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## **Addressing Caregiver Outcomes through Family Guided Routines Based Intervention**

Julie A. Jones  
*St. Catherine University*

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Running head: ADDRESSING CAREGIVER OUTCOMES

Addressing Caregiver Outcomes through Family Guided Routines Based Intervention

Julie A. Jones

A doctoral project submitted in partial fulfillment of the requirements for the degree of

Doctor of Occupational Therapy,

St. Catherine University, St. Paul, Minnesota

May 9, 2017

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**St. Catherine University  
Doctor of Occupational Therapy**

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Addressing Caregiver Outcomes Through Family Guided Routines Based Intervention

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### **Dedication and Acknowledgements**

Many people supported me over the past three years as this project unfolded. First, I would like to thank my husband and family for their patience, sacrifice of time, love, and support through this endeavor. I also want to thank my friends, co-workers, and professional colleagues for their support. Especially Dr. Christine Urish who mentored me and encouraged me every step of the way. Many other mentors deserve acknowledgment; Dr. Kris Barnekow, Dr. Gloria Frolek-Clark, and Dr. Terry Schlabach. A special thank you to Dr. Juliann Woods at Florida State University for her mentorship and doctoral committee participation. Other doctoral committee members to thank include Dr. Renee Hepperlen and Dr. Stephanie de Sam Lazaro. Your guidance and support were invaluable.

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### **Abstract**

Children with special needs can present challenges to caregivers and families. Challenges may occur with daily routines such as mealtime routines, dressing routines, and play routines. These challenges may affect families in many ways and add increased stress to the child's caregivers. Early Intervention (EI) service providers across the state of Iowa are changing their model of service delivery to address the daily challenges in families with special needs children and to comply with Part C regulations of IDEA. This model is known as Family Guided Routines Based Intervention (FGRBI). This project had two purposes, to examine whether FGRBI helped to increase caregiver satisfaction with caregiver-child routines and whether it helped to reduce caregiver stress. A case-study design was used with three caregivers over a 9-week period. Each caregiver identified three family-specific routines to target along with two routines that were the same for all families in the study. Each caregiver-rated their overall satisfaction with the five routines pre-and post-intervention on the Family Routines Rating Scale. Each caregiver also completed the PSI-4SF pre-and post to examine caregiver stress. In addition to addressing caregiver outcomes, practitioner efficacy in learning and implementing a new model of practice, FGRBI was examined. This study had positive effects on caregiver satisfaction with targeted routines. This study also indicates that caregiver stress is an important aspect to consider in EI services. Key insights into strengths and challenges of utilizing and implementing FGRBI from the OT lens were also determined. Thus, EI occupational therapists can address caregiver stress as part of their services to meet the needs of children and families enrolled in Part C services.

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## **Introduction**

The Individuals with Disabilities Education Act (IDEA) is a federally mandated program that ensures children with disabilities have a free and appropriate public education (U.S. Department of Education [USDoE], n.d.a). Part C of IDEA provides services to infants and toddlers with special needs from birth until age three and their families (USDoE, n.d.b). In 2011, new federal regulations to Part C were implemented to include more focus on family engagement and services in the child's natural environment (USDoE, 2011).

### **Early ACCESS Iowa**

Each state assigns a lead agency to administer and carry out Part C of IDEA (IDEA Infant and Toddler Coordinators Association, n.d.). In the state of Iowa, the program is known as Early ACCESS (EA) (Iowa Family Support Network, 2016). EA is a coordination of four state agencies that consist of the Department of Education, Department of Public Health, Department of Human Services, and the University of Iowa Child Health Specialty Clinics (Iowa Department of Education [IDoE], 2013). Through the Department of Education, EA partners with Area Education Agencies (AEA) to provide Part C services of IDEA (Iowa Area Education Agencies, n.d.). Each AEA is responsible for educational and related services such as occupational therapy, physical therapy, speech therapy, as well as other mandated services under Part C (Iowa Area Education Agencies, n.d.).

Census data collected from 2013-2014 indicated 115,192 children ages birth to three years resided in the State of Iowa, and 3,488 of those children received early intervention (EI) services (IDoE, 2013). To be eligible for EI in the state of Iowa, an infant or toddler must demonstrate a 25% delay in growth or development or have a condition or disability with a high probability of later learning difficulties (IDoE, n.d.). Developmental delays may be in the areas



of physical skills, cognitive skills, communication, self-help, or social/emotional development (Iowa Family Support Network, 2016).

### **Response to Iowa Data**

Leadership groups in EA meet regularly throughout each year to address current and future trends related to EI services in Iowa. In 2012, a strategic planning task force was established to look at statewide data and work toward statewide improvements in accordance with the new Part C regulations (IDoE, 2013). Data indicated a downward trend in family outcomes and fewer families reported that EI services in Iowa helped their child learn and develop new skills than previous years (IDoE, 2013). Data also indicated that intervention services from all disciplines were child focused and lacked a family focus which became a requirement per the 2011 updated Part C regulations (IDoE, 2013). Based on these findings, the task force set out to discover why service providers were not more family focused (IDoE, 2013). Through discussions with various stakeholders, the task force concluded that EI service providers were more skilled, trained, and comfortable providing a child-focused approach versus a family-focused approach because it was the only model that was familiar to them (IDoE, 2013).

In response to the data and through stakeholder meetings, it was determined that a shift was needed to move toward a model that embodied evidence-based practices and focused on the promotion of caregiver capacity, improvement of child outcomes, and an increase in parent satisfaction (IDoE, 2013). New leadership groups were formed at the state level to search for an intervention model in compliance with IDEA Part C and terminology such as caregiver coaching, routines-based intervention, and natural environment were frequently discovered (IDoE, 2013). The leadership group recommended the Iowa Department of Education and EA adopt a new

service delivery model known as Family Guided Routines Based Intervention (FGRBI) and to partner with Florida State University where FGRBI is researched to assist in the roll out of the implementation of the model throughout the state of Iowa (IDoE, 2013).

### **FGRBI Implementation**

This new partnership between EA and Florida State University resulted in the need to systematically train service providers and slowly roll out FGRBI over several years (IDoE, 2013). Service providers from a variety of disciplines were selected from different Iowa AEAs to be formally trained. These service providers were placed into cohorts and enrolled in Florida State's Distance Mentoring program which is closely tied to FGRBI. Each year new cohorts are established and enrolled in the Distance Mentoring program as part of a systematic rollout of FGRBI services across the state of Iowa (M. Shihadeh, personal communication, October 27, 2016).

FGRBI is not only a shift in the service delivery process, but it is also a change in thinking for both provider and caregiver. The primary focus of a routines-based intervention model is to build caregiver capacity through caregiver coaching methods and is often used within a transdisciplinary approach (McWilliam, 2010). A transdisciplinary approach often involves aspects such as simultaneous assessments, ongoing sharing of information, and role release from service providers (King et al., 2009). Successful implementation of this approach requires each team member to fully understand each discipline's role within this model of service intervention (Boyer & Thompson, 2013).

This project aimed to determine if and how the FGRBI service delivery model may help to increase caregiver satisfaction with daily routines with their child as well as whether it could help reduce the stress in parents of children with special needs. Additionally, it aimed to provide

useful data that could be helpful to the EI program at the Mississippi Bend Area Education Agency (MBAEA) as part of the transition to the FGRBI model. Case studies of the project will be used as learning tools to train occupational therapists and other early interventionists working in EI at the MBAEA. In the end, this project will demonstrate how EI occupational therapy services are meeting the needs of families enrolled in EA services.

One additional aspect of the project is data collection related to practitioner learning and efficacy of implementation of the model as the principal investigator in the project learned to use the model with fidelity while implementing the project. This information will also be helpful for developing training for staff on implementation of FGRBI.

### **Significance**

This project had the following purposes: (a) to determine whether FGRBI aided in increasing caregiver satisfaction in daily routines with their child, (b) to assess whether FGRBI helped to decrease stress in caregivers of children with special needs, and (c) to determine strategies that promote successful learning and implementation of FGRBI with fidelity for the practitioner who is new to the model.

## **Literature Review**

### **History of Early Intervention and IDEA**

EI services have been part of IDEA since 1986 and were first known as Part H of IDEA (Parent Center Hub, 2014). In 1997, IDEA was reauthorized, and Part H was renamed to Part C and focus was on the child's needs (Parent Center Hub, 2014). In 2011, new regulations to Part C shifted the focus to include family needs, services in natural environments, and kindergarten readiness (USDoE, 2011). Since that time much has been published on the effectiveness of family-centered practices on child outcomes. However, little has been done to examine caregiver and family outcomes. This literature will focus on key principles of early intervention practice including family-centered practices, routines-based intervention, and caregiver coaching, as well as caregiver stress and the role of OT in early intervention practice.

### **Principles of Early Intervention**

EI supports learning and development of infants and toddlers from birth until age three (USDoE, 2011). The Division for Early Childhood (DEC, 2014) provides guidance and support to EI administrators, service providers, and families to promote evidence-based practice and advances in the profession. The DEC (2014) believes

that when practitioners and families have the knowledge, skills, and dispositions to implement these practices as intended, children who have or are at risk for developmental delays/disabilities and their families are more likely to achieve positive outcomes, and families and practitioners are more likely to help children achieve their highest potential. (p.3).

Additionally, the DEC (2014) endorses recommended practices in eight topic areas that include Leadership, Assessment, Environment, Family, Instruction, Interaction,

Teaming/Collaboration, and Transition. The topics of family and environment complement the recent changes to Part C regulations and frequently appear in professional literature. Many professional organizations such as The American Occupational Therapy Association (AOTA), The American Physical Therapy Association (APTA), and The American Speech-Language and Hearing Association (ASHA) support two of the key recommended practice areas, natural environments, and family-centered practices, and relate them to best practice for EI providers (AOTA, 2010; AOTA, 2014a; APTA, 2008; APTA, 2010; ASHA, 2008). Embedded in the principles of family-centered practice and natural environment is the belief that children learn best from familiar people and through everyday experiences (Workgroup on Principles and Practices in the Natural Environments, 2008).

**Family-centered practice.** Defining family-centered practice has become increasingly important as EI programs have evolved (McWilliam, Tocci, & Harbin, 1998). Family-centered practice can be defined as individualized services that engage families to build upon their strengths (Dunst, 2002). Family-centered services are flexible in nature, unbiased, culturally sensitive, and responsive practices allowing families to make informed decisions (DEC, 2014). Each family is appreciated for their uniqueness, preferences, and capabilities (Fingerhut et al., 2013). Families are a collective unit that may include siblings, grandparents, or other extended family members in addition to the parents (Poston et al., 2003). It is recognized that families are dynamic in nature, and their needs change within the entire family unit (FGRBI, 2015).

Through family-centered practice, a partnership is developed between provider and caregiver (Crawford & Weber, 2014; Dodge, Rudick, & Berke, 2011). This partnership creates a learning environment to support both the child's and the caregiver's needs (Dodge et al., 2011). Providers acknowledge that families know their child best and families understand their child's

preferences, emotions, and how to best respond to their child (Woods & McCormick, 2002). The provider also recognizes that families play a major role in all areas of planning and intervention because they are considered their child's first teacher (Woods & McCormick, 2002). Just as families play such an important role in development, the environments in which children participate in activities with their families are also crucial to EI practice.

**Natural environment.** Research supports that children learn best through everyday experiences in their familiar and natural environments (Raver & Childress, 2015; Workgroup on Principles and Practices in the Natural Environments, 2008). The natural environment is not only a physical place but a process where children learn (Woods, 2008). One of the benefits of services in natural environments is that natural learning and incidental teaching opportunities occur (Workgroup on Principles and Practices in Natural Environments, 2008). Naturally occurring routines can be addressed that the child and caregiver perform together throughout each day (AOTA, 2014a). For example, routines such getting dressed, eating a snack, and picking up toys naturally occur and serve as learning opportunities (Woods, 2008).

Several studies have explored the use of natural routines and the natural environments' impact on child outcomes. Kashinath, Woods, and Goldstein (2006) found that intervention through routines with caregivers in the natural environment increased communication in a small sample size of children with autism spectrum disorder (ASD). Wetherby and Woods (2006) found that social communicative behaviors improved in a group of young children ages 25-36 months of age with ASD when parents implemented strategies in the natural environment. Salisbury, Cambray-Engstrom, and Woods (2012) studied the actual use of caregiver coaching strategies and found caregivers engaged in ways to support their collaborative and family-centered services in the natural environment.

In addition to the familial benefits to providing services in natural environments, service provision within natural environments allows the provider to observe and engage with both the caregiver and the child to provide services to the family as a whole (AOTA, 2014a; FGRBI, 2015; McWilliam, 2010; Raver & Childress, 2015). Service provision in natural environments is well supported across disciplines, and it is acknowledged that collaboration across disciplines occurs to facilitate both child and caregiver learning (Muhlenhaupt, Pizur-Barnekow, Schefkind, Chandler, & Harvison, 2015). APTA (2008) supports working in natural environments to promote and reinforce learning of a new skill and believes families serve as role models. ASHA (2008) stated EI speech services support the child's linguistic development and participation in the natural environment. ASHA (n.d.) also believes natural environments allow the provider and family to work together. Finally, AOTA (2011) stated "occupational therapy practitioners use their unique expertise to help children and youth with and without challenges prepare for and perform important learning and developmental activities in their natural environment" (p. S46). Thus, through participation with children and their caregivers in natural environments, occupational therapists along with their interdisciplinary colleagues and team can best support occupational participation of the family.

Services in the natural environment allow EI service providers across disciplines to use observation, reflection, feedback, and problem-solving strategies to support routines and build caregiver capacity (Rush & Sheldon, 2011; Woods, Wilcox, Friedman, & Murch, 2011). Routines-based intervention is an evidenced-based practice which can be utilized in natural environments and is set up to provide services to the child while also building the caregiver capacity (FGRBI, 2016; Florida State University, n.d.b; McWilliam, 2010).

**Routines-Based Intervention**

Family-centered services have always been at the forefront of EI, but a movement toward a model that emphasizes caregiver-implemented intervention within family routines has taken shape (Friedman, Woods, & Salisbury, 2012). This model is known as routines-based intervention, and research suggests it strengthens family participation and builds caregiver capacity to promote child development (Friedman et al., 2012). This new model is different from the traditional model of intervention where the provider brings a predetermined set of toys into the family's home and provides a child-focused and therapist led, hands-on model of service (Crawford & Weber, 2014). Instead, the focus of routines-based intervention is on embedding and building skills within the child and family's routines (FGRBI, 2011; McWilliam, 2010). Objects, materials, and toys within the home are used and set the stage for caregiver carryover and practice of strategies modeled during visits (Crawford & Weber, 2014).

Routines-based intervention is a collaboration between an EI provider and a caregiver to develop child-specific strategies to be practiced during family routines (McWilliam, 2010; Raver & Childress, 2015). The primary goal is to promote both child and caregiver participation within their natural environment (Colyvas, Sawyer, & Campbell, 2010; McWilliam, 2010). Research supports routines-based intervention in meeting functional outcomes and family-identified goals versus the traditional model of home intervention (Hwang, Chao, & Liu, 2013). Kingsley and Mailloux (2013) found that embedding intervention into family routines had a positive influence on both child and caregiver.

Routines-based intervention emphasizes a transdisciplinary model of service delivery (McWilliam, 2010). It is the preferred model in EI, but not all programs have adopted this approach (King et al., 2009). The transdisciplinary model aims to reduce fragmented services



and conflicting or confusing information (King et al., 2009). This model incorporates role sharing across disciplines to provide both direct and indirect family support (Raver & Childress, 2015). The approach involves professional teaming through shared knowledge and skills (Raver & Childress, 2015). It focuses on one provider as a well-rounded coach and uses the provider's professional expertise to meet the family's needs (McWilliam, 2010). The transdisciplinary model sometimes involves joint visits from a variety of disciplines (McWilliam, 2010). Depending on child and family needs, the transdisciplinary model may be less intrusive because there are fewer professionals in the home telling the caregiver what they need to do, and this model may help to reduce caregiver stress (Crawford & Weber, 2014).

A form of routines-based intervention is known as Family Guided Routines Based Intervention (FGRBI). FGRBI is a research-based approach that incorporates Part C of IDEA, caregiver coaching, and evidence-based practice (Florida State University, n.d.a). FGRBI supports family participation and recognizes that the family is an active participant in all levels of EI process (FGRBI, 2015). Family participation is "based on the assumption that adequate information and supports are provided to family members to assist them in making responsible and informed decisions" (FGRBI, 2015, p.1). Thus, coaching models for caregivers and colleagues are an integral part of EI practice within FGRBI.

### **Caregiver Coaching in EI**

Caregiver coaching in EI can be described as the process of observation, reflection, and action to meet the caregiver's ability to support their child's development (Hanft, Rush, & Dunst, 2004). It is nonjudgmental and helps caregivers to develop competence through building capacity (Hanft et al., 2004). With FGRBI, caregiver coaching is used across disciplines and can strengthen the interactions between caregiver and child (Friedman et al., 2012). Parents are

coached to decide when and how to provide interventions (Brown & Woods, 2015; Kashinath, Woods, & Goldstein, 2006; Wetherby & Woods, 2006). A variety of caregiver coaching strategies are used in FGRBI (Florida State University, n.d.b). General strategies may include observation and joint interaction while specific strategies may involve modeling, listening, questioning, providing feedback, problem-solving, and prompting with the caregiver (Woods et al., 2011). These specific strategies are common themes found in adult learning.

Adult learning is defined as “the process of adults gaining knowledge and expertise” (Knowles, Holton, & Swanson, 2011, p. 172). Adult learning concepts may include methods such as problem-solving, reflection, feedback, and active participation in therapy sessions (Woods & Brown, 2011). When teaching strategies are used during coaching, caregivers have reported the value of embedding them into their daily routines (Kashinath et al., 2006). Adult learning can be used to build family capacity, and FGRBI incorporates adult learning concepts into its coaching model (Woods & Brown, 2011). FGRBI is a partnership in learning and caregivers look to the EI provider for direction and support (FGRBI, 2015). A critical component of the caregiver’s learning is their understanding of FGRBI (FGRBI, 2012). The caregiver’s confidence in the FGRBI model is dependent on what, when, and how they learned about it (Woods & Brown, 2011). (See Appendix A for more information on adult learning). Thus, through the application of adult learning concepts in FGRBI, caregivers may become more competent in their parenting role which may also carry over to other areas and may reduce stress in parenting a child with special needs, a critical and common family need for parents.

### **Caregiver Stress**

Caregiver stress in parents of children with special needs may occur for many reasons. It may occur at birth or later when a parent realizes their child is not developing as expected. For

example, the premature birth of an infant is a traumatic and stressful event for many reasons (Gray, Edwards, O'Callaghan, Cuskelly & Gibbons, 2013). Parents of preterm infants often miss out on initial bonding opportunities because the focus is on saving their child's life (Flacking, Ewald, & Starrin, 2007). This stress may continue as the infant grows and develops. Parents of full-term infants born with medical conditions also experience stress. Pope, Tillman, and Snyder (2004) found that parent stress during infancy lasted through toddlerhood in families of children with craniofacial anomalies. Dirks, Uilenburg, and Rieffe (2016) found parents of toddlers with moderate hearing loss reported stress related to their child's poor social-emotional functioning, poor language skills, and general lack of social support.

In addition to stress in parents of children who were born with medical conditions, literature has shown examples of stress for caregivers of children with various medical conditions with onset in early childhood and beyond. Caregivers of medically complex children are fearful and experience feelings of stress related to their child's medical condition (Franklin & Rodger, 2003). A study by Valicenti-McDermott et al. (2015) found that parents of children with autism spectrum disorder (ASD) reported higher levels of stress due to poor sleep and behavior patterns in their child than parents of children with other developmental delays. Didehbani, Kelly, Austin, and Wiechmann, (2011) found that caregivers of children with feeding difficulties and poor caloric intake demonstrated increased stress levels when measured by their salivary cortisol levels. Lastly, caregivers of children with behavioral problems reported elevated stress levels related to perceptions of inadequacy and lack of available supports (Spratt, Saylor, & Macias, 2007).

While the impact of a child's condition on development is one stressor for caregivers, parental or caregiver stress has been linked to other factors as well. Aspects such as chronic fatigue,

emotional frustration, anxiousness, anger, and social isolation were reported in parents of medically complex children (Caicedo, 2014). These same parents also reported feeling that others did not understand their family situation and found it difficult to talk with others including medical professionals about their child (Caicedo, 2014). In a study by Stoner and Stoner (2016), caregivers stated they experienced feelings of disappointment related to career loss, and these feelings increased as time went by and as their child grew older. One caregiver stated she and her husband “are grieving the life of what we thought would be” (Stoner & Stoner, 2016, p. 108).

Every parent wants to feel positive about their relationship with their child and their role as a parent (Mayer, White, Ward, & Barnaby, 2002). However, it may be difficult for parents of children with special needs to perform basic caregiver-child routines such as bathing, dressing, and diaper changes and this may increase stress in the caregiver (Yun & Chandler, 2010).

Perceived lack of parenting skills was found in parents of children with Angelman Syndrome (Miodrag & Peters, 2015). Mothers who lacked self-confidence rated their infant’s temperament as difficult in a study by Pizur-Barnekow (2006). Perceived lack of parenting skills and lack of self-confidence may lead to increased stress in the caregiver. These feelings of stress may also affect the co-occupation of caregiver and child. EI practitioners can support the caregiver-child relationship as well as the co-occupations of the caregiver and child by recognizing and addressing stress in parents of children with special needs.

### **EI Occupational Therapy and FGRBI**

Occupational therapists are well prepared to work within a family-centered team and provide a unique perspective on family-centered practice through examining the relationship between caregiver and child and their co-occupational participation (AOTA, 2014a; Dickie, Cutchin, & Humphry, 2006; Muhlenhaupt et al., 2015). EI occupational therapists support the

co-occupation of caregiver and child through the provision of strategies to enhance both the caregiver's and child's needs and well-being (AOTA, 2014a; AOTA, 2014b). Occupational therapy's roots in mental health allow EI occupational therapists to consider both social and environmental factors that may influence the well-being of the caregiver and child as well as the entire the entire family unit (AOTA, 2016). For instance, the child's developmental age, disability, and temperament are all considered as part of the child's ability to engage in his or her occupation (Humphry, 1989). On the caregiver side, personal characteristics such as the caregiver's emotional health and wellness are also considered (Pizur-Barnekow, 2010).

Additionally, through the use of the occupational therapy practice framework, occupational therapists can play a major role in the EI setting to promote the use of everyday routines such as rest, sleep, play, and other activities of daily living (AOTA, 2010; AOTA, 2014a; AOTA, 2014b). As occupational therapists believe in the promotion of participation, development, and a family's engagement in the natural environment, they are well-equipped to work with children and families within key principles of EI (AOTA, 2010; AOTA, 2014a).

Not only are occupational therapists well-prepared, but they also have a long history of working with children with special needs (Muhlenhaupt et al., 2015). A systematic review by Arbesman, Lieberman, and Berlanstein (2013) studied occupational therapy service delivery models in EI and early childhood. The authors identified themes in practice such as routines-based intervention, natural settings, parent education, home, and community as well as the parent-child relationship (Arbesman et al., 2013). Hwang, Chao, and Liu (2013) found routines-based intervention was more effective in the promotion of functional outcomes to meet family-directed goals than the more traditional model of EI occupational therapy which resembled a clinic model. A systematic review by Case-Smith, Frolek-Clark, and Schlabach (2013) found

that when occupational therapists supported family driven goals related to motor skill development, children made more progress. Kingsley and Mailloux (2013) found that parents highly valued caregiver training and the opportunity to improve their skills to support their child's communication, play, and behavior.

EI occupational therapists consider how the occupational performance of the child and caregiver is influenced by the person, their occupations, and by the environments in which they live, work, and play (Law et al., 1996). This is supported by a holistic model known as the Person-Environment-Occupation Model (PEO) (Law et al., 1996). When applying this model, the occupational therapist not only considers the child's and caregiver's ability to participate in everyday activities and routines but also how the environment influences their engagement and participation in their routines (Case-Smith, 2013). (See Appendix B for more information on the PEO model).

EI services continue to grow and change to meet the needs of children and families. Federal and state legislation and professional organizations such as the DEC provide advocacy, guidance, and best practice advice for all disciplines working in EI. Families have always been considered a part of EI services, but not to the extent they are now. Evidence is lending support to routines-based intervention models to build capacity in families so the child can achieve their developmental milestones. Thus, the purpose of this project was to utilize FGRBI model of services to address caregiver satisfaction in family routines and caregiver stress.

## Approach

### Participants

Four families were recruited and initially participated in this project. Three families completed the 9-week intervention period. One family dropped all MBAEA EI services due to scheduling conflicts with private therapy. This occurred prior to the initiation of the project, but after consent was obtained (See Appendix C for Consent Form). All FGRBI sessions with the families occurred in the child's natural environment of the home with the caregiver present. One family included mother and grandmother of the child. The other two families involved only the mothers as the caregiver attending intervention sessions.

### Design

This project was a case-study design. IRB approval was received from St. Catherine University on December 14, 2016. (See Appendix D). Participants were recruited from a pool of children and families currently enrolled in EI services through the MBAEA. All families in this study were currently receiving services from a service coordinator, an early learning teacher, and an occupational therapist. Some were also receiving services from a physical therapist and/or a speech therapist. None of the participants were familiar with FGRBI and current services for all participants resembled a clinical model where the EI provider brought a toy bag into the home and worked on the child's skill deficits in isolation with the parent assuming a passive role in the therapy sessions. After recruitment, consent was obtained through a face-to-face visit to the participants' homes. Along with obtaining consent, the purpose of the project was discussed, information was shared about FGRBI, and questions were answered.

**Intervention Description.** For this project, a multidisciplinary model was used since FGRBI was in its early stages at the MBAEA and has not yet moved toward the recommended

transdisciplinary approach. Each family's multidisciplinary team, the frequency of services as well as the intensity of services provided each from all disciplines looked different depending on the child and family needs. The OT on the team used the FGRBI model with the three families, while the other service providers on the child's team practiced the traditional model of EI during the 9-week intervention period.

For the OT who was the PI, visits were made to the home every other week during the 9-week intervention period. A coaching plan was completed at each visit that outlined what was currently happening with the child and family, what the caregiver would like to see happen, and what could be done to address the caregiver's and child's needs. Follow-up phone calls and texts were done during the week when there were no face-to-face visits. These follow-up phone calls and texts were to check if the caregiver needed additional clarification regarding embedding intervention or routines that were discussed at the previous visit and to briefly discuss what other service providers were in the home such as an early learning teacher, speech therapist, or physical therapist. If there was another service provider in the home, information was gathered on what occurred during that visit.

The principle investigator's (PI) professional learning of FGRBI was self-monitored through completion of the FGRBI SS-OO-PP-RR Key Indicator Checklist (FGRBI, 2016a). After each face-to-face visit, the PI rated herself in four subsections of the checklist. The sections were as follows: SS stands for Setting the Stage, OO stands for Observation and Opportunities to Embed, PP stands for Problem Solving and Planning Intervention, and RR stands for Reflect and Review (FGRBI, 2016a). Each section was rated Yes, Partial, or Not Observed. A coding rubric guided the selection of ratings. Another learning tool used was video recording of a few visits;



the recordings were observed by colleagues for feedback and uploaded to an online internal coaching site where feedback was obtained from a mentor.

### **Family Outcomes Measurement Tools**

There were multiple tools used in the process of the project including a routines-based interview using the Identifying Family Activities and Routines Conversation Starters by Therapists for Collaborative Team Members for Infants/Toddlers Community Services (TaCTICS, 2000), the Family Routines Rating Scale (See Appendix E), and the Parent-Stress Index-4 SF (PSI-4 SF) (Abidin, 2012). The purpose of these tools was to gather information on routines, obtain ratings of satisfaction with routines, and determine caregiver stress. The tools are described in further detail in the next section.

**Routines-based interview.** The Identifying Family Activities and Routines Conversation Starters (TaCTICS, 2000) was used to guide the interview for each caregiver at the second visit to the home. The caregivers' responses to the routines-based interview were used to guide the caregivers in the identification of three routines she would like to address as part of this project and to assist in intervention and coaching planning. This tool is readily available online for any EI provider's use in practice. Questions surrounded each family's daily routines and activities. Examples of questions included "Tell me about your day?", "What are the routines/activities or places that you go that most often occur for you and your child?" and "Who are the important people who participate in your child's life?" (TaCTICS, 2000, p. 1). Based on each caregiver's responses, follow-up questions were asked such as "What makes this routine enjoyable?" and "What are your family expectations during this routine or activity?" (TaCTICS, 2000, p.2). After the interview, information obtained was summarized with each caregiver. Based on the summarized results, the caregiver identified three routines she would like to address during the

intervention period, and an outcome was written. The three routines identified by the caregiver were added to the Family Routines Rating Scale along with two common routines that were the same for each family.

**Rating of routines.** The Family Routines Rating Scale was used at the beginning and the end of the 9-week period with each caregiver rating their current level of satisfaction of specified routines using a Likert-scale. The Family Routines Rating Scale was adapted from the Satisfaction with Home Routines Evaluation (SHoRE) (McWilliam, 2005). Each caregiver rated her overall satisfaction with the three daily routines identified from the routines-based interview. In addition to the three routines, each caregiver-rated the two routines of Family Mealtime and Sleep/Bedtime. All routines were rated on a 5-point Likert scale with 1 being not at all satisfied, 3 being satisfied, and 5 being very satisfied. An example of the Family Routines Rating Scale can be found in Appendix E.

**Stress.** The Parent-Stress Index-4 SF (PSI-4 SF) was also completed at the beginning and the end of the 9-week period to rate each caregiver's overall stress in parenting a child with special needs. The PSI-4 SF is a shortened version of the PSI-4 and can be used as a quick assessment of parent stress (Abidin, 2012). It is culturally sensitive, appropriate for use with parents of children from 1 month to 12 years of age, appropriate for use with parents with at least a fifth-grade education, and can also be used to design interventions and treatment plans (Abidin, 2012). Completion of the PSI-4 SF takes approximately 10 minutes by answering each question and circling SA (strongly agree), A (agree), NS (not sure), D (disagree), or SD (strongly disagree) (Abidin, 2012).

Thirty-six questions cover the three factors of Parental Distress, Parent-Child Dysfunctional Interaction, and Difficult Child. Parental Distress (PD) as defined by Abidin

(2012) “assesses the level of stress a parent report as a function of personal factors directly related to parenting” (p.3). Parent-Child Dysfunctional Interaction (P-CDI) “assesses the extent to which the parent perceives the child as not meeting expectations and finds that interactions with the child are not reinforcing his or her parenting role” (Abidin, 2012, p.3). Difficult Child (DC) “assesses the temperament or behavioral characteristics of the child that influence the parent-child relationship (Abidin, 2012, p.3). Finally, Abidin (2012) stated the Total Stress rating “assesses the overall level of parenting stress experienced by the respondent” (p.3).

Based on each caregiver’s answers, a raw score is calculated for each factor (PD, P-CDI, and DC). Additionally, a Total Stress (TS) raw score is calculated by adding the raw scores from PD, P-CDI, and DC to provide an overall level of parent stress (Abidin, 2012). Abidin (2012) cautioned examiners that the TS score only reflects the stresses reported in the assessment areas of parental distress, parent-child stress or child behavior stress because it does not consider other life and personal stressors. All raw scores for PD, P-CDI, DC, and TS are converted to percentiles to determine whether the score is in the normal, high, or clinically significant range (Abidin, 2012).

The PSI-4 SF also calculates a scoring factor known as the Defensive Responding scale which can be described as “the extent to which the respondent approaches the questionnaire with a strong bias to present the most favorable impression of him- or herself or to minimize indications of problems or stress in the parent-child relationship” (Abidin, 2012, p. 59). Abidin (2012) suggests the Defensive Responding be examined in relation to the other information obtained on the PSI-4 SF.

### **Outcomes**

After the 9-week intervention period, data were collected to determine whether the FGRBI model of EI increased overall satisfaction with caregiver-child routines and reduced caregiver stress. Three tools were used to collect data including A routines-based interview known as Identifying Family Activities and Routines Conversation Starters, the Family Routines Rating Scale, and the PSI-4SF. All interventions took place in the participants' homes. Practitioner efficacy in use of the FGRBI model was assessed using the FGRBI SS-OO-PP-RR Key Indicator Checklist.

### **Participant Information**

Each family received five home visits (one every other week during the 9-week period) and four follow-up phone call or text contacts with the occupational therapist. In addition to the OT services, all families received once per month service coordination visits and other services listed as follows from other disciplines. Family 1 received face-to-face services every other week from a speech therapist and an early learning teacher (total of 10 additional visits to the home within the traditional model over the 9-week period). Family 2 received physical therapy services and an early learning teacher every other week (total of 10 additional visits to the home within the traditional model over the 9-week period). Family 3 received weekly physical therapy services and an early learning teacher every other week (total of 14 additional visits to the home within the traditional model over the 9-week period).

### **Routines-Based Interview Themes**

Information was gathered from the routines-based interviews through note-taking and verbal confirmation of caregiver information by the PI on the Identifying Family Activities and Routines Conversation Starters tool. The information was analyzed and coded for themes across

the three routines-based interviews that were conducted at the beginning of the project. Three themes were identified as a result of the interviews.

**Theme 1: Play.** All three caregivers identified a concern with their child's ability to play with objects/toys. Caregiver 1 wanted her child to play purposefully with toys instead of throwing them. Caregiver 2 wanted her child to show interest in more than one or two toys and to reach for toys that were not placed directly in front of him. Caregiver 3 wanted her child to reach and grasp for any object or toy.

**Theme 2: Mealtime and feeding.** All three caregivers expressed some concern for mealtime and feeding in addition to the family mealtime routine that was rated for all families on the Family Routines Rating Scale. Caregiver 1 wanted her child to use a toddler spoon or fork instead of his fingers during mealtime. Caregiver 2 wanted her child to play with food, begin to finger feed and hold his bottle. Caregiver 3 wanted suggestions for introducing new foods to her son but stated she was generally satisfied with his feeding.

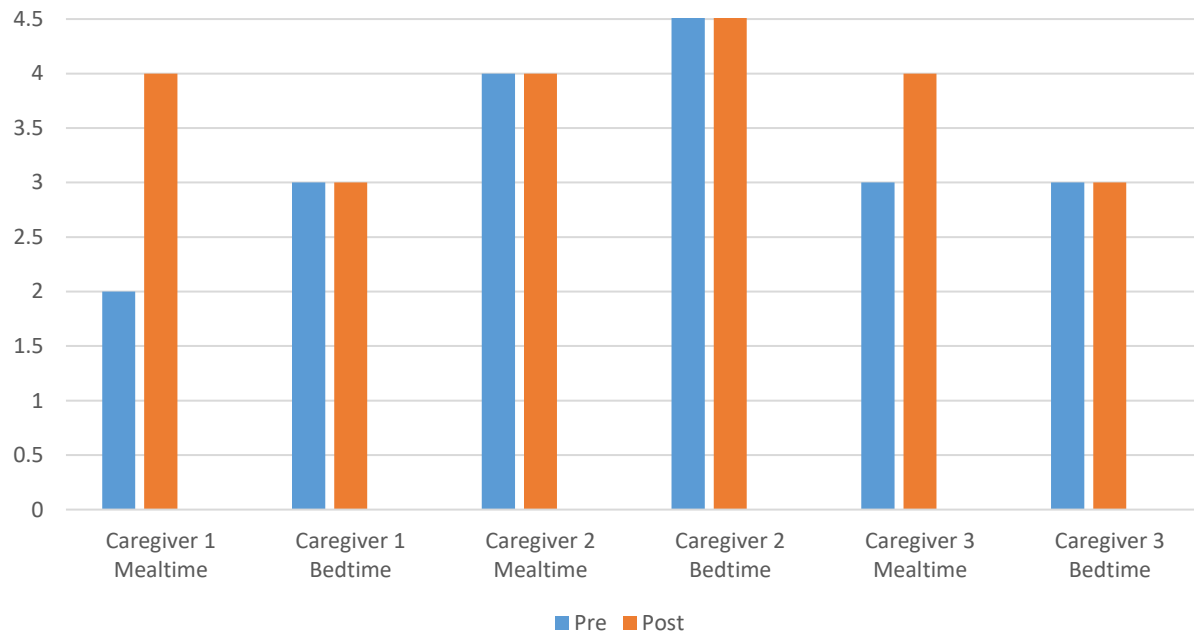
**Theme 3: Individualized concerns.** In addition to play and mealtime and feeding routines identified by all three families, each caregiver identified additional specific areas of priority or concern for their family. Some areas included social interaction, community engagement, and participation in daily living activities. For example, Caregiver 1 wanted to address social interaction with her child. Caregiver 2 wanted to address eating at a restaurant. Finally, caregiver 3 wanted to address the organization of her child's medical reports, information, and appointments.

### **Family Routines Rating Scale**

Pre-and post-data were collected using the Family Routines Rating Scale. All caregivers rated Family Mealtime and Sleep/Bedtime on a Likert scale of 1 to 5 with 1(not satisfied at all),

3 (satisfied), and 5 (very satisfied). Additionally, each caregiver selected and rated three other routines they would like to address as part of the project. A total of five routines were addressed with each family. For the two routines that were rated by all three caregivers (Family Mealtime and Sleep/Bedtime), two of the three caregivers reported increased satisfaction with Family Mealtime and one reported no change in satisfaction. Satisfaction for the routines of Sleep/Bedtime remained the same for all three caregivers during the 9-week intervention period and were rated satisfactory or above at both the pre-and post-rating times. (See Figure 1).

Figure 1. Caregiver Satisfaction with Mealtime and Bedtime Routines



For all three families, an increase in satisfaction was noted on all the caregiver identified and prioritized routines. For Caregiver 1, this included Object/Toy Play, Interaction with Mother, and Sensory Needs. (See Figure 2). For Caregiver 2, data revealed the identified routines were Playing with Food/Finger Feeding, Motivation to Reach and Play with Toys, and Going Out to Eat. (See Figure 2). Finally, for Caregiver 3, Organization of Medical Appointments and Information, Dressing, and Object/Toy Play were identified priority routines. (See Figure 2). All

prioritized routines rose in satisfaction by at least 1 point/increment on the Likert scale from pre-intervention to post-intervention. Additionally, of the nine caregiver's prioritized routines, all seven of nine were rated as a 3 or satisfactory or higher at the post-intervention time frame. (See Figure 2).

Figure 2. Satisfaction in Caregiver Prioritized Routines

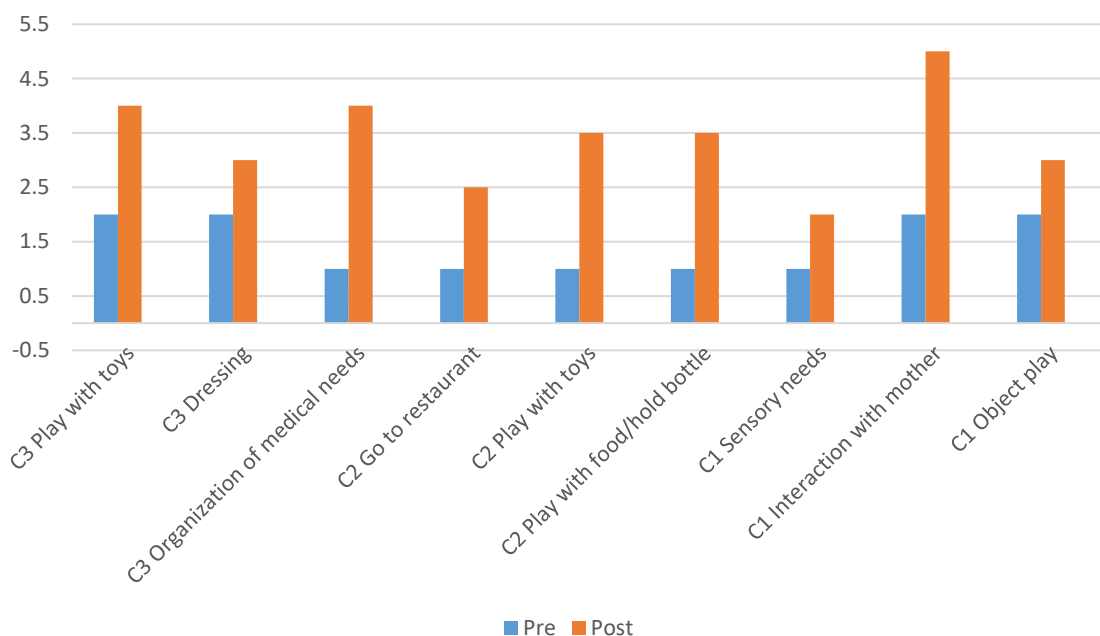


Figure 2. F1 refers to Family 1, F2 refers to Family 2, and F3 refers to Family 3.

### Parent Stress Index – 4 SF (PSI-4SF)

Pre and post data were collected from each caregiver's completion of the PSI-4 SF to rate caregiver stress in three subscale areas of Parental Distress (PD), Parent-Child Dysfunctional Interaction (P-CDI), and Difficult Child (DC). Additionally, a Total Stress (TS) score was calculated by adding the raw scores from PD, P-CDI, and DC and then converted to a percentile. Raw score calculation of the Defensive Responding scale was also done to look at the possibility of strong caregiver bias (Abidin, 2012). For the Parental Distress, Parent-Child Dysfunctional Interaction, Difficult Child, and Total Stress percentile scores, the normal range is 16-84%, High

is 85-89%, and Clinically Significant is >90%. For the Defensive Responding scale, a raw score of <10 is considered Clinically Significant (Abidin, 2012).

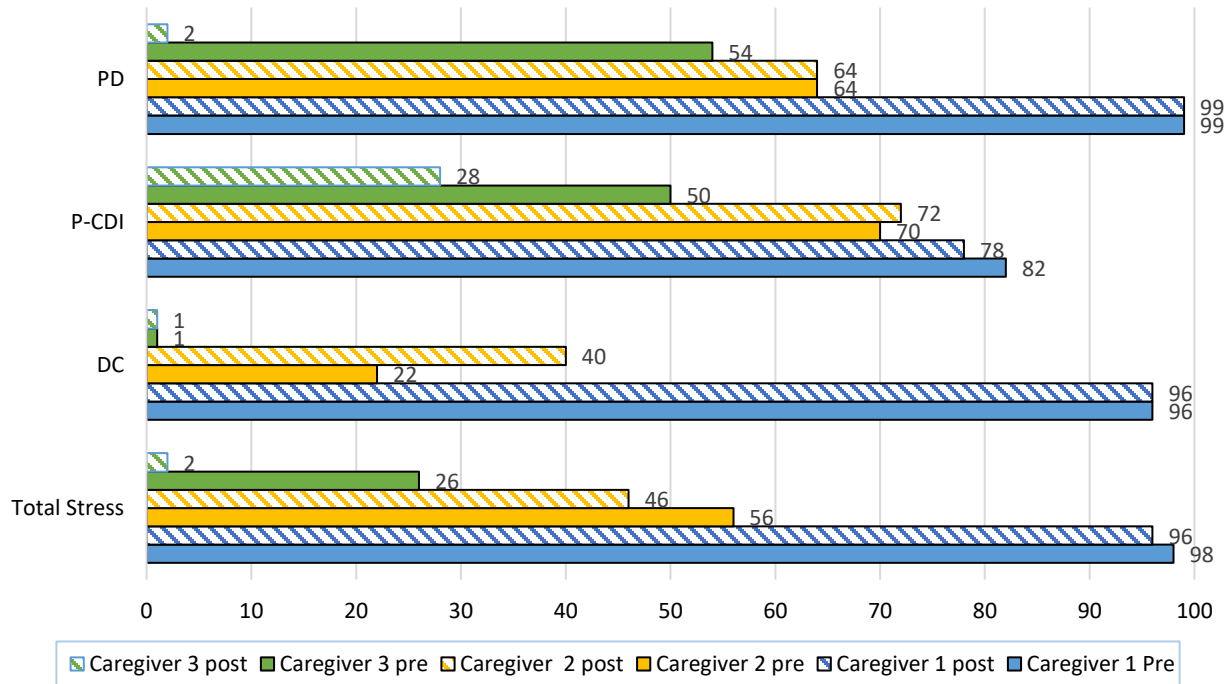
For Caregiver 1, three of the four percentile rankings fell in the Clinically Significant range at pre-test (Parental Distress, Difficult Child, and Total Stress) with the other percentile rating in the normal range (Parent-Child Dysfunctional Interaction). The post-test results were similar with three of the percentile rankings in the Clinically Significant range (PD, DC, and TS) and one in the normal range (P-CDI). (See Figure 3). The Defensive Responding scale score at pre-test for Caregiver 1 was in the normal range (24) and the normal range (32) at post-test.

For Caregiver 2, all four percentile rankings fell in the normal range at pre and post test (PD, P-CDI, DC, and TS). (See Figure 3). The Defensive Responding scale score for Caregiver 2 was in the normal range (18) at pre-test and normal range (19) at post-test.

For Caregiver 3, three of the four percentile rankings fell in the normal range at pre-test (Parental Distress, Parent-Child Dysfunctional Interaction, and Total Stress). The percentile rating for Difficult Child was well below normal range. At post-test, one percentile score was in the normal range (Parent-Child Dysfunctional Interaction), while three percentiles were well below the normal range (Parental Distress, Difficult Child, and Total Stress). (See Figure 3). The Defensive Responding scale score at pre-test for Family 3 was in the normal range (16) at pre-test and in the Clinically Significant range (7) at post-test.



Figure 3: Caregiver Stress Pre and Post Intervention



**Professional Learning**

The FGRBI SS-OO-PP-RR Key Indicator Checklist (FGRBI, 2016a) was used at the end of every home visit to evaluate the practitioner’s (Principal Investigator) effectiveness in providing family centered services. Twelve practitioner behaviors were rated as Yes, Partial, or Not Observed after each home visit over the 9 weeks’ intervention period for a total of total of 36 ratings. The first and final visit ratings were compared to reflect self-monitoring of the PI related to the professional learning of FGRBI Key Indicators through this tool. Overall, growth was shown in the PI addressing the key indicators more often at the end of the project than the beginning. Growth and change were seen in the SS or setting the stage, OO or observation and opportunity to practice, and RR, reflection, and review, however, no change was seen in PP,

problem-solving and planning. This demonstrates growth in three of the four key indicator areas. (See Table 1).

Table 1

*PI Change on SS-OO-PP-RR Checklist*

|  | Yes   | Partial | Not Observed |
|--|-------|---------|--------------|
| <b>Setting the Stage</b>                         |       |         |              |
| Initial  | 25%   | 33.3%   | 41.7%        |
| End  | 41.7% | 50%     | 8.3%         |
| <b>Observation and Opportunities to Practice</b> |       |         |              |
| Initial  | 0%    | 89%     | 11%          |
| End  | 44.4% | 55.6%   | 0%           |
| <b>Problem Solving and Planning</b>              |       |         |              |
| Initial  | 0%    | 100%    | 0%           |
| End  | 0%    | 100%    | 0%           |
| <b>Reflection and Review</b>                     |       |         |              |
| Initial  | 0%    | 55.6%   | 44.4%        |
| End  | 11.1% | 66.7%   | 22.2%        |

## **Discussion**

The purpose of this study was to determine whether the FGRBI model of intervention potentially aided in increasing satisfaction with caregiver-child routines and whether it potentially assisted in decreasing caregiver stress in parents of children with special needs. This study points to some positive yet interesting results regarding increasing satisfaction with daily routines and decreasing caregiver stress.

### **Caregiver-Child Routines**

Sleep/bedtime is a routine that that frequently occurs and sleep problems are not uncommon in children with special needs (Wiggs & France, 2000). It was interesting to note that in this study, none of the caregivers reported this was an area of concern for them and all three caregivers rated Sleep/Bedtime between a 3 (satisfied) and 5 (very satisfied) at pre and post.

Mealtimes are another common routine in which concerns are expressed. It has been reported that 25% of typically developing toddlers refuse certain foods and feeding problems may occur in 80% of children with special needs (Chatoor & Ganiban, 2003). All three caregivers had concerns about child specific feeding skills. However, caregiver concerns were not directly related to Family Mealtime but were more specific to skills such as playing with food, using utensils, and presentation of new foods. At post-test, all three caregivers reported increased satisfaction with their child specific feeding skills and two of the three caregivers also reported increased satisfaction in family mealtime.

For the caregiver identified routines, all three caregivers reported increased satisfaction at the end of the project across all of their individually identified routines of concern. The theme of play routines appeared with all three families, and all three reported increased satisfaction with this routine at post-test. Other routines that were addressed by caregivers as priorities included

community participation and organization of child's medical information, reports, and appointments. Community participation is a common routine for many families. Organization of medical appointments and information is less common for some families, but for families with children with multiple medical needs and limited previous experience in that skill, it can be a challenge. Through the use of the routines based interview, one caregiver indicated it was important to address medical information organization and expressed overwhelming feelings of disorganization with all her child's medical needs, information, and appointments. Thus, this became a priority routine for that family as the child has weekly appointments in with specialty physicians. At post-test, that caregiver (Caregiver 3) reported an increase in satisfaction with the organization of information but continued to report feelings of being overwhelmed with the number of medical appointments her child requires.

It is important to state that not all routines were rated a 3 (satisfied) at post-test, but there was an improvement from a 1 (not satisfied at all) to a 2 (somewhat satisfied) in those routines not identified as satisfactory at post-test. It is also important to note that a positive change or increase in satisfaction was seen in all caregiver prioritized routines. This is a key finding. While it is difficult to ascertain whether or not the FGRBI approach or intervention, in general, contributed to this change due to other services provided simultaneously to FGRBI services, one can infer that focusing on caregiver identified need areas during intervention may lead to greater caregiver satisfaction in participation in those routines.

### **Stress**

PSI-4 SF results for the subscales of Parental Distress (PD), Parent-Child Dysfunctional Interaction (PCD-I), Difficult Child (CD), and Total Stress (TS) were as follows: Caregiver 1 was the only caregiver with scores in the Clinically Significant range in three of the four

percentiles (PD, DC, TS) at pre and post-test. It is important to note the Total Stress score was Clinically Significant both pre (98) and post (96), and according to Abidin (2012), parents who score Clinically Significant in the 91<sup>st</sup> percentile or higher in the Total Stress category should be referred to a professional who can examine and address his or her stress. Additionally, this caregiver's scores in the area of Parental Dysfunction were the same pre and post (99). Of note, the Parental Dysfunction scores were higher than the other two percentiles (P-CDI and DC) which may indicate the need for professional services to help with adjustment to parenting (Abidin, 2012). Caregiver 1 also scored high in the area of Difficult Child (96) in which a score at or above the 96<sup>th</sup> percentile indicates parents may be experiencing difficulty managing their child's behavior and this family should receive professional help (Abidin, 2012). While interventions during the period of this study did not decrease parental stress in Caregiver 1, the pre and post scores did result in the PI providing the caregiver with information for more professional help.

Caregiver 2 had pre and post scores that were in the normal range for (PD, P-CDI, DC, and TS) and were relatively consistent. There was an increase in the Difficult Child percentile score from the 22<sup>nd</sup> percentile to the 40<sup>th</sup> percentile, but after closer examination of the question, the PI infers that caregiver answered the question incorrectly based on past caregiver reports, PI observations, and the child's temperament. Caregiver 2 had a decrease of 10% in the area of Total Stress which may lead one to investigate further whether FGRBI helped to reduce this caregiver's stress, especially since there was reported increase in satisfaction from not at all satisfied (1) to more than satisfied (3.5) in all three caregiver identified routines.

Caregiver 3 had the biggest disparity in pre and post-test scores. For this caregiver, her post-test scores were lower in all areas (PD, P-CDI, DC, and TS) with some scores well below

the normal range (PD, DC, and TS) than her pre-test scores. Caregiver 3's Defensive Responding score was Clinically Significant at post-test (7), but it was not pre-test (16). The Clinically Significant Defensive Responding score at post-test may coincide with one of Abidin's (2012) hypotheses for a raw score of 10 or less as "the parent is trying to portray him or herself as a very competent individual who is free of the emotional stresses normally associated with parenting" (p.59). However, this score should be interpreted with caution especially since this caregiver's post-test scores were well below the normal range.

It merits discussion as to why Caregiver 3 scored well below normal range at pre-test (DC) and post-test (PD, DC, and TS). According to Abidin (2012), parents who score at the 15<sup>th</sup> percentile or lower in the PSI-4 (full version) in the area of Total Stress may experience low levels of stress, but it is more likely that parent-child dysfunction is present. Abidin (2012) gave three reasons for false negatives in Total Stress scores. Type 1 purports that the parent may be defensive, fearful, or somewhat paranoid (Abidin, 2012). For example, Abidin (2012) states a parent might believe "If I have to admit I have these problems, I will fall apart and be overwhelmed" (p. 15). Type 2 suggests that the respondent may be providing false answers (Abidin, 2012). Type 3 suggests that when the TS score is below the 15<sup>th</sup> percentile, the parent may be minimally involved with the child (Abidin, 2012). Given these three types of false negatives and PI knowledge and rapport with the family, Caregiver 2 may be more indicative of Type 2 which suggests she was trying to portray herself in a positive manner.

In this study, all scores were interpreted with caution. Other information obtained included that none of the caregivers scored higher than the 96<sup>th</sup> percentile in Parent-Child Dysfunctional Interaction which would indicate a risk of child neglect, rejection, or physical abuse due to frustration in the parent (Abidin, 2012). Even though it cannot be determined if

FGRBI reduced stress due to many factors, it is important to highlight that it raised a general awareness of stress levels and one of the caregiver's stress needs were referred for professional evaluation and help.

### **Principal Investigator FGRBI Learning and Fidelity**

This was a self-study project regarding learning and implementing FGRBI. The book titled *Routines-Based Early Intervention; Supporting Young Children and Their Families* by McWilliam (2010) was used as a guide. At the end of each chapter, a short test was completed over chapter content. In addition to McWilliam's book, a considerable amount of time was spent on the FGRBI website. Useful links, research articles, and learning modules were continuously utilized as this project moved forward. Video recording of a few home visits was completed with two of the three families to support my learning of FGRBI. The video recordings were uploaded to an internal coaching website through the Distance Mentoring Program at Florida State. The videos were watched, and feedback was provided by an internal coach and Dr. Juliann Woods. This feedback helped the PI to make changes in how questions were phrased, how caregiver identified routines were approached and addressed, strategies were modeled, and how the caregiver's concerns were supported. The internal coaching website also provided the opportunity for the PI to watch a vast amount of FGRBI videos from various disciplines such as speech therapy and early learning teaching which provided valuable learning and understanding of FGRBI. Video recording of visits will be used at the MBAEA as FGRBI is rolled out, and this project further supports its practicality and usefulness for all disciplines in learning this model of intervention.

The FGRBI SS-OO-PP-RR Key Indicator Checklist (FGRBI, 2016a) helped the PI prepare and reflect on each family visit. Over the 9-week intervention period, professional

growth was noted in three of the four areas (Setting the Stage, Observation and Opportunities to Practice, and Reflection and Review) of the SS-OO-PP-RR Key Indicators. The area without a change noted was the use of Problem Solving and Planning Intervention which was surprising. Reflecting on the visits and after reviewing the video recorded visits, a change was noted by the PI and the distance mentors related to moving away from a solution focused approach and towards a problem-solving approach during the intervention period. The FGRBI model is a new way of thinking and a new way of EI occupational therapy practice. Making the shift from informing a parent what they can or should do with their child to jointly problem solving along with the parent, was more challenging than the PI had expected. Additionally, as this project involved learning the FGRBI model along the way, increased comfort and facilitated practice will equip the PI in articulating and carrying out problem-solving strategies.

This project has changed how I practice as an EI occupational therapist. For example, I no longer use a toy bag on my home visits. I have learned the value and importance of using objects and toys within the natural environment and can see how this helped to engage caregivers. The FGRBI model helped the PI recognize that caregivers need time to reflect on what is working or not working with their child. Using open-ended questions can engage a caregiver further in therapy sessions and contributes to capacity building in families. This model also forces the clinician to change the pace of visits to match the needs of the child and caregiver and provides the opportunity for increased active listening with a broader focus.

Key tools and materials that assisted learning and implementing this model included the use of a coaching plan, the SS-OO-PP-RR checklist, and video self-assessments. I have started to write a coaching plan at the end of each visit which further supports building capacity in families.



**Limitations**

Several limitations should be considered with this study. The first limitation of this study was small sample size. This study had a sample size of three families. While this study provided some positive data regarding increasing caregiver satisfaction in targeted routines, the study did not provide much useful information regarding decreasing stress. A larger sample size may have provided more information in this area.

The second limitation of this study was a dosage of only a 9-week intervention period with face to face visits to the home made every other week and non-face-to-face visits on “off” weeks. During “off” weeks phone calls or text messages were used to ask if clarification was needed regarding the previous visit, answer questions, and to follow up with other service providers in the home. Follow up on the “off” weeks was spotty as two out of the three families preferred communication via text, one of the caregivers frequently was out of text minutes and never responded. The third family did not have concerns when contacted but was able to provide information regarding other service providers in the home. Brown and Woods (2015) used a family guided approach with weekly visits for 24 sessions to target communication in children. Woods, Kashinath, and Goldstein (2004) looked at caregivers’ use of teaching strategies within daily routines with weekly visits for 23-32 weeks. For this study, a longer intervention period for this study may have allowed the PI to target the selected routines more robustly. Additionally, a longer intervention period with weekly visits may have yielded different results.

The third limitation of the study is that it was not implemented with a transdisciplinary approach and the other service providers were not providing FGRBI services. Thus, the families in this study received the traditional model of therapy from other disciplines assigned to the family and at a higher frequency in total across disciplines than the provider using the FGRBI

model. Therefore, changes in parental satisfaction and stress ratings cannot be entirely attributed to FGRBI. It would be beneficial to see if results were different if all EI providers were using FGRBI with a transdisciplinary model.

The fourth limitation of this study was that the PI was not yet formally trained in FGRBI and was learning the intervention model along the way. Thus, it could be considered a partial implementation of the FGRBI model. If the PI had been either formally trained or more experienced in FGRBI before the start of the 9 week intervention period, this may have allowed the PI to more easily and readily use caregiver coaching strategies than it did for this study. Thus, the increase in caregiver satisfaction with routines cannot be fully due to the FGRBI model. Other factors may have played a role such as development or other service providers in the home.

Finally, the study did not include any fathers as the principle caregiver. All caregivers in this study were mothers. Thus, the satisfaction in routines and stress scores may look differently as a father's perceptions may be different from a mother's.

### **Challenges**

Several challenges were identified in this study. The first challenge was difficulty with videotaping visits. Videotaping was done as part of the PI's learning of FGRBI. Two families agreed to be videotaped, and one family did not agree. When videotaping, it was difficult to place the camera in a safe location because other children were present in the home and the PI did not consistently have access to someone to join her on visits to hold the camera. Also, it was noted by the PI that one caregiver acted very differently when videotaped and the caregiver later told the PI she did not like being videotaped. Thus, she was not asked again.

Another challenge was that the PI had to explain the difference between the two models of therapy often because Caregiver 1 seemed to prefer the traditional model and initially appeared to struggle to embrace her role as an active participant in the therapy sessions. This was also interesting because Caregiver 1 had Clinically Significant scores on the PSI-4 SF. Thus, her stress may have impacted her desire to actively engage in therapy sessions.

The third challenge in this study was that Caregiver 3 expressed she was very overwhelmed with her child's medical diagnosis and needs. This caregiver was very receptive to FGRBI, in general, but during every visit, much of the time was spent helping her organize appointments and interpret medical reports. Thus, it was difficult to spend very much time on the other identified routines. FGRBI values family identified routines and recognizes that adult learning cannot take place if the caregiver is not ready to learn (FGRBI, 2016b). Thus, the PI believed it was vital to address this caregiver's need to organize her child's medical information and appointments because it is possible that no new learning could occur if she were in a state of disorganization and chaos.

### **Future Research and Implications for Practice**

This study provided a glimpse of how FGRBI and occupational therapy can be implemented in EI to increase caregiver satisfaction in routines and possibly reduce stress in caregivers of children with special needs. Future research with a longer dosage period, weekly visits, and with an experienced transdisciplinary team well trained in FGRBI may yield more impressive results. Caregiver learning is a major component in FGRBI and was not measured in this study, and future research may want to examine caregiver learning in FGRBI. Also, this study did not address stress in fathers of children with special needs.

This study suggests that some caregivers of children with special needs may experience high levels of stress. Caregivers may perceive their child as difficult, and there may be dysfunction in the parent-child relationship. It is important to acknowledge that some caregivers of children with special needs may have clinically significant stress levels which indicates a need for professional help. Caregiver stress may cause a caregiver to perceive their child as difficult or stress may cause dysfunction in the parent-child relationship which further supports the need for EI programs to recognize that stress may impact both caregiver and child. These lessons are not discipline specific to occupational therapy, but all providers can learn from them because these lessons support caregiver learning and capacity building for our families which in turn, may impact child outcomes. Due to the flexibility in the use of PSI-4 with a variety of populations and the outcomes of referral to outside agencies for those caregivers whose scores were in the clinically significant range, the PSI-4 SF could be a quick and easy tool to measure caregiver stress and could be implemented into EI programs. EI occupational therapists are well suited to recognize and address caregiver stress and could use the PSI-4 SF as part of their service delivery.

In general, many caregiver-child routines center around activities of daily living (ADLs) such as mealtime, bedtime, bathtime, playtime, dressing, and community engagement. The Family Routines Rating Scale could be used with the Routines-Based Interview to identify specific routines and monitor their overall satisfaction with the FGRBI. It could be used as a dynamic tool that ebbs and flows as a child's and caregiver's goals are met. This may help to engage caregivers in the EI process as many programs are moving toward routines-based intervention. Occupational therapists are trained at task analysis, adapting, and modifying tasks

to promote independence. Thus, EI occupational therapy naturally fits well with the FGRBI model.

Finally, this project will be shared with MBAEA administrators to support FGRBI within our agency. Three case studies were written as part of this project. Each case study has 8-12 guided learning questions that can be used in training of the FGRBI at the MBAEA. A few select employees across disciplines have been formally trained in FGRBI through Florida State's Distance Mentoring Program where FGRBI is researched and managed. These trained EI providers will be placed in leadership roles at the MBAEA to guide other service providers as they learn FGRBI over the next two years. Three to four formal FGRBI training sessions will be held during the 2017-2018 school year for all EI staff to include occupational therapists, physical therapists, speech-language pathologists, early learning teachers, vision teachers, and hearing impaired teachers. The case studies will be presented to MBAEA administrators as an additional learning tool for current and future EI providers at the MBAEA and possibly other Area Education Agencies in Iowa. Next steps and future directions in implementation and training of interdisciplinary teams on the use of FGRBI and the link to possibly improved child and family outcomes will be crucial next steps for developing the evidence in this practice area.

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### Appendix A: Adult Learning

Adult learning also known as andragogy involves a change in habits, knowledge, and attitudes (Knowles et al., 2011). Andragogical learning shifts the power, responsibility, and motivation of learning away from the teacher and toward the adult learner (Fornaciari & Dean, 2014). Six concepts encompass adult learning (Knowles et al., 2012).

First, adults need to know why they are expected to learn something new (Knowles et al., 2011). This aligns with family guided practices in early intervention as FGRBI (2012) states; adults need and want clear expectations to learn. In FGRBI, caregivers need to understand why strategies presented to them by the provider are important (Woods et al., 2011). The provider must provide explanations as to why a suggested strategy is important and how to implement the strategy, and when to use the strategy (Woods et al., 2011). Adult research suggests three aspects as to why adults have this need to know: they need to know how learning will occur, what they will learn, and why it is of value to them (Knowles et al., 2011). These three aspects impact an adult's motivation to learn (Knowles et al., 2011).

The second concept of adult learning is that adults are self-directed learners and have the self-concept of making their own decisions (Knowles et al., 2011). Self-concept develops as a person matures and moves from a dependent person to a self-directed person (Merriam & Bierema, 2014). Chen (2013) found that an adult's self-directed learning increased when provided opportunities to make their learning a meaningful experience through self-reflection and choice of topic. Woods et al., (2011) stated that "when caregivers are encouraged to participate in the decision-making process, they expand their capacity to generalize the strategy to other activities/routines and settings" (p.383).

The next step is the life experiences of adult learners are reflected in their learning needs, motivation to learn, and learning interests (Knowles et al., 2011). Through a person's experiences, adults form habits and biases that may be reflected in learning (Knowles et al., 2011). Life experiences and learning interests are varied and should be considered a great resource to the educator or facilitator (Merriam & Bierema, 2014). Techniques that tap into an adult's experiences are often used through methods such as group discussions and problem-solving activities (Knowles et al., 2011). This is supported in FGRBI because caregiver coaching strategies such as discussion, sharing of information, problem-solving, and reflection are key elements (FGRBI, 2011).

The fourth concept of adult learning acknowledges the adult learner's readiness to new learning when their life situations create a need to know (Knowles et al., 2011). Caregivers often desire and seek out information relevant to caring for their special needs child. Cultural contexts such as the environment also help to shape how adults learn (Sandlin, Wright, & Clark, 2013). This further supports FGRBI and the caregiver's learning in the natural environment.

Another adult learning principle is linked to the motivation of the learner. Motivation to learn is increased when learning will help them to solve problems within the context of their everyday life (Knowles et al., 2011). Early intervention coaching models, proposes that adults learn systematically and apply their learning to relevant life situations or problems (FGRBI, 2012.).

The final concept in adult learning is also linked to motivation. This concept purports that adults are more motivated to learn through external motivators (Knowles et al., 2011). Motivation can be defined as is "the drive and energy we put into accomplishing something we want to do" (Merriam & Bierema, 2014, p 147). Motivators such as job promotions and salary

increases are external motivators in adult learning (Knowles et al., 2011). Internal motivators such as improved quality of life, improved self-esteem or job satisfaction are also powerful in adult learning (Knowles et al., 2011). In FGRBI, caregivers may be motivated to learn by internal and external motivators related to their child's learning and development which in turn may help to reduce caregiver stress.

Coaching is used in many aspects of adult life to achieve various outcomes (Kessler & Graham, 2015). FGRBI focuses on caregiving coaching to build family capacity (Florida State University, n.d.a.). Providers using the FGRBI model may need an understanding of adult learning concepts such as the caregiver's learning style, attitudes, expectations, self-direction, and motivation to successfully coach caregivers of children with special needs.

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doi:10.1044/0161-1461(2011/10-0016)

### **Appendix B: PEO Model**

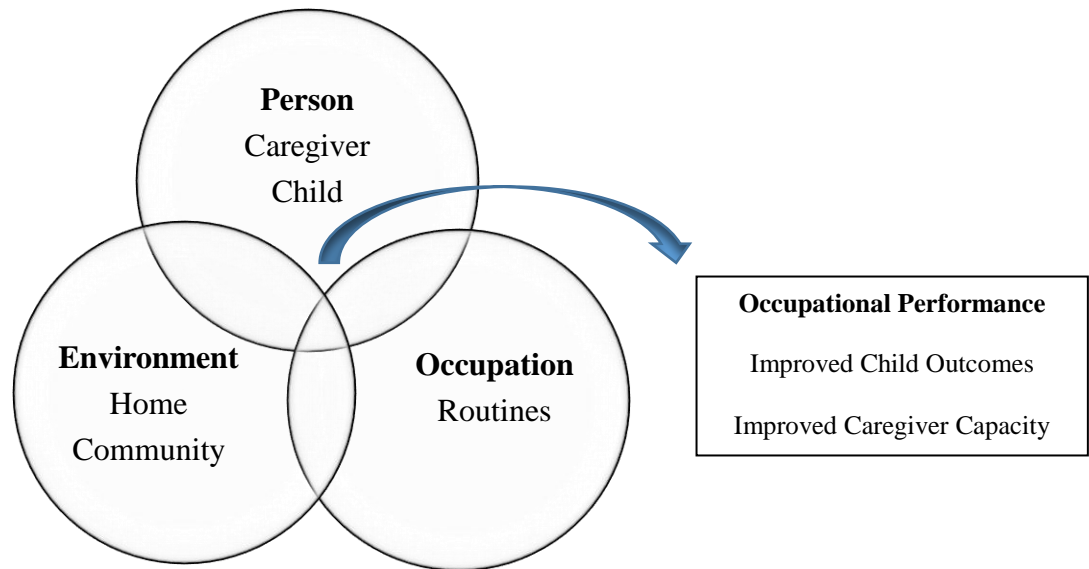
The Person-Environment-Occupation Model (PEO) was founded by Law et al. (1996). It is a framework often used in occupational therapy practice that guides a practitioner's clinical reasoning (Law et al., 1996). The PEO Model is a tool to promote a client's engagement in meaningful occupation (Strong et al., 1999).

The theory behind the PEO model is the dynamic process of how the person, the environment, and the occupation interact and how this process affects occupational performance (Law et al., 1996). This model believes the person is a dynamic being who interacts with his or her environment (Law et al., 1996). Occupations meet the individual's need for self-maintenance, expression, and fulfillment and are necessary functions in life (Law et al., 1996).

The PEO Model is a flexible model and can be used by occupational therapists to articulate their practice (Maclean, Carin-Levy, Hunter, Malcolmson, & Locke, 2012). Therapists can use this model to conceptualize, plan, communicate, and evaluate occupational performance in their clients (Strong et al., 1999). Occupational therapists recognize that a person is part of a bigger system and understand how their client's barriers will affect that system over time (Metzler & Metz, 2010). This model is used in many practice areas of occupational therapy and fits well when using FGRBI in EI.

The PEO Model can be used in EI to view both the child and caregiver's participation in daily life and within his or her environment. It can be used to identify specific interests, routines, stressors, outcomes, and goals in the child and caregiver to increase overall participation.

Figure B1. The PEO Model using FGRBI and Early Intervention



Adapted from Law et al., 1996

### References

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## **Appendix C: Informed Consent**

### **ST. CATHERINE UNIVERSITY**

#### **Informed Consent for a Research Study**

**Study Title:** Family Guided Routines-Based Intervention and Stress in Parents of Children with Special Needs

**Researcher(s):** Julie Jones, MOT, OTR/L

You are invited to participate in a research study called Family Guided Routines-Based Intervention and Stress in Parents of Children with Special Needs. The study is conducted by Julie Jones, doctoral candidate at St. Catherine University in St. Paul, MN. The faculty advisor for this study is Dr. Kathleen Matuska, Ph.D., OTR/L at St. Catherine University.

The purpose of this study is to assess the efficacy of Family Guided Routines-Based Intervention in reducing stress and satisfaction of daily routines in parents of children with special needs. This study is important because we can determine if this intervention reduces your stress and satisfaction of daily routines. If this study is effective, it may help occupational therapists be better prepared to meet your family's overall needs, not just your child's. This will result in improved child and family outcomes. Approximately four families are expected to participate in this research. Below, you will find answers to the most commonly asked questions about participating in a research study. Please read this entire document and ask questions you have before you agree to be in the study.

#### **Why have I been asked to be in this study?**

You have been asked to be in this study because you have a child enrolled in Early Intervention at the Mississippi Bend Area Education Agency.

#### **If I decide to participate, what will I be asked to do?**

If you meet the criteria and agree to be in this study, you will be asked to do these things:

- Step one: A Routines-based interview will be completed with researcher, Julie Jones. This will be done during a home visit lasting approximately 20 minutes.
- Step two: You will be asked to complete the Family Routines Rating Scale with Julie Jones and to rate your satisfaction of Family Mealtime and Sleep/Bedtime on a Likert scale of 1-5. In addition to Family Mealtime and Sleep/Bedtime, you will be asked to identify three other caregiver-child or family routines that you would like to address for this project and to rate these three routines on the same Likert scale as Family Mealtime and Sleep/Bedtime
- Step three: You will be asked to complete the Parent Stress Index (PSI-4) short form consisting of 36 questions.
- Step four: You will be asked to participate in a Routines-based intervention with Julie for 8-10 weeks. Visits will consist of visits every other week in your home. On opposite weeks, a phone call or Facetime visit will be made.
- Step five: Throughout the 8-10 weeks, you will participate in problem-solving and caregiver coaching strategies facilitated by the researcher, Julie Jones.
- Step six: At the end of the 8-10-week intervention period, you will complete the Family Routines Rating Scale and PSI-4 assessments again.

In total, this study will take approximately 45- minutes during face-to-face visits and 10-15 minutes during phone calls (more time during phone call can be available if requested). The total amount of time will be 8-10 hours of participation through face-to-face and phone call or text.

**What if I decide I don't want to be in this study?**

Participation in this study is completely voluntary. If you decide you do not want to participate in this study, please feel free to say so, and do not sign this form. If you decide to participate in this study, but later change your mind and want to withdraw, simply notify Julie Jones, and you will be removed immediately. Your decision of whether to participate will have no negative or positive impact on your relationship with St. Catherine University, nor with any of the students or faculty involved in the research.

**What are the risks (dangers or harms) to me if I am in this study?**

The study has several risks. The parents will be asked to share information about their routines and personal goals and address barriers to these goals. This may appear as an invasion of privacy. The parents may feel embarrassed if they have not met any of their goals or improved their routines at the end of the intervention

**What are the benefits (good things) that may happen if I am in this study?**

The benefit for you as a participant includes becoming better equipped to embed routines into your daily life and reduce overall stress as a parent with a special needs child.

**Will I receive any compensation for participating in this study?**

You will not be compensated for participation in this study.

**What will you do with the information you get from me and how will you protect my privacy?**

The information that you provide in this study will be used to develop case studies regarding the efficacy for Routines-based interventions. All names will be removed to protect your privacy. I will store field notes, assessments, and research results will be stored in a locked cabinet at the Mississippi Bend Area Education Agency. The research advisor and I will have access to the records while I work on this project. I will finish analyzing the data by May 1, 2017. I will then destroy all original reports and identifying information that can be linked back to you.

Any information that you provide will be kept confidential, which means that you will not be identified or identifiable in the any written reports or publications. If it becomes useful to disclose any of your information, I will seek your permission and tell you the persons or agencies to whom the information will be furnished, the nature of the information to be furnished, and the purpose of the disclosure; you will have the right to grant or deny permission for this to happen. If you do not grant permission, the information will remain confidential and will not be released.

**Are there possible changes to the study once it gets started?**

If during course of this research study, I learn about new findings that might influence your willingness to continue participating in the study, I will inform you of these findings

**How can I get more information?**

If you have any questions, you can ask them before you sign this form. You can also feel free to contact Julie Jones at 563-449-8559. If you have any additional questions later and would like to talk to the faculty advisor, please contact Dr. Kathleen Matuska at 651-690-6627 or [kmmatuska@stkate.edu](mailto:kmmatuska@stkate.edu). If you have other questions or concerns regarding the study and would like to talk to someone other than the researcher(s), you may also contact Dr. John Schmitt, Chair of the St. Catherine University Institutional Review Board, at (651) 690-7739 or [jsschmitt@stkate.edu](mailto:jsschmitt@stkate.edu).

You may keep a copy of this form for your records.

**Statement of Consent:**

I consent to participate in the study.

My signature indicates that I have read this information and my questions have been answered. I also know that even after signing this form, I may withdraw from the study by informing the researcher(s).

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Signature of Participant

Date

---

Signature of Parent, Legal Guardian, or Witness  
(if applicable, otherwise delete this line)

Date

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Signature of Researcher

Date

**Appendix D: IRB Approval***St. Catherine University IRB**Protocol Exemption Notification*

To: Julie Jones

From: John Schmitt, IRB Chair

Subject: Protocol #752

Date: 12/14/2016

On behalf of the IRB, I have reviewed your response to stipulations for application **# 752: Family Guided Routines Based Intervention and Stress in Parents of Children with Special Needs**, which has been verified by the St. Catherine University Institutional Review Board as Exempt according to 45CFR46.101(b)(2): Anonymous Surveys - No Risk on 12/14/2016. You have addressed all edits and clarifications as requested. As a result, the project has been approved as revised. You may begin your research at any time.

Please note that changes to your protocol may affect its exempt status. You must request approval for any changes that will affect the risk to your subjects using the Amendment Request Form. You should not initiate these changes until you receive written IRB approval. Also, you should report any adverse events to the IRB using the Adverse Event Form. These documents are available at the Mentor IRB system homepage, which can be accessed through the St. Catherine University IRB homepage. When the project is complete, please submit a project completion form.

If you have any questions, feel free to contact me or email via the Mentor messaging system. We appreciate your attention to the appropriate treatment of research subjects. Thank you for working cooperatively with the IRB; best wishes in your research!

Sincerely,

John Schmitt, PhD

Chair, Institutional Review Board

jsschmitt@stkate.

**Appendix E: Family Routines Rating Scale**

| <b>Routine</b>                                | <b>Not at all Satisfied</b> |   | <b>Satisfied</b> |   | <b>Very Satisfied</b> |
|---|-----------------------------|---|------------------|---|-----------------------|
| 1. Family Mealtime                            | 1                           | 2 | 3                | 4 | 5                     |
| 2. Sleep/Bedtime                              | 1                           | 2 | 3                | 4 | 5                     |
| (left blank for caregiver identified routine) |                             |   |                  |   |                       |
| 3.  | 1                           | 2 | 3                | 4 | 5                     |
| (left blank for caregiver identified routine) |                             |   |                  |   |                       |
| 4.  | 1                           | 2 | 3                | 4 | 5                     |
| (left blank for caregiver identified routine) |                             |   |                  |   |                       |
| 5.  | 1                           | 2 | 3                | 4 | 5                     |