impairments. The parents clearly identified that leisure programs that are open to adaptation can help meet the sensory needs of the child through different movement experiences and appear to be beneficial for meeting the child's sensorimotor goals.

Activities of Daily Living Challenges

All the parents discussed how their child's sensorimotor impairments affected their ability to complete ADL tasks. Many explained how toileting, feeding, grooming, and dressing resulted in difficulties due to motor or sensory issues. A disruption in a routine affected their child's desire to engage in ADLs and routines were affected as a result of their child's ADL challenges. One mom discussed how her child didn't want to take a bath when her routine was disrupted and she was having a meltdown. Many parents explained how they had to set aside more time in order for the child to complete their ADLs. Fine motor, ADL tasks appeared to be a challenging time constraint for many of the parents (Buttons, zippers, tying shoes) Teresa explains:

> *“Buttons are mainly frustrating. Sunday mornings you have to know to adjust time for what he calls church clothes, which include any shirt that has to be buttoned.”*

Some parents also expressed how sensorimotor impairments could result in safety concerns with ADLs. Food stuffing during feeding activities was a concern for one mother because her child would stuff food in their mouth for the proprioceptive input. Another parent explained how her daughter would rip hunks of hair out of her head when brushing it because she was under-responsive to that stimulus. Another parent commented that they had to delay toileting due to sensorimotor impairments, which postponed her moving up in daycare, and she felt her daughter was very bright. Safety concerns also came into play regarding dressing in the wintertime. Cathy reflected on sensory issues impacting dressing and safety by stating:

> *“So the tactile defensiveness has been at times really challenging to deal with because it’s like the middle of winter and he doesn’t want to wear socks or gloves to play in the snow.”*

Overall, sensorimotor impairments appeared to play a role in the child’s ability to engage in ADL tasks and stay on target for age-appropriate progression of classes. Parents discussed how toileting, feeding, grooming, and dressing were impacted. Safety concerns came into play due to sensory avoiding and seeking behaviors, which decreased their ability to complete ADL tasks.

Discussion

Understanding parent expectations and experiences are important for incorporating family-centered principles. The parents from the study established many concerns to consider in order to make therapy services more family-centered. According to the results from the current study, parents discussed that adaptations to their routines and expectations for their children's participation in activities were necessary because of the children's sensory concerns creating a need for consistency to avoid meltdowns. Previous research has indicated that parents have concerns regarding situations that make their children disproportionately upset (Cohn, Kramer, Schub, & May-Benson, 2014). Inconsistent routines had the ability to make the children in the present study have a meltdown, which would be a concern for a parent. In a study by Resch et al. (2010) they discussed how parents tended to feel overwhelmed when they had a child diagnosed with a disability.

The parents in the present study discussed feeling overwhelmed, and they felt unprepared because their expectations for raising a child were different than they envisioned. They were required to adapt routines as a result of their children's responses to overwhelming sensory stimuli. Previous research suggests providing supports to parents in order to help them adjust to their unexpected parenting roles (Resch et a., 2010). Cohn and DeMarinis (2016) suggest providing supports through using best practice and collaboration in a family-centered approach, which means that occupational therapists can demonstrate respect to families by exchanging information to develop an understanding of family concerns to make informed decisions on the best treatment for their child.

Parenting concerns in the present study involved regulating emotions or behaviors. For instance, parents discussed adapting expectations and routines in order to meet the needs of their child with a sensorimotor impairment, because their child was unable to regulate their behavior in multiple aspects of their life (home, school, leisure). Moreover, Cohn, Kramer, Schub, & May-Benson (2014) explained that parents hopes for occupational therapy interventions using sensory integration approaches were that their children could learn to regulate their emotions or behaviors. Regulating emotions also played a large role in the child's social participation, skill development, and confidence (Cohn, Kramer, Schub, & May-Benson, 2014). Therefore, implementing occupational therapy practice that helps parents assist their children in regulating their emotions and behaviors can take into consideration family concerns to make practice more family-centered to assist children in various components of their life (social, occupations, and self-confidence). Implementing these strategies in school-based practice would also be essential to help children regulate their emotions and behaviors to perform better in social and academic tasks.

School supports appeared to be a frustration for many of the parents in the present study, because of the school's lack of understanding for sensorimotor impairments and their child's test scores not being low enough to receive services. The parents also discussed many difficulties in the school setting because the child was not able to regulate their arousal and alertness to improve their academic performance.

According to a research study by Missiuna, Moll, Law, King, and King (2006), parents discussed that their children with developmental coordination disorder were not receiving services in the school system to support their children because the school did not have the resources. Missiuna, et al. (2006) also expressed that teachers often do not understand the child's difficulties and may feel the children are not putting forth effort. This incidence also impacts the children's self-esteem because they feel they are not good enough because of their difficulties in performing school activities (Missiuna, et al., 2006). Self-esteem was also a factor throughout the present study in regards to school performance, leisure engagement, and social participation.

Moreover, social participation appeared to be affected in the present study because the children were concerned about their ability to keep up with their peers when engaging in gross motor activities. Parents also claimed that their children were fearful of ridicule from their peers because of their performance in school and in leisure activities. Missiuna, Moll, Law, King, and King (2006) discussed how difficulties appear to be heightened when a child enters the school system, which can play a role in the children's desire to participate with their peers. They also stated that many children may feel like they are not good enough, or they may fear ridicule from classmates because they are somewhat delayed. Koenig and Rudney (2010) validate that children with sensory concerns often have decreased social participation. They also discussed how motor coordination had a significant relationship to a child's social participation (Koenig & Rudney, as cited in Cummins et al., 2005). Many parents expressed concerns about other peers accepting their child as a result of their difficulties with motor skills.

Occupational therapists have the opportunity to improve social participation and self-esteem for children with sensorimotor impairments. This concern was made evident by parents in the study and can be addressed in a multitude of ways. For instance, occupational therapists can use meaningful occupations in order to promote social participation for children in the school setting, they can implement activities that increase peer interactions, and they can conduct activity analysis in order to determine how to modify activities to improve every child's participation (AOTA, 2008). A child's social participation was shown to impact their self-esteem and can have implications towards the child's academic success. Bazyk (2010) also discussed the implications of promoting positive mental health in children and adolescents with developmental disabilities by fostering positive emotions and individual strengths to enhance the participation and quality of life of children with developmental disabilities.

Furthermore, sensorimotor challenges influenced leisure participation according to parenting concerns in the present study because their children felt over-stimulated when engaging in an activity or felt inadequate in regards to their motor skills compared to their peers. Parents also discussed the challenge of identifying a program that could meet the child's sensory needs. Missiuna, Moll, Law, King, and King (2006) discussed in their study how many parents were unsure if they should challenge their child to participate in activities that their children avoided. They also discussed how parents were hesitant to push their child to participate in leisure activities for fear of lowering their child's self-esteem, and they were concerned about finding a program that was accommodating of their child's sensory needs (Missiuna, Moll, Law, King, & King, 2006).

Parents in the present study also connected their concerns on leisure participation in relation to the fear of ridicule from their peers if they weren't performing at the same level as others.

Moreover, occupational therapists can play a role in recommending sports for children that best match their sensory needs and help to promote health, wellness and social participation. Kirkpatrick (2012) discusses the importance of understanding a child's motor coordination, praxis level, and muscle tone to determine which sport may be best suited for the child. Parents from the current study discussed how sensorimotor concerns influenced their child's ability to play a sport because the child could be over-stimulated. Therefore, Kirkpatrick (2012) suggests choosing sports that have the appropriate energy requirements (ex. high energy: basketball, low energy: bowling), appropriate dynamic components (ex. Bowling is less dynamic because the lane does not change), appropriate individualization, and appropriate motor coordination level. These factors can help occupational therapists assist parents in finding leisure opportunities for their child that are appropriate and can elicit positive emotions. Additionally, Law et al. (2015) discussed the importance of interventions that focused on changing the environment rather than the child in order to support participation of youth. This could also correlate well with children who have sensorimotor impairments that feel overwhelmed with the sound of whistles or sitting in a dugout for baseball.

Many parents from the current study also discussed the difficulties that they faced regarding ADL challenges with their children (dressing, toileting, grooming, feeding). Setting aside more time for the child to engage in ADLs was required.

Additionally, previous research has shown that sensory processing and sensory integration concerns can impact a child's functional performance with ADLs (Koenig & Rudney, 2010). These authors further espouse that sensory over-responsiveness (sensitivity to stimuli) disrupted family routines and made self-care performance more challenging (as cited in Reynolds & Lane, 2008). Difficulty in self-care performance concerns were also an issue in this study because children with sensory under or over-responsiveness were less likely to brush their teeth or hair and shower, which could result in hygiene concerns.

The study illustrated how sensorimotor impairments influenced a child's ability to complete ADLs, which is important for occupational therapists to assess in order to teach strategies in self-care skills. More specifically, Koenig and Rudney (2010) state that occupational therapists should assess a child's ability to perform everyday occupations or ADLs in the school and home in order to determine the individual factors that may be related to the adverse coping strategies of the child while engaging in ADLs. For instance, an over-responsive child may perform the occupation of dressing differently than a child who is under-responsive, and these factors should be taken into consideration by an occupational therapist in order to provide client-centered interventions for that child.

Overall, parents had concerns regarding their perceptions of raising a child with sensorimotor impairments. Their concerns regarding adaptations to routines and expectations, school support, social participation, sensorimotor challenges impact on leisure participation, and ADL challenges were found in previous literature.

Understanding parent experiences is essential for providing family-centered care and improving the quality of life of the whole family.

Implications for Practice

Occupational therapy is founded on client-centered principles, which emphasizes understanding the needs of the client (Cohn, Kramer, Schub, May-Benson, 2014). Viewing the family as a whole is essential when providing services to children because the family works as a dynamic unit and child success is dependent on that unit. Findings from the study encourage occupational therapists to take more initiative in improving services by incorporating parenting expectations into interventions. Moreover, understanding parent concerns to advocate for their children in the school context can help children with sensorimotor impairments receive appropriate services essential for their child's academic success. Developing collaboration with para-educators and educating school administration on the needs for children with sensorimotor impairments could greatly benefit the children's ability to perform school tasks successfully.

Occupational therapists also have an opportunity to provide these children with the tools they need to modulate their arousal levels and alertness to improve their role as a student, family member, and peer in the community. Occupational therapists can address social participation by using meaningful occupations in the school and community setting, implementing activities that increase peer interactions, and they can conduct activity analysis in order to determine how to modify activities to improve every child's participation and success (AOTA, 2008). Moreover, occupational therapists can play a role in recommending sports for children that best match their sensory needs and help to promote health, wellness and social participation in leisure activities. Lastly, occupational therapists can assess a child's performance in ADLs and teach strategies to assist parents in addressing their sensorimotor concerns in ADL tasks.

Limitations and Future Research

One limitation that should be noted when interpreting the results of the study is that the present study had a limited sample size. Six parent dyads were interviewed with similarities in response being noted, but saturation may have not been reached. Another limitation was that the children were recruited for solely sensorimotor impairments, but one also had a diagnosis of Attention Deficit Hyperactivity Disorder (ADHD) and Autism. Parent concerns for this child also involved how these diagnoses impacted their experiences in parenting. Furthermore, the parents were interviewed during the movement program and their perceptions of the movement program may have changed throughout their child's experiences and following the movement recital. Further research may be needed to study how incorporating family-centered principles affect parent expectations and experiences in raising a child with a sensorimotor impairment.

Conclusion

Parenting concerns regarding adaptations to routines and expectations, school support, social participation, leisure participation, and ADL challenges provide insight into the occupation of parenting a child with sensorimotor impairments. Occupational therapists have the ability to provide holistic care to clients with sensorimotor impairments by taking into consideration parenting concerns. Family centered care can make therapy services more effective since families work as a dynamic unit, and a child’s success is dependent on the family unit.

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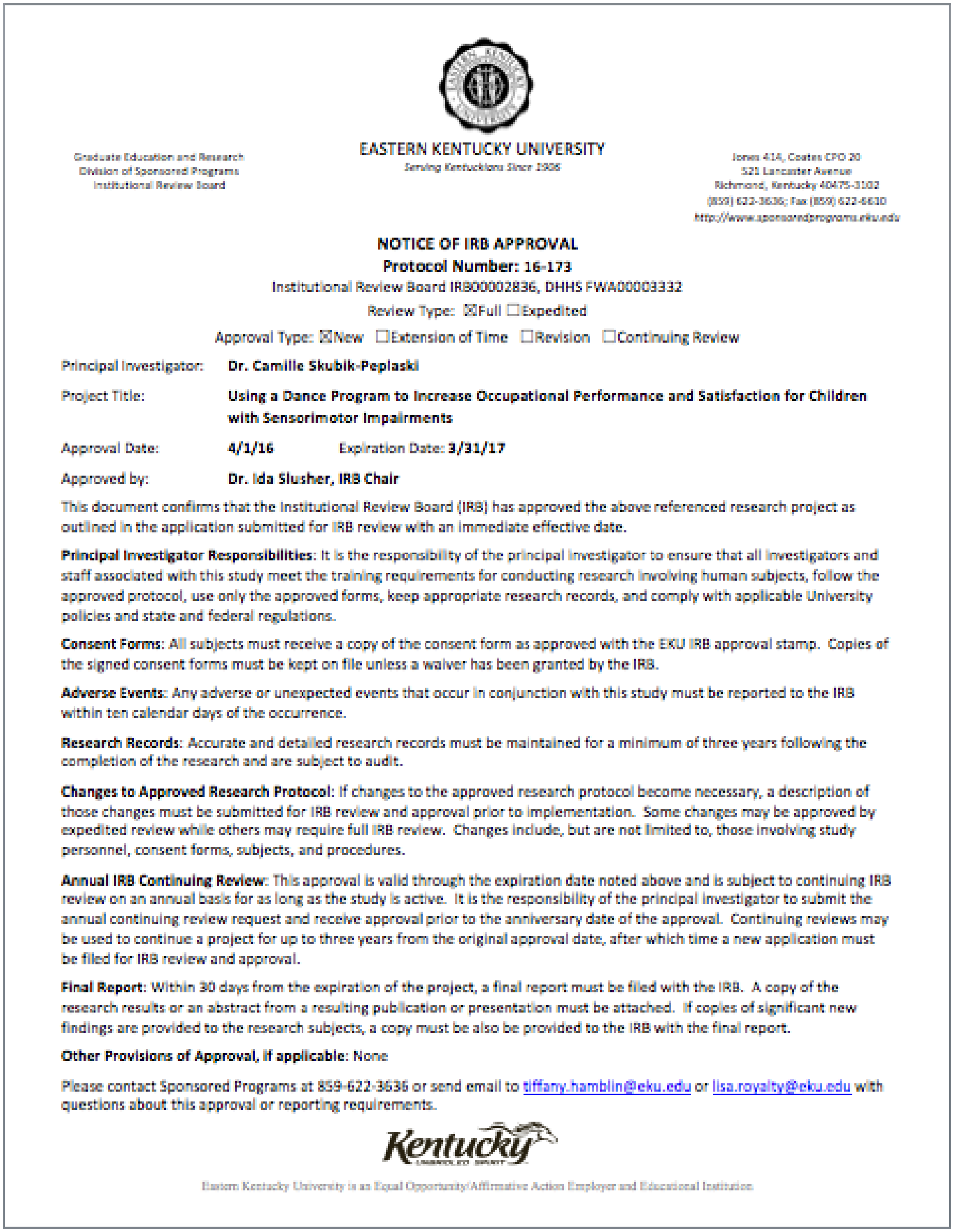
Appendix A:

IRB Approval



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NOTICE OF IRB APPROVAL
Protocol Number: 16-173
Institutional Review Board IRB00002836, DHHS FWA00003332
Review Type: ☒Full ☐Expedited
Approval Type: ☒New ☐Extension of Time ☐Revision ☐Continuing Review

Principal Investigator:	**Dr. Camille Skubik-Peplaski**
Project Title:	**Using a Dance Program to Increase Occupational Performance and Satisfaction for Children with Sensorimotor Impairments**
Approval Date:	**4/1/16** Expiration Date: **3/31/17**
Approved by:	**Dr. Ida Slusher, IRB Chair**

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.

Appendix B:

Consent Forms

Consent to Participate in a Research Study

“Exploring a Dance Program for Children with Sensorimotor Deficits”

Why am I being asked to participate in this research?

You and your child are being invited to take part in a research study about the usefulness of a dance program for improving your child’s abilities, as well as their satisfaction with their abilities, to perform everyday tasks. You are also being asked to answer some questions regarding your child’s current abilities and the experience of raising your child with sensorimotor impairments. You are being invited to participate in this research study because you are a parent/caregiver for a child with sensorimotor impairments. If your family takes part in this study, you will be one of about 16 families to do so.

Who is doing the study?

The person in charge of this study is Dr. Camille Skubik-Peplaski, a licensed occupational therapist and professor of occupational science and therapy at Eastern Kentucky University. Included in the research team are three graduate thesis students: Emily Coleman and Sara Durham, who will be conducting the dance sessions, and Emily Eicher, who will be conducting interviews with each parent. Additionally, 8 other graduate students will be assisting in the data collection process and dance class.

What is the purpose of the study?

By doing this study, we hope to learn more about using dance as a therapeutic approach for children with sensorimotor impairments. We also want to hear your perspective on what it is like to parent your child and how you feel that the dance program might benefit your child.

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

The research procedures will be conducted at the On the Move clinic. You will need to bring your child to the clinic one time for a set of assessments, and then another time to retake those same assessments after the dance sessions have been concluded. You will also need to come to that location two times a week for four weeks to bring your child to the dance sessions. Each dance session will last about 45-60 minutes. During one of those sessions, you will be asked to participate in an interview, which will also last about 45-60 minutes. If this is not convenient, the interview may be scheduled at another time at your discretion.

What will I be asked to do?

You are being asked to participate in an interview concerning your perspectives on raising a child with sensorimotor deficits and the effectiveness of a dance program as an outlet for leisure participation for your child. You are also being asked to give permission for your child to participate in the outlined research project using a dance class as an intervention. Your child will have the opportunity to participate in sensory and movement experiences focused within dance moves.

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

There are no reasons why you should not be able to take part in this study.

What are the possible risks and discomforts?

To the best of our knowledge, the things you will be doing have no more risk of harm than you would experience in everyday life.

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

Will I benefit from taking part in this study?

There is no guarantee that you or your child will get any benefit from taking part in this study. The researchers hope that your child will see an improvement in sensorimotor abilities and performance in everyday activities. However, we cannot and do not guarantee that you will receive any benefits from this study.

Do I have to take part in this study?

If you and your child 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 to be interviewed or if your child does not want to be a part of the dance class, you may agree to allow your child to be a part of a group that takes the pre and post-tests, but does not participate in the dance class. If you do not want to be a part of the study in any way, you can choose to not participate.

What will it cost me to participate?

The only costs you will incur from participating in this study are purchasing appropriate footwear for your child (tap shoes and non-slip shoes) and transportation costs to and from the clinic.

Will I receive any payment or rewards for taking part in the study?

You will not receive any payment or reward for taking part in this study.

Who will see the information I give?
Your 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. However, neither you nor your child will be identified in these written materials.

This study is anonymous. That means that no one, not even members of the research team, will know that the information you provide came from you.

Can my taking part in the study end early?
If you decide to take part in the study, you and your child still have the right to decide at any time that you no longer want to participate. You will not be treated differently if you decide to stop taking part in the study.

The individuals conducting the study may need to end your participation in the study. They may do this if you are not able to follow the directions they give you, or if they find that your being in the study is more risk than benefit to you.

What happens if I get hurt or sick during the study?
If you believe you or your child was hurt or if you get sick because of something that is done during the study, you should call Camille Skubik-Peplaski at (859) 338-2651 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 you or your child get 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 you may lose if you are harmed by this study.

Usually, medical costs that result from research-related harm cannot be included as regular medical costs. Therefore, the costs related to you or 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 to take part in the study, please ask any questions that might come to mind now. Later, if you have questions about the study, you can contact the principal investigator, Camille Skubik-Peplaski, at (859) 338-2651 or Camille.Skubik-Peplaski@eku.edu. If you have any questions about your 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 consent 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 condition or influence your willingness to continue taking 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