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Contextual Aspects Influencing Mothers' Placement Considerations for Their Children with Autism

by

Margaret E. Moffett Boyd

Submitted in partial fulfillment of the requirements for the degree of
Doctor of Philosophy in Occupational Therapy
Occupational Therapy Department
Nova Southeastern University
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Abstract

Background: In 2005, the Centers for Disease Control and Prevention recognized autism as an urgent public health concern understanding families would need supports services at many levels. Parents are the most prominent caregivers of children with disabilities and inadequacy of support services often influences the placement outside of the home. Federal mandates require that states actively avoid placements based on costs, community connections, and least restrictive environments; however, unsustainable family life potentially leads to undesired placements. Mothers with maternal stress raising children with severe autism with behavioral responses at home are at severe risk for social and economic marginalization (Lucenko, Mancuso, & Janssen-Timmen, 2008; Nankervis et al., 2012; Peacock et al., 2012). Placement and respite options are insufficient to meet the current needs for crisis intervention and long-term care, and community health funding has been inconsistent across the states.

Literature review: Interdisciplinary and interprofessional literature on placement considerations, autism, and state, national, and global policy documents such as the World Health Organization was searched. Unique to this study was its inclusion of Sen's (1999) development economics capabilities approach in addition to Law et al.'s (1996) occupational therapy model of practice for its congruence with occupational therapy, its support of freedom and choice, and self-determinacy as a necessity for agency or occupational performance.

Methods: A qualitative phenomenological approach to gain untapped insights into the occupations and environments influencing mothers' placement considerations. Phenomenology is useful when a deeper understanding is necessary, or to identify a vulnerable group, to shape services, or to develop or revise policies when a change is needed.

Results: Data analysis produced six themes (a) feeling judged in their occupational roles as mothers; (b) restricted freedoms and occupational deprivations as a family; (c) the paradox of support services; (d) fears about their families' well-being; (e) occupational injustices revealed through mothers' feelings about placement considerations; and (f) spiritual aspects of childhood placement considerations.

Discussion: The mothers' composite themes were discussed in relation to historical and evolving mental health attitudes, practices and policies, the evolving national health insurance policy, and the economy. The influence of contemporary culture on the mothers placement considerations were discussed in regard to Internet and e-health technologies and new ways of knowing, communicating, and decision-making with public health implications.

Conclusion: Professional implications for research, practice, and justice issues are discussed.

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I dedicate this dissertation to two men: My father Joseph Peter Moffett who would be so proud, and to the man I love more than I can express, Bernard Thomas Boyd, who is just happy that I am finally finished. Let’s take a trip!

Jane, Kiera, Andrew, Liam, and Gavin – who will be the next PhD?

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Chapter 1: Introduction

Background to the Problem

Autism spectrum disorders (ASD) affect 1 in 68 children in the United States, including approximately 1 in 42 boys and 1 in 189 girls. This is a 23% increase in diagnosed cases of ASD between 2006 and 2008, and an astounding 78% increase in diagnosed ASD cases between 2002 and 2008 (Centers for Disease Control and Prevention [CDC], 2012). Of these children with ASD, 31% have co-occurring intellectual disabilities with IQs of 70 or lower, and 23% of the children have IQs of 71-84. Earlier diagnoses of ASD and a broadening of the diagnostic criteria only partially accounted for this increase. The CDC considers ASD to be an urgent public health concern requiring early identification, and provision of essential support to individuals with autism and their families (CDC, 2008; CDC, 2012). Similar ASD prevalence rates in other countries indicate that ASD is also a global issue (CDC, 2012).

Ganz (2007) estimated that annual autism costs to society exceed $35 billion, while the estimated lifetime incremental societal cost of caring for persons with autism in the United States is $3.2 million. A population study by Peacock, Amendah, Quyang, and Grosse (2012) found the average annual medical costs for Medicaid-enrolled children with ASD to be 10,709 per child, about 6 times higher than for children without ASD. Between 40% and 55% of children with ASD have co-occurring intellectual disabilities and their average annual medical costs were found to be $19,200. A child with ASD and co-occurring intellectual disabilities will have medical expenses twice as high as a child with ASD alone. Montes and Halterman's (2008a) population study of parents of 16,282 preschool-aged children found that parents were 7 times more likely to report that childcare decisions substantially affected employment decisions, if they had a child with ASD. In addition, Montes and Halterman's (2008b) employment population study of 11,684 preschool parents found a 14% average loss of income in households that had a child with ASD. Lower incomes, higher medical expenses, and employment challenges related to childcare combine to place a significant financial burden on these families (Liptak, Stuart, & Auinger, 2006).

Multiple symptoms associated with ASD including communication deficits, extreme sensory and behavioral regulation problems, and a propensity for imposing disruptive rituals can interrupt mothers' daily routines and rituals, and restrict participation in social and other health-promoting occupations as a family (Bernheimer & Weisner, 2007; Larson, 2006; Werner DeGrace, 2004). Mothers of children with ASD also experience higher rates of maternal stress and depression (Baker, Blacher, & Olsson, 2005; Ding et al., 2010; Meadan, Halle, & Ebata, 2010; Neely, Amatea, Echevarria-Doan, & Tannen, 2011).

Families constitute the largest group providing care for individuals with disabilities in the United States (Brown, MacAdam-Crisp, Wang, & Iarocci, 2006;

Freedman & Boyer, 2000; Parish, Pomeranz-Essley, & Braddock, 2003). Since children are uniquely dependent on their mothers, protecting maternal health and well-being is a prerequisite to supporting occupational performance of their children and the family as a functioning unit. Unsustainable family life due to unmanageable households, strained finances, and maternal stress places children with ASD and extreme sensory disturbances and behavior problems at high risk for out-of-home child placements or at severe risk if the children have co-occurring intellectual disabilities (Nankervis, Rosewarne, & Vassos, 2012). While mothers with maternal stress raising children with ASD, sensory disturbances, behavior problems, and co-occurring intellectual disabilities are also at severe risk for social and economic marginalization (Koyanagi, 2007; Lucenko, Mancuso, & Janssen-Timmen, 2008; Nankervis et al., 2012; Parish, Thomas, Rose, Kilany, & McConville, 2012a; Parish, Thomas, Rose, Kilany, & Shattuck., 2012b; Peacock et al., 2012).

Understanding the complex dynamics involved in considering the placement of one's young children with ASD and intellectual disabilities is integral to designing relevant family-centered services. Services designed to meet the needs of children with severe autism and the holistic needs of the mothers and their families strengthen the family's capabilities and occupational performance as a functioning unit. Strengthening the family's occupational performance may potentially help families avoid undesired or pressured child placements and delays without compromising maternal health and the family's quality of life. Consideration of how broader economics contexts, social policy, current trends, and ways of knowing and communicating influence placement considerations is essential for planning sustainable options for broad-based community supports and services. In addition to services are needed for the child with ASD, placement options for families in crisis or in need of temporary respite care or when permanent placements. Emerging contexts including technology, economic, political, social, and health environments, new ways of knowing, communicating, and decision-making may influence the mother's placement considerations and decisions.

For mothers of children with ASD and intellectual disabilities, community inclusion and outings as a family are health-promoting and necessary for the entire family's well-being. Local community respite for crisis intervention and short-term respite services can protect family well-being and may during times of crisis or when family is at risk for social and economic marginalization. In some cases, the children's needs will exceed family capabilities and humane, local placement options need to be available so that families can still be remain connected to their children.

Deinstitutionalization: Past, Current, and Future Relevance

The implementation of Phase 1 of the United States Deinstitutionalization Act of 1955 began with the closing of institutions and shifting the locus of care from federal to state control, to families and communities. This shift in caregiving responsibilities without family support or community preparation brought about a plethora of unintended social and economic consequences that still exist in society today, such as homelessness, poverty, substance abuse, and crime (Koyanagi, 2007). These consequences were a result of failure to set up the necessary family and community supports in preparation for the implementation of Phase I in 1955. Phase 2 (community supports), brought about some positive changes towards community integration; however, it still lacked the necessary interagency coordination, adequate funds, and coordination of funding streams. Phase 3

(Deinstitutionalization–*the rights and recovery* phase) began in 1993 and continues today. Lessons learned during Phases 1 and 2 of Deinstitutionalization remind federal and state policy makers to take the necessary precautions to avoid risks and to provide wide networks of support necessary during Phase 3 (Deegan, 2005; Koyanagi, 2007).

Before deinstitutionalization and into the early 1960s, it was not uncommon for children with ASD and intellectual disabilities to be placed into institutional care (Koyanagi, 2007). The goal of the rights and recovery phase of Deinstitutionalization is full community integration. Recovery refers not to full symptom remission; rather, it is the right to self-determination and to live a full life in the community, despite disability (Deegan, 2005; Koyanagi, 2007).

Occupational Therapy's Role With Individuals With Autism and Their Families

Occupational therapy services are highly utilized by individuals with ASD and intellectual disabilities and their families (Interactive Autism Network [IAN], 2008; Kogan et al., 2008; Siklos & Kerns, 2006). It is typical for occupational therapists to be involved in the evaluation and treatment of individuals with ASD and their families at home, or in community settings, at or before the point of diagnosis (Thomas, Ellis, McLaurin, Daniels, & Morrissey, 2007).

Occupational therapists and scientists have widely investigated mothering occupations and co-occupations, and mothers' use of time, place and space, and routines and rituals, compiling a growing body of knowledge in this area (Dunbar & Roberts, 2007; Dunbar & Werner DeGrace, 2001; Francis-Connolly, 1998, 2000; Kellegrew, 2000; Larsen, 2006; Ludwig, 1997; Pierce, 2001, 2003a, 2003b; Segal, 2004; Segal & Beyer, 2006; Tomcheck, 2009; Werner DeGrace, 2004). Knowledge from these studies has expanded the use of occupation-centered treatments with children with ASD and other disabilities (Larson, 2006). Occupation-centered services meet the needs of children with ASD and other disabilities, while also meeting the holistic needs of the family (Larson, 2006). This is important because the impacts of ASD can extend beyond the individuals with autism to the entire family, and to the communities and institutions to which they belong and interact.

Occupational Therapy Practice Framework

The American Occupational Therapy Association's (AOTA) occupational therapy practice framework (OTPF), which guides occupation-centered evaluation and practice is contextualized for everyday living (AOTA, 2002, 2008, 2014). Psychosocial, physical, temporal, environmental, cultural, spiritual, and virtual aspects of participating in occupations are considered. Broader contextual aspects such as socioeconomic, political, social and institutional aspects can potentially influence the freedoms, capabilities, and occupational performance of individuals, families and communities (AOTA, 2014). When freedoms, capabilities, and occupational performance are compromised, health, well-being, and quality of life may become compromised as well.

Over the years, occupational therapy also led in the nosology, concept evolution, research, and development of evaluation tools and interventions often used for treating individuals with ASD and intellectual disabilities, as well as other disabilities and sensory disorders including Ayres Sensory Integration® intervention, the Sensory Integration and Praxis Test's evaluation tools, and a fidelity measure (Miller, Anzalone, Lane, Cermak, & Osten, 2007). Sensory issues from regulation deficiencies can contribute to extreme behavioral responses which can be difficult for mothers raising children with ASD to manage (Baker et al., 2005; Schaaf, Toth-Cohen, Johnson, Outten, & Benevides, 2011).

Maternal Health and the Risk for Out-of-Home Placement

Caring for a child with ASD places a mother at risk for increased stress, anxiety, and depression (Baker et al., 2005; Donovan, Vanleit, Crowe, & Keefe, 2005). As discussed earlier, mothers with maternal stress who have children with ASD and extreme sensory and behavioral problems are considered to be at high risk for child placements. If their children also have co-occurring intellectual disabilities, their child's placement risk moves from high to severe risk (Koyanagi, 2007; Lucenko et al., 2008; Nankervis et al., 2012). Child relinquishment may occur if families have exhausted their social and economic resources and options, or if they have reached a crisis point.

According to Young, Rubble, and McGrew (2009), the term and action of child relinquishment bears the stigma of having given up on one's child, which is most offensive to parents who have acted out of desperation. In child relinquishment, care and decision-making authority are given to the state's control (Goodman, 2003; Nankervis et al., 2012). Therefore, it is conceivable that parents' freedom and accessible opportunities to raise their children at home may be restricted.

Occupational Perspectives Related to Placement Considerations and Placements

An occupation-centered approach allows for meeting holistic needs of families. Within the home, routines may be modified or environments may be adapted for improved occupational performance. Occupational therapists have broad-based interdisciplinary knowledge and special skills for providing occupation-centered interventions. Specific approaches such as Ayres Sensory Integration® are often used in treating children with ASD and intellectual disabilities, and with extreme sensory regulation and behavioral disturbances (Miller, Anzalone, 2007; Miller, Coll, 2007; Schaaf et al., 2014). Within the community, occupational therapists design accessible new environments or suggest affordable adaptations to existing environments for improved access and occupational performance (AOTA, 2009b, 2010).

Viewing occupation as health-promoting and necessary for survival, occupational therapists advocate for inclusion and tolerance. They do this by advocating for access to opportunities for social, occupational, economic, and civic engagement. To promote engagement, occupational therapists enhance skills, grade activities, and adapt environments to promote successful engagement and inclusion, and the valued participation of all of members of society. As a prerequisite for promoting community health, occupational therapy offers an affordable means to improve the occupational performance of individuals, communities, organizations, and institutions through inclusion and tolerance. An occupational perspective on justice includes the right for all to participate in health-promoting occupations and to live full lives in their communities, despite mental or physical disabilities (Wilcock & Townsend, 2000). This notion of full community inclusion is in keeping with the World Health Organization (WHO), the National Institutes of Health (NIH), Deinstitutionalization Phase 3, rights and recovery philosophy (Koyanagi, 2007), as well as Healthy Communities, 2020 as found on its website (www.healthypeople.com).

Dr. Rudolph Meyer, a psychiatrist and founding father of occupational therapy, proposed that clients need “opportunities rather than prescriptions” (Meyer, 1922\1977, p. 641). Opportunities to engage in every day occupations such as household routines provide a sense of order. Engaging in occupations that have particular meaning such as spiritual or cultural rituals, family celebrations, or spending time with friends and loved ones provides a sense of belonging and well-being. Engaging in meaningful occupations allows for individuals to be, to do, and to become (Wilcock, 1998, 2006).

Opportunities to participate in health-promoting occupations to facilitate inclusion may contribute one's sense of value and belonging and may open new avenues for social support. For inclusion to occur, opportunities must be socially, environmentally, and economically accessible for all. To illustrate, a job offer ceases to be an opportunity for an individual who has no accessible means of transportation to the job or no way to access the building, office, or bathroom. Fremstad (2009) asserted that contemporary debate in the United States is often silent about the link between disability and poverty; yet, disability has been regarded as both a fundamental cause and consequence of income poverty. In Fremstad's study, the consequences of the mothers' and their families' unmet needs, extended to their communities, societies, and institutions. Restricted access to supports and services that enable participation, also restricts the freedom of mothers to choose where their children with ASD and intellectual disabilities shall live.

Statement of the Problem

Families of children with autism rely upon a wide range of support services (Blacher & McIntyre, 2006; Kogan et al., 2008; Siklos & Kerns, 2006). Despite high rates of service utilization, families of children with ASD consistently report dissatisfaction with obtaining adequate support services, receiving referrals, and care coordination (Kogan et al., 2008; Siklos & Kerns, 2006). Federal policies require states' active avoidance of out-of-home placements (Wulczyn & Orlebeke, 2006). However, forced or premature placements may occur due to circumstances that are beyond parents' control (Parish & Lutwick, 2005). Conversely, keeping a child at home without adequate support places mothers at risk for maternal health, and the entire family at risk for social and economic marginalization (Peacock et al., 2012).

An occupational perspective of placement prevention would involve occupational therapy services that enable mothers, their children with ASD and intellectual disabilities, and their families to live, work, and play within their homes and communities. By addressing placement prevention in the literature, occupational therapists would be better equipped to support mothers who may face placement considerations and decisions in their assessment of the facilities for the best fit. By exploring the contextual aspects of the mothers' placement considerations and decisions, occupational therapists can explore the need for environmental adaptations to facilitate safe community participation. When placements are necessary to meet the needs of the child with ASD and their families, occupational therapists are equipped to work with local communities to improve the quality and services of existing settings, or to design sensory-friendly and safe, humane environments.

A review of the literature highlighted that the holistic nature of occupational therapy practice and its wide range of services do not seem to be clearly understood. A review of the literature uncovered a gap in the occupational therapy literature on placement considerations and decisions. These placement considerations and decision-making processes may occur, often unconsciously over time as mothers engage in instrumental activities of daily living through child rearing.

Occupational therapy’s unique contribution to health may be better understood through this current study in which the mothers and families' needs were substantial and vast. The complexities of the mothers’ situations illustrated the occupational perspective and approach to health. Through this study, the occupational role in illness prediction (maternal health), health promotion (participation, sleep), remediation and adaptation (roles, routines, and advocacy) was contextualized for others to better understand what the mothers and their families went through. Occupational therapists as mental health professionals with expertise in rehabilitation medical knowledge, and broad skills and training along with the study of occupation can add value and diverse skills and knowledge to primary-care core health teams.

To assert their potential role on the primary-care core team, the occupational therapy profession and its practitioners will need to clarify for others their expanded scientific knowledge and research, and their particular contribution and value to the team. Occupational therapists are mental health and rehabilitation professionals who work in a variety of diverse settings including medical, rehabilitation, mental health institutions, and in community health settings such as home care, schools, and with community organizations (AOTA, 2014).

This transcendental phenomenological study was expected to shed light on how the mothers initially considered the potential need to place their young children, and the complex relationship between occupational and environmental aspects that influenced their placement decisions. In-depth exploration of the decision-making process for placement was integral to gaining untapped insights about what facilitates and hinders the mothers’ and families' participation, occupational performance, well-being, and quality of life.

Purpose of the Study

The purpose of this transcendental phenomenological study was to elicit essential understandings of the mothers’ placement considerations and entry into the decision-making process for placing their children with ASD and intellectual disabilities, and the complex relation between occupational and environmental aspects that influenced their placement decisions.

This study explores mother’s perceptions about out-of-home placements for their children with ASD and intellectual disabilities, along with their considerations about why mothers may place their children, or how they entered the placement decision-making process and arrived at their placement decisions. Exploring mothers’ perceptions of their placement decision-making process was expected to reveal fresh insights. These insights were expected to help practitioners support the mothers and their families engage in their occupations and occupational roles at home and in the community. Moustakas (1994) asserted that transcendental phenomenological research offers an opportunity for readers to enter the participants’ lives, to view their situations in context from an insider’s perspective–in this case, the mothers’ perspectives.

Research Questions and Hypotheses

The research questions addressed in this study were as follows:

- What are the *lived experiences* of mothers of young children with ASD and intellectual disability in regard to the decision-making process for out-of-home placement?

- What are the contextual aspects influencing mothers' placement considerations and decisions?

Occupational and environmental implications were considered.

Definitions of Terms

Agency (operational definition): Equipping individuals with what is needed to participate in a satisfying life of self-determination and hopeful and satisfying life of self-determination, hope, and agency (Baker, 2005).

Child relinquishment (conceptual definition): Parents place their children when community services are insufficient and the family has exhausted its resources or reached a crisis point. Care of the child, decision-making authority, and control are turned over to the state including the child's religion (Goodman, 2003).

Community support (conceptual definition): Family services for families with children with ASD such as childcare, respite, and afterschool care (Thomas et al., 2007).

Confirmability refers to the dependability of the research process, the interpretations, and the value of data (Creswell, 2013). Guba and Lincoln (1985) and Koch (1994) stated that confirmability is established once credibility, transferability, and dependability are achieved.

Context and environment (cultural, personal, temporal, virtual, physical, and social): A wide variety of interrelated conditions within and surrounding the client that influence occupational performance. Contexts includes cultural, personal, temporal, and virtual (AOTA, 2014).

Environment: Refers to the external physical and social environments that surround the client and in which the client's daily life occupations occur (AOTA, 2014).

Family rituals (conceptual definition): Symbolic actions with spiritual cultural or social meaning that contribute to client identity, values, and beliefs that can support or hinder occupational performance. Family rituals can be protective factors against stress and anxiety (AOTA, 2014a; Fiese et al., 2002; Segal, 2004; Segal & Beyer, 2006).

Family routines (conceptual definition): Established sequences of activities or occupations providing structure to family life. Routines are also used to maintain households and families, and they are protective against the factors against potential stress and anxiety (AOTA, 2008a; Fiese et al., 2002; Segal, 2004). Routines may be supportive or disruptive to family function.

Family support service (operational definition): Services provided by state and local agencies including respite, occupational therapy (including environmental adaptive skills, adaptations, assistive devices, fine motor and Ayres Sensory Integration® for sensory and regulation and behavioral responses, among others), personal assistance, mental health care, crisis intervention, physical therapy, speech therapy, behavioral management, and services to enhance care-giving capacities such as parent and sibling support groups (Parish et al., 2003).

Intellectual disability (conceptual definition): A child with an I.Q. of 70 or lower (APA, 2013).

Occupation (conceptual definition): Occupation includes what people want to do and what they need to do. Occupation is perceived as a powerful agent to promote change "Occupation encapsulates doing, being, and becoming" (Wilcock, 1998, 2006, 2006c, p. 343). "Activities…of everyday life, named, organized, and given value and meaning by individuals and culture. Occupations are everything people do to occupy themselves including looking after themselves, enjoying life, and contributing to the social and economic fabric of their communities" (AOTA, 2008, p. 629; Law, Polatajko, Baptiste, &

Townsend, 1997, p. 32).

Occupational justice (operational definition): The availability and promotion of accessible opportunities for all to reach their full potential and to participate in a full array of health-promoting occupations within the community, despite physical or mental disability (AOTA, 2014; Nilsson & Townsend, 2010; Townsend & Wilcock, 2004).

Occupational profile (conceptual definition): An individual's occupational history, patterns of daily living, interests, values, and needs (AOTA, 2014).

Out-of-home placement (operational definition): Placement of the child into foster care, kinder care, a residential school setting or institutional care (Lucenko et al., 2008).

Respite (operational definition): Assuming the caregiving role to allow caregivers time to rest, regroup, or run errands. Crisis intervention care may occur in a residential facility (South Dakota Department of Health and Human Services, Division of Developmental Disabilities [DHHS], n.d.).

Severe autism spectrum disorder (operational definition): Severe autism with limited or no language or functional communication and autism spectrum of disorders, sensory, regulation and behavioral disturbances, intellectual disability and in need of 24/7 line of site supervision (APA, 2013).

Rationale and the Need for the Study

In the past, government policy and professional opinion supported out-of-home placement of children with severe disabilities; however, there has been a radical paradigm shift from this earlier recommendation. Federal policy mandates states to encourage families to raise their children at home with the help of support services. Despite the federal policies and state mandates, families continue to seek out-of-home placements for their children. Research shows that there tends to be an accumulative effect of the stressors or the *many straws* that eventually accumulate until the *last straw* or tipping point when the decision-making occurs. This process often occurs years before the act of placing the child or the event of the placement (Blacher, 2006; Blacher & Baker, 1994; McGill, Tennyson, & Cooper, 2006).

The focus of the study is the occupational implications for mothers' placement decision-making processes and considerations. The research shows that there tends to be a pattern of long-term (sometimes for many years) placement considerations, where a sometimes unspoken or pre-decision making occurs, progressing in different stages. These considerations of parents or caregivers occur before the actual decision-making process for child placement. It is at these earlier stages where placement prevention efforts may be effective in preventing pressured decisions or delaying premature placement (Blacher & Hanneman, 1993).

Exploring how families first considered the notion of child placement, how they entered the decision-making process and arrived at their placement decisions may help occupational therapists to more broadly serve the needs of the mothers and their families. By supporting the mothers and their families in their occupational roles and engagement in necessary and meaningful occupations at home and within in the community, occupational therapists become agents of change in broader community contexts.

The decision-making process for out-of-home placement and child placement considerations are processes which occur for years before a child is placed, or before placement is articulated or conceived as a potential option. Because of the complexity and numerous impacts of severe ASD, particularly when the child has co-occurring intellectual disabilities, it is possible that placement considerations or fears may be ever-present (Blacher, 1990). Placement considerations may be experienced through mothers' fears about the future, even when mothers are adamant in expressing that they would never place their children.

Once placement decisions are made, the decisions are unlikely to be reversed since the final placement decision appears to occur based on the cumulative effect of family impacts followed by one or more consecutive crises leading up to the final tipping point. A mother of a child with ASD and intellectual disabilities, might experience anxiety each time her child with ASD and intellectual disabilities unknowingly places a sibling in danger, or as she feels the child's needs are becoming greater than the families' capabilities to meet them. In some cases, the medical and therapy expenses necessary to raise the child exceed what families can afford, and the family becomes at risk for economic marginalization.

Occupational therapists are often involved in the treatment of children with ASD and intellectual disabilities early on, sometimes before the point of diagnosis, working within the home where mothers face challenges and barriers to carrying out their occupational roles, occupations, and co-occupations. The occupational therapists' interventions are occupation-centered and based on the occupational profile of the children and families served. Occupational therapists are able to support and strengthen the mothers’ and families' occupational performance and well-being. Because children with ASD and intellectual disability are typically referred early on for occupational therapy services (Goin-Kochel, Mackintosh, & Myers, 2009; Green et al., 2006), occupational therapists have a unique opportunity to build a rapport with the mother within the home. From this position an occupational therapy practitioner can assess placement risk factors and build protective mitigating factors such as routines that help the mothers with their daily occupations. Occupational therapists can help mothers through difficult routines and develop strategies to support these routines which contribute to the order and stability of the household and reduce chaos.

Occupational therapy services such as interventions to address problems associated with processing sensory information—such as sensory integration [OT/SI] (Ayres, 1972, 1979, 1989)—are among the most requested services by parents of children with ASD (Goin-Kochel, Mackintosh, & Myers, 2009; Green et al., 2006; Mandell, Novak, & Levy 2005). Schaaf et al. (2014) conducted a rigorous randomized trial for an intervention for children with autism with strict adherence to the procedures of this manualized intervention for children diagnosed with severe ASD based on a gold standard assessment measure.

Occupation-centered interventions including Ayres Sensory Integration® (Ayres, 1972, 1989; Miller, Anzalone, 2007; Miller, Coll, 2007; Schaaf et al., 2014) help children with ASD and intellectual disabilities with the disruptive sensory responses and other symptoms of ASD and improve occupational performance. For this reason, it is important for occupational therapists to consider placement prevention and to promote the mothers’ and families’ capabilities to engage in everyday occupations and in occupations which hold particular social, cultural, and spiritual meaning to promote the families' health, well-being, and occupational performance. In doing so, occupational therapists can help reduce the risk of pressured or undesired placements of children with ASD and intellectual disabilities. At this time, no studies were found that address the occupational perspectives of instrumental activities of daily living related to child rearing and placement prevention.

Significance to the Occupational Therapy Profession

Occupational Therapy and Autism: Out-of-Home Placement and Prevention

Since its inception in 1917 as the Society for the Promotion of Occupational Therapy, AOTA has been involved in helping people with disabilities live full, satisfying lives (Peloquin, 1991). AOTA does this in both leadership and supportive roles (Case-Smith & Arbesman, 2008). However, an extensive literature review and search through EBSCOHOST, OVID, JAMA, JSTOR, Blackwell Synergy, ProQuest, Wilson Web, Web of Science, PSYCINFO, CINHL, and PubMed uncovered no occupational therapy studies about placement prevention or placement considerations.

Occupational therapists provide services to children and adults with ADS and their families. Case-Smith and Arbesman's (2008) review of evidence-based interventions found that the three most utilized interventions were closely related to occupational therapy interventions. These interventions included (a) sensory integration and sensory-based interventions; (b) relation-based, interactive interventions; and (c) developmental skill-based programs. Of the three remaining evidence-based therapies—(a) social cognitive skill training, (b) parent-directed or parent-mediated approaches, and (c) intensive behavior interventions—research from occupational therapy literature were defined. Each of these six aspects of the evidence-based interventions are used in treating children with ASD and intellectual disabilities and supporting their families.

A review of the literature revealed a notable absence of occupational therapy citations in interdisciplinary, intra-professional, and policy literature when its inclusion would have been expected as in topics such as (a) early intervention, (b) family routines and rituals, (c) environmental adaptation, (d) mothering occupations and co-occupations, (e) inclusion, (f) sensory disturbances and behavioral responses, and (g) sensory interventions used in treating children including children with ASD with Ayres Sensory Integration® (Ayres, 1969, 1972, 1989; Baranek, Parham, & Bodfish, 2005; Dawson & Watling, 2000; Dunn, 2002, 1999; Iarocci & McDonald, 2006; Kientz & Dunn, 1997; Law et al., 1996; Miller, Anzalone, 2007; Miller, Coll, 2007; Parham et al., 2007; Parham et al., 2011; Schaaf, 2014; Schaaf, Benevides, Kelly, & Mailloux, 2012a; Schaaf et al., 2013; Schaaf, Hunt, & Benevides, 2012b; Schaaf et al., 2014; Schaaf & Miller, 2005; Schaaf et al., 2011).

The literature review also appeared to suggest that the occupational therapy profession has not fully conveyed to others its substantial educational, scientific, and professional evolution over the past 20 years and its contributions to qualitative and quantitative research on ASD. Another significant finding of the literature review was the confusion about Ayres Sensory Integration® (Ayres, 1972, 1979, 1989), as compared to other sensory-based treatments which may not be evidence based. Sensory-based treatments were sometimes discussed as a group, without distinguishing between those treatments with rigorous studies such as Ayres Sensory Integration® to support their efficacy. These blended reviews of sensory treatments from various disciplines were often followed by statements such as *sensory based treatments are not supported by the evidence,* without distinguishing Ayres Sensory Integration® which is evidence-based, from an assortment of sensory based treatments which may or may not be evidence-based (Ayres, 1972, 1979, 1989; Miller, Anzalone, 2007; Miller, Coll, 2007; Parham et al., 2007; Parham et al., 2011; Schaaf, 2014; Schaaf et al., 2012a; Schaaf et al., 2013; Schaaf et al., 2012b; Schaaf et al., 2014; Schaaf & Miller, 2005; Schaaf et al., 2011).

In one case, misinterpreted results of a less rigorous occupational therapy study which had not followed the prescribed Ayres Sensory Integration® procedures, and a study that did not use occupational therapy evaluators, were used in the decision not to include sensory modulation disorder (SMD) in the 2013American Psychological Association's (APA, 2013) *Diagnostic and Statistical Manual-5* (DSM-5). More rigorous studies were not used for the decision. The same misinterpreted results were then used in a policy statement published in a pediatric medical journal, cautioning that "parents should be informed that the amount of research regarding the effectiveness of sensory integration therapy is limited and inconclusive" (American Academy of Pediatrics [AAP], 2012, p. 1186). It should also be noted that the reviewer went on to promote a competing therapy from his professional discipline. The implications for occupational therapy are significant as children with or without ASD who have sensory issues interfering with their occupational performance may lose access and funding for a treatment which has been shown to reduce anxiety, stereotypic movement, and to improve occupational performance (Lane, Reynolds, & Dumenci, 2012; Miller, Anzalone, 2007; Miller, Coll, 2007; Schaaf, 2014; Schaaf et al., 2012a; Schaaf et al., 2013; Schaaf et al., 2012b).

For occupational therapists, occupational beings are at the center of professional decisions and recommendations. Emerging health systems and uncertainties of future practice environments, along with interdisciplinary and interprofessional collaborations will be essential. Each profession has its value in larger health care systems; turf battles are likely to rise in changing health and economic environments. Although these battles are rarely helpful to clients, at times professions must take a firm stance for the sake of the individuals that they serve and for the integrity of the profession. Dr. Miller and Dr. Clark made such a stance in addressing the American Academy of Pediatrics (AAP, 2012) in their decision to omit the diagnosis of sensory modulation disorder from DSM-5 (APA, 2013), and in their dismissive policy statement about occupational therapy's use of sensory therapies (AAP, 2012).

Such issues may emerge in changing times but collaboration is optimal; occupational therapists, who advocate for the profession when such issues arise, concomitantly advocate for those who need, use, and benefit from these occupational therapy services. This would include individuals and children with or without ASD and intellectual disabilities or other disabilities, and those with sensory issues and other disabilities who benefit from Ayres Sensory Integration® intervention (Ayres, 1972, 1979, 1989; Schaaf, 2014; Schaaf et al., 2013).

Reflecting on the Past to Envision the Future

Occupational therapy's roots were in mental health and influenced by the "Moral Treatment" movement–a humane treatment with a focus on occupations (Bing, 1981, p. 506). Unified by a belief in the curative value of engaging in occupations, a diverse group of occupational therapy founders included a partially trained social worker, a psychologist, a teacher, an architect with a disability, a nurse, and a psychiatrist (Johnson, 1981). Returning World War I soldiers necessitated occupational therapy's expanded roles in medical and mental rehabilitation.

The professions brief adoption of a medical model may have increased professional recognition and growth, and expanded its medical education and skills; however, it also led to a temporary shift away from the occupational therapy profession’s philosophical base (Baum & Christiansen, 1997; Christiansen, 1999). Recognizing this philosophical shift and the need to reconnect with the profession’s epistemological foundations, AOTA (2002) developed the OTPF: Domain and process.

The OTPF and its revised versions OTPF 2nd edition (AOTA, 2008) and OTPF 3rd edition (AOTA, 2014), provided a unifying language and a guide for occupation-centered practice. The OTPF (AOTA, 2014) focus on occupation conveys the profession’s epistemological values and assumptions, the complex nature of occupations, and the transactive process associated with occupational performance (being, doing, becoming).

The OTPF 3rd edition (AOTA, 2014) guides occupational therapy evaluation and treatment, coordinating with concepts and language used by the WHO’s International Classification of Disability and Function (ICF), and with the Centers for Disease Control and Prevention ([CDC], 2012; WHO, 2001, 2008). Congruent language between the WHO (2008), the CDC (2012), and the OTPF 2 (AOTA, 2008) is necessary for communication between disciplines, countries, and global organizations encountering similar health, economic, and societal issues. This congruency among these documents is also important when seeking funding for services and programs that may help the mothers and their families. As the occupational therapy profession faces a new age of centennial challenges including an evolving and debated health system, a compromised economy, high rates of unemployment, and rising rates of diagnosed cases of ASD during the rights and recovery phase (Phase 3) of Deinstitutionalization, the occupational therapy profession might reflect on the words of its revered leaders.

Wilma West (1968) encouraged occupational therapists in her 1967 Eleanor Clark Slagle Lecture to “have a part in determining our future rather than accepting one on assignment or default of others” (p. 10). However, at that time the profession lacked the language to adequately define itself for others due to the complex nature of its unique contribution to health and occupation–or the breadth of its services. In addition, the profession lacked sufficient scientific evidence to assure the occupational therapy profession’s future.

West’s work in the field of public health influenced her understanding of the breadth of occupational therapy’s application within current and future health systems. West was an occupational therapy leader and visionary who strongly valued the rich traditions of the occupational therapy profession. West spoke out against reductionist thinking and practice, and advocated for maintenance and advancement of occupation therapy’s unique contribution to health–engagement in occupation (Ludwig, 2004; West, 1968, 1984).

West’s colleague Mary Reilly regarded man as an occupational creature who could not be healthy in the absence of meaningful occupation. Gary Kielhofner, a former student of Mary Reilly’s, became a prolific contributor to the research on occupation-centered evaluation and practice. Kielhofner stated that “occupation pervades life, is necessary for the human collective, and determines the course of individual lives”

(Kielhofner, 1992, p. 288; Scott, Miller, & Walker, 2004, pp. 311-312).

Occupational Therapy's Renaissance

Holm's (2000) and other occupational therapists called for evidence-based occupational therapy practice, and the profession heeded these messages undergoing a reflective review of its interdisciplinary founders, epistemologies, mental health roots, and its focus on occupation; reclaiming its philosophical base. Informed and inspired through a re-examination of its roots, the AOTA initiated a professional renaissance to transform several critical areas including professional language, education, professional licensure, and specialty certifications. Occupational therapy curricula and AOTA fieldwork performance evaluation ensured graduates' preparedness for occupation-centered and evidence-based practice.

The AOTA developed the OTPF and later its revised editions to provide a unifying professional language that was congruent with the profession's epistemologies (AOTA, 2002, 2008, 2014). The OTPF was also designed to guide occupation-centered practice, addressing the multiple and complex aspects involved in improving occupational performance. In addition, the OTPF captured the holistic essence of occupational therapy, the complexity of occupational performance, and the simplicity of the profession's belief in the healing power of occupation.

Kielhofner (1992) recognized the client narrative to be essential in helping clients make sense of their circumstances and for occupational therapists to understand their individual desires and motivations. Kielhofner also recognized it is the client or group who must *will* the action to choose effective occupations if the therapeutic process is to be effective; the will to change comes from a sense of personal freedom (Kielhofner, 1992; Scott et al., 2004).

Occupational Therapy: Well Prepared for Current and Emerging Health Environments

The AOTA 1993 *Core Values and Attitudes of Practice*, 2011 *Philosophical Base* (AOTA, 1993, 2011), and *Occupational Therapy Code of Ethics* (AOTA, 2010) affirms the value of all individuals. Occupational therapists and scientists accept that participation in meaningful and necessary occupations facilitates adaptation, health, well-being, and quality of life, while barriers to participation can threaten the same (AOTA, 2002, 2008, 2014).

The AOTA (2009a) has also clearly articulated its position and commitment to evaluating and treating ASD. Occupational therapists can assess skills and analyze the occupational performance of individual family members and the family as a functioning unit. More importantly, they can do this in multiple contexts or environments, considering the uniqueness of each individual and family and the many aspects that transact with each other to support or hinder occupational performance (AOTA, 2008; Law et al., 1996).

Occupational therapy interventions can be applied within multiple contexts and environments to facilitate families' participation in health promoting and meaningful occupations at home and in their communities (AOTA, 2008; Law et al., 1996). The occupational therapy profession's interdisciplinary foundations and core competencies in mental and physical health and rehabilitation increase the profession's utility on health teams, in health systems, and on interdisciplinary boards for informed policy and distribution decisions. The pragmatic and holistic philosophy with strong interdisciplinary foundations situates the occupational therapy profession ideally to become agents of sustainable change for evolving health systems and healthy, livable communities (AOTA, 2008; Baum, 2006; Baum & Law, 1997; Law et al., 1996; Law, Baum, & Dunn, 2005).

Occupation-centered interventions are evidence based and cost effective. Because occupation-centered interventions are practical and tailored to families' occupational profile, they are easily integrated into their everyday lives for sustainable and lasting effects (Clark, 1993, 1997; Clark et al., 1996; Zemke & Clark, 1996). Occupational therapy services have the potential to effect change, agency, and interdependence for continued participation despite the course or effect of illness or age.

Occupational therapy's broad knowledge and skills can also be applied to communities, institutions, or organizations. Occupational therapy principles can be applied to the environments or to occupations (activities) to facilitate participation and inclusion. At times, occupational therapy's epistemological foundations and rich interdisciplinary history posed certain challenges to occupational therapists' professional identity as the relatively young profession carved its niche in a changing health system (Friedland, 1998). Academic program growth and economic forecast suggest that the general public recognizes the value of occupational therapy.

Occupational therapists are well equipped to strengthen individual capabilities and occupational performances of children with autism and their mothers and families. Enhancing the occupational performance of the mothers and their families can help the families to adapt to the challenges associated with ASD. Adapting home environments, grading activities, and modifying routines can increase participation and improve individual and family capabilities for enhanced occupational performance (AOTA, 2014).

Core occupational therapy concepts apply to broader arenas as well. There are a number of ways that occupational therapists can connect families of children with autism to wider networks of community support. Knowledge of personal, occupational, and environmental barriers and facilitators to occupational performance supports occupational therapists' abilities to educate individuals and families about living with ASD. Communities, organizations, and institutions might consult with an occupational therapy consultant to improve their occupational performance in promoting tolerance and inclusion. Architects and builders could include an occupational therapist on their team to assure the accessibility of environments and buildings at the planning stages or to discuss feasible, affordable options to adapt buildings for improved access for environments currently inaccessible. In advocating for accessible transportation, opportunities for employment, civic engagement, and social participation, occupational therapists can expand accessible opportunities for community engagement for all, despite disability (Baum, 2006).

By collaborating with community leaders, occupational therapists could initiate occupation-centered community activities to enlighten others about the mutual benefits and the ultimate value that inclusion and tolerance bring to a community (AOTA, 2014; Law et al., 2005). Understanding the mothers' perspectives of the placement decision-making process in context of their daily routines and occupations, as well as within broader socioeconomic and environmental contexts may inspire fresh insights for sustainable, measurable solutions.

The profession's unique focus on occupation allows for complex analysis of the fluid interplay between the person, occupation, and environment. Occupational therapists understand the multiple aspects that transact with each other to support one's capacity to engage or participate. Core knowledge of occupational performance and the physical and social sciences help occupational therapists analyze personal, psychosocial, and physical aspects of a person's performance in relation to occupations and human or non-human environments. Broad-based skills and clinical reasoning enable occupational therapists to assess performance demands, personal capacities, and the complexity of the occupation (Baum, 2006; Baum & Law, 1997, 1998).

The occupational therapy profession has demonstrated its ability to adapt to changing health demands despite fluctuating economies, environments, cultures, and technologies. In the past 20 years, the AOTA has strengthened and increased every level of its educational programs, it has contributed quantitative and qualitative research on the effectiveness of its treatments. The profession has reflected on its epistemologies and interdisciplinary foundations and redirected the profession's central focus on occupation and adaptation; thus, conveying its professional identity through the language of the OTPF (AOTA, 2014). The OTPF (AOTA, 2014) allows for the full expression of the occupational therapy profession's uniquely creative, practical, and cost-effective approach to health through engagement in the everyday necessary and meaningful occupations that comprise a full life. The OTPF (AOTA, 2014) articulates the complexity of the multiple aspects that transact with each other to support or interfere with occupational performance.

Elizabeth J. Yerxa from the University of Southern California, stimulated the Southern California occupational therapy faculty to establish a new academic discipline *occupational science* developed to generate knowledge about the form, function, and meaning of human occupation. Occupation is everywhere and it constitutes a distinct field of interdisciplinary inquiry with adaptation as an essential construct (Yerxa, 1990; Yerxa, 1991; Yerxa et al., 1989; Zemke & Clark, 1996).

Occupational science research contributes to theory that informs occupational therapy practice. The occupational therapy profession has well prepared occupational therapists to serve and assume leadership roles on interdisciplinary boards where critical health and distributive decisions are made that will affect the lives of occupational beings, communities, institutions, and organizations that they serve. The occupational therapy profession has elevated its status to assert its evolution and unique contribution to health at an optimal time in history as changing environments require adaptation. The AOTA met its centennial goals which will strengthen the profession to weigh in on the discourse and policy decisions that contribute to the health, well-being, occupational performance, and quality of the mothers and their families' lives at home and in the community.

Exploring mothers' perspectives of the decision-making process was integral to the discovery process of how autism spectrum disorders symptoms transacted with environments and occupations influencing maternal health, family participation, occupational performance and ultimately their placement decisions. Occupation-centered interventions are contextually based and responsive to the occupational being or entity's particular daily activities and desired occupations, and the particular aspects that enhance or restrict participation and occupational performance. Helping others to better understand and more richly and broadly benefit from occupational therapy services was an important outcome of the implementation of the first of three OTPFs (AOTA, 2002) implementation. Perhaps the OTPF (AOTA, 2002, 2008, 2014) was instrumental in clarifying occupational therapy's unique perspective on health, disability, well-being, and a full life.

Although a review of the literature indicated wider recognition of the occupational therapy profession, the literature review also reflected that the occupational therapy profession is still not clearly or holistically understood by others. Occupational therapy appears to be understood in the bits and pieces of its different practice areas. Yet, those outside of the profession appear to often lack recognition of the central concept of occupation that threads the bits and pieces together and unites the different practice areas. The literature review appeared to suggest that the occupational therapy profession has not fully conveyed to others its substantial educational, scientific, and professional evolution over the past 20 years, and its contributions to qualitative and quantitative research on ASD.

This study offers an opportunity for the occupational therapy profession to convey its recent 20-year educational, professional renaissance and its proliferation of scientific research and science-driven practices. Viewing the mothers' situations from a broad perspective provides a means to contextualize for others how occupational therapy services may be carried out within the context of Healthy Communities, 2020. In this environment, the holistic nature of the occupational therapy profession is more apparent.

Because the mothers in this study were isolated, it was important to understand their situations within the community as well as within the home to consider expanded networks of support from an occupational perspective. The OTPF 3 (AOTA, 2014) allows for language that is understood by policy makers and funders of support services in a language that keeps occupation at the heart of treatment and frames the aspects that transact with each other under the larger OTPF concept (AOTA, 2014). Occupational therapy offers client- and occupation-centered services and sustainable health options to support the mothers of children with ASD and intellectual disabilities and their families to adapt to environmental and occupational challenges despite disability. The OTPF (AOTA, 2014) has broadened its focus to help occupational therapists promote inclusion at the broader level of institutions, organizations, and environments.

The mothers of young children with ASD and intellectual disabilities in this study faced occupational and environmental challenges that were explored in relation to their placement considerations, decision-making processes, and placement decisions. Occupational therapy services are occupation- and client-centered, and evidence-based, offering cost-effective, sustainable options for the mothers and their families to participate in health promoting activities at home and in community settings (Clark et al., 1997, 2012; Jackson, Carlson, Mandel, Zemke, & Clark, 1996; Miller, Anzalone, 2007; Miller, Coll, 2007).

Occupational therapy services help families to sustain home management activities which give the family a sense of security (Larson, 2006; Werner DeGrace, 2004). Broader community health occupational therapy services can support the Healthy Communities 2020, Deinstitutionalization Phase 3 rights and recovery goals and philosophies of full inclusion in the community despite disabilities (Koyanagi, 2007).

From this contextualized understanding of the mothers of children with ASD and intellectual disabilities and their families' needs, the role and value of the occupational therapy profession can be better understood. As members of the mental health professions and in serving on primary care health core teams, occupational therapists will have opportunities to assert their roles and value to improve the occupational performance of individuals, communities, institutions, and organizations. Occupational therapists are well prepared to take the lead with their unique contribution and the power of occupation to create inclusive, healthy communities.

Occupational Justice: Policy, Parity, Participation

Broader contextual understandings are critical for informed community, policy, and distributive decisions made on behalf of the mothers and their families. These distributive decisions potentially affect families' access to support services, opportunities for participation in health promoting activities, full community inclusion, and ultimately, the families' agency. Distributive decisions can also potentially affect the families' freedom in choosing where their children shall live. This understanding has become more urgent with the recent rise in diagnosed autism cases, when an already stressed economy poses an inevitable threat to the services upon which these mothers and their families depend. Mothers' perceptions of the decision-making process for placement may illuminate the complex relation between environmental and occupational factors and their placement decisions.

Mothers of children with ASD and intellectual disability face considerable challenges to engaging in obligatory household routines, desired occupations, and special rituals at home and in their communities. The expectation was to explore in-depth the decision-making process for placement in order to illuminate untapped insights about how ASD symptoms transacted with environments and occupations influencing maternal health, family participation, occupational performance, and ultimately, placement decisions. In-depth exploration of the mothers' placement considerations and decision-making processes was expected to uncover untapped insights about what facilitates and hinders the mothers' health and the entire families' well-being, quality of life, and occupational performance.

Occupational scientists and therapists assert that engaging in occupation is necessary for health, adaptation, and survival (Wilcock, 1998, 2006). Likewise, lack of engagement in occupation is a threat to health, adaptation, and survival. Individuals or families who are unable to access opportunities for meaningful engagement in occupation are considered to experience occupational deprivation (Whiteford, 2000). Understanding the magnitude of the mothers' challenges and the extent of occupational deprivation experienced by the families is paramount to understanding maternal health and the entire families' capabilities of occupational performance well-being. Occupational therapists advocate for occupational justice or the freedom of access to opportunities for all individuals to participate in health-promoting occupations, despite disability. Occupation is considered to be a powerful agent for adaptation, growth, development, and transformation. From an occupational perspective of health, understanding the mothers' perspectives of the placement decision-making process may bring to light environmental and occupational factors related to their placement decisions and needs.

The *Occupational Therapy's Code of Ethics Standards* (AOTA, 2010) asserts the profession's commitment to serving the occupational needs of society. The concepts of freedom and personal choice guide occupational therapy evaluation and intervention (AOTA, 2008, 2010). The occupational therapy profession values the notion of inclusion and defends the rights and freedoms of all to live satisfying lives of meaning, despite physical or mental disabilities (AOTA, 2010). This notion is congruent with Deinstitutionalization’s rights and recovery philosophy. Advocating for accessible opportunities to participation as a family in the community has been shown to serve as a protective factor against maternal stress and decreased family well-being, while access to wider networks of community support may reduce families’ risk of marginalization.

Significance to Society

Goodman (2003) stated that considering the placement of one's young child outside of the home can be traumatic; however, the emotional impact is particularly devastating in the case of forced relinquishment. The term and action of relinquishment carries the stigma of having given up on one's child which is offensive to parents who acted out of desperation (Young, Rubble, & McGrew, 2009). The societal cost for out-of-home placement comprises a large portion of the available resources for people with disabilities (Parish & Lutwick, 2005). The human cost defies measurement. Parish and Lutwick (2005) remind us that the need for care and support systems exceeds the availability, leaving institutions and communities financial burden.

To fully understand how parents first consider the notion of placing their children and arrive at their placement decisions, placement considerations need to be explored in context of their homes, families, communities, and in broader contexts. Mothers and families of children with ASD and intellectual disability rely heavily on government funding for family support and essential services not only for their children with ASD, but also for their families' survival (Goodman, 2003; Llewellyn, Dunn, Fante, Turnbull, & Grace, 1999). Out-of-home placement of the child with ASD and intellectual disabilities may enter the realm of possibilities when the mothers' and families' capacities have been stretched to the limit and their options and resources have been exhausted.

Theoretical Perspectives

Person-Environment-Occupation Model of Practice

The Law et al. (1996) person-environment-occupation (PEO) model of practice is both occupation centered and client centered, and draws from environment-behavioral theories. It emphasizes the dynamic relationships between people, their environments, and their occupational roles. It is assumed that the person, environment, and occupation transact with each other and that the greater the congruence between the three, the greater the occupational performance. The PEO transactional approach assumes the interdependence of the environment and the person. It also accepts that there is a continual shift in contexts which requires behavioral changes to accomplish goals. The PEO measures the effectiveness of interventions through occupational performance and offers multiple avenues for intervention across contexts (Price, 2005). Environments may include households or communities cognitive, emotional, spiritual, or physical attributes (Law et al., 1996).

Environments are those places where occupation would occur; the environments could influence occupations, occupational roles, persons or occupational performance including cultural, spiritual, institutional, physical, socio-economic, and social influences. Occupations would be self-directed activities in which individuals engage throughout the lifetime. These occupations meet intrinsic needs for participation, skill development, expression, and enjoyment (Law et al., 1996). A person's experience of occupation is subjective (e.g., cooking a special dinner for a persons' gourmet club as compared to a tired mom coming home from work to cook for her family; in other words, enjoyable creative expression versus chore). The PEO model also has interdisciplinary roots and a measurement tool that can be used by other disciplines (Law et al., 1996).

Economic Approach: Amartya Sen's Capabilities Approach

Unique to this study was its inclusion of an economic approach in addition to the occupational therapy model to view the resulting data. Understanding the need for interdisciplinary discourse and attention to the mothers' situation, the principal investigator (PI) sought to invite interdisciplinary reflection and discourse towards socially just, sustainable alternatives for these vulnerable mothers and their families.

Amartya Sen (1999), 1998 winner of the Nobel Peace Prize in economic science, developed the capabilities approach (CA)–"a broad framework to assess well-being and social arrangements used for policy development and social change" (Robeyns, 2006, p. 352). The CA is used in academia welfare economics, disability studies, development studies, policymaking, and public health. Sen's CA offers a unique economic approach that has gained favor in academia, welfare economics, disability studies, public health, and policymaking circles including the World Health Organization.

The CA framework supports the notion that monetary poverty or affluence does not reveal all dimensions of deprivation and well-being. Core concepts of CA are a person's functions (what a person actually achieves) and capabilities (what a person might achieve), or the valued things that people are able to do, or to be, as a result of their resources and accessible opportunities, with an underlying concept of freedom of choice which is believed to be a necessary prerequisite to agency.

Assumptions and Limitations of the Study

Phenomenology is a qualitative approach to research which uses inductive reasoning to explore complexities, essential meanings, contexts, and subjectivity (Moustakas, 1994). Phenomenology differs from other qualitative research in that the researcher accepts the participants' subjective realities as the true essence of the phenomenon. An assumption of this transcendental phenomenological study was that the essence or true meaning of experience could only be fully known by those who have lived or shared the experience (Moustakas, 1994).

A limitation of this transcendental phenomenological qualitative design is that the results of this study cannot be generalized; however, transferability can be achieved as others can relate to the situation. Another limitation of the design was the potential opinion of the PI's own values and bias based on years of practice. However, specific procedures such as reflexivity through pre-action and post-action bracketing, and in-action journaling and reflexivity, employed checks to control for potential bias. In addition, a peer reviewer who is an experienced researcher and completed an ethics course on human subject research completed secondary analysis of the data and conducted a peer-review session. The purpose of the peer-review session was to challenge the PI's assumptions, interpretations, and representations, and to ensure strict adherence to specific phenomenological. The peer review as an external check to strengthen emerging themes and to contribute to the rigor of the study.

Delimitation was the difficulty in collecting data. The PI experienced multiple cancellations and rescheduling, mostly because of crises involving the children with ASD. A seventh mother, who had initially wished to participate, changed her mind after her child was assaulted on the bus by a child who had been regularly bullying her young daughter. The mother was extremely distressed by her daughter's situation. A delimitation of this study was its narrow recruitment criteria. Each mother in this study had to have a child or children with low-spectrum autism and co-occurring intellectual disability and at least one other child with typical development. Each mother considered the decision-making process for out-of-home placement. The age of the child at the time of the placement, potential placement, or consideration had to be 12 years or younger, and the placement decision-making process needed to have occurred within the past 10 years. Therefore, it would have been possible for a mother of a 22-year-old child with autism to qualify, if the decision process occurred at the age of 12 years. Another important delimitation of this study was the difficulty in locating mothers who fit the criteria, as they rarely belonged to the typical parent and autism groups–indicative of their isolation.

Summary

This qualitative, transcendental phenomenological study was initiated to provide a voice for six mothers of young children with ASD and co-occurring intellectual disabilities. Based on the severity of the children's ASD, the presence of maternal stress, co-occurring intellectual disabilities, and behavioral responses, each of the children would be considered to be at high risk for out-of-home placement. Mothers who experienced the decision-making process for placement or potential placement of their children shared their experiences of this decision-making process. The remaining mothers, some who were adamant about not placing their children, were asked to consider how mothers of children with severe ASD and intellectual disabilities might potentially find themselves in the position of entering the decision-making process for placement (DHHS, n.d.). Based on the participating mothers' situations of raising children with ASD and intellectual disabilities with sensory disturbances and behavioral responses, and being a mother with maternal stress, the mothers would be considered at severe risk for out-of-home child placements. The participating mothers who were adamant that they would not consider placing their children, were asked to consider the reasons why mothers of children with ASD and intellectual disabilities who placed their children may have felt the need to do so. Learning about the mothers' decision-making processes may help others to better understand what the mothers go through and to inform policy makers and others whose decisions and actions could influence their families' capabilities, occupational performance, and quality of life.

The purpose of this study was to elicit essential understandings of the mothers' entry into the decision-making process for child placement and the complex transactions between environmental and occupational aspects influencing their placement decisions. Exploring mothers' perspectives of the decision-making process was integral to the discovery process. The expectation was to illuminate untapped insights about how ASD symptoms transacted with environments and occupations influencing maternal health, family participation, occupational performance, and ultimately, their placement decisions.

West (1968) cautioned occupational therapy professionals to be aware of future trends and to consider broader applications of occupation. A compromised economy and an evolving and uncertain health system claiming to cover more people for less, has currently exceeded all cost projections (Day, 2006; Orient, 2010). At the same time, the country is in Phase 3 of the Deinstitutionalization and the ASD rates are rising at an alarming rate, adding to the competition for support services upon which families rely which places the mothers at even higher risk for occupational and socioeconomic marginalization.

Unique to this occupational therapy study was its inclusion of an economic approach with CA, in addition to the occupational therapy model (Law et al., 1996). PEO was the occupational therapy model used to view the resulting data, recognizing the need for interprofessional thought and discourse on this justice issue.

Occupational therapists and scientists have demonstrated their long-term commitment to inclusion and engagement in health-promoting occupations for improved well-being, quality of life, and occupational performance. The AOTA commitment to occupational justice will play an important role in building sustainable healthy communities along with other disciplines, professionals, and community members. An essential instrumental freedom to occupational justice and to healthy communities is the full inclusion and valued participation of all of its members, with or without disabilities.

The challenge is great and it is complex. The AOTA has prepared its members at every level for the complexities involved in this 21st century challenge.

Understanding the challenges of the mothers and how to meet their occupational needs provides a critical occupational challenge. How well the profession responds to meeting the occupational needs of the mothers in light of their complex situations, and in light of their occupational deprivation, will provide preliminary evidence for the power of an occupational perspective and for the application of occupational therapy services to promote and achieve occupational justice.

If the occupational therapy profession can begin to address the vast needs and occupational deprivations of the mothers of children with ASD and intellectual disabilities, then they will establish their essential role on the primary care core health team. Several features of the profession make its presence on interprofessional teams and interdisciplinary teams. Interdisciplinary foundations allow us to examine more broadly but also more deeply the essential aspects of occupational performance. The profession's historical underpinnings were in mental health and it was because of the effect that occupational therapy services had on the clients that led the medical community to expand occupational therapy's role to serve as rehab therapists for returning soldiers who were experiencing mental health issues such as posttraumatic stress. The focus on occupation expands our repertoire of services to include multiple venues for treatment and in diverse settings. The mothers in this study and their families' needs represent a challenge to communities in the current health and economic environments, particularly in relation to long-term care, disability, and respite services.

Community health poses risks to the mothers and families in regard to funding for services, supports, and respite necessary to care for their children at home, or humane community-based options for residential and long-term care when health and safety are at risk or families are at risk for social and economic marginalization. The mothers in this study offer a major 21st century community health challenge. The fate of their children and their families may lie in their communities' capacity for tolerance, inclusion, and their valued participation of the children with ASD and their families. An interdisciplinary milieu with professional collaboration may generate multiple solutions. In confronting the families, and occupational and economic disparities in this justice issue, occupational therapists and scientists may open new eyes to the power of occupation for the well-being of all occupational beings.

Chapter 2: Selected Review of the Literature

Introduction to the Chapter

The purpose of this literature review was to identify, review, explain, and evaluate the existing qualitative and quantitative research and theories related aspects influencing mothers' considerations for out-of-home placement of their young children with autism spectrum disorders (ASD) and intellectual disabilities. The literature review explored six major areas of theory and research surrounding mothers' meanings of the experiences of their placement considerations, decision-making process, and decisions.

The first major area of the literature review was the historical perspectives of mental health and disability to better understand these aspects in the context of societal attitudes and practices over time. Particular attention was placed on the United States Deinstitutionalization Act of 1955, because of its past and current relation to out-of-home placements and the consequences of this policy's implementation. The second major area presented a summary and a critique of the literature on mothering children with ASD, supports, services, and relevant frameworks including models, academic disciplines, and approaches. The impacts of the disorders on everyday family life and participation at home and in the community were explored. Maternal health, family well-being, and occupational performance of the mother and family to raise the child at home were considered in relation to placement decisions. The third area focused on the role of occupational therapy in supporting children with ASD and their families including the occupational perspective of participation for health promotion, prevention of illness and secondary illness, and treatment and evaluation of individuals with ASD and their caregivers. The fourth area expanded the scope to examine the placement decision-making process and decisions in relation to occupational justice, focusing on the effects of the disorders in relation to occupational justice. Intertwined with the impact on caregivers and families is access to opportunities for participation and the influence of broader contexts on capabilities and occupational performance. Thus, this section also examined occupational deprivation in relation to maternal health, family well-being, capabilities and occupational performance, and placement considerations and decisions.

The fifth area explored current mental health policies on out-of-home placements and perspectives related to accessing opportunities to engage in health-promoting occupations in multiple contexts. Finally, the sixth area explored the current issues and trends influencing parental attitudes regarding health institutions, technology, economics and parental health decision-making for their potential influence on placement decisions and population health.

Literature Search

The search was limited to literature from 2003 to 2013 for currency; however, earlier, significant research or landmark articles were included when relevant or necessary to gain a deeper understanding of the topic. Databases for the search included CINAHL, Cochrane Library, EBSCOHOST, OVID, Medline, ProQuest, and PubMed, using search terms and phrases such as *out-of-home-placement and young children with severe autism spectrum disorders; maternal health; occupational therapy and autism; Ayres' Sensory Integration® and occupational therapy; economics and autism spectrum disorders; and Sen's Capabilities Approach*.

Occupational therapy research included qualitative and quantitative research on theories related to ASD and its impacts on maternal health, participation, well-being, quality of life, and occupational performance. Occupational therapy research also provided insight to mothering occupations, co-occupations, time use, rest and sleep, routines, roles, rituals, time, space, place, surveillance, caregiving for children with disability and autism, spirituality, and meaning-making. Research on Ayres' (1972) Ayres Sensory Integration® [OT/SI] was addressed as one of the many frames of reference used in occupational therapy, because of its particular relevance to ASD in treating sensory issues that could intensify behavioral responses.

Economic, psychology, public health, social work, and social science articles provided research studies on community supports, service utilization, costs of ASD, and safety nets. Public health and law research shed light on placement and current laws, parental rights, and stigma related to placements. Medical articles focused on medical conditions and related costs, the costs of support services, childcare and other barriers to employment.

Law and social work journal articles provided quantitative and qualitative literature on out-of-home placements and on placement risk prediction. Psychology studies addressed applied behavioral analysis, coping, maternal stress, and depression. Government policy documents from the National Institutes of Health (NIH) provided insight to funding streams, health statistics, service utilization, and preparedness for transformation to community health.

This study shed light on a group of mothers who considered or experienced the decision-making process for out-of-home placement of their children with severe ASD and intellectual disabilities. The study took place during a pivotal time in history, as several events simultaneously converged. At this time, the United States is in

Deinstitutionalization’s rights and recovery phase of which calls for the full shift from institutional to community health which has implications for the availability of placement options. At this same time, the country is economically compromised with high unemployment rates. The country is also engaged in navigating an evolving complex and debated government health insurance program that has exceeded all projected costs, and which proposes to cover more individuals with a wider range of services at a lower cost. In addition, there has been a significant rise in ASD rates, adding to health expenses and education costs, and the likelihood of greater competition for already limited services and supports. Emerging technologies and e-health options as well as current ways of knowing, communicating, and decision-making have broad implications for public health. If support networks are further diminished, how does society protect the health and well-being of those who are already struggling such as the mothers of children with severe autism and their families? These evolving economic, health, and technological environments complicate the processes of health promotion and the prevention of illness, disability, and health disparities. Within these rapidly changing health and economic environments occupational therapists and other health professionals and members of other disciplines will be challenged to problem-solve creatively and collaboratively doing more, with less.

Occupational and economic theoretical perspectives were selected to gain a better understanding of how the mothers’ transactions and interdependence with broader contexts influenced their occupational performance and placement considerations. The Law et al. (1996) PEO model—an occupation-centered, occupational therapy model of practice—was selected to guide this study, and Sen’s (1999) capabilities approach (CA)–a development economics approach designed for developing nations and welfare policies was employed in reviewing the data. Both of these lenses allowed for examination of mother of children with ASD capabilities, occupational performance, and placement decisions related to broader issues of economic and occupational justice.

The literature search uncovered no occupational therapy studies about out-of-home placements, and a gap in the literature on placement decision-making and placement risk prevention. Current interdisciplinary research about out-of-home placements was sparse, with more current literature focusing on identifying parents or caregivers who may be at risk for out-of-home child placements and placement prevention. There was a greater focus on the therapy services and supports that are highly utilized by children with ASD and intellectual disabilities and their families' and caregivers' needs. Reviewing the purpose and function of placements, the evolution of societal attitudes about mental health and disability, and deinstitutionalization in the United States, provided a foundation and context for exploring the decision-making process for placements.

Out-of-Home Placements of Younger Children With Autism: Purpose and Function

Residential schools fulfill the following several functions: (a) provide an educational curriculum with supports and services; (b) relieve the parent or caregiver of the burden of securing, scheduling, and maintaining intensive therapy schedules around their other family responsibilities; (c) provide around the clock supervision; (d) provide an option for families who are no longer capable of sustaining family life, work, finances, and community life; and (e) provide temporary placements or respite for families and caregivers to regain their strength and well-being (Brown et al., 2006).

Brown et al. (2006), Freedman and Boyer (2000), Goodman (2003), and Siklos and Kerns (2006) have all argued that families of children with ASD and intellectual or other disabilities should be able to care for their child at home, without jeopardizing services. Out-of-home placements comprise a large part of the available disability resources, and the need for long-term care exceeds the facilities and services available which affects institutions, communities, and families (Parish & Lutwick, 2005; Parish et al., 2012b).

Global Perspectives on Deinstitutionalization and Federal Mandates for Child Placements

There is currently a global push to end institutional care. Current federal legislation mandates are actively seeking to prevent out-of-home placements; yet, funding for community support for families or respite services for caregivers in need of a break from their 24-hour responsibilities remain limited (Wulczyn & Orlebeke, 2006). Parish and Lutwick (2005) remind us that out-of-home placements have societal and economic implications. The argument against out-of-home placements is based on (a) outcomes, (b) unavailability of placements, (c) ability to connect with the community, and (d) cost containment (Goodman, 2003). Placements also comprise a large portion of the budget for persons with disabilities (Hostyn & Maes, 2007; Parish & Lutwick, 2005). Out-of-home, residential, kinship, or foster care placements may be considered in extreme cases if family life becomes unsustainable. Kogan et al. (2008) found that families of children with ASD rely on large networks of support in order to function.

Placement Considerations

Placement decision-making is a long-term process, which should not be confused with a child’s placement which is an event. The decision-making process for a child’s placement typically occurs years before a parent chooses to or chooses not to place a child outside of the home. Sometimes the placement decision is to raise the child at home. Decisions may also be undesired and made out of desperation.

Several models have been used to understand how parents and caregivers arrive at their placement decisions including family stress models, family resilience, ecological, and family quality of life models (Gallimore, Weisner, Bernheimer, Guthrie, & Nihira, 1993; Llewellyn, McConnel, Thompson, & Whybrow, 2005). A study by Morris, Abbott, and Ward (2002) of policy and practice in the placement of children with disabilities at residential schools revealed that education and social services officers believed that the most common reason for out-of-home placement was the effect of the child's impairments on the family.

When mothers and families are isolated from family, community, or supports and resources are insufficient, maternal stress may be negatively impacted. Goodman (2003), Hostyn, and Maes (2007), Nankervis et al. (2012), Parish and Lutwick (2005), and Peacock et al. (2012) have claimed that placements are more likely to occur with decreased maternal physical and mental health, aggressive behaviors, child or sibling safety risks, and impaired capabilities, or when the occupational performance of the mother or the family as a functioning unit. If the necessary services for the child with ASD and the family become unaffordable, then the family may be at risk for social and economic marginalization, and the child with ASD becomes at risk for out-of-home placement (Lucenko et al., 2008).

In the past, research on placements focused on stress models, the stressful event, resources and supports, perceptions of events, and coping strategies employed (Hoestyn & Maes, 2007; McCubbin & Patterson, 1983). Out-of-home placements of young children with ASD have substantial implications for community, society, policies, economics, institutions, and organizations in relation to resources, supports, service delivery, and cost (Brown et al., 2006; Goodman, 2003; Grey, 2002; Maes, Broekman, Dosen, & Nauts, 2003; Parish & Lutwick, 2005).

Brown et al. (2006) and Freedman and Boyer (2000) agree that families continue to be the most prominent caregivers and supporters of children with disabilities. Maternal stress, unmanageable households, and insufficient funds for supports and services can potentially place children with ASD at high risk for out-of-home child placement. Mothers experiencing maternal stress, who have children with ASD and behavioral problems, have been found to be at high risk for child placement. In addition, if their children also have co-occurring intellectual disabilities, then the risk moves from "at high risk" to "at severe risk for placements" (Lucenko et al., 2008, p. 1). Mothers in the "at severe risk" category as well as their families are also considered to be risk for social and economic marginalization (Fremstad, 2009; Koyanagi, 2007; Peacock et al., 2012).

Community and family resources and services can potentially remove certain barriers to facilitate participation of individuals with ASD and their families. Likewise, services such as respite services can give mothers and their families a break from 24/7 caregiver responsibilities to regain their strength and capabilities for improved occupational performance in their caregiving and mothering roles.

Out-of-Home Placements Related to Occupational Justice

Freedman and Boyer (2000) and Goodman (2003) have suggested that parents of some children with disabilities, who would prefer to raise their children at home, may be unable to do so because of inadequate support, resources, and services. Premature placement may be forced due to circumstances beyond the parents' control (Freedman &

Boyer, 2000; Goodman, 2003). Goodman (2003) stated that facing the decision to raise one's child at home or to opt for out-of-home placement is traumatic for a family. Furthermore, forced relinquishment due to inadequate services and supports to raise the child within the home is tragic. When families are no longer able to sustain family life raising the child with ASD within the home, out-of home placement may be viewed as a viable option but the availability of placement is limited (Freedman & Boyer, 2000; Goodman, 2003; McGill et al., 2006; Nankervis et al., 2012; Parish & Lutwick, 2005). A brief historical review of evolving societal attitudes and language of disability in society illustrated the complexities of community life, when living with disability.

Evolution of Disability Language, Attitudes, and Beliefs Over the Ages

Classical Period Through the End of the 19th Century

During the Classical period–1500 B.C. to 475 A.D., individuals with disabilities were described as idiots and considered to be inferior, and the solutions were death or abandonment. In the Medieval or Renaissance period, individuals with disabilities were labeled madmen or incurables, considered immoral, segregated, or used for amusement and eventually abandoned. Inhumane attitudes and practices prevailed until the Enlightenment period during the 17th and 18th centuries when new helping attitudes emerged and individuals with intellectual disabilities and *deaf-mutes* were considered to be capable of learning. The 19th century brought a rise in mental health institutions. In 1848, institutions trained, taught, socialized, and taught self-help skills focusing on resident life, not community living. Patients were segregated and the language of the times included words like *feeble-minded* and *un-teachable* (Minnesota Governor's Council on Developmental Disabilities, 2013).

20th Century Disability Beliefs, Attitudes, and Language

During the 20th century, there was a shift in the beliefs, attitudes, and language regarding disabilities. This change began when a national movement in the 1940s through 1950 promoted the concept that “The Retarded Can Be Helped” (Minnesota Governor’s Council on Developmental Disabilities, 2013, para. 1). Parents advocated on behalf of their children and won legal and civil rights for their children. Attitudes began to change when celebrities like John F. Kennedy and Pearl S. Buck, who had family members with disabilities, went public (Minnesota Governor’s Council on Developmental Disabilities, 2013). The popular culture and media was instrumental in bringing about change.

From 2000 to Present Times

Beginning in 2000 and through the present, the language used in the occupational therapy profession changed to *person first language* (e.g., from *disabled individual* to *individual with a disability*) highlighting that the individual is first and foremost is a human being (Minnesota Governor’s Council on Developmental Disabilities, 2013). In 2010, Rosa’s Law changed references in many federal statutes to replace the term *mental retardation* with the current term *intellectual disability*. Inclusiveness and accessibility in schools, recreation areas, hospitals, stores, public transportation, housing, and workplaces significantly improved over time as have societal attitudes; however, stigma in mental health still exists. According to Corrigan and Watson (2002), stigma is inherent in social structures as evidenced by the way laws, social services, and political and justice systems are structured and how resources shall be distributed (Corrigan & Watson, 2002).

The impacts experienced by caregivers and families of individuals with mental illnesses include participation restrictions, economics, and subsequently impaired occupational performance as a functioning family unit (Corrigan & Watson, 2002). Caregivers of young children with mental disorders such as ASD often experience significant economic, social, and occupational barriers impacting their participation and quality of life (Montes & Halterman, 2007, 2008a, 2008b; Nankervis et al., 2012).

Certain strategies have been suggested to reduce social stigma including protest, education, and contact. Education programs about mental illness have been shown to lessen negative stereotypes, improve social attitudes, and increase the public's ability to make informed decisions (Corrigan & Watson, 2002). However, Corrigan and Watson (2002) suggested that a potent stigma change, more likely to be sustained over time, is actual contact with individuals with mental and physical disabilities as neighbors and community members where stigma can be reduced and sustained through community integration.

The most significant changes in societal attitudes have occurred over the past 60 years fueled by parents and families of individuals, and professional advocates for individuals with disabilities, and subsequently, through key legislative initiatives to fund services and supports for individuals with disabilities, their families, and their caregivers (Minnesota Governor's Council on Developmental Disabilities, 2013).

Key Legislative Advances for Mental Health in the United States

Certain key legislative advances occurred in mental health in the United States. A significant act that changed the course of mental health in America was the Deinstitutionalization Act of 1955 which began with the closing of institutions (Koyanagi, 2007). Deinstitutionalization will be discussed in more detail in relation to its relevance to this study. From the 1960s to 1970, legislation was enacted to fund improvements for state institutions, community services, education, and job opportunities. In 1970, the number of institutions substantially dropped. Between 1955 and 1977, the population of individuals in institutional care dropped from 560,000 to

160,000 with deinstitutionalization. In the 1980s, health management organizations (HMO) and a business-like atmosphere lead to budget cuts for mental health services including community-based mental health services established after the closing of institutions (Minnesota Governor's Council on Developmental Disabilities, 2013).

Other legislative actions to protect individuals with mental and physical disabilities followed. Funding became available to educate the *educationally deprived* with the Elementary and Secondary Education Act of 1965. In 1973, Section 504 of the Rehab Act protected people with disabilities from discrimination in all federal programs. The 1975 Education for all Handicapped Act, now known as the 1990 Individuals with Disabilities Education Act (IDEA) as stated on the United States Department of Education website (http://idea.ed.gov), ensured that public schools offered all children with disabilities a free appropriate education in the least restrictive environment in relation to their individual needs as found on the U.S. Department of Health and Human Services website for the Office for Civil Rights (http://www.hhs.gov/ocr/) and by the Minnesota Governor's Council on Developmental Disabilities (2013).

To increase community participation and independence for individuals with disabilities, other legislative measures followed. The 1990 American Disabilities Act (ADA) promoted the goal of full participation and independence for persons with disabilities (Minnesota Governor's Council on Developmental Disabilities, 2013). The Olmstead Act of 1999 helped to increase community health services with its focus on increasing contact of individuals with mental disability with individuals without mental disability. Later on, the 2001 Olmstead Supreme Court Decision Interpreting the ADA declared that the federal government must assist states and communities in implementing the Olmstead Decision, as found on the ADA website (http://www.ada.gov). This included ensuring that all Americans had the opportunity to live close to their families and friends, to live independently, to engage in productive employment, and to participate in community, as found on the Northeast Independent Living Program website (http://www.nilp.org).

A brief contextualized history of the Deinstitutionalization Act of 1955 fueled by the government on behalf of human rights and also as a cost-cutting measure, was provided as a context in which to explore the phenomenon of out-of-home placement. Deinstitutionalization also provided a means to understand the complexities of community health and multiple aspects that influenced maternal health and family well-being, capabilities, and occupational performance, and ultimately, health decisions including out-of-home child placement decisions.

United States Deinstitutionalization Act of 1955: Historical Overview

The history of deinstitutionalization and its implementation provides a context in which to reflect on the current situations in this study of participating mothers raising children with ASD and intellectual disabilities. Deinstitutionalization is current because it exists today in its third phase. Several pivotal aspects converge during this third phase of deinstitutionalization that potentially place the mothers and families at greater risk for social and economic marginalization or forced placement decisions (Goodman, 2003; Koyanagi, 2007; Lucenko et al., 2008; Peacock et al., 2012). The following overview of the history of the deinstitutionalization policy is presented for a better understanding of the current concerns related to out-of-home placements.

Phase 1 of Deinstitutionalization began with a shifting of the locus of care for individuals with mental illness from state institutions back to their families and began with the closing of mental institutions. Phase 2 of Deinstitutionalization was to up the necessary community networks of support. Phase 3, the rights and recovery of Deinstitutionalization, exists today (Koyanagi, 2007). Phase 3 involves the full transformation from institutions to community health, and shifting the burden of care from federal to state control and to communities and families. At the same time, the United States is experiencing several emerging forces of change for consideration.

As states and communities prepare for full transformation to community health–the completion of Phase 3, the country is facing other challenges. The United States is economically compromised with ll.2% of the population living below the poverty level (United States Census Bureau, 2014, 56). For female householders with no husband present, the 2013 rate of women below poverty was 30.6% (United States Census Bureau, 2014, p. 56). At the same time, there has been a significant increase in diagnosed cases of ASD which has implications for increased needs for services and supports (CDC, 2012). A further complication is the impending implementation of a new, uncertain health system which has exponentially exceeded all budget projections (Orient, 2010). The implementation of the current health policy under present conditions poses a potential threat to the economy and to full-time employment (Day, 2006). This is because, to avoid the cost of mandatory coverage of employees, some employers are cutting company benefits by hiring part-time employees or cutting the benefits for employees' families (Orient, 2010).

Kogan et al.'s (2008) study on unmet needs explained that mothers of children with ASD depend upon wide networks of supports and services to survive. Goodman (2003), Lucenko et al. (2008), Koyanagi (2007), and Peacock et al. (2012) have claimed that if services are not available to help these families to function as a unit, the mothers of children with ASD and their families are at greater risk for social and economic marginalization or forced premature placement decisions.

Policy decisions made at this critical point may directly affect mothers and families in this study and other groups who rely on large networks of formal support services. An occupational perspective of health demands an examination of occupational beings in context of a full range of daily activities, but also transacting with the multiple environments that influence health, well-being, and occupational performance (AOTA, 2014). Deinstitutionalization offers a relevant historical context for examining current context to consider potential risks to the mothers in this study, their children with autism, and their families, and to understand potential solutions.

Deinstitutionalization, Phase 1: Shifting the Locus of Care

Long-term care has always posed major federal and state policy challenges. The first phase of Deinstitutionalization was the closing of institutions and shifting of the locus of care from institutions to communities and families. Deinstitutionalization provides the context to gain a conceptual understanding of the relation between long-term care funding and out-of-home placements (Koyanagi, 2007; Peacock et al., 2012).

Before the Deinstitutionalization Act of 1955 and into the mid-1960s, there were no special programs for children with special needs. Children with ASD and intellectual disability were often placed into institutional care (Koyanagi, 2007). Deinstitutionalization successfully met its Phase 1 goal of closing institutions; however, the policy makers failed to recognize the complexity of the deinstitutionalization process. They did not understand the vast changes needed in many related areas for a smooth transition to community health and to support the caregivers (Koyanagi, 2007;

Tabatabainia, 2003). Potential implications of deinstitutionalization policies were not carefully considered before implemented.

The evaluation criteria for the policy's success was bed reduction and recidivism rates to hospital care, meanwhile other outcomes including placements in other institutions such as jails or nursing homes and community quality of life measures were ignored (Koyanagi, 2007). Insufficient state, federal, and third party payer funding sources as well as insufficient coordination of multiple funding streams, left the released clients without the necessary support services to help them integrate into their communities. Even though hospitals reduced the number of beds, institutions initially remained opened due to employment along with worker and union responses (unions opposed decreased beds on behalf of their workers). The costs for running hospitals did not decrease despite reduced beds, because the institutions did not close (Koyanagi, 2007).

Areas impacted by deinstitutionalization included (a) housing; (b) essential services; (c) the connection between state policy and federal policy for community care; (d) failure to include quality of life in the community as a measure of success; (e) insufficient state, federal, and third party payer funding sources; and (f) insufficient coordination of multiple funding streams (Koyanagi, 2007; Tabatabainia, 2003). Deinstitutionalization goals for community were incongruent with the communities' goals. The positive aspects of deinstitutionalization were the closing of institutions and subsequent changes in community services and supports, more people with mental health living in the community, and somewhat reduced stigma of the disability (Koyanagi, 2007).

Deinstitutionalization, Phase 2: Community Supports

With the completion of Phase 1 of Deinstitutionalization and the shifting of the locus of care from institutions to the community, Phase 2 involved establishing community supports and multiple streams of funding. In 1975, the NIH established the community support program for planning a range of comprehensive services. Congress later enacted the Mental Health System Act, which would have expanded mental health services beyond clinical care, but the act was repealed and hundreds of thousands of people with mental illness were left without income.

Congress and the Supreme Court amended Supplemental Security Income/Supplemental Security Disability Insurance rules, and in the 1980s Medicaid's imbursement of rehabilitation services led to improved function of people with serious mental illness (Koyanagi, 2007). Disability rights were expanded and protected through the Fair Housing Act. The ADA of 1990 included Medicaid funding and more rights to benefits (Buck, 2003).

Deinstitutionalization, Phase 3: Rights and Recovery

Phase 3 began in 1993, 40 years after deinstitutionalization first began, with more state-controlled mental health resources for community care. Medicaid funding was the most significant source of support for public mental health systems. Recovery philosophy promotes the notion of living as normal a life as possible, despite serious mental illness which would include individuals with autism spectrum disorders and intellectual disability. The 2003 New Freedom Commission on Mental Health transformed mental health to a recovery-oriented system (Carter Center, 2003). Medicaid has become the primary financial resource for funding mental health services and reforming traditional long-term mental health care (Day, 2006; Cooke, 2006).

The NHI funded interdisciplinary panels to evaluate the best practices and existing evidence for the effectiveness of community-based health services such as Healthy Communities, 2020 (www.healthypeople.com). The NIH also conducted community-based studies to predict and reduce potential risks and to promote mental health (Cooke, 2006; Day, 2006). However, Day and Cooke as well as others argued that Medicaid—the most prominent funding source for a seamless transition from institutional to community health—and its policies created barriers to the transformative process (Cooke, 2006; Day, 2006; Onken, Dumont, Ridgeway, Dorman, & Ralph, 2002; Unützer, Schoenbaum, Druss, & Katon, 2006).

Medicaid policies which are based on a medical model, do not support implementing recovery goals which are based on best practices in community health. Recovery goals include self-determinacy, flexibility, and freedom of choice measuring success with transformation to full community health and participation in community life, despite disability. Medicaid accounted for 35% of all public expenditures for mental health services in 2001 and 50% of all public funding for mental health services in the United States in 2003; this percentage is expected to rise to 75% by 2013 (Day, 2006). Public mental health systems have slanted towards Medicaid-covered individuals and services and non-Medicaid funding did not keep up; therefore, there is a disparity in mental health coverage between low-income individuals who do and low-income individuals who do not qualify for Medicaid (Day, 2006).

System changes have forced fee-for-service providers to seek out Medicaid clients to ensure necessary revenue for crisis stabilization and flexible community support services. However, Medicaid benefit plans and provider qualifications reflect evidence-based philosophies rather than community health best practices; therefore, multi-systemic transformation has not been applied across all states (Day, 2006). According to Day (2006), Medicaid's service definition limitations actually provide disincentives for employment, which professionals and consumers regard as a significant aspect of recovery in mental health. Day (2006) considers such disincentives a significant policy oversight in regard to sustainability of recovery programs in mental health.

Policies and Funding Related to Maternal Health for the Mothers

The research has consistently established that Mothers of children with ASD often experience depression (Crowe & Florez, 2006; Gallimore, Keogh, & Bernheimer, 1999; Larson, 2000, 2006; Tominik, Harris, & Hawkins, 2004; Werner DeGrace, 2004). However, Medicaid funding for depression often consists of medication distributed by primary care physicians without the additional mental health services to treat the condition (Day, 2006). Again, the Medicaid based on a medical model created barriers to the recovery model and best community mental health practices, and is incongruent with the recovery model and with community health philosophies and best practice models (Day, 2006; Onken et al., 2002; Unützer et al., 2006). Wraparound services were conceived in the 1980s and intended to be an alternative to institutional care, helping families with children with challenging behaviors to be able to function within the community.

Sometimes described as an array of services, wraparound is actually an approach based on the following 10 underlying concepts: (a) Family voice and family choice, (b) team-based; (c) natural supports, (d) collaboration, (e) community-based, (f) culturally competent, (g) individualized, (h) strength-based, (i) persistent, and (j) outcome-based. These 10 elements comprise wraparound processes and practice. Meeting all 10 elements, wraparound services may include respite services, personal aide, occupational therapy services, speech services, behavioral services, educational services, psychological service, sibling services, certain medical evaluations, and other community-based services.

Deinstitutionalization’s Policy Assumptions and Errors

The primary problem during the early stages of mental health legislation was that policy makers neglected to consider the difficulty of finding resources to meet marginalized groups of people living in sites scattered within the community (Koyanagi, 2007). Multiple but uncoordinated funding sources were not organized to provide comprehensive service packages. Large federal programs were not controlled by those responsible for mental health care, so other interests often took precedence over mental health policy. For this reason, critical housing, disability, education, and employment programs often failed to provide appropriate access for individuals with mental illness (Koyanagi, 2007).

Koyanagi (2007) stated that cost-cutting philosophies led to minimizing services rather than facilitating best practices in mental health care (Koyanagi, 2007). Lessons learned during Phase 1 of Deinstitutionalization cautioned society to predict risks and provide safety nets and sustainable funding sources to protect vulnerable populations. Deinstitutionalization’s policy goals appeared to be humane and ethical; however, there was an underlying incentive to cut costs and shift responsibility back to families and communities. Koyanagi (2007) stated that insufficient risk assessment, transition planning, and funding for community integration led to a plethora of unforeseen consequences that still exist today, nearly 60 years later.

Deinstitutionalization’s Unforeseen Community Consequences

The closing of institutions during Phase 1 of Deinstitutionalization lead to two-thirds of patients discharged from institutions returning home. Approximately 1% of the released individuals with serious mental illnesses were incarcerated. Families and communities were also affected by the unintended consequences of the patients' sudden release from mental institutions. Families did not receive the necessary support to care for their loved ones and communities were left unprepared to address the risks or impacts of the sudden release of clients from institutional care, frustrated with the increased substance abuse and crime in their neighborhoods. Unintended consequences of Phase 1 of Deinstitutionalization included drug and alcohol abuse, homelessness, crime, and overcrowded jails (Koyanagi, 2007). Housing, disability education, and employment programs all became necessary (Goodman, 2003; Koyanagi, 2007; Peacock et al., 2012).

Funding Long-Term Health Care and Community Health

Long-term care funding has continually posed major federal and state policy challenges (Koyanagi, 2007; Peacock et al., 2012). Motivated by the need to cut long-term health care costs and the desire to shift the locus of care back to the families and communities, deinstitutionalization was implemented. The government assumed that families would be prepared to assume full responsibility for caregiving, its related caregiving costs and subsequent expenses, without supports or services. Without the necessary risk prediction, safety networks, and services and supports to assist caregivers to care for their family members with special needs, the expected shift in the locus of care did not occur. The individuals with special needs and their communities experienced the consequences of a decision to implement policy which was based on a faulty assumption and a lack of planning and risk prediction.

Lessons Learned

Deinstitutionalization’s history provides a powerful, contextually-based perspective of the complexities involved in planning for Healthy Communities, 2020 and community health funding. Deinstitutionalization also offers a background to consider mothers’ perspectives of the decision-making for out-of-home child placements. Koyanagi (2007) described deinstitutionalization as a cautionary tale for those who make distributive decisions, and to policy makers to predict the risks and consider the potential, complex implications of their proposed policies before they are implemented. Koyanagi stated further that sustainable funding sources and wide safety networks of support need to be in place before policies are implemented. The history of deinstitutionalization’s policy failures can serve to guide mental health policy in the United States, or they can be ignored and potentially repeated (Koyanagi, 2007).

Sustaining Family Life: Mothering a Child With Autism and Intellectual Disabilities

Unsustainable family life due to unmanageable households, strained finances, and maternal stress places children with severe ASD and behavior problems at high risk for out-of-home placement or at severe risk if they have co-occurring intellectual disabilities (Lucenko et al., 2008; Nankervis et al., 2012). The families of mothers with maternal stress who are raising children with severe ASD with extreme sensory and behavioral reactions and co-occurring intellectual disabilities at home, are also at severe risk for social and economic marginalization (Koyanagi, 2007; Lucenko et al., 2008; Nankervis et al., 2012; Peacock et al., 2012). An estimated 10-15% of children with intellectual disabilities are also at higher risk of developing challenging behaviors (Alborz, 2003).

Montes and Halterman’s (2008a) population study of mothers of children with ASD and intellectual disabilities found that mothers rely on multiple services simply to manage their households and their day-to-day family life. Kogan et al. (2008) and

Montes and Halterman (2008b) stated that without the necessary services and supports, mothers are left without feasible options or financial resources to care for their children with ASD while supporting the needs of the entire family.

Family Supports and Services

The National Center on Birth Defects and Developmental Disabilities (2005), Kogan et al. (2008), and Liptak et al. (2006) found that children with ASD and their families require a wide range of interventions and supports. The wraparound approach, described earlier, was designed to avoid out-of-home placements by helping families with children with challenging behaviors to be able to function within the community. A wraparound approach may include early intervention services, either home-based or center-based, occupational therapy, speech therapy, educational therapy, behavioral therapy, psychological and social services, respite and sibling services, and certain medical evaluations.

Impacts of Autism on Maternal Health and Occupational Performance

Mothering Roles

Dunbar and Law (2007) stated that within the home a mother is faced with balancing multiple roles within ever-shifting contexts and environmental influences. Mothers are challenged to support children’s diverse developmental needs of all her individual children while maintaining households, preparing meals, and meeting schedules. Mothering occupations also need to support the occupational performance of the family as a functioning unit (Law & Dunbar, 2007). Mothering a child with ASD can challenge the mothering role in terms of disrupted household routines, extra time in care-giving activities, and increased time in seeking, scheduling, and attending various therapy sessions and medical appointments. Creating opportunities for participation and maintaining calm, stable households when raising a child with ASD is challenging. Mothers of children with ASD take on additional roles as child advocates, service coordinators, teachers, and child development therapists (Sawyer et al., 2010).

Mothering Routines

Routines are patterned behaviors that have instrumental goals which give life order such as brushing teeth or completing a series of activities. Mothers and their children participate in familiar, daily routines. These routines can be the typical dressing and bathing routines or more symbolic and meaningful rituals such as bedtime prayers (Kellegrew, 2000; Segal, 2004; Segal & Beyer, 2006). Young children depend on their mother's structuring of home routines for reinforcing their emerging skills, and mothers continually gage their children's skill acquisition and mastery throughout the process (Kellegrew, 2000; Pierce, 2003a; Segal, 2004; Segal & Beyer, 2006). Dunbar (2007) stated that mothers must also consider their young children's human-environment which is of particular importance in understanding the need to support maternal health and well-being. The child's well-being is uniquely dependent upon the mother and potentially influenced by the state of maternal health status and well-being (Dunbar, 2007).

Ludwig (1997) reminds us that since the earliest writings in occupational therapy literature, routines have been promoted as being therapeutic in terms of organization of time and occupations. In Ludwig's (1997) qualitative study using grounded theory methodology to explore how routine facilitates well-being in older women, findings revealed that routines were linked to nine adaptive outcomes. These were identified as follows: "(1) meet obligations; (2) maintain activity level; (3) maintain health; (4) look forward to things; (5) maintain control; (6) balance work, rest and play; (7) accomplish and achieve; (8) feel good about oneself; and (9) provide continuity" (Ludwig, 1997, p. 213).

Ludwig's (1997) grounded theory study findings provide evidence to support the propositions of occupational therapy founders such as Meyer (1922/1977), Reilly (1962), and Slagle (1922) regarding the use of routine to balance work, rest, and play. Ludwig's (1997) study suggested that these adaptive and meaningful strategies that contribute to well-being routines can be culturally influenced and personally meaningful. Ludwig grounded theory study of how routines promote well-being and meaning in older women discovered that the participating mothers used routines as adaptive strategies to achieve the nine specific outcomes related to physical and mental health (Ludwig, 1997).

Kellegrew (2000) stated that daily routines are beneficial for all children in terms of development and skill acquisition; however, some children are more sensitized to home routines which can be critical for skill acquisition and maintenance. Bernheimer, Gallimore, and Weisner's (1990) ecological model and ecocultural theory used daily routines of the home as a unit of analysis. Gallimore, Bernheimer, and Weisner (1999) stated that sustaining daily roles and routines are major family functions, not to be confused with coping or stress. Dunst, Trivette, Humphries, Raab, and Roper (2001) and Dunbar and Werner-DeGrace (2001) stated that family life provides opportunities for child learning and development and that the role of the service provider is to empower families to expand learning and developmental opportunities for children. Dunbar (1999) and Law, and Dunbar (2007) remind us that mothers are considered a child's human environment, reinforcing mothers' key roles in children's development.

Larson (2000) studied mothers' daily occupations, roles, and routines and determined that in the process of orchestrating occupations, roles, and routines, the mothers “made sense of their past, designed their present, and planned for their future” (p. 1) and that of their family members. Werner DeGrace (2004) phenomenological study of the everyday occupations of children with ASD found family routines to be a stabilizing force for the family, a means for family identity to develop, and a protective force that promotes family health. Larson (2004, 2010) and Segal (2004) found that routines have also mitigate against stress; furthermore, to add a measure of protection to family well-being, mothers’ routines are of particular concern when planning family-centered interventions in the home with a child with ASD.

Rituals

Rituals are special occupations that mothers and fathers use to instill in their families a sense of belonging and family identity. Kellegrew (2000), Markson and Fiese (2000), Larson (2006), and Werner DeGrace (2004) agree that rituals provide a mechanism for building family identities. Rituals’ elements of symbolic and affective meaning are strengthened by the families’ participation and performance of the rituals, which construct and affirm family identity. Rituals have been found to promote well-being of family members and to act as a protective factor against anxiety. Conversely, disruptions in rituals have a negative effect on the family's well-being. Rituals may include family traditions and religious traditions, mealtime, and annual celebrations or birthdays. Children with ASD may experience difficulty participating in such events due to their extreme sensory and behavioral reactions, report difficulties and accommodations in public outings (Larson, 2006; Werner DeGrace).

Mothering Occupations and Co-Occupations

Larson (2006, 2010) and Werner DeGrace (2004) studied mothering occupations and co-occupations which can be observed as mothers’ use their daily household routines while the children play and learn, satisfying the needs and goals of both mother and child. Routines are used by mothers to create order and a sense of security in their homes. A common symptom in children with ASD is their propensity for imposing rigid, unhelpful rituals or obsessive routines on others, which can greatly interfere with mothers' household routines and with the co-occupations of siblings (Larson, 2006; Werner DeGrace, 2004).

Space, Place, Time, Pace, and Temporality

Occupational scientists have sought to understand the nature of occupations and how they are arranged within the daily lives of people (Primeau, 1998; Primeau, Clark, & Pierce, 1989; Pierce, 2001, 2003b; Yerxa et al., 1989). As mothers carry out their mothering responsibilities and household tasks, they orchestrate a wide range of occupations. Occupational engagement requires attention, muscular energy, and focus on available resources. Blanch and Parham (2001), Pierce (2001, 2003a), and Zemke (2004), described how mothers use scaffolding of tasks to achieve their home maintenance goals and facilitate their children's development. In this way they create safe play spaces and often embed play activities within their household work; thus, they are able to carry out several obligations at once.

Rowles (1991) described how the quality and intensity and duration of experience with a place can make that place become a component of self, layered with history and meaning of life experiences in that place. Tuan (1977) stated that space is transformed into place to give it meaning. Hasselkus (1998) similarly defined the act of creating and maintaining places as place-making.

Time Use for Mothers of Children with Autism

Throughout the literature was a common theme of parents reporting on the endless, exhausting fight for necessary services and fears about the loss of services. The Department of Health and Human Services found that 10% of families spend more than 11 hours per week arranging or coordinating services (Magasi, 2012; Rosenau & EveryChild, Inc., 2010). A large body of evidence throughout the literature supported that parents need the accessible supports and resources to raise their children within the home, without fear of jeopardizing services to do so (Blacher & McIntyre, 2006; Brown et al., 2006; Freedman & Boyer, 2000; Goodman, 2003; Gray, 2002; Nankervis et al., 2012; Parish & Lutwick, 2005; Siklos & Kerns, 2006).

Crowe and Florez (2006) found that mothers of children with disabilities averaged 13.1 more hours per week in caregiving activities than mothers of children without disabilities (Crowe & Florez, 2006). Less hours of sleep and more hours in caregiving activities can affect a mother's well-being and occupational performance. Sleep disorders in ASD may also affect the occupational performance of other family members if the child wakes them out of their sleep. Sawyer et al. (2010) studied the time demands of caring for children with ASD in relation to maternal mental health. After adjusting for the effects of other variables including children's ages, mothers' social support, children's behavior problems, it was time pressure that had a significant positive relationship with maternal mental health, as opposed to hours of caregiving.

Surveillance

Rowles (1991) also discussed the relevance of space in surveillance. As a person develops routines in and out of their home, neighbors may take notice that an elderly person sits on their porch at a particular time of day. If then, this person does not sit on the porch one day at their usual time, this could potentially trigger a response from a neighbor who may then check in on their neighbor (Rowles, 1991). For mothers of children with ASD who wander or bolt to unsafe places, Rowle’s (1991) concept of surveillance may potentially be applied to add a layer of protection for the children, if neighbors are made aware of the children’s tendencies to wander.

For mothers of children with ASD and intellectual disabilities, time can become an object of stress. The necessary pace to accomplish all that needs to be accomplished is often more than the time available to them (Kellegrew, 2000). Routines are often interrupted and activities of daily living also can take longer when child has a disability (Larson, 2006). Mothers experience added time constraints applying for services, seeking service providers, scheduling and coordinating medical and therapy appointments for the child (Rosenau & EveryChild, Inc., 2010).

Maternal Stress and Health Status of Mothers of Children with Autism

Blacher and McIntyre (2006) examined the impact on 282 caregivers’ well-being when caring for individuals with moderate to severe intellectual disability and other disabilities. ASD and intellectual disability were associated with the highest scores in multiple behavior problem areas as well as reports of lower well-being for mothers of children with ASD. Research has established that maternal stress is prevalent among mothers of children with ASD, particularly when the child exhibits extreme sensory reactions and behavioral problems (Baker et al., 2005; Beck, Hastings, Daley, & Stevenson, 2004; Capara & Steca, 2006; Larson, 2006; Lloyd & Hastings, 2008; Montes & Halterman, 2007; Neece & Baker, 2008; Oelofsen & Richardson, 2006; Tomanik, Harris, & Hawkins, 2004; Werner DeGrace, 2004).

Decreased maternal well-being can negatively affect the well-being, capabilities, and occupational performance of the mothers, and subsequently, the families of children with ASD and intellectual disability being raised within the home (Blacher & McIntyre, 2006). Children with disabilities are typically raised at home now due to advances in interventions and home is also considered the most appropriate environment for the children's social and psychological health.

Sawyer et al. (2011) cited the omission of considering the risk factors for maternal mental health as a major failure of home-based care. Home-based care also reduces the economic cost of funding residential care. However, the unpaid mother or caregiver experiences greater time pressure in maintaining households, schedules, and meeting the needs of other family members. Delayed or interrupted routines and diminished rituals may leave little or no time to connect socially or seek employment or leisure activities.

Donovan et al. (2005) conducted a retrospective study of 38 mothers of children with disabilities using the Canadian occupational performance measure (COPM). The investigators were interested in how occupational goals of mothers of children with disability were influenced by temporal, social, and emotional contexts. Six themes emerged from qualitative analysis of the data from the COPM as follows: (a) Doing and being alone: Taking care of my own health and well-being; (b) doing and being with others: Expanding my social life; (c) improving my child's quality of life; (d) household management: Organizing time and resources; (e) balancing work, home, and community responsibilities; and (f) sharing the workload. The above themes and patterns denote occupational imbalance and inadequate discretionary occupations. Extra time for necessary work is often taken from sleep, which leaves the mothers sleep-deprived and physically exhausted. Occupational imbalance potentially leads to diminished well-being and life satisfaction (Donovan et al., 2005).

Among parents of typically developing children, parents' level of concern about their children as they reach adulthood typically decreases; however, for parents of children with ASD reaching adulthood, parental concerns remain high. Parents worry about who would care for the children with ASD if something happened to them. The level of concern in parents of child with ASD reaching adulthood is nearly twice as high when compared to the parents of children without ASD in all of the following areas: (a) independence, (b) financial well-being, (c) quality of life, (d) employment, (e) housing needs, (f) education, and (g) health. Seventy-eight percent of parents of children with ASD worry about their children fitting into society (Harris Interactive, 2008).

Safety Concerns for Children with Autism and Their Siblings

Limited Safety Awareness

As discovered on their website (http://www.autism.org.uk), the National Autistic Society warned caregivers that children with ASD and intellectual disabilities may have a limited sense of safety awareness as observed in head-banging behaviors. Some individuals with autism have little or no safety awareness as evidenced by their fascination with objects that exist in everyday environments such as electrical sockets, radiators, and hot water. Many have an obsession with water and turning faucets on and off, and could potentially scald themselves. Mcllwain and Fournier (2012) found that children with ASD's obsession with water also places them at higher risk for potential drowning. Law, Anderson, and Kennedy Krieger Institute (2011) reported that two out of three parents of children with ASD reported their missing children had a "close call" with a traffic injury, and 32% reported a "close call" with the potential for drowning due to wandering or elopement (Mcllwain & Fournier, 2012).

Aggressive Behaviors Towards Others and Self-Injurious Behaviors

Self-injurious behavior can be seen in children with ASD. Children with ASD may bite, pinch, and slap themselves or others. Other behaviors include inappropriate sexual expressions, aggression, and violence (Grey, 2002). Other self-injurious behaviors include head banging on floors, walls, or other surfaces, hand or arm biting, hair pulling, eye gouging, face or head slapping, skin picking, scratching or pinching, or forceful head shaking. Individuals who have severe autism and co-occurring conditions such as intellectual disabilities may engage in even more severe self-injurious behaviors. During times of stress, illness, or change these challenging behaviors may escalate. According to the National Autistic Society, behavioral intervention approaches may not always be appropriate to address this situation due to the complex nature of the behaviors and the level of risk to the individual's safety.

Bullying of Children with Autism

According to the United States Department of Education website (http://idea.ed.gov), children with ASD are bullied by their peers at a rate three times greater than that of their peers. Children with ASD often have co-occurring conditions such as allergies and epilepsy. Children with epilepsy and/or allergies are also more likely to be bullied more than their peers (Hamiwka et al., 2009). Bullying behaviors can escalate to *disability harassment*, which is prohibited under Section 504 of the Rehabilitation Act of 1973 and Title II of the ADA of 1990 as found on the United States Department of Education's website.

In addition, according to the United States Department of Education's website, disability harassment includes any intimidation or abusive behavior toward a student based on their disabilities which creates a hostile environment that interferes with or denies students' participation. Disability harassment may include verbal harassment, physical threats, or threatening written statements which can restrict or interfere with the receipt of benefits, services, or opportunities in the institution's program. Children who are bullied are more likely to experience depression, anxiety, and health complaints. They may have increased feelings of sadness or changes in sleeping and eating patterns. Students who have been bullied have also demonstrated decreased academic achievement and school participation, or they may miss or skip school.

Wandering/Elopement and Bolting

Dr. Law and colleagues (2011) conducted research on elopement and wandering with 800 parents of children with autism to explore the topic of elopement and wandering. Law and colleagues found that 48% of the children with ASD attempt to elope from a safe environment. This statistic is significant particularly because greater than one-third of the children with autism are rarely able to communicate their name or phone number (Law et al., 2011).

Sixty-two percent of the families whose children eloped reported that the potential risk of elopement prevented them from enjoying activities outside of the home. Wandering or elopement was ranked among the most stressful ASD behaviors by 58% of the parents of children with ASD who elope from home. The top five parent-reported reasons for elopement for the child with ASD are as follows:

1. Enjoys exploring (54%);
2. Heads to a favorite place (36%);
3. Escapes demands anxieties (33%);
4. Pursues special topic (31%); or
5. Escapes sensory discomfort (27%) (Law, 2011).

Wandering was assigned a new medical diagnostic code V40.31 (wandering in

Diseases was classified elsewhere), as a new subcategory in DSM-5 (APA, 2013). Billstedt, Gillberg, and Gillberg (2005); Gillberg, Billstedt, Sundh, and Gillberg (2010); Howlin, Goode, Hutton, and Rutter (2004); and Mcllwain and Fournier (2012) have stated that safety concerns about children with ASD who elope creates another barrier to social participation for mothers, caregivers, and their families who are already at risk for social isolation. Multiple barriers to participate and function as a family unit over time can lead to a families' marginalization (Fremstad, 2009; Peacock et al., 2012).

Accidental Drowning

Mouridsen, Bronnum-Hansen, Rich, and Isager (2008) found the mortality rate among people with ASD to be twice as high as the general population. The study found that higher ASD death rates were largely attributed to accidental drowning. In 2009, 2010, and 2011 accidental drowning accounted for 20 out of 22 total deaths reported in the United States in children with ASD who were 14 years old or younger (Law et al. , 2011).

Serious Medical and Mental Conditions

Children with ASD may have serious medical conditions such as seizure disorders, gastrointestinal disorders, and allergies which need to be monitored by physicians, adding to the mothers' busy schedules. Levy et al.'s (2010) population study found that children with ASD and with co-occurring intellectual disabilities were at greater risk than children with ASD without co-occurring intellectual disabilities for being diagnosed with mental and psychiatric disorders over time.

Family Occupations: Restricted Freedoms and Social Participation

Sensory Disturbances and Behavioral Responses

Behaviors associated with the ASD can disrupt family flow in everyday household routines and restrict the family's participation in social, leisure, and community events and outings (Larsen, 2006; Werner DeGrace, 2004). Parents have also reported that some of the most difficult behaviors include poor communication skills and inappropriate and embarrassing public behavior. Parents commonly cited the inability to socialize as a family as being one of the most difficult impacts of ASD (Dillenburger, Keenan, Doherty, Byrne, & Gallagher, 2010). Other parents reported that disruptions and destruction in the home is stressful including glass breaking. Inappropriate or socially unacceptable behaviors such as obsessions related to eating, toileting, smearing, hand-slapping, or putting inedible objects in the mouth can be difficult for the family (National Autistic Society, n.d.).

Unpredictable Outbursts or Violent Behaviors Directly-Indirectly Affecting Siblings

Children with ASD may react from oversensitivity to noise crowds, sights, sound, touch, or smells. They may react by pinching, kicking, or slapping others. In some cases they may spit or pull hair. Sometimes they may exhibit self-injurious behavior. These behaviors may be threatening to siblings who may have been on the receiving end of these behaviors at times (National Autistic Society, n.d.).

Siblings Impacts and Risks

Conway and O'Neil (2004) interviewed siblings of children with special needs to explore the negative and positive experiences of siblings of children with special needs who had been placed outside of the home. The researchers expected that aggression would be the worst experience related to living with a child with special needs, but were surprised to find that the lack of personal space was rated as the highest negative memory by 40% of the respondents. Sleep deprivation was rated by 17% of sibling respondents as their worst experience. Important to note is that 65% of the siblings interviewed reported that they missed their brother or sister being there, being together as a family, and being able to share and play with their brother or sister (Conway & O'Neil, 2004).

Siblings of children with ASD were found to be more embarrassed in the presence of peers than siblings of children with other intellectual disabilities such as Down syndrome (Hastings, 2003). Professionals and parents agree with the view that siblings of children with ASD have feelings of being neglected and treated unfairly, and expressed worry about the future associated with ASD. However, professionals viewed siblings as more sensitive and resentful, with feelings guilt and fear while parents' concerns were more about siblings' feelings of engagement (Dillenburger et al., 2010). Parents of younger children reported greater concern about ASD impact on siblings.

Hastings et al. (2005) conducted a systematic analysis of psychological functioning of children with autism, their parents, and their siblings without disabilities. Findings suggested that the siblings were at increased risk for behavioral and emotional disturbances. Dillenburger et al.'s (2010) study of siblings of children with ASD supported these findings. Hastings et al. (2005) suggested that viewing the interdependence of relationships between family members and the child with ASD may suggest future research designs that could be more useful in identifying complex interactions.

Unmet Needs of Parents

Siklos and Kerns (2006) compared the unmet needs of parents of children with Down syndrome and ASD. Both groups experienced similar unmet needs; however, the ASD group reported significantly less satisfaction with the help received since the child was diagnosed. Ninety-three percent of the parents with children with ASD reported that they did not receive adequate financial support for therapies compared to 63% of the parents in the group with Down syndrome (Siklos & Kerns, 2006, p. 928). Overwhelming, evidence led the authors to conclude that formal services and programs were important for the families' successful adaptation to ASD (Siklos & Kerns, 2006). The evidence supports that mothers and caregivers of children with ASD spend a great deal of time trying to gain access to services (Ekas, Lickenbrock, & Whitman, 2010; Magasi, 2012; Nankervis et al., 2012).

Interprofessional and interdisciplinary communication, research, and advocacy are important aspects of quality service provision for the children with ASD. Strong communication skills and systems are also necessary for effective programing and service provision and for collaborative, integrated service provision. An example would be the World Health Organization (WHO, 2013) *Exposure Draft Manual of WHO – ICF - for comment*.

Family Routines and Autism

Living with a child with ASD impacts the families' occupational performance as a functioning unit and makes it difficult for the families to maintain orderly households and meet schedules while meeting the individual needs of each family member (Larsen, 2006; Werner DeGrace, 2004). A common theme among mothers and families of children with ASD is the difficulty creating routines that help to sustain family life (Larson, 2006; Werner DeGrace, 2004).

During daily routines of bathing, dressing, grooming, and eating, mothers are able to monitor their children's development. However, when routines are delayed or disrupted due to sensory or behavioral reactions, teaching opportunities are frequently abandoned to allow mothers to keep pace with their busy schedules and time press

(Kellegrew, 2000). Disruptions in daily routines can lead to a lack of order and a decreased sense of security (Segal, 2004; Segal & Beyer, 2006). Family routines and rituals contribute to the family's sense of security and calm, while improving the occupational performance of the family as a functioning unit. Conversely, restricted routines and rituals can have the opposite effect (Segal, 2004; Segal & Beyer, 2006; Hastings et al., 2005).

Autism and Family Rituals

Segal and Beyer (2006) described family rituals as occupations that are have meaning to the participating individuals such as family dinners, bedtimes, birthdays, religious and national holidays, and celebrations. Family rituals such as holidays and birthday celebrations provide a sense of identity as a family and a sense of belonging (Segal, 2004). Werner DeGrace (2004) found that some families of children with ASD felt the effort required to go out as a family given the nature of ASD, was sometimes not worth even attempting an outing, which led to decreased opportunities to participate as a family. If missed opportunities for meaningful engagement and special family events occurs too frequently over time, families may experience occupational deprivation.

Sleep Deprivation

Sleep is an area of occupation defined by the American Occupational Therapy Association (AOTA, 2008), occupational therapy practice framework (OTPF). Understanding what promotes and interferes with sleep is of concern to occupational therapist. Sleep deprivation can negatively affect occupational performance. Sleep problems are a major health concern in children with ASD (Goldman, Richdale, Clemons, & Manlow 2012; Phetrasuwan & Miles, 2009). Children with ASD prevalence rates for sleep problems are 50-80% compared to typically developing children at 9-50%

(Couturier et al., 2005; Krakowiak, Goodlin-Jones, Hertz-Picciotto, Croen, & Hansen, 2008; Richdale & Schreck, 2009).

According to the NIH sleep problems are recognized as a coexisting symptom with ASD that can influence the severity of the disorders (Parthasarathy & Vitiello, 2012). In Goldman et al.'s (2012) population study of 1,859 children participating in the Autism Treatment Network, parents completed the Children's Sleep Habits Questionnaire (CSHQ), a validated parental questionnaire of 45 items related to clinical sleep complaints. Younger children had more bedtime resistance, sleep anxiety, parasomnias, and night wakings. Significant findings on the sleep questionnaire also included sleep duration and daytime sleepiness. Other problem areas included waking another child, waking in a negative mood, seeming tired, being afraid of sleeping alone, or needing a parent in the room to sleep (Goldman et al., 2012).

Dangerous Combination of Wandering Behaviors and Sleep Disorders

Forty-five percent of parents of children with ASD who wander/elope reported that they suffered sleep disruption due to fear of elopement (Mcllwain & Fournier, 2012). Couturier et al. (2005), Nicolson (2005), Krakowiak et al. (2008), and Richdale and Schreck (2009) found that wandering behaviors in children who have co-occurring sleep disorders can contribute to the fear and worry experienced by those parents of children with ASD. Crowe and Florez (2006) found that mothers of children with disabilities spent 8 hours per week less time at rest or sleep than mothers of children without disabilities. In families with children with ASD, sleep deprivation was a health concern for family members.

Gabriels, Cuccaro, Hill, Ivers, and Goldstein (2005) and Goldman et al. (2009) reported associations of ASD sleep behaviors with daytime behaviors. Short sleep duration has been associated with stereotypic behavior and social skill deficits (Schreck, Mulick, & Smith, 2004) and sleep onset delay with anxiety (Paavonen et al., 2008).

Implications for Sensory Integration/Occupational Therapy [SI/OT]

Reynolds, Lane, and Thacker (2011) conducted a study to examine the relationship between physiological responses to sensation and sleep in 55 children with and without ASD using a descriptive cross-sectional design. The results suggested a link between sleep and sensory modulation deficits, linking sensory modulation disorders with sleep deficits which may have implications for the treatment of sleep dysfunction. Schreck, Mulick, and Smith (2004) and Paavonen et al. (2008) found that sleep deprivation could exacerbate sensory disturbances and behavioral responses in children with ASD and negatively impact their occupational performance in terms of stereotypic behavior, social skills deficits, and anxiety.

Autism’s Impact on Participation

The Easter Seal’s Living with Autism study conducted an online survey of 1,652 parents of children with ASD and 917 parents of children without ASD. Parents of children with ASD were found to have concerns about their children fitting into society. Specifically, they found that few parents of children with ASD feel that their children will be able to (a) make their own life decisions, (b) have friends in the community, (c) have a spouse, (d) be valued by their community, (e) participate in activities, (f) have strong religious affiliations, or (g) develop age-appropriate recreation skills (Harris Interactive, 2008).

Economic Impacts of Autism

Decreased employment opportunities. Autism can substantially affect a family's financial situation. A nationally representative study estimated that households which include a child with autism earn 14% less income (Montes & Halterman, 2008a, p. 202). Liptak et al. (2006) found that besides higher medical expenses for children with ASD, they also required more educational and behavioral services. Annual medical expenses for children with autism were $6,132.00 compared to $860.00 for other children; thus, having a negative impact on family economics (Montes & Halterman, 2008a, p. 202). If the family becomes unable to sustain a manageable household or to afford the necessary services for their child with ASD, the child becomes at greater risk for out-of-home placement (Freedman & Boyer, 2000; Goodman, 2003; Nankervis et al., 2012). Parents of children who would prefer to keep their child at home may be unable to do so because of insufficient supports, resources, and services (Brachlow, Ness, McPheeters, & Gurney, 2007). Those parents who raise their children at home without sufficient supports and services are at severe risk for economic and social marginalization, while options for permanent or temporary placements and respite are reduced (Lucenko et al., 2008; Nankervis et al., 2012; Peacock et al., 2012).

Childcare problems. Montes and Halterman (2008b) population study found that issues related to ASD can affect employment opportunities. To illustrate, "39% of parents reported quitting a job, not taking a job, or greatly changing a job, due to having a child with autism" (Montes & Halterman, 2008b, p. 207). Montes and Halterman's (2008b) population study involving parents of 16,282 preschool children also found that autism is associated with a higher use of childcare services. A statistically significant higher use of Head Start programs was also uncovered in this study. This significant finding may be due to the Head Start program’s provision of services such as occupational therapy and speech therapy with no out of pocket expense. In addition, Head Start programs have regulations against expulsion for negative behavior (Montes & Halterman, 2008b).

Medical expenses. Liptak et al. (2006, p. 871) stated that in addition to children with ASD needing more educational and behavioral services than most children, the medical expenditures were also higher. Children with ASD may have gastrointestinal problems, allergies, and seizure disorders. Peacock et al.'s (2012) population study found the average annual medical costs for Medicaid-enrolled children to be $10,709 per child, about 6 times higher than for children without ASD. Children with ASD and co-occurring intellectual disabilities had average medical costs of about $19,200 (Peacock et al., 2012).

Family Well-Being, Quality of Life, and Occupational Performance

Marriage. Parenting children with ASD and intellectual disabilities can be particularly challenging for both mothers and fathers; reports of marital stress were consistent throughout the literature. Lofholm (2008), Mitchell (2006), and Winfrey (2007) found that some parents of children with ASD are under the impression that there is an 80% rate of divorce due to a published claim that was later found to lack empirical evidence to support the claim. Hartley et al. (2010) found that parents of children with ASD had an overall divorce rate of 23.5% compared to 13.1% in parents of typically developing children.

Marital satisfaction in relation to use of respite service. Harper, Dyches, Harper, Roper, and South (2013) conducted a correlation study from data collected from a demographic questionnaire of 101 parents of children raising at least one child with ASD (total-number of children was 118). The questionnaire also included one question about their satisfaction with their respite care provider who was also included, along with another questionnaire to measure marital satisfaction. The study examined was twofold as follows:

1. To examine the relationship between respite care and the quality of marriage for couples with children with ASD with stress as a mediator.
2. To examine maternal and paternal uplifts as potential mediating variables.

The number of hours of respite were positively related to a significant improvement in marital quality for both husbands and wives. A 1-hour increase in weekly respite care was associated with a one-half standard deviation increase in marital quality for both husbands and wives. The results suggest the importance of respite in mediating against stress in families raising children with ASD, particularly when policy-making and planning services (Neely, Amatea, Echevarria-Doan, & Tannen et al., 2011).

Family Accommodations

Bernheimer, Gallimore, and Weisner (1993) and Gallimore, Weisner, Kaufman, and Bernheimer (1989) found that families of children with ASD and intellectual disabilities make multiple accommodations for children with disabilities. An accommodation is an intentional adaptation or change to daily routines or activities, at least in part because of the ASD. These accommodations can be minimal or extensive. For instance, parents might take turns sleeping because of a child’s sleep issues or take a lower paying job due to the flexible hours. Multiple accommodations over time may affect family well-being and quality of life.

Impact on Engagement in Necessary and Meaningful Occupations as a Family

A child’s rigid routines and sensory and behavioral reactions can envelop the families, affecting their freedom to choose from a variety of activities and leaving families with the self-described identity of an autistic family (Werner DeGrace, 2004).

Werner DeGrace (2004) conducted a phenomenological study on the everyday routines of families of children with a child with ASD and several themes emerged to describe their family life such as (a) the whole family life revolves around autism, (b) feeling robbed as a family, (c) occupy and pacify, and (d) fleeting moments of feeling like a family.

Spirituality and Religiosity

The AOTA incorporates spirituality, well-being, and quality of life into its OTPF as a concept related to occupational performance (AOTA, 2014). Other disciplines that have explored and researched spirituality's relation to health include nursing and psychology. Wilding and Muir-Cochrane (2005) conducted a phenomenological investigation of spirituality to better understand the phenomenon of spirituality and its relationships to occupation and the experience of mental illness. Three themes related to occupations and spirituality that emerged from the data included (a) some specific occupations are engaged in to enhance a person's spirituality, (b) spirituality can also be experienced during ordinary occupations, and (c) spirituality within an occupation that is shared with others is very important. The overall finding of the study was that spirituality sustained and enhanced the lives and occupations of each of the six participants with mental illness. Participants described that spirituality gives meaning to their occupations and provides them with a sense of purpose in being and doing. Spirituality helped regain energy and strength, a sense of peace and well-being, and a means to find guidance for answers to their questions (Ekas et al., 2010).

Ekas, Whitman, and Shivers (2009) conducted survey research with 119 mothers of children with ASD completing a 38-item multidimensional measure of religiousness/ spirituality. Higher scores associated with religious beliefs and spirituality were associated with higher self-esteem, life satisfaction, positive life events, positive affect, psychological well-being, optimism, and internal locus of control. Examination of the relationship of religious beliefs, and particularly spirituality, also suggested protection from negative outcomes (Ekas et al., 2009). Brown et al. (2006) conducted a correlation study between three groups of caregivers for three different groups of children those with Down syndrome, those with ASD, and a control group without disabilities.

Quality of Life: Family and Caregiver Impacts and Risks

The Family Quality of Life survey was used to collect data to assess nine quality of life domains including (a) health, (b) financial well-being, (c) family relationships, (d) support from other people, (e) support from disability related services, (f) spiritual and cultural beliefs, (g) careers and preparing for careers, (h) leisure and enjoyment of life, (i) and community and civic involvement. Caregivers of the children with ASD scored lower than the other two groups in 8 of the 9 quality of life domains. The one domain in which the ASD group scored higher than the caregivers of children with Down syndrome was in the spiritual and cultural beliefs section (Brown et al., 2006).

Nankervis et al. (2012) conducted a retrospective study of 32 individuals who had relinquished care of their family members to out-of-home respite facilities. A thematic analysis of the results found precipitating factors to be the (a) characteristics inherent to the family member with intellectual disability, (b) characteristics inherent to the caregivers and families, and (c) characteristics of the support experienced by the caregiver and families. The majority of cases (64%) had challenging behavior with high medical needs. Twenty-two of the 32 files reviewed required constant line of site supervision, increasing maladaptive behaviors, caregiver's inability to manage behaviors as the children grew, and posing an extreme risk to the caregiver or other sibling Nankervis et al. (2012).

Relevant Frameworks, Models, and Academic Disciplines

OTPF

Using the AOTA OTPF, occupational therapists begin with an occupational profile to learn about the individual, family, community, or organization they will be treating as *an occupational being/occupational beings*. The occupational profile focuses on activities that the individual or group needs to do and what they desire to do to live a full and meaningful life (AOTA, 2014). An occupational being is accepted by OT to have an innate drive for mastery over the environment and to adapt for survival (Wilcock, 1998, 2006, 2006c). Occupational beings are also perceived to have particular interests which hold meaning for them and contribute to their sense of self, identity, and belonging (Christiansen, 1999). Occupations offer a means and a mechanism for adaptation through participation to foster skill development and transformation. Occupational therapists promote participation in necessary and meaningful occupations to promote health, well-being, and occupational performance for living a full, quality life (AOTA, 2014).

The occupational profile is at the heart of intervention planning, developed in collaboration with the client incorporating the client’s needs and desires in context of their lives. The occupational therapist analyzes the demands of the occupation, client capabilities, and human and non-human environments. Personal physical or psychosocial skills may be developed or the necessary adaptations may be applied. Occupations can be graded in either direction to support occupational performance. In addition, appropriate adaptations may be applied to environments and barriers may be removed. Tools and equipment can be adapted such as splints and special tools fabricated, or adaptive equipment provided to create the just-right-fit between the person, the occupation, and the environment for improved occupational performance (AOTA, 2014).

The breadth of the OTPF (AOTA, 2014) allows for using other models, frames of reference, and treatment approaches under an over-arching, an occupation-centered, and a contextually rich framework. Principles applied to individuals also apply to groups, families, communities, and organizations expanding its usefulness for promoting healthy, inclusive communities. The OTPF (2014) language is congruent with that of the WHO (2008) International Classification of Disability and Function (ICF). The significance of this congruence between the WHO (2008) and the OTPF (AOTA, 2002, 2008, 2014) documents and philosophy is its relation to funding for services consistency of language for international, interdisciplinary and interprofessional understanding and communication.

Person-Environment-Occupation Model of Practice

The goal in occupational therapy is to enable participation in health-promoting occupations through engagement in meaningful occupations (AOTA, 2014). The person-environment-occupation (PEO) model of practice may be used to understand and to enhance participation in multiple contexts (Law et al., 1996). The occupational therapy model selected to provide context for understanding the phenomena of mothers' placement considerations is the Law et al.'s (1996) PEO model. Law et al.'s (1996) PEO model was developed by occupational therapists and based on environmental and ecological multidisciplinary theories from psychology, social science anthropology, human geography, and architecture. The PEO model postulates that its three major components (a) person, (b) environment, and (c) occupation continually transact with each other over place and time. The more congruent the fit is among person, environment, and occupation, the better the occupational performance (Law et al., 1996; Ludwig, 2004).

The PEO model allows the occupational therapist to view the person, environment, or occupation and relate this to the client's or group of clients' occupational performance (Law et al., 1996). The PEO model's inclusion of temporality and routines increase its flexibility for incorporating family goals, accommodations, and routines within multiple contexts over time (Law et al., 1996). In Law et al.'s (1996) PEO Model, continual shifts in contexts are expected, requiring behavioral changes to accomplish goals. This transactional dynamic of the PEO model assumes the interdependence of the person, occupation, and environment (Law et al., 1996).

Broader external facilitators and barriers such as societal attitudes, economics, politics, institutions, and organizations can also be considered using Law et al. (1996). Broader issues can be addressed through research and dissemination, client and professional advocacy, professional leadership activities, interdisciplinary panels, or in state and community planning meetings. Another element of Law et al.'s (1996) PEO model is the Canadian occupational performance measure (COPM) for measuring outcomes (Law et al., 1998, 2000). The PEO model also has the availability of a validated interdisciplinary assessment tool (Law et al., 1996; Law, Baum, & Dunn, 2005; Ludwig, 2004.) Law et al.'s (1996) PEO model's interdisciplinary influence may broaden attention to the mothers' situations to gain even broader understandings for generating diverse, multiple solutions for mothers going through the decision-making process for placement.

Academic Discipline of Occupational Science

Occupational science (OS) was included because of its relevance to occupational therapy practice. OS is an academic discipline initiated by Elizabeth Yerxa (1990) and developed by occupational therapy faculty at the University of Southern California (Zemke & Clark, 1996). Originally conceived as a basic science, with a unique traditional base from the practice of occupational therapy, its concern is with adaptation through engagement in occupation. OS has progressed to an academic discipline towards interdisciplinary study of occupation to generate knowledge about the form, function, and meaning of human occupation. OS is not constrained by a positivistic view, and it is open to forms of inquiry that are non-mathematical and subjective. Zemke and Clark (1996) remind us that occupation is everywhere and everything. OS is devoted to learning how engagement in occupation promotes health, well-being, and quality of life across the lifespan and how engaging in occupation can address global health concerns (Zemke & Clark, 1996).

OS brings science to life as it fills in the gaps left from quantitative data studies with meaning and relevance. OS enhances the potential to serve occupational beings' potential in all contexts including the therapeutic context to enhance health well-being and quality of life. Occupational scientists and occupational therapists have widely contributed to a quickly expanding knowledge base that informs occupational therapy practice and other disciplines. OS has highlighted the importance and centrality of occupation from a variety of interdisciplinary standpoints.

Occupational scientists have further defined and classified key concepts such as occupation, play, work, and adaptation for a shared sense of meaning, clarity, and precision for efficient communication of goals and purposes. The dimensions of occupations including time, space, habits, routines, emotions, and temporal adaptation have been further conceptualized, clarified conceptualized, and used in practice (Zemke & Clark, 1996). OS has contributed to the literature on development of adaptive skills on mothering occupations and co-occupations relevant to this study including the interactions of mothers and children engaged in caregiving and receiving, play, and household routines (Zemke & Clark, 1996). Studies from occupational scientists such as Clark et al. (1997); Clark et al. (1991); Frank (1996); Ludwig (1997, 1998); Ludwig, Hattjar, Russell, and Winston (2007); Larson (2000, 2004, 2006, 2010); Larson & Zemke (2011); Rowles (1991); Zemke (2004); and Zemke and Clark (1996) were included in the literature review on routines, surveillance, space, place, time, and temporality related to mothering children with ASD while sustaining family life.

OS guides our observations to attend to the temporal and spatial synchrony that develop in this interactive process and heightens attention to social and psychological elements of occupation. Occupation is a complex, fluid, and transactional experience, which engages biological sensory, social, and environmental aspects. As a complex living system, the human being needs to be understood at a deeper biological level to make the necessary links between these biological mechanisms and their occupational performance in multiple contexts (Zemke & Clark, 1996). Frank (1996) stated that "occupational science is intended to embrace the spectrum of human activity" (p. 47). Zemke (1996) credits the lives of individuals with disabilities for clearly defining adaptation from an occupational science perspective. Gela Frank (1996) defined adaptation in this way, "Adaptation is a process of selecting and organizing activities (occupations) to improve life opportunities and enhance quality of life according to the experiences of individuals or groups in ever-changing environments" (p. 50). The uniqueness of adaptation through an occupational science lens is its emphasis on orchestrated occupations; the adaptation occurs through doing things (Frank, 1996). A child is uniquely dependent on the mother. Children with ASD and intellectual disabilities remain dependent on their mothers and caregivers. As noted earlier in the section Sustaining Family Life: Mothering a Child With Autism and Intellectual Disabilities, mothers also carry out a central role in the function and well-being of the family. For this reason, it is critical to protect maternal health.

Economics Approach

Amarta Sen (1999), an economics theorist (development economics), philosopher, and professor won the 1998 Nobel Peace Prize for Economic Science for his work on Welfare Economics and for his development of the capabilities approach (CA). The CA was designed in order to make transcultural judgments on quality of life, offering an alternative to mainstream cost-benefit analysis. Sen (1999) developed the CA to be used for welfare state design in affluent society, and for government and non-government development policy in developing nations such as Africa and India where the basic needs for food, water, housing, and health care are extensive. The World Bank (n.d.) defines a developing country as one “in which the majority [of the population] lives on far less money—with far fewer basic services—than the populations in highly industrialized countries” (para. 1). In 1998, Sen challenged the notion of measuring development based on gross domestic product, or GDP, alone. The CA is increasingly used in academia, welfare economics, political philosophy, development studies, disability studies, public health, and policy making (Robeyns, 2006, p. 352).

The CA distinguishes between function and capability. Sen (1999) placed a deep correlation between freedom and function. A capability would include the following: (a) having the possibility or an accessible opportunity to participate, (b) the skills and power to participate, and (c) having no external barrier to participate. According to a CA, a person cannot flourish if the individual is unable to perform functions that are necessary to partake in the capabilities (Robeyns, 2006, p. 352).

Sen’s (1999) CA offered a means to understand the mothers' situations in relation to their experiences of deprivation and to freely explore what might facilitate the mothers’ and their families' well-being. A critical element in Sen’s CA was the notion that monetary poverty or affluence alone did not sufficiently reveal all dimensions of well-being or deprivation. The core concepts of Sen’s (1999) CA include a person’s functionings (what a person chooses to be and do) and capabilities (the actual opportunity or freedom to realize functionings).

An underlying concept in the CA is the exercise of freedom of choice, which is also considered a prerequisite for agency (Mitra, 2006; Sen, 1999). Because Sen’s (1999) CA is used in welfare policy, it appeared to offer a good fit for the mothers in this study, who were dependent on larger institutions, experienced health disparities, and depended on policy-decisions for services and supports to protect their families’ well-being (Akire, 2002).

Sen’s CA offers a framework for understanding the mothers’ interdependence on larger institutions, to explore institutional barriers, and to consider potential facilitators to health and well-being. CA honors the individual’s self-determination and freedom of choice as to what constitutes living a full life. These tenants of self-determinacy and freedom are apparent in both occupational therapy philosophy and phenomenology. Mitra (2006) stated that the medical model’s normative strength is incongruent with disabilities models as to what constitutes well-being. Under the traditional medical model, a person with a permanent disability cannot get well because this would mean that they can function like a normal person (Mitra, 2006).

Sen’s (1999) CA focuses on a person’s interests more than their actions or behaviors, as he views a person’s interests and fulfillment as being a function of well-being and advantage. Sen intentionally avoided completing the list of commodities, environmental factors, or capabilities necessary to achieve well-being and advantage (Mitra, 2006). Sen (1999) allowed for freedom of choice and plurality in his deliberate avoidance of assigning value or rank to the capability sets, as this could change according to the interests and transacting variables or circumstances (e.g., freedoms, accessible opportunities, and personal choices).

Sen’s (1999) refusal to produce a specific list of commodities, environmental factors, or capabilities has challenged researchers and policy makers to operationalize this appealing approach. However, Sen argued that he never suggested that his CA was a model. Sen honored freedom of choice and democracy, considering both elements essential for agency, and stood firm in his allowance for plurality (Mitra, 2006). Law’s et al. (2000) Canadian occupational performance measure could potentially provide the means with which to operationalize Sen’s CA without restricting plurality, freedom of choice, or self-determinacy, and without a prescribed requisite list of commodities to represent what is deemed acceptable as living a full life. Sen (1999) often spoke out about the link between disability, poverty, and deprivation. Sen’s influence is observed in major documents of the WHO, as Sen contributed to welfare economics and understanding the economic mechanisms that underlie poverty and famine. Sen’s work added an ethical dimension to the science of economics.

Global, National, and Community Health Perspectives

WHO

The WHO (2013) is the directing and coordinating authority on international health guidelines and standards, and works to promote research and to help address public health issues and global health problems and improve individual's well-being.

The WHO's (2001, 2008) International Classification of Diseases (ICD) is a disability model influenced by Sen (1999). The WHO's (2008) ICD-IFC is used as a classification system for disability and its codes relate to the American Psychiatric Association (APA, 2013) *Diagnostic and Statistical Manual-5* (DSM-5). The ICD is used to classify diseases and other health problems and has become the international standard used for clinical and epidemiological purposes. Classifications of diseases in the DSM-5 are also related to the funding provided for services; therefore, the WHO ICD and ICF (WHO, 2008) and the DSM-5 (APA, 2013) are relevant to the mothers and families in this study.

NIH: Definition and Mission

Definition. The NIH are a part of the Department of Health and Human Services and the principal federal agency for health research in the United States. Comprised of 27 institutes and centers, the NIH invests more than $28 billion annually to research medical issues ranging from heart disease to sudden infant death syndrome to depression. The NIH origins were in Staten Island where it was created in 1887 as the Laboratory of Hygiene at the Marine Hospital. The NIH has the National Library of Medicine and SNOMED CT–the clinical terminology standards (NIH, 2014).

Mission. The mission of the NIH is to seek fundamental knowledge about the nature and behavior of living systems and the application of that knowledge to enhance health, lengthen life, and reduce illness and disability (NIH, 2014). NIH goals are,

- to foster fundamental creative discoveries, innovative research strategies, and their applications as a basis for ultimately protecting and improving health;
- to develop, maintain, and renew scientific human and physical resources that will ensure the Nation's capability to prevent disease;
- to expand the knowledge base in medical and associated sciences in order to enhance the Nation's economic well-being ensuring a continued high return on the public investment in research; and
- to exemplify and promote the highest level of scientific integrity, public accountability, and social responsibility in the conduct of science. (NIH, n.d., para. 2)

The NIH is relevant to the occupational therapy profession because of its influence on the nation’s research agenda and on the funding of research that is used to improve the health and well-being of individuals. The NIH is relevant to the mothers in this study because it sets the agenda for what is to be studied, how it is to be studied, and how funding for research will be determined (NIH, 2011).

Institutions to Communities: Healthy People 2020

Health-related quality of life. The goals of deinstitutionalization were to close institutions, to shift the locus of care from the government to families, and to offer community support for individuals with disabilities and their families. The NIH developed a Patient Reported Outcomes Measurement Information System (PROMIS) for the Healthy People 2020 program for improving population health (Office of Disease Prevention and Health Promotion [ODPHP], 2010). It proposes to do so by aligning state and local governments with federal efforts to improve health (ODPHP, 2010). The government program uses the Health-Related Quality of Life (HRQoL) to assess the program's impact on population health (ODPHP, 2010). This multidimensional concept includes physical, mental, emotional, and social function, but it also assesses well-being or the positive aspects of an individual's life including positive emotions and life satisfaction (ODPHP, 2010).

The occupational therapy profession's long-term commitment to and investment in advancing the quality of life for its clients and their families suited well to the process and goals of Healthy People 2020. However, the PROMIS focus is quite narrow and limited in context occupations as it refers only to jobs; leisure pursuits are under the social domain as described on its website (www.nihpromis.org/), so occupational therapy's influence is not apparent in the PROMIS. Healthy People 2020 and PROMIS are areas where occupational therapy input can expand services into the communities where people live, work, and play. Healthy Communities, 2020 can benefit communities in a wide range of areas that support clients' participation within the community.

Exploring sustainable community support options for mothers such as those in this study and their families, and for all individuals or groups who require networks of support or whom experience barriers to participation, empowers occupational therapists to better serve their clients. Proactive advocacy for the occupational therapy profession and its clients may necessitate assuming leadership roles in interdisciplinary and interprofessional community health panels and community development projects. If activities become restricted and opportunities for participation in social occupations cannot be accessed, these continual barriers to participation place mothers' caregivers and their families at risk for social and economic marginalization (Fremstad, 2009; Peacock et al., 2012).

Advocacy in changing health environments may require more civic involvement in the political process than in the past. Changing times call for evolving and enhanced roles to meet the occupational needs of society. Occupational therapists will have new opportunities to weigh in evolving community health policies by providing feedback on draft policy documents of the WHO and NIH such as the PROMIS. Opportunities are emerging for new health teams and approaches, offering occupational therapists the opportunity to assert the full essence of occupational therapy profession and its contributions to health as well as occupational therapy's contributions to occupational science research. Recognizing the fragility of the current times, a powerful means to support vulnerable populations is to ensure their access to opportunities to participate in their communities.

Occupational Therapy and Community Health

Federal policy influenced the shift from institutional care to community life, yet full inclusion is not always apparent in the community, and mental health funding for resources and funding for community-based services have not kept pace with the needs of the client and families (Day, 2006; Trisi, Sherman, & Broaddus, 2011). Occupational therapists unique contribution to health and well-being through engagement in occupation is congruent with the complexities involved in community health practice.

Baum and Law (1998) encouraged occupational therapists to focus on the need to take an active role in WHO's Healthy Communities, 2000 initiatives (Rosenau & EveryChild, Inc., 2010). Over the years, occupational therapists have adapted to the societal needs of individuals, groups, communities, and societies. In addition, occupational therapists have also worked in hospitals, rehabilitation centers, skilled nursing facilities, and schools. In each of these settings, occupational therapists' unique skills and philosophy have contributed to the promotion of inclusion and participation (AOTA, 2001, 2014).

Outcomes from occupational therapy's occupational approach to health has resulted in outcomes of job readiness, improved parenting, and caregiving skills, school performance, independence, and well-being (Baum & Law, 1998). Occupational therapy research has contributed to the knowledge base in the fields of medicine, psychology, education, work, play, and leisure. Skills in adapting environments and fabricating equipment have allowed individuals to experience full lives at home and in the community, and to contribute to efforts such as aging in place through home modifications. Contributions to the fields of medicine and education have been substantial, providing a vital and cost-effective, evidence-based service (Clark et al., 1997). Expanded competencies in socioeconomic and political arenas have moved the profession ahead and enhanced occupational therapists' capabilities in forging new ground in community health (Baum, 2007; Baum & Law, 1998; Townsend & Wilcock, 2004; Whiteford, 2000; Wilcock, 1998, 2006). Healthy People 2020 (WHO, 2013) may open up new opportunities to gain prominence in community and mental health as well as primary care.

Community health offers a suitable fit for occupational therapy's broad competencies. Client-centered community approaches and initiatives along with group work for restorative and preventative services may bring occupational therapists closer to their roots in mental health (AOTA, 2004; Baum, & Law 1998; Fidler & Fidler, 1978; Mosey, 1996; West, 1968; West; 1984; Wilcock, 1998, 2006). Community offers a broad array of opportunities to participate in health-promoting occupations to support health and well-being.

Wilcock (2006) urged occupational therapists to seek out instances of community members who are occupationally deprived, alienated, or lacking occupational imbalance. She also proposed that occupational therapists need to research the cause and effects, and actively advocate for change on behalf of those who are less able. Wilcock viewed occupation as a determinant of health, as the occupations that individuals choose potentially affect their health and well-being (Wilcock, 2006).

Occupational Justice

An occupational perspective of health relies on individuals' accessible opportunities to participate in necessary and meaningful occupations (AOTA, 2014). Engagement in occupation facilitates learning, growth, adaptation, and transformation. Participating in occupations helps individuals, group, and community organizations to adapt as they transact with multiple environments and contexts. Occupation promotes adaptation, learning, and growth, and eventually transformation (Wilcock, 2006).

Participation in everyday routines and engagement in occupations within the community is health promoting. Conversely, barriers to access for participation can have the reverse effect on health. The mothers in this study experienced many barriers to occupation at home as they attempted to participate in the daily routines to maintain their households and their schedules while caring for their children. Community outings can be particularly difficult for the mothers of children with ASD due to the children's sensory reactions and behavioral responses to breaks in their routines. For this reason occupational therapy's commitment for inclusion and valued participation of all community members, despite mental or physical disabilities is an important aspect in its role in building and sustaining healthy communities.

NIH's Relation to Community Health and Inclusion

During Phase 1 of Deinstitutionalization, institutions were closed and no funding or support was available for the families and caregivers who were then expected to resume caregiving responsibilities for those individuals who were released from institutions. During the current rights and recovery Phase 3 of Deinstitutionalization, the expectation is a full shift from institutional to community health, with the expectation that individuals will be expected to live, work, and play in their communities despite mental or physical disability. However, the current system of payment uses Medicaid which favors a medical model and evidence-based practice.

The NIH created and funded interdisciplinary panels to prepare for community health in order to avoid the policy errors and consequences of the past, as during Phase 1 of Deinstitutionalization, described under the Deinstitutionalization section of this chapter. However, the philosophy, goals, and payment structures for Medicaid are towards medical diagnoses, medications, and more restrictive institutional care. Community health goals of promoting living and working in the community despite disability are often in direct opposition to the goals of their main funding source, Medicaid. The established Medicaid rules for reimbursement favor a medical model rather than a community health model. A medical model favors compliance, while a community health model favors self-determination. While the medical model's main focus is on the cure and evidence-based practice, the community health model's focus is on engagement and qualitative measures and outcomes of engagement despite physical or mental challenges (Day, 2006; Onken et al., 2002).

The philosophical differences and goals of community health's main funding source–Medicaid's payment system, which are incongruent with *Best Practices in Community Health*, create barriers to funding for community health services. For example, Medicaid policies have fixed services with less freedom and self-determination for the client which can create barriers to community health and recovery goals and objectives of self-determination.

Community health tends to be more client centered and oriented towards self-determination with flexible spending for services, community care, and opportunities to live, work, and play in the community. Community health services are not mandatory services; therefore, this could be a disincentive for states to provide these services (Unützer et al., 2006). Mothers of children with ASD and intellectual disabilities have limited access to opportunities to work without community support, and limited accessible and affordable opportunities for childcare services (Hostyn & Maes, 2007; McGill et al., 2006). Medically-oriented interventions and community-based interventions use different criteria to measure success. A medical orientation may focus on illness reduction or medical management, while community-based practice focuses on increased participation, agency, well-being and quality of life (Unützer et al., 2006).

Mental health policy decisions made at this critical juncture potentially affect vulnerable populations such as the mothers in this study and their families and communities. Day (2006) and Koyanagi (2007) agree that families and communities will inherit the burdens of care and cost of secondary illness, disabilities, and decreased quality of life for deficient community health and integration plans.

The full transformation to community health involves clients receiving mental health services and professionals carrying out community-based services. Its success hinges on societal tolerance and community inclusion as well as the will of communities and society for community health. Its success is more likely to occur if the goals of recovery coincide with community goals (Day, 2006; Koyanagi, 2007; Minkler, 2012).

Deinstitutionalization, Phase 3: Rights and Recovery

A full transformation to community health also depends upon a paradigm shift toward recovery orientation and societal and community acceptance of individuals with mental disabilities, along with the support for the notion that individuals with mental health disabilities have the right to live, work, and play in the community, despite disability (Koyanagi, 2007; Onken et al., 2002). Onken et al. (2002) stated that recovery is and must remain based on self-agency, and be understood through the lived experiences of the persons who are in the process of recovery. Onken et al.'s (2002) study used a grounded theory approach and conducted 115 focus groups to contribute to the knowledge for redesigning more effective systems of mental/behavioral health care. This national research project for the development of recovery facilitating system performance indicators highlighted several indicators that either helped or hindered mental health recovery (Onken et al., 2002).

Several indicators for what hinders recovery related to the mothers in this study. These indicators of what hinders recovery include (a) a culture and organization that is pathology- or illness-focused and dominance of the medical model; (b) a lack of change and innovation; (c) a lack of a holistic orientation (neglecting spirituality and physical health); (d) social segregation limited, crisis-oriented funding; (e) and failure to reinvest in the community voucher system (Onken et al., 2002).

Deinstitutionalization's Phase 3 rights and recovery and community goals, and reimbursement policies and processes based on medical models rather than community health models, may hinder the final transformation to community health (Day, 2006). Further complicating the transformation to full community health are a compromised economy with rising unemployment and poverty rates increasing ASD rates, and an evolving universal health plan that continues to exceed cost projections (CDC, 2012; Orient, 2010; Trisi et al., 2011; U.S. Bureau of Labor and Statistics, 2012).

Relevant Contexts and Reflexivity

Societal Trends and Potential Health Implications

The rising prevalence of autism diagnoses, both nationally and globally, poses challenges to individuals, families, communities, institutions, and societies. Parents of children with ASD are uniquely dependent on the services they receive and become quite distressed if they believe that their services will be cut. Throughout the literature of multiple disciplines of mothers and caregivers of children with autism, and particularly with co-occurring intellectual disabilities, are the ever-present themes of fighting for services and unmet needs. The fight for services adds another layer of responsibility and stress to the mother/caregiver's already overwhelming schedule (Ekas et al., 2010; Nankervis et al., 2012; Parish et al., 2012b; Siklos & Kerns, 2006).

The continuous and time-consuming activity of trying to secure services for their children has been well established and cited as a major source of parental stress and anxiety (Ekas et al., 2010; Magasi, 2012; Nankervis et al., 2012; Parish et al., 2012b; Rosenau & EveryChild, Inc., 2010; Siklos & Kerns, 2006). The Department of Health and Human Services found that 10% of families spend more than 11 hours per week arranging or coordinating services (Rosenau & EveryChild, Inc., 2010, p. 11). Parent fears can be heightened if they believe that policy changes may threaten essential support services for their children and families. A heightened parent awareness and parent participation in parent group discussions on the Internet, where much of the chatter is about vaccine safety (Kaufman, 2007; Offit & Moser, 2009). Parent discourse about vaccine safety, debating scientists, and a plethora of conflicting information may be used for health decisions, evidence based or not (Kaufman, 2007).

The CDC (2007) announced autism to be an "urgent public health concern" (p. 12) more than several years earlier when autism prevalence rates were 1 in 150, higher than previously thought–1 in 166 (CDC, 2007). According to Kaufman (2007), parents were alarmed to hear about this short-term increase in autism cases and were confused, even suspicious about the CDC's reluctance to publicly confirm that autism prevalence rates were rising.

Autism Speaks has been outspoken about the need for appointed officials to acknowledge autism as an epidemic that needs an emergency funding and research strategy in place as stated on their website (http: //www. autismspeaks.org/). However, before the 2012 MMWR report, the CDC could not clearly substantiate that there was an actual rise in diagnosed autism (now, ASD) cases, despite the alarming ASD prevalence rates (CDC, 2012). Measurement issues caused inconsistent data collection methods diagnoses. For example, certain states did not submit education data along with health data, causing missed ASD cases, accounting for as many as 15% to 68% missed ASD cases. Additionally, broadened diagnostic criteria and early diagnoses contributed to the count, so an actual rise in autism's prevalence could not be discerned, or confirmed (CDC, 2008).

Measurement issues were fiercely debated among experts, activists, and scientists trying to accurately discern if there was a true rise in autism's (ASD) prevalence, which did not help the situation; still, the CDC was unable confirm or deny the actual rise in ASD prevalence rates, and parents appeared to regard the CDC's omission of a public statement as suspect. Kaufman (2007), Keelan and Wilson (2011), and Offit and Moser

(2009) reported that parents were less influenced by arguments about scientific measurement than by what they were seeing, hearing, reading, and observing in their families and communities, as well as in the media and on the Internet.

Parents began to voice their skepticism about the government's reluctance to declare autism an epidemic and high profile celebrities became involved, making television appearances on shows such as the *Larry King Show* (April of 2008), in which the topic was the vaccine-autism debate (Gross, 2009; Kaufman, 2007). Outspoken critics of vaccines and multiple media sources became involved in the debate. Examples of this were Robert F. Kennedy Junior's 2005 article "Deadly Immunity" in the *Rollingstone* and Jenny McCarthy's—a celebrity mom of a child with ASD—appearance on the *Larry King Show* as well as her book about her son's recovery, which influenced parents of children with ASD (Gross, 2009; Kaufman, 2007).

The significance of these events was the growing erosion of trust and the portrayal of vaccine advocates as the villains. Parents seemed to begin to doubt and distrust the institutions that were established for their protection. They also seemed to be losing trust in institutions that were the lifeline to their families' health and well-being (Baker, 2008; Gross, 2009; Kaufman, 2007; Rajang, 2005). Keelan and Wilson (2011) and Offit and Moser (2009) believed that in addition to the vaccine, the parents also appeared to fear the ASD. Differing opinions being debated by experts in the field did not improve the situation.

Gust, Darling, Kennedy, and Schwartz (2008) and Offit and Moser (2009) agreed that the vast majority of scientific studies and reviews of the past decade uncovered no causal connection between the vaccines and ASD. They also recognized that parents were more influenced by a temporal correspondence between the increase in the number of vaccines administered, and the increased number of children in the United States affected by broad neurodevelopmental problems.

American Academy of Pediatrics (AAP, 2005); Diekema (2005); Freed, Clark, Hibbs, and Santoli (2004); Gust et al. (2008); Kaufman (2007); and Offit and Moser (2009) agree that ASD is rarely discussed without mention of the controversial vaccine theory, possibly because it can elicit fear, guilt, and anxiety for many parents. Some parents have actually expressed their belief that the government mandated vaccines caused autism or at least contributed to its rising prevalence.

Significant Increase in Diagnosed Cases of Autism

ASD affects 1 in 68 children in the United States. This represents a 30% increase between 2012 and 2014. Before this time, there was a 23% increase between 2006 and 2008, and a 78% increase in diagnosed ASD cases between 2002 and 2008 (CDC, 2012, p. 1). Earlier diagnoses of ASD and a broadening of diagnostic criteria only partially accounted for this increase. The CDC considers ASD to be an urgent public health concern requiring early identification and provision of essential support to individuals with autism and their families (CDC, 2012). Similar ASD prevalence rates in other countries indicate that ASD is a global issue (CDC, 2012). Coinciding with the parents' confusion and fears about the increasing autism rates was the APA's (2013) proposed revision of the autism diagnosis in its revision of ASD in its *Diagnostic and Statistical Manual-IV* ([DSM-4], APA, 1994).

APA Revision of the DSM-4

The *Diagnostic and Statistical Manual* contains all current mental health disorders and includes a diagnostic coding system with precise criteria for diagnosing disorders such as ASD along with measurements for conducting research and for determining the necessary funding for supports and services (APA, 2013). The APA proposed plan to change the classifications of the autism disorder in the new DSM-5 had potential implications for funding for services (APA, 2013). Parents feared that the change in the diagnosis may lead to classifications that will potentially affect necessary services for their children and families. Autism Speaks also subsequently announced its plan to fund a scientifically rigorous study with a large sample of children recently diagnosed with autism with the DSM-4 criteria to monitor the impacts of the change in the diagnostic criteria (Autism Speaks, 2014).

Specifically, the researchers' proposed plan was to examine the effects of the proposed DSM-5 criteria (Autism Speaks, 2014). The American Psychological Association has since published the APA, DSM-5 (APA, 2013). The significance of the revision of the APA DSM-4 is that the classification system affects the funding of services for their children with ASD. Another classification that was debated for admission into the revised edition of the DSM-4 was the sensory modulation disorder (SMD) which was of concern to the parents of children with ASD and occupational therapists who treat their children.

Sensory Issues and SMD

Occupational therapists advocated for SMD to be added as a classification. Although children with ASD often exhibit signs of SMD, not all children with signs and symptoms of SMD have ASD. Ayres Sensory Integration® therapy has been demonstrated to reduce anxiety and sensory sensitivity, and improve social interaction and play. Years of clinical research by A. Jean Ayres (1969, 1972) on Ayres Sensory Integration® and subsequently refined by other occupational therapy scholars and master clinicians, is used by occupational therapists to benefit children with ASD and other disabilities with sensory issues (Miller, Anzalone, 2007; Miller, Coll, 2007; Schaaf, 2014; Schaaf et al., 2012a; Schaaf et al., 2013; Schaaf et al., 2012b).

The APA DSM-4 (APA, 1994) was designed to correspond with codes from the WHO (2011) ICF of Diseases-9 and the ICD provide a unifying framework for classification of health and function along with the specified criteria to do so (CDC, 2012). The DSM-4 was used for classifying autism cases reflected in the most current rise in autism prevalence rates (APA, 2013).

Compromised Economy During Phase 3 of Deinstitutionalization

Several temporal environmental, personal, and occupational aspects may influence decisive actions and inactions related to placement decisions and decisions related to the health and well-being of their children with autism and intellectual disabilities include (a) rising ASD diagnoses (CDC, 2012); (b) a compromised economy with increased poverty and unemployment, reduced services, and a universal health program proposing to cover more people with less money (Orient, 2010; U.S. Bureau of Labor Statistics, 2012); and (c) Phase 3, U.S. Deinstitutionalization Act: Rights and Recovery’s push for deinstitutionalization and the shifting of long-term care responsibilities to families and communities (Fremstad, 2009; Garfield, 2009; Gray, 2002; Koyanagi, 2007; Siklos & Kerns, 2006; Wulcyzn & Orlebeke, 2006).

Institutional Mistrust, Vaccine Safety Fears, and Related Public Health Concerns

Many parents fear the mumps/measles/rubella (MMR) vaccine linking the vaccine to autism (Salmon, Moulton, Omer, deHart, & Halsey, 2005). However, parents may not fully appreciate the risks and impacts of a measles epidemic if the immunity drops below the 90% level. Parents who never experienced the impacts and complications caused by measles, mumps, or polio epidemics may focus more intently on what they are personally seeing, reading and experiencing right now. Parents may also have a false sense of security since measles has been eradicated in the United States since 2000 (Ravindran & Myers, 2012; Smith, Wood, & Darden, 2011).

Grosse (2009) and Kaufman (2007) explained that when vaccines are working, fear about diseases tends to subside while the focus may shift towards vaccine safety. Some parents who are fearful that the vaccines may be causing ASD are beginning to distrust the institutions upon which they rely for governmental information and services. Indicators of this eroding government trust are evidenced by increasing numbers of parents claiming, and applying for, state-mandated vaccine exemptions. Further evidence of this trend is the majority of pediatricians who report parents in their practice who refuse at least one vaccine (AAP, 2005; Diekma, 2005; Gust et al., 2008; Offit & Moser, 2009). Salmon et al. (2005) stated the main reason given for vaccine exemption requests is safety. AAP (2005), Diekma (2005), Gust et al. (2008), and Offit and Moser (2009) have all cited a proliferation of peer-reviewed pediatric journal articles responding to parents' doubts with reassurance about vaccine safety.

Omer et al. (2005) explained that many parents fear MMR linking the vaccine to ASD, more than the diseases of mumps, measles, and rubella for which the MMR vaccine was developed to prevent. Parents are aware of autism's presence, so there is a sense of urgency and immediacy involving autism. Kaufman (2007) agreed, stating that parents may not fully appreciate the risks and impacts of a measles epidemic if the immunity drops below the 90% level.

Measles cases are rare in the United States due to high immunization. Measles was eliminated (by public health statistical standards), which means that if an unvaccinated person came in contact an individual with measles, the disease can be contained because the vaccination levels are at the established protective rate of 90% (Omer et al., 2005). Kaufman (2007) explained that parents who never experienced the impacts and complications caused by measles, mumps, or polio epidemics may focus more intently on what they know, in this case ASD.

In 1986, a Vaccine Injury Compensation Program (VICP) was instituted to allow for a fair hearing of vaccine concerns, to maintain confidence in the vaccines, to protect vaccine manufacturers, and to give parents, who presented a reasonable case, compensation for injury. Keelan and Wilson (2011) and Ravindran and Myers (2012) reported that the United States Court of Federal Claims adjudicated 5,000 claims for the National VICP. Parents who received compensation without solid evidence may have interpreted this compensation as the government’s confirmation of the link between the vaccines and ASD. AAP (2005), Diekma (2005), Gust et al. (2008), and Offit and Moser (2009) agree that if the rate drops 99%, the risk a measles epidemic would greatly increase.

The issue of doubt and fear sheds light on understanding how mothers of children with ASD and other Internet seekers of health information, advice, and research make critical health decisions for their children and families. Mothers may be influenced to decide whether to vaccinate their children, manipulate the timing of the dosage, or elect to seek exemption for their child (Grosse, 2009; Kaufman, 2007). Kaufman (2007) and Grosse (2009) state if the parents no longer have faith in the experts and government institutions and mandates, and fear that the vaccine is harmful to their children, they may seek a vaccine waiver.

Potential Impact to Population Health

Sharon Kaufman (2007), professor of Medical Anthropology, History, and Social

Medicine claims that the Internet is changing the way the parents seek knowledge and make decisions. Parents acting on current cultural pressure to question institutions, to become more aware and self-reliant, gather information often from Internet sources, some of which may not be reliable. Parents also seek research on health information and to assess health risks, as in the case of immunizations. Kaufman (2007) and Gross (2009) stated that "public health, popular culture, and science have been areas where the vaccine-autism connection has been observed since the late 1980s” (Kaufman, 2007, p. 1549).

Kaufman (2007) stated that self-determination is valued as the basis and indicators of freedom, but with freedom comes responsibility and risks. The information on the Internet is abundant, however, questions whether most parents are sufficiently trained to assess the rigor of the studies for the highest level of evidence to make informed health decisions or risk assessments. In addition, parents often blog with others in similar situations for increased information, which can be accurate or inaccurate (Kaufman, 2007).

Emerging Technologies, Health Trends, and Environments: Implications for Public Health

Wilma West (1968) asserted that health professions cannot practice without being keenly aware of the many forces shaping their future, nor can they neglect their duty to examine the implications of these forces on their professions and upon those whom they serve. The current and rising ASD prevalence has broad implications for the mothers in this study, their children with ASD, and their families. Understanding cultural, temporal, societal, and institutional undercurrents and trends may potentially help to predict future consequences. Parent, public, and professional perceptions and ways of knowing can be influenced by technology for decisive actions and inactions (Garfield, 2009; Kaufman, 2007; Offit & Moser, 2009).

Technology

Technology is changing health cultures and ways of knowing and communicating, which in turn are beginning to shift the power balance between physician and client (Grosse, 2009; Kaufman, 2007). Health professionals are using technology for evolving health service delivery models such as telehealth service delivery models (Cason, 2012; Hinojosa, 2007). There appears to be a growing mistrust of the government institutions that were formed to protect individual and population health and to prevent the spread of disease, those provisions of necessary services and supportive networks related to mandatory vaccines, and parental fears about rising ASD rates (Garfield, 2009; Grosse, 2009; Kaufman, 2007; Keelan & Wilson, 2011; Offit & Moser, 2009). Current immigration policies and issues in the United States pose risks to herd immunity and will be a matter of public health concern requiring surveillance and awareness of all health professionals.

Hinojosa (2007) reminded occupational therapists in his 2007 Slagle Lecture that the future of occupational therapy is under our control, but we need to become innovative, reflective practitioners and innovators of change. The next section will address the effects of technology and new ways of knowing, social and cultural trends, and a shifting of the balance of power. Emerging environments such as telehealth and Internet technologies and trends may potentially influence the mothers and families in this study and their placement decisions.

An example of how technology and ways of knowing and communicating have empowered parent groups was New York State's recent attempt to cutback the early intervention budget by 11 million dollars, which had received a 10 million dollar cutback the previous year. A swift backlash from parents, administrators, and early intervention service providers lead to the 11 million dollar cutback being reduced by half (Gross, 2009; Kaufman, 2007; Keelan & Wilson, 2011; Ravindran & Myers, 2012). Given current economic pressures and cutbacks, broad-based initiatives may be necessary (Orient, 2010; U.S. Bureau of Labor and Statistics, 2012). Creating bold new approaches begins with shedding new light on the phenomenon. Phenomenology offers a means to enter the participant's *lifeworlds* for deeper understanding of lived experiences in context (Moustakas, 1994).

Parental Views and Fears About Immunization and Autism and Population Health

Measles is the most infectious virus that affects humans (Sugarman et al., 2010). According to the WHO (2014) fact sheet on measles, 30% of individuals who contract measles develop complications such as pneumonia which is most often the cause of death in younger children, ear infections (1 in 10 cases) with some infections resulting in permanent hearing loss, and diarrhea (8% of cases).

In children less than five years of age and adults over 20 years old, approximately 1 in 1,000 who gets measles will develop encephalitis, which can lead to convulsions, deafness, and mental retardation. Measles leads to miscarriages, premature births, or low-birth weight. Globally, measles is responsible for the death of nearly one million children per year (WHO, 2014). Subacute sclerosing panencephalitis (SSP) occurs in approximately 4-11 individuals infected after 5 years of age. SSP is a fatal degenerative disease of the central nervous system from a measles virus infection acquired earlier in life. Symptoms of SSP typically appear seven to 10 years post infection; however, they can appear any time from one month to 27 years post infection (Bellini et al., 2005, pp. 1686-1693).

Social Isolation and Exclusion

Mothers of children with severe ASD and intellectual disabilities often find it difficult going to the community with their children for safety reasons due to wandering and socially difficult situations such as public tantrums and unpredictable behaviors. Ryan (2010) stated that individuals with disabilities and their families continue to experience social exclusion, intolerance, and other barriers to community participation. Families of individuals with ASD and intellectual disabilities often report that they experience negative remarks or disapproving stares when their children have tantrums in public, and parents can feel judged for not controlling their children's behavior in public (Ryan, 2010).

Kogan et al. (2008) found that support services, including respite care was limited and although the cost of living is higher for families raising children with ASD, the opportunities for employment are lower due to a lack of accommodations. However, the Internet has opened up a forum for support options for parents and it has also become a virtual health research forum for many (Ryan, 2010); thus, the Internet opens up opportunities as well as threats.

Relevant Contexts: Reflexivity, Knowledge, Experience

Prior Knowledge and Reflexivity/Pre-Action Bracketing

My prior experience and education include a BS in Occupational Therapy with a focus on pediatrics. I also have a master’s in public health and through that perspective, I believe that federal, community, and local supports and resources can indirectly contribute to maternal and family health. Through my occupational therapy lens, inclusion and accessible opportunities and self-determination are possible with the will of the community. It is a matter of reframing our thinking for access, tolerance, and in the words of a mother in this study “willful hospitality.”

In speaking to two different mothers, on separate occasions, occurring within about one month of each other, I was introduced to the concept of out-of-home placement of younger child with severe autism spectrum disorders. I was touched by the mothers’ stories and sad recognizing how little I knew about out-of- home placement despite the many years I had worked as an occupational therapists with children with ASD and their families in home, hospital and community based settings.

Pilot Study to This Dissertation

I felt compelled to explore this topic and completed a NOVA, HPD, IRB-approved phenomenological pilot study to this dissertation, on the topic of out-of-home placement of the young child with severe autism. The themes from the pilot study were as follows: (a) urgent quest for a diagnosis–the need for answers; (b) coping with self-blame, guilt, and punishment; (c) no typical days–autism’s influence on family occupations; (d) feeling overwhelmed–things spinning out of control; (e) fighting for services; (f) inconceivable trauma of placing your child; and (g) what mothers need others to know about their lived experiences.

It became clear to me through this pilot study that the more important aspect of the phenomenon of out-of-home placement of a child was the parent’s arrival at the decision-making process and their placement decisions. I selected to explore this phenomenon in greater depth, but also in greater breadth because of the mothers’ dependence on larger institutional and social support which emerged through the pilot study.

Pre-Action Bracketing

Exploring my own feelings about the decision-making process for out-of-home placement of a younger child, I imagined that this experience would be extraordinarily difficult for a mother of a younger child and that placing one’s child outside of the home was unlikely to occur, unless it was necessary. If the mother and family were satisfied that out-of-home placement was necessary for the child with ASD and the family, I would regard this as a viable and acceptable option for the family. Conversely, if a family wished to raise their young child with severe ASD within the home, then it was my belief that they should have sufficient support to do so.

For a parent to have to choose to place their child outside of the home because they had no “real” or accessible opportunities to do so without jeopardizing the well-being of the family seemed to be an unthinkable injustice. In other words, parents should not have to choose the placement option because they cannot otherwise afford the necessary services care for their child at home and supports to without risking economic and social marginalization.

Reflexivity in the Selection of the Literature

The literature reviewed for this study was selected to explore in-depth, the mothers’ experiences living with a child with ASD and intellectual disabilities, and their consideration of the decision-making process for child placement. Literature from multiple disciplines and other vantage points were explored to examine the topic from a variety of interdisciplinary and interprofessional viewpoints to expand reflexivity and reflection and possible solutions.

Data Analysis and Reflexivity

Moustakas' (1994) modification of the data was analyzed through an occupational therapy model of practice and considered through a development economics approach for expanded possibilities. Law's (1996) PEO model of practice offered a way to understand the mothers' situations from an occupational perspective on health and well-being, and the contextual aspects which transact with each other over time and space that affect the mothers' and families' occupational performance and placement considerations. Sen's (1999) CA provided the means to explore the mothers' situations through a development economic lens to better understand those aspects that support or hinder the mothers' and their families' capabilities, and their freedom to choose to raise their children with ASD at home.

Post-Action Bracketing (Journaling)

I had not realized the magnitude of the social isolation and intolerance experienced by mothers raising a child with ASD and intellectual disability. In reviewing the literature on the decision-making for out-of-home placement, it occurred to me that the enormity of the situation for the mothers of the children who faced this situation could be unaffordable even under the most robust of economies, considering their needs are so great. I reflected on what it would take to support these mothers and families and those in similar situations. It seemed that the country is transitioning and that bold new approaches may be possible particularly if they become necessary.

Summary of the Literature

A review of the literature exploring the decision-making process for out-of-home placement of the child with severe ASD and intellectual disabilities resulted in limited studies that were older, while more recent articles focused on placement prevention and placement risk factors. The literature search uncovered no occupational therapy studies on out-of-home placement, placements, risks, or placement decision-making. There was a notable absence of occupational therapy citations in literature from other disciplines, where its presence would have been expected such as in the case of Sensory Integration Occupational Therapy [SI/OT] Ayres Sensory Integration® (Ayres, 1969, 1972, 1979; Baranek et al., 2005; Dawson & Watling, 2000; Dunn, 1997, 1999, 2002; Iarocci & McDonald, 2006; Kientz & Dunn, 1997; Law et. al., 1996; Miller, Anzalone, 2007; Miller, Coll, 2007; Parham et al., 2007; Schaaf, 2014; Schaaf et al., 2012a; Schaaf et al., 2013; Schaaf & Miller, 2005; Schaaf et al., 2011). Ayres Sensory Integration® therapy is often used for treating children with sensory difficulties and extreme sensory disturbances, including children with autism (Ayres, 1969, 1972; Miller, Anzalone, 2007; Miller, Coll, 2007).

Another finding was confusion about sensory-programs which were grouped together with Ayres Sensory Integration® (Ayres 1972, 1989; Miller, Anzalone, 2007; Miller, Coll, 2007; Parham et al., 2007; Schaaf et al., 2012a; Schaaf et al., 2013; Schaaf et al., 2012b) resulting in confused terms, incompatible comparisons, with frequent statements about a lack of evidence to support the to support effectiveness of the treatment. In one case, a reviewer’s faulty assumptions based on misinterpretation of study results were offered to support a decision against the classification of a disorder often observed in children with and without ASD. The same faulty assumptions were then used for a public recommendation against the use of Ayres Sensory Integration® which has been found to decrease anxiety and maladaptive sensory reactions in children with sensory modulation disorders. This would suggest that occupational therapy literature needs to be more widely disseminated through cross publications (Ayres 1972, 1989; Miller, Anzalone, 2007; Miller, Coll, 2007; Parham et al., 2007; Schaaf et al., 2012a; Schaaf et al., 2013; Schaaf et al., 2012b). Much of the literature from other disciplines focused on the behaviors of the children with ASD, maternal stress, coping, service utilization, and impacts of the ASD on the individual with the disorders and the families.

Occupational therapy and occupational science studies reviewed tended to focus on mothering occupations, home routines, rituals and mothering children with ASD and other disabilities. Context and environments were typically addressed in these studies as well. Occupational therapy studies also included numerous studies on Ayres Sensory Integration®, many of them were relatively new research and other occupational therapy intervention approaches, models, and SMD, and impacts childhood and family occupations (Ayres 1972; Clark et al., 2011; Miller, 2012; Miller, Anzalone, 2007; Miller, Coll, 2007; Parham et al., 2007; Schaaf et al., 2012a; Schaaf et al., 2013; Schaaf et al., 2012b).

Psychology articles tended to quantify the many psychosocial aspects related to ASD symptoms, particularly behavioral symptoms and maternal depression and coping. Social work and economic articles contributed to a better understanding of the institutional and social barriers to participation; thus, confirming the value of including the economic approach along with the occupational therapy model for viewing the data.

Social work research contributed to aspects on out-of-home placements and Risk prevention as well. Social and economic policy documents opened up pathways to understanding the need for at-risk prediction and prevention related maternal health and family well-being, and for policy implementation. Law documents were useful in understanding the legal and personal aspects of out-of-home placement. Policy studies provided a broader understanding of the complexities of community health. The meaning of a mother’s experience in arriving at the decision-making process, and placement decisions for her young child’s placement outside of the home can only be known to her. Given that placing a younger child would be an unlikely occurrence, the expectation is that this phenomenological study will illuminate untapped insights about the mothers and their families’ experiences and needs.

Overall, the literature review resulted in a large body of evidence to support that those mothers of children with ASD and intellectual disabilities experience higher levels of maternal stress, less sleep, more hours spent in caregiving and managing services for their children with ASD. Stressors include worries about the safety and well-being of their children with ASD and of their other children, as well as the financial stability of the family. The literature reviewed indicated that the community supports for a full transition to community health may not be sufficient, and funding sources may not be congruent with a community model of practice or the recovery-oriented approach of Deinstitutionalization, Phase 2.

Although attitudes about disability have changed, the literature suggests many mothers of children with ASD and other disabilities still experience judgmental stares and comments when in public with their children. The review of the literature on current health and culture trends suggested that parents are seeking knowledge and making health decisions based on information gathered from the Internet, which has implications for public health, as in vaccine refusals. There appears to be a growing lack of trust in government institutions designed to protect them.

These future trends were considered to be important as the country is facing evolving, uncertain health system during the Phase 3 of Deinstitutionalization. At the same time, the country is experiencing a compromised economy with increased unemployment and navigating an evolving health system. The rates of diagnosed ASD cases are rising at unprecedented rates to currently 1 in 66 children–a 30% rise in the past two years (CDC, 2014).

The intention of this study was for deep exploration into the lifeworlds of the mothers through a transcendental phenomenological approach. To gain insight about how a mother of a child with ASD and intellectual disabilities first enters the decision-making process for placement and eventually arrives at their placement decisions. Because of the mothers' reliance on external supports and institutions, their data was viewed through both an occupational therapy model of practice and an economic approach to better understand how these aspects influenced their decision-making process and placement decisions. This understanding is necessary for understanding how to help the mothers and their families.

Chapter 3: Methodology

Introduction to the Chapter

The purpose of this chapter is to specifically describe aspects of the research design and approach selected for this study in order to answer the following research questions:

- What are the lived experiences of mothers of young children with autism spectrum disorder (ASD) and intellectual disability in regard to the decision-making process for out-of-home placement?
- What are the contextual aspects influencing mothers' placement considerations and decisions?

The first section, Research Design and Methodology describes the research design and approach selected for this study. Section two, Rationale for Selection of Selection of Research Design Approach, provides a description of the terminology and historical foundations and rationale for the selection of transcendental phenomenology for answering the research question. The third section, Specific Procedures, describes particular steps that the principal investigator (PI) followed to carry out the study procedures, and the fourth section, Strengths and Limitations of the Research Design Approach discusses the strengths and weaknesses of the design and details the number of participants. The fifth section, Inclusion and Exclusion Criteria, explains how each was determined, and the characteristics of the participants. Also included in this section are the recruitment procedures, concluding with ethical considerations and Institutional Review Board review. The sixth section, Study Setting, describes the interview location and private setting of the participants' preference, and the section Data Collection Tools describes the research instrument (see Appendix A). The seventh section, Pilot Study, briefly describes the pilot study conducted as a precursor to this study and its relation to this dissertation study (Boyd, 2008). The Data Collection Procedures, the eighth section, details the specific steps used to collect the data. The ninth section, Data Analysis, describes all data analyses methods used, the management of the data, and the analytical procedure for data type in order to answer the research questions. Section 10 concludes with a chapter summary.

Research Design and Methodology

A transcendental phenomenological approach was employed to conduct this qualitative research study. Transcendental phenomenology was developed by Husserl (1970). "The word phenomenon comes from the Greek phaenesthai–to appear, to flare up or to show itself…or to bring light, the maximum (Moustakas, 1994, p. 26). Phenomenon is what appears in consciousness and "phenomena are considered the building blocks or starting point for all knowledge" (Moustakas, 1994, p. 26). The term transcendental refers to "transforming the world into a mere phenomena" (Moustakas, 1994, p. 26). Reduction is a process that is said to lead us back to the source of all knowledge, and transformational refers to the researcher seeing things freshly as if for the first time. Husserl (1970) asserted that, "Ultimately all genuine, and in particular, all scientific knowledge rests on inner evidence: as far as such evidence extends, the concept of knowledge extends, too" (p. 61). This phenomenological approach later became a guiding concept for Moustakas (Cresswell, 2013).

In transcendental phenomenology the pure consciousness or subjective realities are given privileged status in providing the essential meanings of the phenomenon and scientific facts are doubted. In transcendental phenomenology, the researcher seeks the source of all knowledge through the ego state where knowledge is pure and all has meaning. Through a structured and rigorous scientific process, the researcher enters an internal place, where knowledge is purified to gain fresh new insights about phenomenon and follows rigorous procedures to analyze the data described in the next section (Moustakas, 1994).

Using a transcendental phenomenological approach, the researcher sets aside prejudgments and knowledge about the phenomenon under investigation. The researcher relies on intuition, imagination, and universal structures to gain an understanding of the essence of the experience and systematic methods of analysis are employed (Cresswell, 2013).

Rationale

Transcendental phenomenological research is well-suited to gain an understanding about several individuals who shared a similar experience when a deeper understanding of the phenomenon is needed to develop policies or to design or shape services (Creswell, 2013). Phenomenology can also be used to identify marginalized groups, when reform is necessary, and when providing a voice for vulnerable groups (Kielhofner, 2006; Luborsky & Lysack, 2006).

This transcendental phenomenological study was conducted to elicit essential understanding of mothers' perceptions of their entry into the decision-making process for placement of their young children with ASD and intellectual disabilities, and the complex relationship between occupations and environmental aspects and placement decisions. Considering that family occupations are embedded in home and community life, the mothers were asked to discuss their mothering roles and occupations and their families' participation in these contexts.

In-depth exploration of the mothers' perspectives of the decision-making processes for their children's placements or placement consideration was integral to understanding how parents enter the decision-making process and arrive at their placement decisions. Transcendental phenomenology provided the means by which to enter and explore participants' lifeworlds in context of home and family for a deeper understanding of the meaning of the phenomenon. Luborsky and Lysack (2006) explained that qualitative research reveals intentions, emotion and meanings, as well as complex contradictions that can be missed using fixed questions. Because participants' phenomenological accounts are descriptive, nuanced stories in context, they give meaning to existing quantitative data.

Transcendental phenomenology is congruent with the pluralistic nature of, and allows for the discovery of, the meaning of experiences in its purest form through a conscious state as well as further contemplation of the meaning of the experience in context. Philosophical assumptions of transcendental phenomenology include common elements of embracing features of human science research, and about the experience as it appears in the conscious state, then the wholeness of experiences, viewing experiences and behavior as integrated. The following elements of transcendental phenomenology were a fit for exploring the phenomenon:

- Meaning is at the core of transcendental phenomenology science.

- Transcendental phenomenology offers a means to acquire data and analyze data using a structured approach with rigorous procedures. At the same time, other aspects of the data collection and analysis processes are flexible such as the interview, and imaginative variation through contemplation and reflection.
- This data collection and data analysis process satisfies the qualitative researcher's need to understand the phenomenon in its own right, and in its totality, yet it also employs rigorous procedures making the research accessible for both quantitative and qualitative researchers (Cresswell, 2004; Moerer-Urdahl, 2003).
- Using systematic procedures throughout the research process sets aside prejudgments. By implementing the above procedures, the researcher's mind becomes open to the totality of the phenomenon to gain fresh new insights, as if for the first time; thus, the process is called transcendental. Moustakas's transcendental phenomenology explicates the essence of human experiences (Moerer-Urdahl, 2003).
- The epoche process of bracketing and journaling to maintain a phenomenological attitude and open mind allows the participants to ascribe their own meanings to their experiences. Elements of meaning and freedom are central to occupational therapy, and the freedom to choose is relevant to parents' placements decisions.
- Transcendental phenomenology produces rich, thick descriptions which can be understood by wider audiences; therefore, the dissemination can be through a variety of venues. In addition to peer-reviewed journals, the findings of

phenomenological research can be modified for broader dissemination to the non-scientific community for wider readership.

- The rich, thick descriptions also strengthen the rigor of the study, as they allow the reader to judge for themselves whether the interpretations of the PI are congruent with the participants' statements, which may contribute to the study's rigor and confirmability.

Transcendental phenomenology has the unique capacity to elicit essential understanding of the mothers' subjective realities and meanings of their experiences of the impacts of ASD, but also to convey the magnitude of these impacts. In other words, phenomenology examines what were the mothers' experiences and how did the mothers feel about their experiences or what meaning was derived from the experience. Moustakas (1994) discussed the use of literature in a phenomenological study such as framing a problem and setting the stage for inquiry.

Transcendental phenomenology provided a means to explore the decision-making process for child placement in relation to relevant historical events and in light of current trends and contexts that could potentially influence mothers' and families' capabilities or placement decisions. Transactional environmental aspects were considered for discovering new insights about risk prediction and prevention. Examples of these environmental aspects included evolving health environments and economies, technology, and new ways of knowing and communicating. These emerging health economic and technological environments have implications for parents' health decisions and potential implications for public health, rising ASD rates, and eroding trust in government institutions.

In phenomenological research, context is valued and expressed by the participants through rich, thick descriptions or nuanced story telling of mothers. This makes the data more accessible to a broader audience for increased understanding and informed decisions-making for policies and relevant services. Wider dissemination across broader venues of publication is useful for informing decision policies, shaping services, and providing insight for setting up the necessary support networks for individuals with ASD and intellectual disabilities and their caregivers. Phenomenology's inclusion of contexts allows for exploring how mothers' and their families' capabilities and occupational performances may have been affected in relation to participation, inclusion, social, economic, and occupational justice. This exploration of the mothers' lifeworlds and struggles of the mothers and their families is necessary if we are to understand and support these caregivers and their families.

Specific Procedures

Upon receiving Nova Southeastern University Health Professions Division Institutional Review Board (IRB) Research *Protocol No. 08161017* approval, recruitment flyers (see Appendix B) were distributed. The recruitment flyers detailed the specific inclusion criteria. The flyers were widely distributed using a snowball approach (professional networking, friend, community members). Once the participant made the initial e-mail or phone contact to the PI expressing interest, the PI replied to the individual by e-mail or phone (see Appendix C). Eligibility for the study was determined by phone or e-mail following the PI's initial contact. Under the original IRB procedures, once the participant's eligibility was established by phone or e-mail, an interview date was scheduled.

After determining the eligibility of the participant through the initial contact, if the participant expressed interest in participating, the interview was scheduled at a convenient time and private location of the mother's preference. There were two to three interviews and a member check as a part of the data collection procedures on the IRB, however, it was also stated in the IRB that there would be some flexibility recognizing that the mothers schedules were very limited due to child care issues. The member check was to be an additional interview. Each of the mothers asked for accommodations on the number of visits, from two to three 1-hour-long interviews to one interview lasting 2 to 3 hours. For the member check, the mothers requested that they receive the themes first by e-mail followed by a phone discussion. After the mother's had received and responded to their impressions of their themes, the PI arranged for a phone contact with the mothers for further discussion.

For the first interview, the Adult/General Consent Form (see Appendix D) was sent ahead to the participant and a copy was also brought to the interview where it was reviewed with the mother. The mother expressed her satisfaction with the process as outlined in the consent form and signed the consent form just before the interview.

One year lapsed before the second participant made the initial contact, then the remaining mothers made contact shortly after. The procedures for the Nov 14, 2012 IRB Continuing Review and an Addendum was sent to change the process of sending the consent form in advance of the interview. The consent form for the next five participants was signed just prior to the start of the interview. The PI felt that sending the consent form and a list of licensed counselors might be intimidating to potential mothers, and a potential barrier to recruitment. The PI also felt that it was important for the mothers to be able to review the consent form when the PI would be available to answer questions or explain something if it was not clear.

Although no ill effects were expected, due to the sensitive nature of the phenomenon under investigation (child placement considerations and decisions) a list of local licensed counseling professionals (see Appendix E) in the mothers' geographical areas were provided at the time of the interview. The statement on the consent form was: *Although it is not expected that you would experience any discomfort, due to the sensitive nature of the research topic, this list is being provided in the event that you feel that you need to talk to a licensed counselor.* The purpose of the list of licensed counselors (Appendix E) was described in the consent form (Appendix D). Both documents (Appendices D and E) were explained in person just before the interview. It was also clarified for each mother, as described in the consent form (Appendix D), that any counseling would be at the mother's own expense.

After each mother signed the consent form, the PI once again reminded each participating mother that she could stop the interview or withdraw from the study at any time during the interview, even though she had signed the consent form (Appendix D) before starting the interview. Interviews were digitally recorded for accuracy, and then downloaded onto the hard drive of a password- protected computer used only by the PI. The recordings were encrypted and sent to a professional transcriptionist under obligation of contract with the transcription company to protect the participants' confidentiality. Interviews were transcribed verbatim, typed, and double spaced, with numbered pages and numbered lines for quick reference.

Once each mother’s data was analyzed and the themes that potentially described their lived experience were extrapolated through the analysis process, the PI conducted a member check with each mother. The purpose of this first member check was to confirm that the initial individual themes of each mother accurately and authentically represented their lived experiences. Each mother requested that the themes be e-mailed to them rather than having to schedule another visit, due to childcare issues and tight therapy schedules.

After the mothers reviewed the themes, they discussed with the PI by e-mail or phone their understanding of the themes that emerged from their data. They were asked to provide their perspectives as to the accuracy and authenticity of the themes in describing their lived experiences and to offer any changes the mothers felt were necessary. The mothers reviewed the themes, then either responded by e-mail or phone to discuss the results. The mothers suggested that the themes were clear and each mother confirmed either verbally or by e-mail that the characterization of their lived experiences of the placement decision-making process and considerations were authentically represented in the individual themes. One mother expressed that the themes were “perfect” in regard to describing her situation and also the occupational aspects of their home and community life in relation to her placement considerations. None of the mothers offered any changes or challenges to their individual themes. Once the individual themes were confirmed by the member check of each participant, the PI then constructed structural-textural description, composite themes, or universal themes that comprised the essence of their experiences.

The next part of the analysis involved constructing a structural-textural composite description of the mothers’ themes which was considered to be the essence of the phenomenon. Once the mothers' themes had reconstructed to one composite or universal description, the PI conducted a second member check of each mother. Following the second member check, the PI implemented a secondary analysis of the data by a research scientist and subsequent peer-review process for triangulation. The peer-review process and purpose will be discussed directly following this section on the second member check.

A second member check was conducted following secondary analysis and a peer-review session, which was implemented to strengthen the rigor of the study. The secondary analysis and peer-review process will be discussed following this discussion of the results of the second member check. Each mother was contacted for the second member check of the composite themes–as these themes are the essence of the mother's experiences for a universal essence of the mothers' experiences. Since these themes represented the composite essence, it was important that the mothers were satisfied with the themes in regard to understanding their lived experiences and perspectives of their placement considerations, decision-making process, and placement decisions.

Each mother was called to discuss the themes. A message was left in each case stating the themes would be e-mailed and that there would be a follow-up phone call to discuss the composite themes. The composite themes of the six mothers were e-mailed to them as per their request. Themes were sent to each mother by e-mail, which explained how the PI arrived at the composite themes, with an explanation of the themes. Follow-up phone calls were made to each mother to discuss the new themes. Although the main themes were similar to their individual themes, the themes now conveyed a more occupational justice tone in some areas. The composite themes had a broadened focus, which considered the contextual aspects influencing the mothers' placement considerations and decisions.

The PI called each participating mother to alert the mother to the arrival of the composite themes by e-mail. Subsequent phone and e-mail conversations allowed the mothers to discuss their perspectives of the composite or universal themes, or the essence of their placement considerations. Two mothers responded at this time. Linda and Dorian agreed with the occupational justice themes in the third member check, each expressing that they did not think that the themes had really changed that much.

Following the PI's completion of the data analysis, a secondary data analysis and subsequent peer review was conducted by a research scientist from a renowned psychiatric institute, which will be described in a later section under triangulation.

Strengths and Weaknesses of the Design

Strengths of the Design

The strengths of the of Husserl's (1970) transcendental phenomenology research approach is how it captures the essence of the experience and uncovers contextual meanings that defy quantitative expression. Conklin (2007) stated that transcendental phenomenology reveals knowledge that is particular to the individual and regards it as a leverage tool to understand the other. Conklin further claimed that transcendental phenomenology is a must for professionals who attempt to improve health and quality of life. Because phenomenology also tells a story in terms that can be readily understood by everyday people, phenomenological research may potentially shed light when reform is needed, or identify a vulnerable groups. The inclusion of relevant contexts allows the researcher to explore and better understand the other aspects that may influence how participants may experience or interpret the same phenomenon in different ways (Moustakas, 1994).

Another strength of Moustakas's (1994) transcendental phenomenological approach was a set of detailed procedures used before and during the data collection and data analysis processes that helped to keep potential biases separate from the findings. This process was achieved through Moustakas's epoche process and through pre-in-action and post-action bracketing and journaling. Using the epoche process of bracketing and journaling throughout the research process, the PI was able to bring potential biases to consciousness, helping to keep these potential biases separate from the study findings which increased the study's rigor.

Weaknesses of the Design

A potential limitation of this study was the number of participants (*N* = 6). However in phenomenological research the goal is to gain a deeper understanding of the phenomenon under investigation. However, Mother 1, Mary completed this same process, except for the composite themes review a year earlier. More participants do not necessarily contribute to the depth of the investigation and could potentially impede the level of depth required to achieve the necessary depth explained in greater detail ahead, under the section Number of Participants.

Another potential limitation of the phenomenological approach is due to the fact that the qualitative research results cannot be generalized; however, generalization is not a goal of phenomenology. Still, transferability can be achieved as individuals recognize or relate to the participants descriptions (Cresswell, 2013).

The greatest threat to rigor in phenomenology is substitution of the participants' meanings with those of the researcher's, leading to invalid findings

(Kielhofner & Fossey, 2006). The phenomenological researcher has to guard against guiding participants based on preconceived assumptions or advanced knowledge (Kielhofner & Fossey, 2006). Transcendental phenomenology has several procedures to guard against substitution of meanings including the epoche processes, pre- and post-action bracketing and journaling, triangulation through secondary analysis of the data, and triangulation through the peer-review process described in depth under the triangulation procedures, which is found under the section Threats and How They Are Addressed.

Another potential limitation of phenomenology is that it requires skill on the part of the researcher and knowledge of phenomenological concepts and processes. Strict adherence to the phenomenological procedures reduce this threat and were carried out in this study to prevent such threats to rigor. According to Moustakas (1994), threats to rigor are minimized through strict adherence phenomenological procedures and by multiple measures to assume and maintain a natural or phenomenological attitude. Use of the epoche process, which will be described in depth later on in this section, is one of the means by which the PI kept an open and curious mind, in order to control for biases and preconceived notions. The epoche process was instrumental in controlling for prior knowledge and theory about the phenomenon based on the PI’s years of occupational therapy practice with children with ASD and intellectual disabilities and their mothers and families. The pre- and post-action bracketing and in-action bracketing through frequent journaling throughout the research collection and analysis process helped to achieve and sustain an open and curious mind.

Another potential limitation was the recruitment of participants who would not be able to articulate the phenomenon in a way that could be understood by others, or that could result in the absence of rich, thick descriptions which are essential to the rigor of the study. Rich, thick descriptions in the participants' words are essential to allow readers to gain a deeper understanding of the phenomenon from the participants' perspectives and to allow readers to judge the quality of the PI's interpretations. This threat to rigor was minimized by use of a snowball approach which enabled networking so that professionals who understood the nature of the study could provide flyers to the appropriate potential participants. This threat to rigor was also controlled after the PI responded to the participant with the e-mail script (see Appendix C).

Threats and How They Were Addressed

Trustworthiness. Kielhofner and Fossey (2006) and Curtin and Fossey (2007) stated that the greatest threat to rigor in phenomenology is substitution of the participant's meanings with those of the researcher, leading to invalid findings. To address this primary concern, phenomenologists use specific procedures for collecting and analyzing data to contribute to the trustworthiness of the findings and the rigor of the study. The PI employed the following methods to minimize and address the risk of these threats to the validity and rigor of the study.

The trustworthiness or validation standards of a qualitative study is a form of verification of the authenticity and accuracy of the findings similar to validity in quantitative research (Creswell, 2013). The trustworthiness in this study was secured through strict adherence to procedures, and multiple measures to protect the rigor of the study and to evaluate the research process and findings including external evaluation. The following measures were implemented to ensure the trustworthiness of the study.

Epoche process. The PI assumed a natural attitude or an open mind, bracketing or setting aside, to the best of her ability, all preconceived notions, and prior knowledge, keeping the mind open for new learning. The epoche process was carried out through pre-action, in-action, and post-action bracketing. Pre-action bracketing was carried out before the participants were interviewed in the PI's full phenomenological account (see Appendix C). In-action was completed by journaling throughout the process. Post-action bracketing was completed by journaling after the data collection and after the data analysis was complete.

***The first and second epoche processes*.** *Reflexivity* is the process by which the researcher makes explicit any knowledge, experiences, biases or values that the researcher may bring into the research study. Reflexivity is demonstrated in the following two fundamental procedures that Husserl (1970) adopted and considered to be necessary for the study of experience:

1. The epoche of the natural sciences.
2. The epoche of the natural attitude.

The word epoche means abstention and refers to refraining from judgment (Cresswell, 2013; Moustakas 1994).

Epoche of the natural sciences. The first epoche is abstaining from or bracketing of prior or scientific knowledge about the phenomenon under investigation. The phenomenological investigator focuses on lifeworld to gain fresh perspectives from the participants about their lived experiences of the phenomenon by reflecting on their concrete examples (Creswell, 2013).

Epoche of the natural attitude. The second epoche that of a natural attitude is also called *phenomenological reduction* (Wertz, 2011). Phenomenological researchers assume a natural attitude or an open mind and suspend judgments. Recognizing that the greatest threat to rigor in phenomenology is substitution of the researcher's perspectives for those of the participant, bracketing is methods used as a means of controlling for bias, misinterpretations, or misrepresentations. Two other important concepts in phenomenology are related to *intentionality* and reflexivity (Moustakas, 1994).

Intentionality. Husserl's (1970) transcendental phenomenology is bound to the concept of intentionality (of consciousness) which refers to discerning features of the consciousness essential for individuation of objects (real or imaginary) as they appear in the consciousness or "what it is, that we are experiencing" (Moustakas, 1994, p. 29). Intentionality is comprised of *noema* and *noesis* described as follows:

1. Noema gives consciousness it direction toward specific objects(Moustakas, 1994). Noema was apparent in the mothers' accounts about the phenomenon. For instance, mothers' understandings about descriptions about life with autism and out-of- home placements.
2. Noesis refers to individual' acts of consciousness for explicating how beliefs about objects (real or imaginary) may be acquired. In other words, "how it is, that we are experiencing, what we are experiencing" (Moustakas, 1994, p. 29). Noesis involves thinking, reflecting, feeling, remembering, and judging. When perceiving an object, an individual's intentional experience is a combination of perceiving the outward appearance of an object as contained

> in one's conscious-ness, based on memory, image and meaning memory (Moustakas, 1994, p. 29).

Noesis was achieved through the mothers' perceptions of how it felt to consider or experience the decision-making process for placement of one's young child with ASD. In-action bracketing or the process of journaling allowed for the PI to keep her own noema and noesis open and in sight.

Reflexivity. Reflexivity is a deliberate and systematic process of self-examination from inward reflection and looking at what is learned outside of the inward reflection. Understanding that biases cannot be fully eliminated, only controlled, the PI used reflexivity to control biases in this study through self-awareness, and to distinguish bias from what is learned outside of the inner self.

Journaling and bracketing. Journaling and in-action bracketing were employed as additional measures of reflexivity throughout the research process employed by Wall, Glenn, Mitchinson, and Poole (2004). Transitions of thought that occur during the research process are indicators of increased rigor in the study, as evidenced during this study by instances of new learning or transitions in thought. For example, the PI's interviews suggested that the participating mothers used the Internet to seek health information and support. The PI was not aware of the mothers' perceptions that the typical ASD websites were more geared towards mothers of children of ASD at higher levels of function than their children. For this reason, the mothers did not feel that the websites were helpful to them, nor did they feel like they fit in with this support group since their needs were vastly different from the needs of the other mothers; therefore, the mothers reported that they stopped visiting these sites.

For example, knowing the mothers used the Internet as a main source of communication, the PI could have potentially assumed that the mothers were also finding some support through the autism websites, which in this study would be inaccurate. For this reason, using journaling in addition to adhering to the Moustakas (1994) phenomenological procedures was an additional tool for further reflection and a useful evaluative tool for the PI to maintain a phenomenological attitude; thus, strengthening the rigor of the study.

The journaling that was done at earlier points in the research helped to keep track of concepts that would not become clear until later in the process. For instance, this knowledge about the mothers' feelings that they did not really fit in with the typical groups was written in the journal. A year later, the several mothers in the study discussed this same phenomenon. The journal kept track of this new discovery for a later time, when further statements reinforced this as a more common experience among the mothers.

For example, knowing the mothers used the Internet as a main source of communication, the PI could potentially assume that the mothers were also finding some support through the autism websites, which would be inaccurate in this study. For this reason, using journaling in addition to adhering to the Moustakas (1994) phenomenological procedures served as an additional tool for further reflection and a useful evaluative tool for the PI to maintain a phenomenological attitude; thus, strengthening the rigor of the study.

Journaling was done following the interviews and throughout the research process. The journaling not only helped to bring preconceived notions to the surface, but over time, hidden meanings of the experiences became more apparent. For instance, the mothers in this study who considered the placement decision-making process were able to fully articulate why they were adamant about not placing their children. Conversely, they were also knowledgeable about and able to fully articulate why other mothers might feel the need to place their children.

With reflection and journaling the links became clear that the mothers were engaged in on-going considerations about child placements and perhaps fears about placements. The iterative process of reading the transcripts and journaling thoughts appeared to release a flood of insights in some cases, and minor or undetected insights at other times. The effect was powerful, and it kept the PI faithful to the data and the discovery process. The journaling also helped the PI to clarify connections that were not so obvious. As the PI's journaling progressed, thoughts became more globally about the mothers and their situations. If the current system was unable to support their needs, what would happen to the mothers and their families? Certain disparities came to light through the literature review.

Strict adherence to specific phenomenological procedures. Strict adherence to the specific phenomenological procedures for organizing and analyzing the resulting qualitative data were Moustakas's (1994) modification of the Stevick, Colaizzi, and Keen method of analysis for phenomenological data. These procedures are described in detail under the Data Collection section later on in the chapter.

Another potential threat to rigor is preconceived notions or assumptions from the PI's professional experience and knowledge about ASD and intellectual disabilities and working with parents. As a pediatric occupational therapist working with children with ASD and intellectual disabilities and their families in multiple settings (home, early intervention, hospital, community, school settings), there was potential for the PI to introduce bias from prior knowledge.

Moustakas's (1994) modification of the Stevick, Colaizzi, and Keen method of analysis phenomenological data briefly stated this process begins before the data collection phase of the research process using the following four steps which will be described in depth under the Data Analysis section: (a) the epoche process, (b) extrapolating themes, (c) data analysis process, and (d) integrating themes into a composite textural structural or essence of the experiences.

During the epoche process, the PI engaged in writing a full phenomenological description of the phenomenon under investigation before the study began. The purpose of this epoche process was to bracket or set aside and reveal prior knowledge or potential biases so that readers could better judge the quality of the PI's interpretation of the data. The epoche process brought to the PI's consciousness preconceived notions or biases that could potentially lead to misinterpretation or misrepresentation of the data, which is the greatest threat to rigor in phenomenology (Kielhofner, 2006).

Misinterpretations or misrepresentations of the participants' data can potentially render the study findings useless, defeating the purpose of phenomenological research which is to understand. Bracketing and journaling throughout the research process kept the PI alert to potential biases so that the biases remained separate from the participants' data. The epoche process is a strength of transcendental phenomenology which strengthens the study's rigor.

The PI wrote a textural-structural description of the phenomenon and employed a structured method of analysis, specifically Moustakas' (1994) modification of the Stevick, Colaizzi, and Keen method of analysis of phenomenological data. The four steps of the analysis procedure described earlier were carried out by the PI assuming a natural phenomenological attitude and in the data analysis process for each of the transcripts for each of the six participants.

Credibility. Credibility was established through the PI's completion of the Collaborative Institutional Training Initiative (CITI) course in Protecting Human Research Participants (see Appendix H). The PI was a National Board for Certification in Occupational Therapy (NBCOT) certified, and New York State licensed and registered occupational therapist with over 20 years of experience in pediatric occupational therapy in multiple settings including hospital-based, homecare, and school settings. With a master's degree in public health from New York Medical College, the PI's special focus was on early intervention, developmental disabilities, and ASD, and a strong interest in community health. The PI was involved in interviewing parents throughout her occupational therapy career in various settings including the home. In her role as an occupational therapy educator, the PI regularly conducted admissions and interviews for potential faculty and instructors. The PI also successfully conducted a successful pilot study as a precursor to this dissertation study.

In the areas of medical-model practice and program development, the PI was initially trained in a large university teaching hospital in a metropolitan area serving infants and children with disabilities and developmental disorders and delays. The PI also developed an in-hospital early intervention program and a high-risk infant follow-up program in a local hospital. In this setting, the PI worked closely with the Neonatal Intensive Care Unit (NICU) neonatologists, neurologists, doctors, nurses, therapists, parents involved in the programs, and the local department of health's early intervention program to establish funding for evaluation and therapeutic services. The PI was a contributing author to several chapters in the *NBCOT Review and Study Guide* and co-author of the chapter on Human Development, Neurological System Disorders between 2004 and 2014.

In the area of community health, the PI developed several community fieldwork placements with different populations including children of migrant workers attending a pre-school and daycare program–an inner-city program in a low income area, and an on-campus wellness program for retired Sisters (nuns). The PI co-authored two articles in *OT Practice* on community fieldwork development and was contributing author to a book on occupational therapy leadership, specifically the chapter on leadership in the community.

Dependability. Dependability was supported by the use of digital recordings and by checking the transcribed recordings against the participants' transcripts for a secondary check of accuracy (Taylor & Kielhofner, 2006). The digital recordings were very clear and the transcriptions from the transcription service were completed with double spaces and numbered lines, and noted pauses in speech and details like laughing, or crying. The tapes were also accurate when compared to the recordings.

Rich, thick descriptions. Rich, thick descriptions refer to the descriptions from participants' interview transcripts. The more detailed information with abundant interconnected details and concrete examples allows for others to relate sharing characteristics, which relates to transferability.

Related to the rich, thick descriptions are the processes and study criteria. The study criteria for selecting individuals who are articulate in conveying the lived experiences and meanings of their experiences so that others can understand was to ensure that the interviews would result in rich, thick descriptions form the foundation of the study.

The *purposeful sampling* and *snowball approach* also supported the potential for the rich, thick descriptions in recruiting through groups that would be aware of the criteria and to potentially identify appropriate research participants. Rich, thick descriptions offer another avenue for confirmability and evaluation of authenticity and accuracy of the findings. To clarify, PI provides the means for other researchers to assess the PI's processes and path to discovery so that readers can corroborate the evidence for themselves as a measure of confirmability. Importantly, the path to discovery also guides future researchers who may be interested in the topic, or readers who are may be emotionally moved to act on behalf of the participants.

Transferability. Transferability is the quality of a study's findings to be understood outside the context of the study, or meaningful or applicable to a reader's own experience (Guba & Lincoln, 1989; Koch, 1994). Transferability is not to be confused with generalizability which is not a goal of phenomenological research. From the mothers' transcripts, a reader could easily relate to the findings. For example, a mother describing her child having a temper tantrum in a store and how she felt at the time is a situation that could be understood outside of the study's context.

Member check. A member check is the process by which the researcher solicits the participants' views of the credibility of the perspectives and views interpretations and findings (Guba & Lincoln, 1985). In the current study, the member check was arranged according to the mothers' preferences, which was for an e-mail check. The themes were emailed to the mothers for their confirmation, or for an opportunity to suggest changes. Each mother confirmed that the results were an accurate representation of their experiences and no mother suggested any changes. The subsequent member check involved a discussion about the composite themes. The composite themes were confirmed. The participants appeared to understand how the their themes connected with more global aspects of disability and inclusion, even policies, perhaps because of their self-educated position on those aspects which affect their lives so deep such as the services and supports that helped their families to survive.

Independent, secondary analysis of data. After the PI completed the data analysis, a peer debriefer independently completed a secondary analysis of the data. The procedures used for secondary data analysis by the peer debriefer were the Moustakas (1994) modification of the Stevick, Colaizzi, and Keen method of analysis phenomenological data described in detail under the Data Analysis section. Following the same four-step procedure as PI, the peer debriefer independently analyzed the data. After the independent secondary analysis was completed, the peer debriefer conducted a peer-review process with the PI. Secondary analysis was carried out by a clinical psychologist with a PhD, a research scientist at a psychiatric institute, as well as a registered and licensed occupational therapist. The PI submitted a certificate of completion of the NIH Protection of Human Research Subjects and Ethics course (see Appendix F). This same research scientist also conducted a peer review with the PI following the secondary analysis.

Peer-review process. Creswell (2013) describes peer review or peer debriefing under standards of validation and evaluation in qualitative inquiry and research design as a form of triangulation. The role of the peer debriefer is to complete a secondary analysis of data. The secondary analysis and peer review process were scheduled following the PI's completion of the primary analysis and second member check. The peer review process was conducted by the peer reviewer for approximately 1 hour. The role of the peer reviewer was to ask difficult questions of the PI and challenge the PI's interpretations, representations, and adherence to strict adherence to phenomenological procedures. The peer reviewer debated potentially conflicting interpretations with the PI until both parties were satisfied with the accuracy of interpretations. The peer reviewer helped to keep the PI alert to potential underlying assumptions or biases, which involved the reviewer analyzing the data (transcripts, in this case) separate from the PI. The secondary analysis and peer-review process provided an evaluative, external check on the PI's procedures, interpretations and representations as a triangulation procedure to increase the rigor of the study.

During the peer-review session, the researchers engaged in discourse about the findings of their independent analyses. The results of the PI's analysis and the independent secondary analysis of the peer debriefer were remarkably similar. Perhaps this was because the participants were able to clearly articulate and convey their experiences; therefore, the transcripts were richly detailed with descriptions, meanings, and concrete examples. However, there were a few instances when the hidden meanings of the themes emerged from both the peer debriefer and the PI's findings. In discussing and debating these hidden meanings, the themes were clarified and strengthened, which served the purpose of the peer review as a triangulation method to external check of the rigor of this study.

The reasons that peer debriefing is important in qualitative research is that any one analysis is considered incomplete (Creswell, 2013). Peer debriefing offers an external check on the accuracy of the researcher's interpretations and an opportunity to argue for clarification of the interpretation. Lysack, Luborsky, and Dillaway (2006, p. 353) reminds researchers that the peer-debriefing process may be the only way for opposing or contrary explanations for the phenomenon to be aired. Lysack et al. (2006) described peer debriefing as "an important point of departure from more standardized fixed set of measures, conducted identically with each participant" (p. 353). According to Lysack et al. (2006, p. 353), the use of peer debriefing adds to the legitimacy of the final version of the study findings and confirmability and dependability of the research process, the interpretations, and the value of the data.

Triangulation. Triangulation is the researcher's use of different methods, multiple sources, investigators or theories for corroborating evidence to validate the accuracy of the study. Triangulation was achieved through the (a) rich, thick data with direct participants' quotes and concrete examples that related back to the literature and provided a means to confirm the themes through the participants' verbatim quotes; (b) member check or confirmation of the themes by the mothers as accurately representing their lived experiences and their meanings of those experiences; (c) independent secondary analysis; and (d) the peer-review process or peer-debriefing session described above.

Confirmability. Confirmability refers to the dependability of the research process, the interpretations, and the value of data (Creswell, 2013). Guba and Lincoln (1985) and Koch (1994) stated that confirmability is established once credibility, transferability, and dependability are achieved. Transferability and dependability were achieved in this study as described earlier; therefore, confirmability was also achieved.

Participants

The participants for this study were mothers of children with ASD and intellectual disabilities, who had experienced or considered the decision-making process for out-of-home placement, or made the decision to place their young child with ASD and intellectual disabilities.

Number of Participants and How Determined

The number of participants described in detail under Characteristics, was six mothers (*N* = 6). The number of participants set by the PI's chair for this dissertation was 10 but later reduced to eight, then finally to six due to significant recruitment challenges. In phenomenology, it is the depth of the exploration of the phenomenon that is important. Large numbers do not necessarily add to the knowledge gained, particularly if the depth of exploration was not considered sufficient. Several theorists have discussed the number of participants needed for phenomenological research.

Kielhofner (2006) stated that the number of participants in phenomenological research is usually between five to 25 participants. This is because in phenomenology what is important is not the number of participants but the depth and richness of the data collected. Ranges of sample size were reported from one participant (Dukes, 1984) to 325 participants (Polkinghorne, 1989). Larger pools tend to be used for a collective story (Creswell, 2013). Giorgi (1997) suggested three or less participants. Dukes (1984) recommended studying one participant in phenomenology to meet its depth. Wolcott (2008) stated that any case over one reduces the level of detail that can be provided by the researcher.

As a precursor to this study, the PI completed an IRB-approved pilot study of two mothers, as a partial requirement and preparation for this dissertation (Boyd, 2008). The rich, thick descriptions resulted from the mothers' interview transcripts in this pilot study with only the two participating mothers providing the depth of information necessary to answer the research questions. Therefore, six participants for this study was considered sufficient to reach the necessary depth to answer the research questions, and to corroborate with the evidence from the literature reviewed, the pilot study, and the theorists' support of smaller numbers for phenomenological research described above.

Inclusion Criteria and How Determined

Inclusion criteria included being a mother of a child with ASD and intellectual disability with sensory and behavioral disturbances, and having at least one other child with typical development. The mother had to have experienced the decision-making process for out-of home placement or potential placement of a child, at a time when the child was age 12 years or younger.

Mothers' perspectives of placement considerations, decision-making, and decisions were considered necessary to explore the phenomenon of out-of-home process and placement of their young children. This is because the research suggests that mothers are typically the primary caregivers for children and particularly for children with disabilities. In addition, children are uniquely dependent on their mothers and the strong mother-child bond makes understanding the topic of out-of-home placement more compelling.

The age of 12 years or younger was selected due to the unlikelihood of parents placing a child at this young age outside of the home. Developmentally, children age 12 years or younger are still somewhat attached to their parents, spending more time at home than an adolescent who would begin to decrease their reliance on parents (Havinghurst & Levine, 1979). The mothers' perspectives of the placement decision-making process were essential for gaining untapped insight into the phenomenon. It was an expectation of this study that by exploring the lived experiences of the participating mothers' placement considerations, decision-making process, and their placement decisions would review untapped insights about how to better meet the needs of the mothers and their families.

All of the participating mothers fit the criteria of being able to clearly articulate, providing detailed descriptions of the decision-making process. Each mother was also able to describe how she experienced the placement decision-making process with the depth, detail, and clarity necessary to shed light on their lived experiences so that others could better understand what happened to the mothers, and how they felt about it, which was determined during the PI's and potential participant's initial phone call.

Finally, the decision-making process or placement must have occurred within the past 10 years, so that the mothers could recall the details of their experiences. Blacher (1990) and Nankervis et al. (2012) agree that the act of placing one's young child outside of the home can be an extremely emotional and even traumatic process for parents, particularly the mothers. In all instances, the mothers were able to clearly remember, articulate, and describe what they experienced and how they experienced the placement decision-making process. The criterion of 10 years was considered by the PI to be a reasonable number of years for a mother to recall the details of the decision-making process given the extreme nature of the event and decision-making.

Exclusion Criteria and How Determined

Participants who did not have a child with ASD and intellectual disabilities with sensory and behavioral disturbances were excluded, as the study was intended to focus on more challenging family situations. Participants whose children were over the age of 12 years before they first engaged in the decision-making process for their children's placement were also excluded.

Characteristics of the Participants

The names of the six participating mothers and their family members have been changed to protect their confidentiality. The six participating mothers were primary caregivers for their child with ASD and co-occurring intellectual disabilities. During the period of time that the consideration or decision-making process for placement or placement decision was made, or the placement event occurred, the mothers were all considered to be at severe risk for placement based upon the severity ASD symptoms present in their children, and other factors that placed them at high risk. Each mothers' predicted risk of placement met the criteria of being at severe risk for placement due to the severity of the disorder. A partial list of the caregiver risk factors experienced by the mothers in this study were (a) maternal stress, (b) having a child with autism and behavior problems combined, (c) assault/injury/severe behaviors, (d) high supervision needs (line-of-site/or at an earshot), (e) no or minimal activities of daily living skills (ADL), and (f) seizure acuity.

Of the six participating mothers, Dorian engaged in the decision-making process before her child was age 12 years and decided to place her child at that time;

however, she was unable to do so because of limited state facilities. Dorian did place her young child in foster care, but her child was returned by the foster parents within two weeks when they were unable to handle the child's aggressive behaviors. Mary placed her child at age 10 due to safety issues, but her child was returned back home after three years in a residential school setting. Denise and Soo were adamant about not placing their children and were asked to consider what might influence other mothers in their position to opt for placement. Linda experienced a change in her child's behavior which caused safety issues for both her child with ASD and her other child, which was found to be related to a medication change and the placement was no longer necessary. Linda and her husband were relieved that the placement was not necessary. Elise was in crisis and likely to have to consider placement in the near future due to severe behavioral, economic, and safety issues placing her child with ASD and her other two children (fraternal twins – one child with typical development and another with mild ASD) at risk. Elise wanted to avoid the placement of her son; however, she expressed fear that she may someday need to place him due to her lack of family support and supports and services, and the effects on her other children's' lives. Refer to Appendix G for more details in a table format.

Contextual Aspects Influencing Mothers' Placement Considerations for Their Children With Autism

Mother 1, Mary. Mary was married to Matt, a protestant pastor, and they lived in a suburban neighborhood of Kentucky. Mary's and Matt's' first-born daughter Helen, age 11 years old, had ASD and intellectual disability. Helen's sisters Stephanie (age 8 years) and Ellen (age 2 years), had typical development at the time of the placement. The family moved from South Carolina to North Carolina to a neighborhood that was welcoming and where they felt at home. Helen was placed in a special education program. Friends encouraged Mary to push for Helen to attend an integrated school program. While the special program was more restrictive, the integrated program was not a fit for Helen who was then bullied. Matt and Mary were dissatisfied with Helen's school placements. At the process for placement, Helen was just under the age of 12 years and by that time, the decision-making behavioral problems escalated enough to cause safety concerns for her and for her two younger siblings. Mary and Matt found a residential school for Helen in Kentucky; however, the weekend visits were too draining, so the family relocated to Kentucky to be closer to Helen. Matt’s and Mary's parents helped with the expenses for this residential school.

After three years, Mary and Matt brought Helen back home. With the structure of the residential program, Helen's behaviors became more manageable and becoming accustomed to living in a non-chaotic household, the family was in a better state to firmly renegotiate Helen's terms of reintegration into the family once more. Helen and her family are doing much better. The family missed the sense of community that they had in North Carolina where they felt more accepted by the community. Mary and Matt had never lived close to their families and found it difficult to attend social events where Helen was accepted. Matt and Mary were happy to have Helen at home again; however, they had few options for social participation and Helen did not have friends that called her. They appeared to accept their circumstance in a spiritual way. Since the interview, Mary and Matt moved to Virginia due to a change of employment.

Mother 2, Elise. Elise lived with her husband Ned and their three children, Kenny (age 7 years**)** with ASD and intellectual disability, Nicole (age 5 years), and Evelyn (age 5 years). Elise's family was in crisis. Elise wanted to raise the child in their home, but struggled to secure sufficient services and supports to keep her son at home. Elise was fearful that she may have needed to consider a placement due to Kenny's aggressive behaviors towards himself and others, and his tendency to wander or bolt, placing Kenny and his sisters at risk. Kenny's language skills were insufficient for a conversation. Kenny was recently potty trained, but he did not always indicate when he needed to use the potty. Kenny had a seizure disorders and he also had certain nutritional deficiencies for which he was given supplements. Kenny had two younger sisters, Evelyn and Nicole, who are five-year-old fraternal twins. Evelyn had ASD, however, her she attended school with her twin sister, Nichole, who had neurotypical development. Evelyn sometimes had behavioral meltdowns.

Elise and Ned moved their family from North Carolina to Florida when Kenny's special services were dropped. Elise stated that her son's services were dropped due to his "limited rehab potential." Elise relocated to Florida after researching, then finding, a special school for Kenny. Elsie, Ned, and their family had no friends or family in Florida, except for Elise's mother who was elderly and could not be around Kenny. Ned was in poor health and in need of an organ transplant, however, he was still able to work from home. Elise was a stay-at-home mom who spent any free time completing forms and writing grants in an attempt to access special services to help Kenny. Elise was desperate to keep her son at home, but she was concerned for her other two children's safety and well-being as she could not manage all three children by herself outside of the home, without the assistance of an aide.

Without sufficient support, Elise feared that there may come a time when she would be unable keep Kenny at home. Elise believed that immunizations caused her two children's autism disorders and she expressed anger and frustration with the government-mandated immunizations and government’s reluctance to help her with a problem which Elise believed they caused. Elise was skeptical of the research studies that refuted the claim that immunizations caused autism. Elise was physically exhausted and mentally stressed attempting with very little support and limited sleep to raise her family in a new community. Elise and her family were in survival mode at this time with limited resources, and with no back-up caregivers for support. Elise expressed that she was catholic and wanted to find a church to join in her community, but she had been under pressure of deadlines to submit applications for government support and grants to help her children at this time.

Mother 3, Linda. Linda and Gary lived in a suburb southeast of New York City with their two children Mattie (age 6 years) who had ASD and intellectual disability and Jeremy (age 3 years) who had neurotypical development. Mattie was a social child and she had language. Linda and Gary had no previous intentions of placing Mattie until she began to exhibit unsafe and increasing aggressive behaviors which placed both Mattie and her brother at risk. Linda and Gary considered placing Mattie due to these safety issues which resolved after a medication change. Both parents were relieved when they did not have to place Mattie. The idea of placing her child was extremely stressful to Linda, who felt conflicted between her feelings about placing her daughter outside of the home and her concern for the safety of both of her children. Linda expressed the trauma she felt in having to face such a decision as a mother.

Linda reported that she and her husband Gary enjoyed a social life with friends, family, and neighbors. They had some family support and they could afford to secure occasional respite services and qualified babysitters. Linda also sought out appropriate community activities in which Mattie could participate. Linda felt that many people could be judgmental and intolerant, particularly when Mattie had a tantrum or meltdown in a public place.

Mother 4, Soo. Soo was born in South Korea. She and her husband, Kim, moved to a New York suburb approximately 25 miles northwest of New Jersey. They had three children. Their firstborn child Michael was 7 years old and had ASD with co-occurring intellectual disability–limited language development. Soo and Kim had two other children, a 5-year-old daughter Grace and a 4-year-old son Eugene, both had neurotypical development. Michael had a serious seizure disorders when he was very young, which appeared to be under control at the time of this study. Soo and Kim had no family in the United States, and they had no time to socialize or make friends. Soo mentioned that they enjoyed being connected to a church and that they were looking for a church in the area. Soo stated that the services they received for Michael would never have been possible had they remained in South Korea. She explained that in South Korea, her son would not have received services and he would not have been accepted by society, adding that she was grateful for the services she received. Soo stated that she was adamantly opposed to placing her child outside of the home, and believed that placing her son would cause her more stress than relief, as she would not know what was happening to her child. Soo respected the fact that other parents' situations and feelings about placements could be quite different from hers, and she would not judge others in their placement decisions.

Michael's language was limited and although he exhibited difficult behaviors and was subject to behavioral meltdowns, his behaviors had never been aggressive. Soo believed that all children needed to behave, and although she recognized Michael's problems, Soo still expected him to at least try to gesture to communicate his frustrations. Soo and Kim focused on raising their families and meeting their educational and career goals, so they did not notice the absence of social support as much.

Mother 5, Dorian. Dorian was a single mother at the time of the placement decision-making process with two daughters, Katie (age 10 years) with ASD and intellectual disability, severe aggressive, violent behaviors, and no language skills and her daughter Ashley (age 11 years) with neurotypical development. Dorian lived in Arizona with her second husband, Doug. Dorian and her first husband Richard had lived in New Jersey with their two daughters. Dorian moved from New Jersey to Arizona to be closer to her mother and brothers, following the breakup of her marriage to Doug. At the time, Ashley was 6 years old and Katie was 5 years old. Dorian’s mother expressed to her that she believed Katie should be institutionalized and Dorian was shocked at this suggestion. Dorian's brother apparently concurred, but avoided getting involved. Dorian's mother and family distanced themselves from Dorian and her daughters; therefore, Dorian was lived in another state without any support. Although placement became necessary given the escalating severity of Katie’s aggressive and dangerous behaviors towards her mother, sister, and towards babies and small children when in public, Dorian decided to place her child by the age of 10 years.

Dorian sought placement for her daughter because of significant safety issues for her daughter Dorian and her older sister. Because of substantial budget cuts to disability services in Arizona, Dorian was unable to secure a placement until Katie was arrested at the age of 16 when she assaulted Dorian in a public place. Dorian refused to bring Katie back home out of fear for her other daughter's safety, which facilitated the placement. Dorian met Richard, a man from her neighborhood in Arizona, and they got married. Dorian and Richard visited Katie regularly and they also took her on outings, this was extremely difficult.

Mother 6, Denise. Denise and her husband Robbie lived in a suburb of Northern Westchester with their children Albert (age 11 years), Charlie (age 9 years), Susan (age 4 years), and Ann Marie born two weeks post-interview. Denise was adamant that she would not place her child; it scared her when she saw her friends placing their children who are older than Albert. Robbie worked as a school administrator and the couple lived in a two-family house with Denise's parents. Her parents sold their home and bought this two-family house so that Robbie and Denise could afford to live in the town, based on the reputation of its school district's special services. Denise's and Robbie's extended family were extremely supportive and they had sufficient resources.

At the time of the interview, Denise was pregnant and her due date was in three weeks, with a high risk pregnancy. Nevertheless, Denise was anxious to participate in the study because she believed that it was important to share her experience. Denise delivered her fourth child, a healthy baby girl, Ann Marie, two weeks following her interview. Albert was her firstborn son. Albert had ASD and intellectual disabilities. Albert also had a severe allergy to gluten, so the entire family was kept on a gluten-free diet and all visitors were expected to wash their hands entering the home. Albert also tended to wander and get himself into trouble, so he required 24/7 line-of-site care. Albert was fairly calm, with limited expressive language; however, he still had a fair amount of behavioral meltdowns. Denise reported that Albert slept for exactly seven hours at night, so she had to keep him up until at least 11:00 p.m., or he would get up during the middle of the night.

Denise's children had significant food allergies and Susan developed autistic-like symptoms when she was exposed to milk. Once milk was removed from Susan's diet, her symptoms disappeared and she appeared to be developing normally. Denise was suspicious of immunizations, and believed that they may have caused Albert's autism. She felt obliged to warn other mothers. Denise and Robbie worked together as a team. They had a well-developed system to manage household tasks. Denise could not imagine placing Albert outside of the home, yet she recognized how a mother could feel the need to place her child in a different situation. Denise worried about Albert's future in the event that she become unable to care for him in the future. Albert was being home-schooled at the time of this study.

Recruiting Procedures

Selection of the Participants

Purposive sampling and a snowball technique helped to target participants who may have been more appropriate candidates for the study based on the criteria specified and professional networking which enabled outreach by those who understood the criteria of the study. The participating mothers had all experienced having a child with ASD and intellectual disabilities and at least one typically developing sibling. They also experienced decision-making processes for out-of-home placement of their young children with ASD and intellectual disabilities at the age of 12 years or younger or considered why other mothers may have felt the need to do so.

Using a snowball approach, purposive selection was used to recruit six mothers for this study, based on their shared experiences of the decision-making process for out-of-home placement of their young children with ASD and intellectual disabilities. All of the participating mothers fit the criteria of being able to clearly articulate, providing detailed descriptions of the decision-making process. Each mother was also able to describe how they experienced the placement decision-making process with the depth, detail, and clarity necessary to shed light on their lived experiences so that others could better understand what happened to them, and how they felt about it.

The mothers' experiences, the diversity of their geographic locations, and their contexts offered a sufficient variability to maximize the range of experiences and to provide the necessary detail to explore the phenomenon and answer the research questions. The mothers who made the initial contact were screened during the first phone call as to their likelihood to provide the rich, thick descriptions necessary for in-depth exploration of the phenomenon. The mothers selected met the inclusion criteria for this study as follows:

1. Mothers had to be willing to articulate their experience in a way that others could understand;

2. Mothers of a child with autism (low spectrum with severe sensory/behavioral disturbances–now known as ASD) and intellectual disabilities, and at least one typically developing child;
3. The placement decision making process and/or placement had to have occurred at the time that the child was age 12 years or younger; and
4. The decision-making for placement or potential placement must have occurred within the past 10 years.

For Criteria 1—the ability to clearly articulate—was necessary for the purpose of this phenomenological study, which was to gain a better understanding of the phenomenon. Luborsky and Lysack (2006), Polkinghorne (1989), and Patton (2002) agreed that the ability to articulate in a way that others can better understand is essential to the rigor and the intention of phenomenological research. The rich, thick descriptions are essential to understanding the phenomenon and necessary to triangulating data which also strengthens the rigor of the study.

Ethical Considerations and Review

The PI, research chair, and second committee member completed the Collaborative Institutional Training Initiative (CITI) program in Protecting Human Research Participants. The third committee member and the peer debriefer completed the NIH Extramural Research Basic Training course in Protecting Human Research Participants. All submitted their respective CITI or NIH certificates (see Appendix F).

The Nova Southeastern University, Health Professions Division (NSU-HPD) IRB approved Protocol # 08161017 Exp. on September 22, 2010. The protocol was examined to ensure that all risks to the participants were considered, and that safeguards were in place to minimize risk and protect confidentiality. Ethical implications were examined as well. Procedures were followed to recruit participants between September 22, 2010 and September 21, 2011, but resulted in only one mother of a child with ASD and intellectual disabilities in the first full review under this IRB.

The remaining qualified participating mothers were recruited under the approved IRB *Continuing Review and Amendments to the 2010 Protocol # 08161017 Exp*. to extend from the period of November 15, 2011 through November 14, 2012. The currently approved IRB, *Continuing Review* began September 26, 2013 and ended September 26, 2014. The IRB-approved initial e-mail or phone script responses (Appendix C) was used to reply to mothers who had e-mailed or phoned the PI expressing interest in participating in the study after seeing the recruitment flyer (Appendix B) which contained both criteria for the study and the PI 's contact information.

For the first mother in the study, procedures from NSU-HPD IRB Protocol # 08161017 Exp. were followed. The next five mothers followed procedures outlined in the November 15, 2011 through November 14, 2012 approved IRB Protocol #08161017 Exp. Interviews were digitally recorded for accuracy and then downloaded onto the hard drive of the password-protected computer used only by the PI. The recordings were encrypted and sent to a professional transcriptionist whose company contract held its employees to protect the participants’ confidentiality (see Appendix H). Interviews were transcribed verbatim, typed and double spaced, with numbered pages and numbered lines for quick reference.

Study Setting

Two participating mothers chose to be interviewed in their own homes. One mother preferred to be interviewed in the PI's home office: A babysitter (a special educator and learning consultant) was provided for her two children who were engaged in play activities in a playroom on the same floor as the office. One mother chose to be interviewed in the bed and breakfast in which the PI was staying: A small private dining room was reserved for the interview. One long-distance mother chose to be interviewed by phone.

One mother who originally requested a phone interview tried on several occasions; however, she was continually interrupted or pressed for time. The mother requested a copy of the interview questions in advance of the next phone call (Appendix A), so that she could think about them before the call. Time passed but finding the right time for a phone call became difficult due to the chaos in the household and the difficulty finding the right time for a phone call without interruptions. This mother was anxious to participate, and one evening when all of her children were asleep at once, she used the interview guide (Appendix A) to write about her lived experience of the decision-making process and sent it as an attachment to an e-mail sent to the PI, with no mention of this before the fact. The mother explained that she was finally able think about the guiding questions and her experiences, so she took advantage of a quiet household with all the children asleep to be able to participate in the study, the only way she could find.

Instruments and Measures

Interview Guide

The instrument used to assist the PI in exploring and collecting data from the mothers' bibliographical accounts of their experiences of the decision-making process for placement their children was an interview guide (Appendix A). However, in order to gain all the possibilities, no specific structure was imposed (Luborsky & Lysack, 2006). This interview guide was adapted from an earlier interview guide developed by the PI based for the pilot study to this dissertation which investigated the topic of mothers' perceptions of childhood placements of their young children with severe autism.

The interview guide was initially developed based on an exhaustive literature review on the topic of autism (now known as ASD) and childhood placements that included studies from the disciplines of economics, law, occupational therapy, psychiatry, psychology, and social science (Blacher,1990; Freedman & Boyer, 2000; Goodman, 2003; Grey, 2002; Helzen & Asplund, 2002; Larsen, 2006; Law et al., 1996; Llewellyn et al., 1999; Maes et al., 2003; Parish & Ludwig, 2005; Parish et al., 2012a; Parish et al., 2012b; Pulleyblank Coffey, 2004; Sen, 1999; Tabatabinia, 2003; Tanguay, 2000).

Questions for the interview guide were developed based upon the research and gaps in the research on childhood ASD and out-of-home placements (Boyd, 2008). The pilot study's interview guide was adapted for the dissertation study placing the focus on the decision-making process for placement. The interview guide for the dissertation study was also influenced by the interview process and results of the pilot study for the dissertation study which illuminated gaps in the existing literature on the topic. Questions were designed to elicit rich, thick descriptions of the phenomenon through exploration of the mothers' accounts.

The interview guide (Appendix A) was used to help participants delve into the topic. However, it is important to note that in phenomenological research, it is the participant that guides the emergence of topics and ascribes individual, personal meaning to the phenomenon under investigation (Moustakas, 1994; Wertz, 2011).

Digital Recorder

A digital recorder was used to tape the mothers' interviews for this dissertation study. A tape recorder was used to record the pilot study interviews. Taylor and Kielhofner (2006) included recording instruments in their list of tools for data collection used by qualitative researchers. Interviews were recorded with IRB approval and participants' signed consent to ensure the accuracy of the data. The transcribed interviews were checked for accuracy against the recording. All recordings will be deleted three years after the research study has concluded.

Pilot Study Summary and How Linked to the Study

An IRB and NSU-HPD approved pilot study, Protocol No. 02010702 Exp., of February 12, 2007 (Boyd, 2008) used as a precursor to this dissertation was conducted between 2007 and 2008 as partial credit for the dissertation. This transcendental phenomenological pilot study entitled Autism and Childhood Residential Placement: The Lived Experience of Two Mothers examined the lived experiences of two mothers of children autism and intellectual disabilities and explored the mothers' experiences in placing their young children with autism outside of their homes at the time their children were ages 12 years or younger. The parents' stories began with the children's birth, through their long quests for diagnoses, struggles for relevant services and subsequent, and painful decisions for out-of-home placements. Perspectives regarding home life post-placement were also discussed. What became apparent during this study was the need to focus on the parents' path and arrival to the decision-making process for placement and the experiences that led to their decisions to place their children. It is essential to know how parents make their placement decisions if we are to understand their situations, implement preventative measures to avoid pressured or forced placements, and design and implement treatments that strengthen families' capabilities and improve occupational performance of the mothers, fathers, and children as functioning unit.

A transcendental phenomenological approach was used to conduct the pilot study which was a precursor to this dissertation study. Moustakas (1994) modification of the Stevick, Colaizzi, and Keen method of analysis phenomenological data was used in both the pilot study and this current dissertation study. This process was described in detail in the Research Design and Methodology section. The findings from the pilot study are presented in Chapter 5.

Data Collection Procedures

The PI conducted in-depth interviews (Appendix C) of each of the six mothers for between 1 and 2.5 hours. The mothers were given the choice of two to three visits and a follow-up visit or phone call, with flexibility to accommodate their schedules. All six mothers chose to complete the interview in one session due to the difficulty scheduling their interviews around their family schedules and arranging for childcare for the child with ASD. Four out of six mothers had to reschedule their original interviews due to crises at home with their children with ASD.

A seventh mother who originally expressed interest in participating never signed the consent form because she had to cancel her interview when her child was assaulted by a boy who had been bullying her at school. This mother was too distressed with her daughter's situation to take part in the research at the time. This mother expressed her regret, even guilt, about not participating because she felt that telling her story may help her daughter. The mother was reassured that there were enough participants and the research would be carried out despite her inability to participate; she expressed her relief to hear this.

The six participating mothers were offered the option of being interviewed in their homes, at the PI's office, or at a private location of their choice. All efforts were made to build a rapport with the mothers and to help them feel at ease during their interviews. An interview guide (Appendix A) provided the means to collect qualitative data regarding the decision-making process for out-of-home placement. However, it should be noted that in phenomenology it is the participants who ascribe meanings to the phenomenon under investigation, so the interview guide was used for delving into the topic. Haggman-Laitilia (1999) caution researchers not to guide their participants as preconceived assumptions or advanced knowledge could contain the PI's own interpretation.

The interviews of each mother were digitally recorded to ensure accuracy. The interviews were transcribed by a professional transcriptionist who signed a letter of agreement of to protect the participants' confidentiality (Appendix H) and transcripts were then compared to the digital recordings as an additional measure of quality control. The transcripts were double spaced with numbered pages and lines for easy reference. To protect confidentiality, transcripts were labeled by number, without names and kept in a locked file in the PI’s office. The label key was maintained in a separate locked file cabinet.

Pre-action bracketing (Appendix I, described earlier under the Epoche Process section, was used to separate the PI 's preconceived ideas from the emerging participants’ themes and as a way of reducing bias by preventing any substitution of the PI 's perceptions with those of the participants. In-action, and post-action bracketing was continued throughout the interviews and data analysis, followed by a post-action bracketing. The value of this epoche process (bracketing) was to encourage the PI to attend to, and set aside, potential bias and to keep an opened mind to gain fresh new insights about the phenomenon from the participants. Bracketing was used during the interviews and subsequent data analysis, through reflective understanding (Moustakas, 1994; Wall et al., 2004).

Data Analyses

Moustakas' (1994) modification of the Stevick, Colaizzi, and Keen method of analysis phenomenological data was used to collect, organize, and analyze the resulting qualitative data which involved the following four steps:

- Step 1: Using a phenomenological approach (keeping the mind open and curious to discovery of new knowledge), the PI wrote a full description of the phenomenon (to bring to awareness any prior knowledge or preconceived notions of the phenomenon). Step one occurred before and throughout data collection and analysis and post data analysis through pre-action, in-action and post-action bracketing.
- Step 2: From the verbatim of the transcripts, the PI completed the following steps:
    1. considered each statement in regard to its significance to the experience;
    2. recorded all relevant statements;
    3. listed each non-repetitive, non-overlapping statements or meaning unit;

    4. related and clustered the invariant meaning units and themes into a description of the textures of the experience (textural descriptions are the experiences of the participants or what they experienced);
    5. synthesized the invariant meaning units into themes into a description of the textures of the experience including verbatim examples;
    6. reflected the PI's own textural description through imaginative variation and constructed a description of the PI's own structures of the experience; and
    7. constructed a textural and structural description of the meanings and essences of the PI's own experience.

- Step 3: From the verbatim of the transcript regarding the experiences of the PI and each participants', completed the steps 1 and 7 as described above in Step 2.
- Step 4: From the individual textural-structural descriptions of the PI's and the participants' experiences, the PI constructed a composite textural-structural description of the meanings and essences of the experience, integrating all textural-structural descriptions into a universal description representing the group as a whole (Moustakas, 1994, pp. 121-122).

Data analysis began with the data from the first interview and continued throughout the research process. In phenomenology, data analysis begins once the first data are collected as this analysis will guide the PI's decisions with further data collection (Louborsky & Lysack, 2006). The analysis began with iterative process of reviewing the mothers' transcripts, considering each statement in regard to the phenomenon, the recording of all of the mothers' relevant statements, and the listing of invariant horizons or non-repetitive statements. Each statement was give equal status. Following this analysis, the invariant meaning units were related and clustered to form themes. The resulting themes were then synthesized into a textural description of the experience.

Reflecting the textural experience through imaginative variation, the PI then constructed a description of the structures of the experience. The final step of this individual data analysis was to construct a textural-structural description of the meanings and essences of the PI's experiences (Moustakas, 1994).

The PI repeated steps 1 through 7 as stated in Step 2 above, separately for each mother, in an iterative process going back and forth between the data and the literature, spending time reviewing and then reflecting, until the themes became clear. Next, the PI wrote a textural structural description of each of the mothers' textural-structural descriptions based on the interview transcripts to explicate a reduced meaning and essence of the mothers' meanings and experiences integrating the PI's and the participants' descriptions into a universal description of the experience that is considered to represent the group as a whole (Moustakas, 1994). Once the PI had completed the data analysis process, and conducted the initial member checks were as described earlier, a peer reviewer completed a secondary analysis.

Following the completion of secondary data analysis by the peer reviewer, the reviewer conducted a peer-review session with the PI. The purpose of the peer-review session was to serve as an external check on the accuracy, interpretation, and authentic representation of the data. The peer reviewer or peer debriefer and the PI compared their analyses to discuss agreement between the analyses and to examine any competing interpretations until the themes became clear to both researchers.

Creswell (2013) described peer review or peer debriefing under standards of validation and evaluation in qualitative inquiry and research design as a form of triangulation. The role of the peer debriefer is to ask difficult questions of the researcher and keep the researcher honest about underlying assumptions. The peer debriefer analyzed the data separately from the PI. Peer debriefing sessions occurred after the secondary analysis of the data. The purpose was to discuss and/or argue potentially hidden or competing themes. Peer debriefers challenge the researcher to be honest about assumptions, characterized by Creswell as playing *devil's advocate*.

Cresswell (2013) stated that peer debriefing is important in qualitative research because any one analysis is considered incomplete. Peer debriefing offers an external check on accuracy of the researcher's interpretations and opportunity to argue for clarification of the interpretation. Lysack et al. (2006) reminded researchers that peer debriefing process may be the only way for opposing or contrary explanations for the phenomenon to be aired. Lysack et al. (2006) described peer debriefing as "an important point of departure from more standardized fixed set of measures, conducted identically with each participant" (p. 353). According to Lysack et al. (2006), the use of peer debriefing adds to the legitimacy of the final version of the study findings and confirmability of the study. Confirmability refers to the dependability of the research process, the interpretations and the value of data (Creswell, 2013). Guba and Lincoln (1985) and Koch (1994) stated that confirmability is established once credibility, transferability, and dependability are achieved.

Format for Presenting Results

Study results were presented in narrative form under the themes and subthemes that emerged from the data (see Chapter 4). The PI's analysis was supported by statements quoted directly from the participating mothers' interview transcripts, along with concrete examples provided within the mothers' texts. Themes and subthemes from each mother were presented as well as the composite textual description. Sen's (1999) CA and Law et al.'s (1996) person-environment-occupation (PEO) model of practice were used to view the data within a broader context of occupational and economic justice. Integration of the concepts of occupational and economic justice will be displayed in the Chapter 5 section Discussion.

Assumptions and Limitations of Methods

Phenomenology is a qualitative approach to research which uses inductive reasoning to explore complexities, essential meanings, contexts, and subjectivity (Moustakas, 1994). Phenomenology differs from other qualitative research in that the researcher accepts the participants' subjective realities as the true essence of the phenomenon. An assumption of this transcendental phenomenological study was that the essence or true meaning of experience could only be fully known by those who have lived or shared the experience (Moustakas, 1994).

A limitation of this transcendental phenomenological qualitative design is that the results of this study cannot be generalized; however, transferability can be achieved as others can relate to the situation. Another limitation of the design was the potential opinion of the PI's own values and bias based on years of practice. However, specific procedures such as reflexivity through pre-action and post-action bracketing, and in-action journaling and reflexivity, employed checks to control for potential bias. In addition, a peer reviewer who is an experienced researcher and completed an ethics course on human subject research completed secondary analysis of the data and conducted a peer-review session. The purpose of the peer-review session was to challenge the PI's assumptions, interpretations, and representations, and to ensure strict adherence to specific phenomenological. The peer review as an external check to strengthen emerging themes and to contribute to the rigor of the study.

Delimitation was the difficulty in collecting data. The PI experienced multiple cancellations and rescheduling, mostly because of crises involving the children with ASD. A seventh mother, who had initially wished to participate, changed her mind after her child was assaulted on the bus by a child who had been regularly bullying her young daughter. The mother was extremely distressed by her daughter's situation. A delimitation of this study was its narrow recruitment criteria. Each mother in this study had to have a child or children with low-spectrum autism and co-occurring intellectual disability and at least one other child with typical development. Each mother considered the decision-making process for out-of-home placement. The age of the child at the time of the placement, potential placement, or consideration had to be 12 years or younger, and the placement decision-making process needed to have occurred within the past 10 years. Therefore, it would have been possible for a mother of a 22-year-old child with autism to qualify, if the decision process occurred at the age of 12 years. Another important delimitation of this study was the difficulty in locating mothers who fit the criteria, as they rarely belonged to the typical parent and autism groups–indicative of their isolation. For future research, Internet research options such as autism websites that also cater to the needs of caregivers with children with ASD and intellectual disabilities may be more likely to attract future participants due to their unpredictable schedules and difficulties accessing childcare.

Summary

ASD affects 1 in 68 children in the United States. This is a 23% increase between 2006 and 2008 (CDC, 2012). Federal and state policies require states to proactively avoid out-of-home placements (Wulczyn & Orlebeke, 2006). However, premature placement may be forced due to circumstances beyond the parents' control (Parish & Lutwick, 2005).

This qualitative study used a transcendental phenomenological approach to examine the mothers' lived experiences of the decision for out-of-home placement of their young children with ASD and intellectual disability with extreme sensory and behavioral reactions. A transcendental phenomenological approach was selected in order to delve into the phenomenon to uncover the depth and magnitude of the mothers' experiences in context.

A phenomenological approach is congruent with occupational therapy philosophy for several reasons. The stance of the phenomenological researcher and the occupational therapists is similar. The phenomenologist focuses on the subjective realities of the research participants and the occupational therapists become the empathetic learners as they gather insights about the subjective realities of the occupational beings they serve to create meaningful and sustainable interventions.

In phenomenological research, the participant is central to the research process, just as the occupational being is central to the process in occupational therapy evaluation and treatment. Phenomenology and occupational therapy accept that participant or occupational being as the only individual that can fully understand or ascribe meaning to their own their lived experiences. Phenomenological researchers emerge from contextual understandings through the participant's or occupational being's lifeworld experiences, which may go undetected in other forms of inquiry.

Occupational therapists have long been associated with the evaluation, treatments, development of assessments, and research of children with ASD and intellectual disabilities within clinic, home, and community settings. A broad range of occupation-centered, evidence-based treatment approaches are used by occupational therapists to increase the capabilities and occupational performance of the children with autism and their mothers and families. Occupational therapists have diverse skills for facilitating inclusion and participation through environmental adaptations and institutional adaptations for inclusion and reduction of barriers to participation. Interdisciplinary foundations of the profession have prepared occupational therapists to appreciate multiple aspects that comprise occupational performance.

Understanding the mothers' decision-making process for placement is necessary if we are to better understand how to meet the needs of the mothers and families. Understanding is need about the impacts of the ASD and intellectual disabilities on the mothers' ability to carry out mothering occupations and to live full quality lives with their children and families. Unique from the previous occupational therapy literature, the resulting data was viewed through an economic approach, Sen's, (1999) CA and an occupational therapy model of practice, Law et al.'s (1996) PEO model of practice. This combination is expected to draw broader attention to the needs and struggles of these mothers of children with ASD and intellectual disabilities and their current unfreedoms and occupational deprivations. These unfreedoms and occupational deprivations potentially affect their well-being and economic status, and potentially their freedom to choose where their children shall live, making their situations an occupational justice issue to be addressed.

Chapter 4: Results

Introduction to the Chapter

Chapter 4 presents the results of a phenomenological data analysis of the participating mothers' transcripts using Moustakas's (1994) modification of the Stevick, Colaizzi, and Keen method of phenomenological analysis. A qualitative, transcendental phenomenological approach was used to answer the following research questions:

1. What are the lived experiences of mothers of young children with autism spectrum disorder (ASD) and intellectual disability in regard to the decision-making process for out-of-home placement?
2. What are the contextual aspects influencing mothers' placement considerations and decisions?

Six mothers participated in this study. Each mother had a child with ASD and intellectual disability and at least one other sibling. Of these six mothers, two mothers made the decision to place their children, one mother seriously considered placing her child, one mother was at severe risk for a potential undesired child placement, and two mothers were adamant that they would not consider placing their children–these two mothers considered how other mothers may have arrived at their placement considerations and decisions from their perspectives of raising children with ASD and intellectual disabilities. A quick reference of participants' characteristics showing contextual aspects influencing mothers' placement considerations for their children with ASD can be found in Table 1.

Table 1

Participating Mothers' Quick Reference Table

Contextual Aspects Influencing Mothers' Placement Considerations for Their Children With Autism

Mothers	Children/w Disorder	Husbands & Other Children	Placement Considerations and Decisions
#1 Mary	**Helen (11)**	***Matt*** Stephanie (8) Ellen (2)	Family reached Crisis Point-Aggressive Behaviors Sibling Safety Issue-Child for Placed in Residential School and returned home after 3 years
#2 Elise	**Kenny (7)**	***Ned*** Fraternal Twins Nicole (5) Evelyn (5)	Family is in Crisis Elise wants to raise child in their home Struggling to secure sufficient services and supports to keep her son at home. Fearful that she may need to consider a placement.
#3 Linda	**Mattie (6)**	***Gary*** Jeremy (3)	Did not want to place her child Almost had to do so because of safety issues which resolved after a medication change- Parents were Relieved when they did not have to place Mattie.
#4 Soo	**Michael (7)**	***Kim*** Grace (5) Eugene (4)	Adamant that she would never place her child It would not relieve her, it would make her worry about him even more than now
#5 Dorian	**Katie (10)**	***Richard*** Divorced Ashley (11)	Had to seek placement because of safety issues- had to wait 5 years due to appropriate options for her in Arizona- Katie's assault on her mother in a public place and her arrest facilitated a placement for Katie.
#6 Denise	**Albert (11)**	***Robbie*** Charlie (9) Susan (4) Ann Marie (0) Born 2-weeks post-interview	Adamant that she would not place her child – It scares her when she sees her friends placing their children who are older than hers.

6 - children have (severe) ASD and intellectual disabilities
All of the children would be considered to be at severe placement risk

Placement Predictors

- * Caregiver Risk (Maternal Stress)
- *Autism + behavior problems combined
- * Assault/Injury/Severe Behaviors
- *Supervision need level- line of sight or at an earshot
- *Intellectual Disability
- *Line of sight supervision/or at an earshot
- *No or minimal ADL
- *Seizure acuity
- *No back-up caregiver

(DHHS, n.d.) * More Detailed Characteristics in Chapter 3, Methodology, Participants under Participant Characteristics

The expectation of this transcendental data analysis process was to extrapolate themes that illuminated perceptions of the decision-making process or placement considerations the environmental and occupational aspects related to the child placement decision-making process and placement decisions. Consideration was given to occupational implications of the mothers' placement decisions.

The purpose of the study was to elicit essential understandings of the mothers' placement considerations, entry into the placement decision-making process, and placement decisions for their young children with ASD and intellectual disabilities, with considerations of occupational implications. Exploring mothers' perceptions of the placement decision-making processes and considerations is expected to reveal fresh insights for occupational therapists to support the mothers and their families to carry out occupational roles and to engage in occupations at home and within in the community. Understanding the process that the mothers' engaged in during the decision-making process and the considerations was integral to understanding the mothers' needs.

Data Analysis Results

Moustakas' (1994) modification of the Stevick, Colaizzi, and keen method of transcendental phenomenological data analysis described in Chapter 3 was employed to analyze the verbatim transcripts from the mothers' digital recordings. The mothers' responses yielded six major themes and salient subthemes. The six major themes were (a) feeling judged in their occupational roles as mothers, (b) restricted freedoms and occupational deprivation as a family, (c) the paradox of support services, (d) fears about the families' well-being, (e) occupational injustices revealed through mothers' feelings about the placement decision-making process, (f) spiritual aspects of the decision-making process. Table 2 presents a synthesis of these themes.

Table 2

Contextual Aspects Influencing Mothers' Placement Considerations for Their Children with Autism
Composite Essence – Textural-Structural Descriptions
Theme # 1   Feeling Judged in Their Occupational Roles as Mothers
Marginalized by judgmental stares and comments *Unfairly judged by others and sometimes by themselves*
Theme # 2   Restricted Freedoms and Occupational Deprivations as a Family
Restricted participation as a family in health-promoting and meaningful occupations *Seeking tolerance and acceptance of their families–appreciative of small acts of kindness*
Theme # 3   The Paradox of Support Services
Gratitude for services that support their mothering roles and occupations *Maternal distress caused by accessing, managing and scheduling services* *Needing wide networks of support, respite, and to live in the " right state"* *Resentment of government: for the imposed occupational burden of fighting for services for families' survival* *Growing mistrust of the government institutions upon which their families depend*
Theme # 4   Fears About Their Families' Well-Being
Fears regarding the disorders' impacts on families' occupations and quality of life *Internalized placement fears* *Safety fears* *Fears about their financial capacity to meet the needs of their child and their families'* *Fears about the future*
Theme# 5   Occupational Injustices Revealed Through Mothers' Feelings About Placement Considerations
Restricted freedoms and exhausted economic and occupational capabilities *Environmental and occupational aspects influencing placement considerations* *Family crises and final tipping points to forced placement decisions–conflicting emotions*
Theme #6   Spiritual Aspects of Childhood Placement Considerations
Finding a sense of joy and purpose in daily occupations, despite the hardships *Mothers' shared beliefs about humanity and inclusion* *Spiritually deepened through the child-placement decision-making process* *Inspired occupational roles: To Educate-Inform-Advocate*

Findings

Theme 1: Feeling Judged in Their Occupational Roles as Mothers

Extremely challenging situations were reported by some of the mothers including the unfair judgments and unkind remarks they experienced when they went out into the community with their children with ASD. The range of reactions to their children's behaviors were glaring looks of disapproval or comments about their discipline approaches, complaints to the management, or changing seats in reaction to their children's disruptive sensory responses, and aggressive or compulsive behaviors. Comments or glaring looks from others that were often interpreted by the mothers to be judgments about their mothering skills or approaches. Mothers also spoke about the reactions of their other children who sometimes felt embarrassed by their siblings and sometimes guilty for having these feelings (Hastings et al., 2005). Lecavalier, Leone, and Wiltz (2006) found that siblings of children with ASD were at higher risk for emotional issues. The subthemes below include narrations of the mothers' reports about how they felt judged in their occupational role as mothers.

The accounts of the mothers as they ventured into the community to shop and run errands indicated that the mothers were frequently subjected to unwelcoming or judgmental looks or comments and innuendos about their mothering skills or approaches. Such interactions were extremely distressful to the mothers, who spent the majority of their waking hours in their mothering roles with children whose needs were substantial. Comments came from family members, friends, acquaintances, and even complete strangers when the mothers were out in public with their families.

The mothers' experiences of these disparaging community interactions were recounted by the mothers with frustration, anger, eye-rolling, and sometimes with humor. Denise told of an incident where a distant relative told her about someone she knew who with a grandchild who did not speak and the proposed solution to getting the child to speak (Denise's verbal account of the conversation and her narration of her thoughts at the time, made me laugh out loud along with her). Denise waved her hand in the air and said, "Oh, I've got a million of them!" Her nonchalant attitude and humor in recounting some of these events appeared to suggest that Denise had adapted to these frequent reactions to her son Albert's behaviors as if they were to be expected in raising a child with ASD and intellectual disabilities. However, some of her personal accounts were deeply painful to Denise even with the passage of time, and she seemed to be wounded again in the re-telling of them. Each mother could easily come up with multiple encounters, both laughable and painful, from their ventures within the community.

Sometimes mothers wishing to protect their children and themselves against unpleasant community interactions began to restrict their already limited interactions, as in Elise's explanation about attending mostly autism-friendly events where she did not feel the need to continually explain or apologize for Kenny's behaviors. Dunbar (2007) reminds us that mothers are considered both person and environment to their young children (Dunbar, 2007: Dunbar & Roberts, 2007). An occupational perspective of health and well-being supports expanding opportunities to adapt to ever-expanding opportunities for engaging in occupations in varied environments. Occupations offer the means to adapt, grow, and develop.

When mothers' environments are restricted, their children's environments are also restricted, as are the expanded opportunities for growth and development. The occupational perspective of health supports expansion of participation, engagement in ever-expanding occupations in new and varied environments for continued opportunities to adapt, grow, develop, and transform. This freedom to engage can be protected through the judicious facilitation of inclusion and an understanding of the value and benefits of inclusion. The benefits of inclusion do not belong solely to the currently excluded. Inclusion is for the benefit of all. Inclusion is an important area for mothers of children with ASD and intellectual disabilities. Their lived experiences inform society that there is work to be done.

Subtheme: Marginalized by judgmental stares and comments.

Mary (after Helen was placed).

> You know, I had several mothers who danced around the fact that, you know, if I had done something different, you know, if I had been more or whatever…That you could have done this, you know, and if we had this, and they are supportive of you... his own mother was, I think there were times when she thought, you know, if I could just be in there, you know, just let me be in there for while …Yeah. Actually, everybody has got there, so there was a lot of that before.

Elise.

> It's challenging to go out in public with [Kenny] frequently throws tantrums because he can't speak in sentences [and] continually repeats words or phrases and speaks immaturely so people are always staring at us or asking me what is wrong with him.

Linda.

> I think some people are very judgmental... people will give you the look like... this mother is not taking care of their child. This child is a brat or they don't understand and they're very quick to judge and to give you that…what are you doing?... kind of look.

After this recount, the principal investigator (PI) asked Linda, "What would you like people to know about mothers of children who are struggling with their child in public?" Linda responded, Don’t judge first of all and take a moment… and really if you don’t have that situation you really shouldn’t [judge] …It’s like step out of your comfort zone a little bit. If you see somebody struggling and that’s just human nature… you see somebody struggling don’t be so mean...go and try to help out and just ask ...Do you need any help? And it’s up [that person] to say yes or no, thank you ...I’m okay, but I appreciate you asking… Reaching out would be appreciated I think ...for me and probably for a lot of people.

Soo.

I was at the checkout counter in a store, and my son went behind the counter. He often does this at stores. The woman working the register told my son that he doesn’t belong there, which made me feel bad as a mother...like my son wasn’t behaving well... In another way, I felt kind of good that she thought he is normal.

Dorian.

I...think...what happens is that the people [who] have…higher functioning child [ren] that can be taught things…maybe not easily, but at least they can take it in [learn]. I can’t let [Kristin] go to the bathroom by herself. I have to hand her the toilet paper and physically tell her you can’t get up until you wipe. You can’t leave until you wash your hands…And [mothers with children [who are] high functioning are telling me to provide more structure and discipline? [They] don’t get it...

Denise.

This one woman, I think it was actually a member of our family…distant relative and also [another woman] who said the same thing to me. They said that they had a child or a grandchild…[who] didn’t speak and really all they need[ed] to do is be spanked. And I remember thinking...You’re insane! Due to be[ing] spanked? You know?… I’m like…you’re insane. This is my disabled child who spins in circles [since] he was three...you know…and you just discipline them?...Smack them out of it?

Subtheme: Unfairly judged by others and sometimes by themselves.

Mary.

I had a lot of feelings of… I should be able to do this, you know, I should be able to help her, I should be able to manage her ...and my husband…because he was working fulltime and I was the stay at home mom...Mothers just don’t do that. That was my message to myself.

Linda.

> It was a very stressful period of time…what felt bad…was that I couldn't do anything to help my child… I felt hopeless…or not even hopeless… just really helpless…that I couldn't do anything to make [Mattie] feel more comfortable. And then I felt like if I had to place her in a home, I would be a bad Mom, like I was just giving up.

Denise.

> I shouldn't judge them [mothers who placed their children with ASD]. I'm not proud of the fact that I am judging them but I am... because in my mind, I [know that I] just sound horrible...In my mind, I've made this pact with my child and I don't think there is anything in the world that could break that... I mean even my own marriage…What I am saying, like if God said, you [Denise and Robbie] couldn't be together ever again but he [Albert] would be cured, we would do it, you know... we would do it...that bond is so incredibly strong... that child and parent bond, you know. No judgments… and you know? Like even though I [judge people] I shouldn't... judge people because...I don't know [the situation] they're in.

Dorian made the decision to place her daughter Katie at the age of 10 years when conditions in the home were unsafe for her other child. Unable to find a suitable placement option for her young daughter, Dorian as single mom and her young daughter who was 11 years old at the time were suffering with the turmoil and Katie's unpredictable and violent behaviors. Dorian was unable to place her daughter until six years later at the age of 16 years after she was arrested for attacking her mother in a public place. Dorian stated, "It's very emotional. Something you never think you'll ever do…it got to the point [that it was a] necessity. You feel so guilty because you're like this is my child, I should be the one caring for her. …"

Dorian has remained involved in her daughter's life and always checks on her care. Dorian gets upset with the "I'm not ready to give up yet message" when speaking about placements, because this message assumes that she gave up on her daughter. In Dorian's words, "I will never give up on my daughter, I just needed to present an environment that is best for everybody." Dorian and her other daughter experienced restricted freedoms and occupational deprivation as a family as Katie was extremely difficult to manage in public places and she was aggressive towards others.

Dorian.

> The one thing [that] I keep stressing [So] much…because [other mothers are] always telling you the … I can't give up [on my child] message…I am not giving up on this yet… I never will give up on Katie. It's just that you're trying to present an environment that is the best for everybody.

Theme 1 summary. One of the most upsetting comments for the mothers who placed their children with ASD outside of the home out of desperation was the comment that the mothers gave up on their children. In Theme 2 below, the mothers who experienced placing or potentially placing their children discussed their feelings about their decision-making processes for placement. The mothers who did not experience the decision-making process themselves discussed how other mothers might find themselves in this position, and discussed how these mothers might have felt about their placement considerations and decisions.

Mary and Dorian placed their children. Linda faced the decision-making process for placement of her eight-year-old daughter Mattie when her behaviors were becoming unsafe and there was concern that she could unintentionally hurt herself or her younger brother due to her unsafe behaviors. A medication change led to improved behaviors, so that Mattie's parents did not have to place their young daughter outside of the home. Linda and Gary were greatly relieved to be able to keep Mattie at home.

Theme 2: Restricted Freedoms and Occupational Deprivation as a Family

The themes have some over-lap as one central theme: Creating conditions for others. In this theme, the mothers talk about how their freedoms for participation in activities that came natural to other families were often difficult for families' of children with ASD and intellectual disabilities. These occupational freedoms are related to the social encounters noted in the next section. Linda and Denise had strong support networks; Mary, Elise, and Soo had very little or no support from family and friends and very little help to manage their children safely in the community. Five of the six children with ASD in this study were wanderers, which added a safety risk in community settings. The mothers spoke about their experiences and interactions in the community.

Soo who came to this country from South Korea had no family in the United States. Soo had also recently relocated her home to a suburb northwest of New York City. It seemed that Soo did not expect to have social support or a social life, as she and her husband were more focused on family, school, and career goals; therefore, having a social life was missed less. Soo and her husband were seeking a new church to join as this was important to Soo and her husband Kim who were active in their previous church community. Soo mentioned that church was important to her and that she was seeking a place of worship for her family.

In the next theme, the mothers spoke about their experiences and interactions at home and in the community as they participated in everyday activities and the instrumental activities of daily living at home and in the community in carrying out their maternal occupational roles, routines, and responsibilities. In the following subtheme, the mothers' discussed their participation as a family in everyday and meaningful occupations.

Subtheme: Restricted participation as a family in health-promoting and meaningful occupations.

Elise.

> We [Elise and Ned] are unable to get our son [Kenny] to sit at the dinner table and eat with us without an aide so we let him eat alone in front of his computer while the rest of us eat together. I have to leave him at home and take the girls [Nicole and Evelyn] out so the family is constantly split up. Kenny spends way too much time at home unengaged [with the family] on the computer or iPad now because I am unable to take him out with us if he has no aide. An aide would keep him more active and engaged so he would not self-stimulate as much on non-functional things and get more exercise. If we do try to attend a function or event, we take 2 cars.

Linda.

> Our family [can't go out together] as much as we want to do and we try to go out in the typical community, it is difficult at times. We can do certain things, but timing wise has to be limited. Like there is a certain threshold that we can do. We can take her to like, to go get a slice of pizza, you know but that's fast and fun and fabulous that four of us can do that, but…restaurants... It's too overwhelming. We've tried taking her to the movies before... [not in a while]... [Movies were] better when she was younger, but not so much as she gotten older. She doesn't have the patience...it's too long...and she will be up and up. It doesn't work.

Soo.

> As much as possible...I arrange for someone to be with the child with special needs when we have to attend an event where distracting behavior cannot be allowed.

The mothers reported certain difficulties in engaging as a family in occupations within the community. Aspects of community interactions were difficult for them. Elise and her husband Ned found it difficult to do things as a family due to Kenny's extreme sensory responses and behavioral reactions. In the next theme, the mothers described their experiences and interactions with others during their social occupations or as they ran errands within the community.

Linda and Gary found they could go as a family if it was a fast activity such as going for pizza, but they faced restrictions depending on the nature of the activity or the time it took. Mary and her husband Matt found it difficult to do things together in the community as Helen's sensory responses and behavioral reactions could be difficult.

Soo and Kim and their three children did not attend many social events; however, if they did attend an event and the event was such that disruptive behavior would not be tolerated, she left her son Michael at home with a caregiver. Dorian, who was on her own with her two young children, had little opportunity to participate as a family in the community due to the extreme and aggressive behaviors of her daughter Katie.

Debbie and Robbie found creative ways to be together as a family as in her Sunday trips to the gluten-free bakery and rides through rich neighborhoods where they pretended with their children that they would move there some day. Debbie and Robbie had a method to going out in the community which was exposure. If Albert had a problem with carnivals, they would plan to bring him to 15 carnivals until he finally began to enjoy them. They applied this concept to all of their social and community outings, even family vacations. This method was successful for them, as Albert enjoyed going to social events and on vacations.

Mary found that people did not reach out to her family socially. In the next theme, Mary spoke about two incidents when she experienced kindness and acceptance and how appreciative she was for how her family was treated on those occasions. One experience was a neighborhood in which she lived when she had met friends who accepted her family; another time was an incident that occurred during her daughter Helen’s meltdown in a dress shop when she experienced acceptance through the kindness of a stranger.

Subtheme: Seeking tolerance and acceptance of their families.

Mary.

> The Asperger’s has sort of a, I mean the word that I always use to talk about is kind of sexy in our culture it’s like, “Oh wow! They have this musical ability or they have this [whatever], and it’s interesting…And I think our culture handles that better than we handle people who are both autistic and developmentally disabled, mentally retarded, whatever phrase you use....and so in support groups I found it difficult to find where I fit in. Groups that support kids with DD are so [broad] you know… is Down syndrome and there[are] all these syndromes in areas in Helen’s diagnosis. She just has autism [ASD] and mental retardation [intellectual disability] and so it’s been hard to find a group to fit in with. The autism groups are a lot of times focused on kids who don’t have low IQs …and it’s a whole different ballgame!...The first time, we [the whole family] had friends was when we moved to South Carolina. So... that was a real gift. We were really honest and you know, [we said] This is our family… This is who we are and they just embraced that, because that’s the kind of community they were.

Mary also thinks that people tend not to be so welcoming to persons with disabilities. In the following description, Mary speaks about her feeling about inclusion, and what Mary referred to as “willful hospitality”:

> Nobody here [current town in Kentucky] talks... but you know…I had a mom come up to me, there was a child with [a] disability and [the child] was very loud and the mom stopped bringing her to church. This mother was concerned about the mother of the child with the disability when she did not see the mother and child in church anymore. The mother told her that he stopped bringing her [child] to church because people were staring… [the mother of the child said that nobody has ever asked who we are…come from a spiritual understanding…I would say that there is a real lack of hospitality towards people with autism and people with disabilities. And by lack of hospitality… I mean… [being in a store with all your children and the child with autism has a tantrum as you are on the check-out line]. And I think the situation…arouses so much fear in people and panic… [that] it’s much easier not to do anything… But I think that’s what I would ask for on a local level… is just a willful hospitality people [with disabilities]…and that’s something that they [people with disabilities] don’t get. The feeling of being included… and asked to be included. I did a lot of workshops on…incorporating people with disabilities into faith communities which is something I speak about a lot

> [and about] life stages. Those are just two of the big pieces…[community inclusion and life transitions].

Mary's next experience of tolerance and acceptance of her family occurred when Helen was asked to the prom by a boy in her class and Mary and her other daughter Stephanie—who is 3 years younger than Helen—took Helen to a shop to try on the prom dress which they had dropped off for altering. When the dress did not fit, Helen's response was a significant meltdown in the dressing room. Mary knew that she was in trouble, because it was difficult to intervene once Helen lost control of her temper. Mary described her feelings during the event:

> [Helen] was just furious and she started screaming at the top of her lungs and there are all these people in there getting stuff….and she grabs the straps and they start ripping… and I am like no, and I grab her hands and this is when [the woman who does the alterations] came in, and she has this most calming demeanor, and she said…'I make you beautiful' and it was just…[so] effective…The woman said, 'okay, let me get you dress up, let me get you dress up.' Just to have [Helen] calm down, the woman [said] 'Helen, you are going to look like a princess and I am going to help you' and she just pinned it up really fast and as soon as the pins were in it, Helen…was okay…and I was so…grateful.

Mary, who had witnessed Helen's frequent outbursts in public places, was so grateful that the woman who was altering the dress was able to calm Helen. Mary recalled that her younger daughter for the first time appeared to feel sorrier for Helen than she felt embarrassed for herself. Mary said that she thought at that moment that Stephanie began to realize how hard things were for her older sister, Helen.

Theme 2 summary. Denise was the only other mother besides Mary to comment on the kindness of others while in public places. In an incident that occurred in a store when Albert was being chastised by a saleswomen for not listening when she told him that he was not able to sit underneath the clothes racks. A mother of a child with ASD, who saw the argument came across the floor towards

Denise to offer support to Denise who was becoming overwhelmed. In Theme 3, the mothers' statements indicated a paradox between being grateful for the services received, and resentment and anger for having to fight so hard to access and maintain services that they felt were necessary for the children with ASD and their families to function.

Theme 3: The Paradox of Support Services

The mothers in this study were receiving many services for their children. The topic of support services elicited a strong response from all of the mothers. Each mother expressed the value and necessity of services and supports for their children with ASD and intellectual disabilities and to support the family. Family support services are a wide range of services provided by state and local agencies. These services may include respite services to give caregivers a break from their 24/7 responsibilities. They may include occupational therapy, speech therapy, and applied behavior analysis therapeutic services, counseling, or personal aides and services to enhance the caregiver's capabilities or occupational performance in caregiving. These services may also include parent and sibling support groups (Parish et al., 2003).

Subtheme: Gratitude for services that support mothering roles and occupations. Mary expressed disbelief when she was informed that her daughter Helen would be discharged from her school-based occupational therapy services, having met her final goal related to the education domain–cutting with scissors,.

Mary.

> I loved our occupational therapy experience... I distinctly remember the day... and I felt so sorry for her [Helen's OT]. She looked at me and she said Mary, Helen can cut with scissors now. We have to be done with her case... and I

> said what are you talking about? ...Helen’s occupational therapist said that Helen is doing well in school.... and I said are you kidding me? ... she said no... and it was just like a killer...because [Helen] can cut with scissors now, which was our last goal. Start cutting with scissors? It’s not enough...and so …when you talk about occupation, you know...to me, that’s what the world is! ...The world is going to end! And I came up with all kinds of things [Helen’s occupational needs] and [the OT] said all that is outside of the school domain...and these kids [who] are too low functioning for services...that’s ridiculous even if the kid isn’t making academic strides, you also have to think about the dynamics of the family and the household. You know that the services have to be in place in order for these…families to function, too...they need to have [these services]...it’s not like respiratory [therapy]...you’re still trying to reach these children who have low, low functioning...but maybe [if you can] calm them for the rest of the day....maybe you [will] have done something important for that family and for that child. Unless you give [the children] services, you’re not going to ever know their potential.

Some of the anger expressed was in relation to the amount of extra work involved in fighting for and maintaining services that help the family to function better. The mothers were already overwhelmed with the amount of extra time and effort needed to raise their children with ASD and intellectual disabilities, while also caring for their other children and carrying roles and responsibilities to sustain family life and calm households. In the following subtheme, the mothers spoke about their frustrations and resentments in regard to the work involved in accessing and maintaining services.

The mothers expressed fear about losing the necessary support services and what this would mean for their families. The mothers sometimes appeared to equate the loss of services with a loss of hope for their child, expressed in either sadness or anger. There appeared to be agreement among the mothers that families of children who really need assistance should not have to fight so hard for these services. Each of the mothers valued support services and viewed them as necessary to support their child’s’ continued development. Five of the mothers viewed support services as being necessary to sustain manageable households, to meeting the occupational needs of the families, and for the family to operate as a functioning unit.

Subtheme: Resentment towards the government for the imposed occupational burden of fighting for services needed for their families' survival.

Elise. Elise also commented on the crisis-driven nature of the state's response to requests for necessary the services,

> Thankfully, Kenny's school tuition is free...but parents are asked to help with fundraising and volunteer[ing] their time. We are making some great progress with Kenny, yet with many *wows* there can be...set backs...Kenny has regressed in many self-help skill areas, yet the strides he is making cognitively with speech are amazing due to the new autism school he is now in… Since our move to Florida, I lost all outside services. I was told that it was next to impossible to be bumped ahead on the [7-yr.] waiting list [unless it is] a crisis situation ...unless your child gets hit by a car, or severely injures himself or someone else. I haven't had 1 hour of respite or help since August making it impossible to fill out the piles of applications necessary to get on the painfully long wait lists for services… so I don't feel like a prisoner in my own home. I don't understand how services can vary so much from state to state…many of our kids are elopers [wandering, bolting] and need project lifesaver GPS tracking bracelets. With this move to a new state I have no help yet. I am in survival mode. If my son was not making such academic strides right now in the specialized autism school he attends in Florida, I would be planning to move the family again to another state, which offers outside services and help.

Denise stated that a great deal of stress was caused by the constant fight for services. She explained how Albert's services not only benefitted him, but the benefits of the services extended to the family such as when the services received brought him to a calmer state, then the household became more calm.

Denise. Denise was vocal about the services that she believes are necessary to allow her family to function and to survive. Denise resented the fact that so much of her time and energy were spent in trying to secure and maintain these services. Denise described how she felt the pressure of losing necessary services each year which she said placed stress on her and on her marriage and family, because she worried how she and her family would survive without the support. Denise blamed this fight for services for most of the stress that she experienced as evident in the following recount told by Denise,

> This is what upsets me. I understand...fighting for Susan's services, [her] needs are not so cut and dry...she can grow out of this…That being said the therapy has made a real difference in Susan's outcome…But I don't understand fighting for Albert's therapy…[Albert] is locked in himself…without therapy he wouldn't have his academic skills, he would not understand the concept of greater than or less than…that…oh my God, numbers have meaning…[Albert] may be low functioning but he does double digit addition, he does plotting on a graph…clocks…his name…all these academic skills. [What] I'm trying to say…I guess [is why do I have to] fight for something that has such an impact in Albert's life…So I guess mostly I'm worried about...why is there such a fight you know why, you know it should be...autism [is] diagnosed, we see it, I can give you like a 1,000 videos of it, it should be quick…fast, you go to the woman, she signs this paper and go home…but no, every year I'm going to prove that Albert still has celiac disease that he still has to stay home and be home school[ed] because he is a danger to himself…and because the services are necessary for the families' survival…Here is the point, most of the stress…that you have is [about] getting the kid the services that they need and…Is [it the stress about that] one service, [what] caused fights between your husband and you?...that caused anxiety and terminal of the house?...And at the same time here, it's right now April and May is when everything…hits the fan, because…you don't know what next year will be like. I have fear, I have friends of mine who are now placing their kids in placements and they are ahead of me…Albert is 11, their children are 20. What will I feel like when he is 20? Here I am big and pregnant, and I'm going to be 40…39 this …July. And I'm bent over [the] tub cleaning up my child's accidents and am exhausted…Am I going to live (to) 60…am I going to be physically able …I am not in their shoes what makes them feel like they have to do this? Maybe I'll feel that way later on….So that cause me a lot of fear…that I will feel that way…So [I] think about what's going to happen today, how am I going to get past this hurdle that's approaching me and also how am I going to get to find happiness for me…[It] just makes you insane thinking about the future.

> ***Dorian.***
>
> My understanding and I don't get really involved in politics and all, but at least in the State of Arizona, the budgets have been cut so drastically that…Policy makers are looking strictly at the dollars and they don't understand the situations that people are in.

Mary.

> They [the siblings] are kids, they go all alone...even now, and this is for your next study, but my middle daughter has had to have a whole lot of therapy. What she started doing was internalizing everything to her stomach and two years ago her stomach started hurting so bad that she could not go to school, it was just constant and so…we took her to Children's Hospital Cincinnati and she had all these tests and everything and it was nothing, it was just absolute…stress.

Subtheme: Growing mistrust and resentment of government institutions.

Dorian.

> At one point, they [the state] wanted to take my other child, [Stephanie] out of the house and put her in a foster home to give her a safe place to live…and I was like, you're going to totally ruin my other child's life....If they continue to cut these budgets, the agency that Katie is with right now may not even be able to survive.

Elise. Elise blamed the government for her son having ASD and expressed her resentment and anger for her son having ASD. Elise believed that her two children's autism were caused by government mandated vaccines. Her resentment is noted in the following passage:

> I want the government to take responsibility for creating this epidemic and take action to try to end it and assist those families who have been affected. I want the government to stop brainwashing the public into thinking that vaccines are safe when they are causing whole generations of our children's neurologic and nervous system damage. I want the American Academy of Pediatrics and CDC to eliminate unnecessary vaccines, stop adding more vaccines to the schedule, and remove all neurotoxic ingredients from the vaccines. I want the government to make it mandatory for insurance companies to cover autism therapies and autism doctor specialists such as GI, Defeat Autism Now neurologists. I want hyperbaric oxygen therapies to be FDA approved as a therapy for autism coverage for GPS tracking bracelets for all autistic children who elope.

Denise.

> I remember when Albert was one year old, my friend's child was getting his MMR [mumps, measles, rubella] shot and I am like are you giving [them to] him [all] at once, why don't you separate them [doses]. [Her friend said] I am

> not worried about that, he is fine, and I'm thinking please just separate them, just do it... you know, but it's like then he gets diagnosed with autism at 2.5 [2 years, 5 months]… And nobody, I'm telling like deepest, darkest secrets nobody wants anybody diagnosed with autism.

Theme 3 summary. The mothers' statements indicated a paradox between being grateful for the services received, and anger and resentment for having to fight so hard to access and maintain services that they perceive as necessary for the child and family to function, and in other cases such as Dorian and Elise's situation, for the family to survive. Some of the anger expressed was in relation to the amount of extra work involved in fighting for and maintaining services that helped the family to function better. The mothers were already overwhelmed with the amount of extra time and effort needed to raise their children with special needs, while also caring for their other children and carrying out their maternal roles and responsibilities to sustain family life and calm households.

Theme 4: Fears About Their Families' Well-Being

The topic of fear of the future and well-being of the family were frequently cited and extremely detailed and/or emotional. These expressed maternal fears were about the safety and well-being of the children with ASD and intellectual disabilities and sometimes for their other children's well-being, and in some cases, their safety. Some mothers expressed strong feelings against out-of-home placements, but even these mothers who had no intention of placing their children expressed fear about the notion being in a position of having no choice. These same mothers were able to offer thorough explanations and detailed descriptions of how the mothers who placed their children might have felt about it despite their position on the topic, which might suggest that they have at least explored or considered their opinion on placements before.

Subtheme: Needing wide networks of support, respite, and to live in the right state.

Mary.

> Because the residential options are so low and the support is so low. You've got to have a huge network and I hate to be...you know…part of my cynicism I think on a policy level is those networks are fewer and fewer…Unless you have endless funds, those networks…you really have to seek them out…and you have to be in the right state.

Elise. Elise had recently moved from North Carolina to Florida with her husband Ned and their three children in order to secure services for her son Kenny, age 7 years, who had severe ASD and intellectual disability. Kenny had two sisters, fraternal twins, who were 5 years old. Nicole has neurotypical development and her twin sister Evelyn has ASD but functions at a higher level and is attends school with her twin sister in a mainstreamed class. Elise's husband Ned is ill. Ned needs a liver transplant and he currently works from home. Elise sheds light on how she experienced Kenny's discharge from services in her previous state, "Our little guy was written off and dumped from outside therapies because he had limited rehab potential. I knew they were all wrong…and we moved to Florida."

***Elise*.**

> But if the government would provide us with in-home help, then maybe out of home placement would not be necessary and it would be cheaper to keep the child in the home with his own family.

Subtheme: Fears regarding the disorders' impacts on families' occupations and quality of life.

Mary.

> It’s really easy to forget [that your other kids] have needs...What I did was I turned to my middle daughter…I put all my hopes on to her…A therapist look[ed] at me and [said] she is not perfect, she can’t be perfect…I didn’t even know I was doing that…I had no idea! [Stephanie] was so afraid of disappointing [me] because of all she had seen…Unless you just have endless funds, you really have to seek out [Networks of support] and you have to be [live] in the right state.

Subtheme: Internalized placement fears.

Elise.

> As long as I am emotionally and physically capable, I will do anything I can to keep our family unit together. I thought about placing Kenny in a residential home one day, but the thought of letting him go brings me to tears. I don't know what Kenny’s future holds…he may one day have to transition out of the home and I hope God will give me the needed strength…I am still thinking that I could never put my beautiful baby boy in a group home. I feel it is my responsibility to take care of [Kenny] but realistically I have to plan for his future because I am not going to be around forever…I would need to find my son a place to live long after we were gone. I have always had this on the back of my mind.

Denise.

> I will not be here forever…I may not be able to care for him one day…Friends [have put] their kids in placements. But….from my perspective with each time I have had a child it is like a vow that I take to each of [my children]. And it means that no matter what, I’m going to be there… And if I were to put him in a place, first of all… Would he be sick every day? Yes, because [he would] be exposed to gluten and he has celiac disease…it leads to cancer…it leads to onset diabetes. And for his own physical safety, I mean but besides that…emotional well-being. You know it’s my job to make sure that his life is as smooth as possible, now that being said, I’m going to die one day and so I’m hoping I live [till] 90, you know, then Albert will be like 60 something…so I can give most of his life at my home.

Subtheme: Fears about financial capacity to meet the needs of the child and the family. Each mother was able to provide detailed and emotional descriptions on the topic of child placement, despite their personally adamant position against placements. Despite a mothers’ strong desire to raise their children at home, there appeared to be some fear and recognition that circumstances could change in the future.

Elise.

> But if the government would provide us with in-home help, then maybe out of home placement would not be necessary and it would be cheaper to keep the child in the home with his own family.

Subtheme: Safety fears.

Elise.

> My increasing inability to physically deal with Kenny when he gets in his rages or needs his teeth brushed is concerning. I have permanent scars from when he bit my arm. I have to think how I am going to protect his siblings in the future.

Subtheme: Fears about the future.

Denise.

> One of my darkest fears is that Albert will have an epileptic seizure and die…he doesn't have seizures right now, but in puberty that's going to begin for a lot of these children with autism. My greatest fear is that I will lose him…I have fear, I have friends of mine who are now placing their kids in placements and they are ahead of me…Albert is 11, their children are 20. What will I feel like when he is 20? Here I am big and pregnant, and I'm going to be 40…39 this …July. And I'm bent over [the] tub cleaning up my child's accidents and I'm exhausted…Am I going to live [to] 60…am I going to be physically able…I am not in their shoes what makes them feel like they have to do this? Maybe I'll feel that way later on….So that cause me a lot of fear…that I will feel that way...So [I] think about what's going to happen today, how am I going to get past this hurdle that's approaching me and also how am I going to get to find happiness for me…[It] just makes you insane thinking about the future.

Theme 4 summary. In this theme, the mothers discussed those pivotal moments that build up until the crisis point is reached. The mothers experienced many melt downs and extreme behaviors leading up to this point, but eventually, the moment arrives when the mother feels emotionally overwhelmed and physically depleted. In all three instances, safety was the tipping point for the placements.

Occupational injustices began to emerge as the mothers discussed their feelings about the children's placements and/or their considerations as to why some mothers feel that they need to place their children. In Theme 5, occupational injustices are revealed through mothers' feelings about their children's placements.

Theme 5: Occupational Injustices Revealed Through the Mothers' Feelings About Placement Considerations

In this theme, the mothers discussed their restricted freedoms and their exhausted economic and occupational capacities as they tried to sustain family life. The mothers also discussed their feelings about the restrictions imposed on their other children and the impact of these restrictions in daily activities and special events on their other children's well-being and quality of life.

Subtheme: Restricted freedoms and exhausted economic and occupational capabilities.

Mary.

> It's really easy to forget [that your other kids] have needs...What I did was I turned to my middle daughter…I put all my hopes on to her…A therapist look[ed] at me and [said] she is not perfect, she can't be perfect…I didn't even know I was doing that…I had no idea! [Stephanie] was so afraid of disappointing because of all she had seen…Unless you just have endless funds, you really have to seek out [Networks of support] and you have to be [live] in the right state.

Elise.

> Regarding [Kenny's] 5 year old sisters, we try our best to give equal time but it is challenging. Evelyn, who is high functioning autistic, resents Kenny because we allow him more time on the iPad simply to keep the peace in the house. Nicole craves special alone time with us but we are so weary and stressed it is hard to do...I have not been able to schedule his sisters for Brownies or a gymnastic class because I have not been able to afford or train a babysitter. I can't take all three kids to most places. Kenny is an eloper and Nichole [has] horrible meltdowns.

Linda.

> You need a support system. I think that if you are a mother of a disabled child…you need a team of people…to help, because it is overwhelming. Especially if you have other children in your household, you can't devote all of your time to your disabled child…you have to divide and conquer…I think the more help you have, the better you feel, the better you are able to deal with life and all its stuff.

Denise.

> My mom is a person who always takes care of my kids when I have to do appointments…My sister and I have this sort of system where this month I get a date, next month you get a date the month after that we are off. So we can stay out of the house and get some like sanity back you know. But the reality of the situation is that we don't have normal lives. We always are going to be attached to our children.

Subtheme: Environmental and occupational aspects influencing placement considerations.

In this subtheme, the mothers spoke about their children and how hard the mothers try to keep their families functioning as they took care of the needs of the children with ASD. Family outings or vacations were difficult for most of the mothers and their families who often mentioned having to split the family; that is, one parent cares for the child with ASD and the other parent takes the child's siblings to the events. Therefore, attending family celebrations and religious events, or community gatherings or outings to a local restaurant, rarely occurred. The capabilities and occupational performance of family members and of the whole family as a functioning unit were affected when the services and supports were inaccessible or withdrawn as noted in Elise's move to a different state with a special school for children with ASD.

Elise moved to out of state so that Kenny would be able to attend a special school for children with ASD and she lost all of her therapy services and her aide for

Kenny due to the differences in services from state to state. Kenny was difficult to manage due to extreme sensory issues and behavioral reactions, aggression, and wandering. Because Kenny was a runner, Elise could no longer keep all three children safe in most public places, so she was no longer able to take all three of her children out together to the park or other public places, extending the impacts of ASD to the siblings. Most of the families in this study moved to other states to secure the necessary services for their children, since funding for services varies from state to state, often leaving other support networks of families and friends behind.

Mary.

> Just as in any child's life, you have these pivotal moments…you know, sort of despair…in an autistic child's life and so it was just this horrible moment and we sent her to a camp for autistic children one summer and it was only like a three-week camp and it was such…not having to deal with the day-to-day was so incredible. The sense…that I could breathe, when [Helen] went to this camp, it was so remarkable to me, and the guilt that went along with that you know, it was ridiculous, and so when she came back from this camp…[Helen] hated the whole camp experience and it was a therapeutic camp and they knew what they were doing, but she hated it.

Subtheme: Family crises and final tipping points to forced or premature placement decisions.

Mary described two events that marked the progression towards a pressured placement and a pivotal event that preceded the final placement decision for her daughter Helen.

***Mary*.**

> This is before she [Helen] could ride the bus, the bus was just too much for her to handle. It was too loud and…[and] she had separation anxiety. So Matt was driving her to school and he did not have his priest clothes on because he was going for a [medical test]. And I was in the car because I had to drive Matt home and that was not the routine…Hannah got so upset over this change that she unbuckled her seatbelt and she crawled from the back, while

> Mike was driving …and she grabbed off his glasses and I mean, he couldn't see and he was driving…and I am trying to grab her…it was so horrible.
>
> [Helen] hated being out of the routine and the day she got back [from camp], she was so angry that Stephanie, my middle child was standing around her room…in the door frame, and Helen just knocked the hell out of Stephanie. It was very dangerous and Stephanie hit her head and it was bad. And I was so angry at Helen for I couldn't believe the anger I felt towards my own child and that's another thing that you [mothers] are never supposed to say about this child. You are supposed to just sort of internalize this aggressive behavior.

Next, the PI asked Mary, "were you and Matt in agreement about the plan to place [Helen]?" Mary responded,

> We agreed about the plan. [Matt's] plan was to get her home as soon as possible. In other words, if we could find a different school placement. This was a temporary setting for him…My view was [that]… Oh my God, I can probably breathe…and I don't really care how many years this lasts, if I am breathing. So...we went through [with] it…I had many feelings…it's all so complicated…Here is what you are not supposed to say to people overall feeling was incredible relief and initially I struggled with myself [in] how much relief…I was feeling…you know…As a mother…what I was supposed to be feeling was incredible sadness, incredible, which I did feel the sadness, but I was supposed to be feeling just horrible that…I was placing my child…it was a struggle for me [conflicting feelings between sadness and relief]…I was thinking about my other [two] children...[I felt] resentment that this is what I had to do to make our family be able to function, to help Helen to function… [it was] hard and painful in that, this is what our life had become...

Elise.

> As long as I am emotionally and physically capable, I will do anything I can to keep our family unit together. I thought about placing Kenny in a residential home one day, but the thought of letting him go brings me to tears. I don't know what Kenny's future holds, but he may one day have to transition out of the home and I hope God will give me the needed strength…I am still thinking that I could never put my beautiful baby boy in a group home. A couple of years ago, I visited a horse farm which was in the beginning stages of setting up a community for adults on the spectrum, knowing that I would need to find my son a place to live long after we were gone. I have always had this on the back of my mind. Every time my 7 year old gets aggressive or violent the thought crosses my mind. But I keep praying that I will figure out how to reduce these behaviors or cure him with the right protocols. After trying so many protocols and only making small gains, we are becoming financially and emotionally drained and don't know how we are going to be

able to continue our pursuit to find the cure. I have not given up but I know I can't keep up…

Linda.

We [Linda and Gary] began to think about an out-of-home placement…as a result of situations in our home that Mattie's behavior was becoming dangerous to herself and her sibling. [It was] heartbreaking… Heartbreaking. Very painful. Very…I mean…if I was talking with my spouse, it was very difficult, just very, very difficult…where he was more realistic looking into the future and they [others] would just harp [at] us…I'm the mom you know and that's my baby…Regardless of anything you know. It was a very stressful period of time…what felt bad was that I couldn't do anything to help my child, that I felt hopeless…or not even hopeless, just really helpless…that I couldn't do anything to make her feel more comfortable. And then I felt like if I had to place her in a home, I would be a bad Mom, like I was just giving up.

Soo.

There are many moments even in a single day, when I just have to take a deep breath…Tell myself that it's ok...that I can do better...that is gradually going [to get] better and that it [could] be worse…so I don't lose my mind like so many mothers [of children with autism] have.

Dorian.

It's very emotional. Something you never think you'll ever do…it got to the point of, it's a necessity. You feel so guilty because you're like this is my child, I should be the one caring for her. my mother is a little bit elderly and could not be around Katie…I moved to Arizona, [when] Katie was five, and my mother saw how she was…she said you know she needs to be institutionalized and I was like what? ...

Denise.

In my mind, I have made a pact with my child and I do not think that anything could break it. I mean even my own marriage. That's one of my fears, that I would be in that [position] [Albert] having more accidents at night, not in the day. But that's the stressful part, it's like you know you are up at night, you are bathing, changing the beds… your lights are on in the bathroom, you are doing laundry because it's going to ruin the clothes…So you do it right away or else, so you are doing it [laundry] at 2 o'clock, 3 o'clock in the morning. Now you went to bed at 3 and you are getting up at 5 and now you have an hour in the middle where you're like….and you do it four nights in a row, are going to die. And so that's... I can see why they would say that…it is very difficult...

Theme 5 summary. Theme 5 provided a window to see how the mothers struggled to meet the needs of the child with autism sometimes leaving them depleted for meeting the needs of the entire family and maintaining calm households. Mary understood that she needed a break, time to breathe, and a series of crises led her to make the final decision. The three-year period where Helen was in a residential placement, gave Mary and her family time to reestablish a peaceful household. When Helen returned, the family was prepared to hold on to the peaceful environment created in Helen's absence, and Helen learned to adapt to a new environment through her residential placement. In this case, the three-year residential placement allowed Mary to reclaim a more peaceful environment in her home and everyone grew from the experience. As the straws of certain events begin to accumulate, families may reach a critical point. Often there are pivotal moments, which precedes the tipping point, when the family has reached a crisis point, the placement decision-making process is at the next level, and a decision may be made to place the child. Once the parents reach a crisis point, it may be too late to reverse or delay placement decisions, for at this point the family is in crisis and respite becomes necessary.

For Mary and her family, the outcome was positive in that Helen received the structured environment and services that she needed while the rest of the family had a chance to reclaim the calmness of the household. When Helen returned, the entire family was in a better position to live together in a more peaceful environment. Dorian's safety issue was at a critical point, and required a crisis for her to access the permanent placement that her child with autism and her sibling required for their well-being. Dorian and her family were at extreme risk in this situation without placement and reasonable options for crisis intervention.

In Theme 6, the mothers shared their meanings of their lived experiences of the decision-making process. The mothers' provide insights and philosophies derived from their placement considerations, decision-making experiences, and placement decisions. Their reflections also provide insights as to the information about what helps or hinders community participation.

Theme 6: Spiritual Aspects of Childhood Placement Considerations

In Theme 6, the mothers shared their meanings of their lived experiences of the decision-making process. The mothers provided insights and philosophies derived from their placement considerations, decision-making experiences, and placement decisions. Their reflections also provided insight as to the information about what helps or hinders community participation.

Subtheme: Finding a sense of joy and purpose in daily occupations, despite the hardships.

Denise.

> I can't wait for Saturday comes when Robbie and I…can do our things which like… one of our rituals is…to the gluten-free bakery…it's all gluten-free the whole bakery. We don't go inside. [It's] just too chaotic, we take all the stuff into the car, the kids get all their goodies and then we go get coffee at Starbucks and then we take a ride through all the rich expensive areas around here. And we look at the horses, and look at the houses and children are always like when are we going to have a mansion? … So, you know we just day dream basically and the kids love the ride, we love the ride and it's a chance for me and Robbie to talk because the kids occupy themselves…and it keeps us sane… So think about what's going to happen today, how am I going to get past this hurdle…and also how am I going to find happiness for me [and] my family, despite the hurdles because really you have to like just shut it off…

Subtheme: Mothers' shared beliefs about humanity and inclusion.

Mary.

The worst, worst part is, you know Helen has no friends and part of it is that she doesn't know how to be a friend and we tried to train her and teach her…but I think that social aspect, the relational aspect is just this huge missing piece, and it is really sad and nobody deserves to live in a world [with no friends].

Linda.

Can I tell you? No one has ever offered me a helping hand when I was struggling with my child in public.

Subtheme: Spiritually deepened through the decision process- Inspired occupational roles.

Mary.

You know, I hear people say Did you develop a resentment to God…That's not exactly what I feel…I think that it [raising a child with ASD and intellectual disability has actually enhanced my spirituality…because, well I see the spirituality in the pain…if anything…I've learned that spirituality is not always a place of joy…

Linda.

So some people say like if God…didn't want you to have this child…you couldn't handle this child, you wouldn't have had this child. I mean it's presentable, but it's hard to think or believe that somebody would intentionally do this to somebody you know…and like okay when you are the chosen parent that you're going to be the patient one and you're going Family events and holidays are very difficult. It helps to be like…this is your purpose in the world…I find that to be a bunch of b. s…or like angry with God [for giving me more than I could handle] …Yeah, I feel like that a lot…I think I'm past the point of questioning. It's so funny, I don't feel comfortable … [I] can't lean on anybody else for my situation, you know, or like people asking for help from like a Rabbi or a priest.

Subtheme: Inspired occupational roles: To educate-inform-advocate

Mary.

I'd say if you want to keep your child at home that's wonderful. You need a huge network [of support] and if you have that, that's great. You need to make sure that you are comfortable with asking [for help] and tapping into it [the network of support]…you need to build [it] in time, if you have other children…that would be the main thing…[your other children] have needs.

Elise stated that “Respite is critical to the journey. Don’t be afraid to apply and ask for help.”

> **Soo.**
> I look at things positively and take a deep breath to survive it all, without losing my mind like so many mothers have. There are many moments even in a single day when I just have to take a deep breath, tell myself that it is ok, that I can do better, that it is gradually getting better, and allowed to just cry and scream without attempting to communicate what is wrong, in the case of my child who is very limited in communication skills and can only primitively gesture, I still require him to at least try and gesture, instead of acting out or getting mad. Every child needs to be told what is acceptable and what is not. that you’re trying to present an environment that is the best for everybody.
>
> **Dorian.**
>
> But the one thing I keep stressing is the “I can’t give up on my child message” I did not give up on Katie. I will never give up on her, you can’t give up on her. It is just that you try to offer an environment that is best for everybody.
>
> **Denise.**
>
> I have a life…that I feel blessed in many ways. I’m lucky…because I have my mother, my father, I have Robbie’s mother, I have Robbie, I mean, Robbie is amazing. I have the most amazing husband, people meet Robbie and they are just like I am gifted, you know. I want the whole world to be autism free, I pray for every single week, you know I pray for autism free, cancer free, cystic fibrosis free. I just feel like all people suffer you know and…I remember when Albert was first diagnosed we brought him to Montefiore for a 48-hour video EEG and I thought this is the worst moment of my life…was kicking and screaming, turned purple fighting and struggling …they put all these electrodes on his head…So, I am thinking this is the most horrible thing. The kid next to me is unable to talk, unable to eat, is in a wheel chair, is not functioning, having seizures left and right, has alarms attached to his body, and the minute…he vomits he could kill himself in his bed…He [was] like four years old and I am thinking to myself…God!...snap out of it woman because this kid you have functions, he eats, he sleeps he baths.
>
> **Linda**.
>
> I think the more help you have, the better you feel. You need a support system. I think that if you are a mother with a disabled child…you need a lot of people to help, because it is overwhelming. Especially if you have other children in your household…you can’t devote all of your time to your disabled child…you have to divide and conquer so that you are able to deal life and all its stuff.

Denise.

> This weekend alone, my husband was upset, [Albert] had another accident, I was at religion class and I come home…my husband is upset and angry the entire day because [Albert] had an accident in the morning, he is just cranky you know. And I am like…You know I understand the upset, but we can't carry it for 17 hours you know…you have to just let it go...let it go so we can still have a Sunday that's beautiful okay? So salvage it…he understood…we were fine…but it's just difficult sometimes…sometimes, as a person, I just wanted to say… I'm going to like shut down for the day, I'm done...I have had it you know.

Theme 6 summary. Theme 6 highlighted the insights of the mothers demonstrating how much they have reflected on the meaning of life and the humanistic aspects that benefit all human kind. The mothers learned a great deal from their experiences of their placement considerations, decision-making process, and placement decisions and each mother was eager to share her insights. These mothers were fiercely dedicated to their children, though often sleep deprived, and struggling much of the time. Their insights can help occupational therapists to create new environments and build creative communities with new ways of incorporating individuals like the mothers in this study's children with ASD and intellectual disabilities.

Current economies are likely to demand health professionals to do more with less. For occupational therapists, this is an opportunity to convey its unique contribution and value to become part of the primary care core health care team and to demonstrate the effectiveness of its services in community and mental health. Occupational therapists have knowledge, creativity, expertise in adapting the everyday and special occupations; and creating, adapting and promoting enabling environments, and inclusion.

Summary

Six mothers of children with ASD and intellectual disabilities shared their experiences of placement considerations and decisions so that others could better understand what the mothers and their families have gone through. The decision-making process for placement and placement considerations should not be confused with the placement event. Placement considerations begin years before mothers or parents articulate serious consideration of the need to place their children. Placement considerations also appear to occur with mothers who have no intention of placing their children, as noted in the mothers in this study who are adamant about their decisions not to place their children.

When asked to comment on how other mothers might arrive at the child placement decisions-making process or placement decisions, these mothers were able to articulate all of reasons cited by the mothers who made the decision to place their children. This may suggest that the there is an ever-present internal consideration process that escapes the mothers' conscious awareness.

The mothers' perspectives helped to shed light on how the mothers who placed their children first entered the decision-making process for the actual placement, how they arrived at their placement decisions and how they felt about those decisions. The mothers who were firmly against placing their children considered why other mothers who placed their children might have decided to do so, and were asked to consider how the mothers may have felt about their placement decisions.

The evidence from the literature review supported the notion that placement considerations are influenced by the context of the mother's lives, and in relation to reactions to events over time and space. The literature review pointed to a cumulative process and effect over time, or notion that placement considerations regarding young children occur over time as part of a long process in context of daily lives, and in relation and reaction to multiple events over space and time (Blacher, 1999; Blacher & Baker, 2006). The actual placement decision typically occurs following a series of crises, the many straws of the ASD and intellectual disabilities impacts. At this point, the family is in crisis. Phenomenology allows us to enter into the mothers' lifeworlds to illuminate for others how environment and occupation affected the entire family's engagement in health-promoting occupations affecting their occupational performance to raise their children at home. Occupational deprivations can diminish capacities and occupational performance to raise a child with ASD and intellectual disabilities at home.

The mother's perspectives also shed light on how their placement decisions were influenced by environmental aspects that affected their mothering occupations, participation, and occupational performance of each family member and the family as a whole. Raising a child with ASD can be challenging and the impact of the disorders extends beyond the child with ASD affecting each individual family member and the entire family as a functional unit. If the child with ASD has co-occurring intellectual disabilities, the impacts of the disorders substantially increased (Washington State Department of Social & Health Services, n.d.). ASD impacts can include decreased maternal health, family well-being, and quality of life, within the home, community life, and finances. Medical expenses create additional burdens for the families who care for children with ASD and intellectual disabilities. Each family impact is inter-related and the impact of families' unmet needs extends to their communities, institutions, and organizations.

The resulting composite textural-structural description of the mothers' descriptions of their lived experiences resulted in a universal essence of the phenomenon. The resulting universal essence of the decision-making process was comprised of six major themes with supporting subthemes.

All of the mothers greatly valued the supports and services that they have received. The majority of mothers equated the services with a means to survive and with hope for the child with ASD and intellectual disabilities as well as the well-being of the family. The mothers also experienced varying levels of stress at the amount of time and energy fighting for services and as a major source of stress.

The feelings that mothers expressed provide a lens to their dependence on the services and supports they received. For some families, the support services were reported to be necessary for the families' survival. Some mothers perceived the loss of their children's services as confirmation that others did not see the potential in their children. Services that the mothers received not only helped them in managing their maternal roles and occupations, but gave the mothers a sense of hope and a sign those others expected their children to live full quality lives.

The mothers expressed many fears about the future of their children with ASD and intellectual disabilities and the safety and well-being of all their children. They were fearful of their children with ASD wandering into unsafe environments and about their children's lack of safety awareness and sometimes violent outbursts, endangering themselves or their siblings. This fear was heightened if the children also had wandering tendencies and co-occurring sleep disorders.

Fears about the emotional and physical well-being of the other children was discussed in terms of the other children not receiving sufficient attention and insufficient sleep when woken by their sibling when sleep disorders were present. Some mothers expressed anger but also fears about vaccine safety for their own children, but also for their friends and family members. Denise who believed that her child's ASD was related to the vaccine advocates for vaccine refusal or for at least dividing the doses. When Denise advised friends about vaccines, she felt upset and fearful for mothers who do not heed her advice to avoid or lessen the dose of immunizations. Anger and mistrust of the government and anger about state-mandated vaccines, and in relation to institutions that make decisions about funding for services and were a strong theme.

Each mother had experienced incidences of feeling judged as mothers when their children had extreme sensory reactions and extreme behavioral reactions in public places. The mothers all experienced hurtful comments and unhelpful advice which made them angry and sometimes left them feeling marginalized and judged. Many times, the mothers reported judgmental stares from strangers which upset them. In general, the mothers' and their families' freedoms and access to opportunities for participation were greatly restricted as individuals and as a family due to environments, particular occupations, and due to intolerance or social exclusion. Five mothers reported that no one ever asked them if they needed help when they were out in the community with all of their children and their children with ASD had meltdowns in public (e.g. grocery store, shopping, and running household errands). Linda said, "Can I tell you? No one has ever offered me a helping hand when I was struggling with my child in public." The mothers in this study answered the following questions: (a) What are the ‘lived experiences” of mothers of young children with ASD and intellectual disability in regard to the decision-making process for out-of-home placement, and (b) what are the occupational and environmental aspects related to the mothers’ placement decisions? Occupational implications for placement decisions were considered. The mothers also provided fresh insights into what helps and hinders participation in occupations within the home and community.

Chapter 5: Discussion

Introduction to the Chapter and Summary of Earlier Chapters

Chapter 5 is organized into seven sections. Section one begins with a discussion and summary of earlier chapters. Section two discusses conclusions, interpretation, and speculation about the results. Sections three and four discuss implications for practice and implications for future research, respectively. Section five addresses limitations and delimitations based on the results, including those that were unexpected, followed by sections six and seven, the recommendations for the profession, concluding with the chapter summary and post-dissertation personal and visual reflections about Healthy Communities, 2020 on where we go from here.

This qualitative, transcendental phenomenological study was conducted to elicit essential understandings of mothers' perceptions of placement considerations, entry into the decision-making process for out-of-home placement of their young children with autism spectrum disorder (ASD) and intellectual disabilities, and the relationship between their occupations and environments in placement decisions. Occupational implications for placement decisions were considered. Chapter 1 discussed historical perspectives of mental health attitudes and practices over the ages and the implementation of the Deinstitutionalization Act of 1955 (Koyanagi, 2007). The significance of the evolution of mental health in the United States provided a context to better understand stigma, intolerance, and exclusion that individuals with mental health issues experience along with their caregivers and family members. In looking back over the ages, it becomes apparent that the most significant change in mental health in the United States occurred over the past 60 years (Koyanagi, 2007).

A brief interlude during the Moral Treatment movement (Bing, 1981, p. 506) facilitated a sense of altruism in people, and individuals were assigned institutional training programs away from their communities. When these individuals were released from the training programs and re-entered their communities, negative attitudes re-emerged. Policies can have a significant impact on individuals and communities. The institutional training programs were well intended, providing skills for individuals with disabilities; however, the living was institutional, which is not the same as community living. The tolerance for these individuals was reduced in their absence as evidenced by the re-emergence of negative attitudes. Perhaps their communities had become unaccustomed to interacting with individuals with disabilities.

During Deinstitutionalization's Phase I and the closing of institutions, the failure to assess and predict risks and potential benefits and to set up the necessary networks of support that left country with an abundance of social impacts including drug abuse, crime, and homelessness, which remain in American society today. The benefits were that individuals with mental health began to live in the community, and the stigma of mental health was reduced. The relevance of Deinstitutionalization Act of 1955 (Koyanagi, 2007) to this study is in reflecting on past lessons to inform decision makers for future policymaking and implementation. Deinstitutionalization's lesson to future policymakers is the importance of predicting unintended consequences and avoiding them or minimizing them, and setting up layered networks of support in the event of policy failure.

Parallels can be drawn between Deinstitutionalization currently in Phase 3, the rights and recovery phase, and the current Affordable Care Act, with an expectation of full community inclusion. As discussed earlier, several events are converging at this particular point in time. These events include (a) Deinstitutionalization is in Phase 3–a full shift from institutional health in the community; (b) a currently challenged economy with high unemployment; (c) an evolving and fiercely debated national health insurance plan which has exceeded all budget projections and proposes more extensive and comprehensive coverage for greater numbers of individuals at lower costs (Parish et al., 2012b); and (d) rising rates of ASD which are likely to create increased competition of services. For mothers of children with severe ASD and intellectual disabilities, any reduction in the current services might leave them unable to sustain family life. For those mothers and their families facing the decision to place, there will be reduced options for long-term care (Parish & Lutwick, 2003; Parish et al., 2012a; Parish et al., 2012b).

Occupational perspectives were discussed in relation to ASD and intellectual disabilities impacts, occupational therapy and occupational science research, and practice for the impacts on the children with the disorders and subsequent impacts on maternal health and family well-being. Law et al.’s (1996) person-environment-occupation (PEO) model of practice was discussed related to understanding the complex transactions among persons, environments, and occupations and how the occupational performance is enhanced by the *just right fit* among these aspects. From an occupational perspective, Law et al. (1996) provides thee different avenues for providing intervention for improved occupational performance.

The occupational therapist working with a child with severe ASD and intellectual disabilities may need intervention targeted at all three aspects considering the particular context over time and space throughout the lifespan allowing for flexible, fitting treatments. To illustrate, a young child with sensory issues related to the disorders may struggle with anxiety and stereotypic movement; the research has shown that Ayres Sensory Integration®/OT interventions have been shown to reduce these symptoms in children with sensory issues in children with and without ASD, as mentioned earlier. An environmental approach to intervention may be the establishment of a comfort room where children have an opportunity to become calm. Such occupational therapy applications as the *snoozlen* rooms have been shown to reduce the need for restrains in institutional care. Another calming area more accessible to everyday people might be a small uncluttered, quiet area with lower light and possibly calming music or a tent where a child could calm an overstimulated sensory system. Deep pressure and brushing techniques have been useful interventions that are accessible to all.

The occupation is of course at the center of all occupational therapy interventions; occupation is everywhere, or as Mary said “occupation is the world, it’s everything.” Occupations can be chosen by the person. There is a natural gravitation towards activities which interest individuals. A child with ASD and intellectual disabilities may be attracted to certain sensory elements while other sensory elements may be aversive to the individual. By understanding the particular sensory deficits and the sensory needs, the occupational therapist can create the sensory diet or an intervention which is particular to the child and his or her sensory issues.

Mothers and caregivers are also considered the child's environment, as mothers provide developmental occupational challenges and monitor their children's development. Mothers do this through a scaffolding process that occurs during the everyday basic and instrumental activities of daily. Certain characteristics of ASD pose problems for the mothers in maintaining household routines and promoting and monitoring their children's development. For the child with ASD and intellectual disabilities, this concept is relevant to intervention as mothers of children with ASD spend more hours in caregiving and experience higher levels of maternal stress.

The family impacts of the ASD disorder include maternal health, sibling well-being and quality of life, participation (BADLs; ADLs engagement in meaningful and necessary occupations at home and in the community occupations, safety concerns, employment and finances. The effect of these multiple ASD impacts, can impede occupational performance of the family and their capabilities as a functional unit to raise the child within the home.

Economic perspectives were introduced along with Sen's (1999) development economics, capabilities approach (CA) which asserts freedom as a prerequisite to development and agency. Occupational justice was argued to be a missing and measurable element of Sen's list of basic freedoms and the most basic element of socioeconomic consideration for developing human potential and agency.

Current cultures, ways of knowing, decision-making, technological, and health trends were also discussed in regard to their influence on placement decisions. The chapter concludes with a discussion of the American Occupational Therapy Association's (AOTA) Centennial Vision and the completion of the AOTA Centennial Goals and the leadership roles for which the profession has been preparing its membership over the past 20 years.

Chapter 2 reviewed the literature from multiple professions and disciplines and from different countries perspectives' of mothering occupations, and the impacts of the disorders on maternal health and family participation and well-being by expanding on the topics introduced in Chapter 1. State, federal, and global health policies and initiatives were explored and the World Health Organization ([WHO] 2001, 2008, 2013) provided global perspectives on health and on deinstitutionalization for global perspectives. Interdisciplinary studies were explored for research on out-of home placements and services utilization, and impacts of the disorders on the families and medical research for the co-occurring symptoms and costs associated with raising children with ASD and particularly with co-occurring intellectual disabilities.

Medical research, economic, and other interdisciplinary research shed light on economic impacts of the disorders on the health status of the mothers and their families and issues including issues related to maternal stress and secondary illness, health and safety of their children with and without ASD, child care, child and family supports and services including respite services and employment. State policies and law documents as well as interdisciplinary research provided insights into the residential and other out-of-home placement options including child relinquishment and its impact on the families' rights and involvement with their child.

Occupational performance of the mother and family to raise the child at home were considered in relation to their placement decisions. The role of occupational therapy in supporting the mothers of children with ASD and their families and caregivers was discussed and considered in relation to social, economic, and occupational justice.

The occupational perspective of engagement in occupation and community participation for health promotion, prevention of illness and secondary illness, and treatment was explored, along with evaluation of individuals with ASD and their caregivers. The placement decision-making process also revealed restricted freedoms in regard to placement decisions. Influential aspects of broader contexts social, economic, and environmental impacts of the disorders on mothers' and caregivers' capabilities and occupational performance were also explored. Concluding with current issues and trends influencing parental attitudes regarding health institutions, technology, economics, and occupation with implications for public health.

The literature review revealed that there was a gap in the occupational therapy literature on out-of-home placements and placement prevention, and the decision-making process for placements. Also uncovered during a review of the literature was a notable absence of occupational therapy research from other disciplines and professional literature where it would have been expected. Occupational therapy and occupational science research on maternal roles, routines, and rituals (Larsen, 2010; Werner DeGrace, 2004) and Ayres Sensory Integration® research (Ayres, 1969, 1972; Baranek et al., 2005; Miller, Anzalone, 2007; Miller, Coll, 2007; Parham et al., 2007; Parham et al., 2011; Schaaf, 2014; Schaaf et al., 2012a; Schaaf et al., 2013; Schaaf et al., 2012b; Schaaf et al., 2014; Schaaf & Miller, 2005; Schaaf et al., 2011; Watling, 2010; Watling, & White, 2001).

The significance of these omissions of occupational therapy research from studies of other literature includes the resulting confusion about what actually qualifies as Ayres Sensory Integration®. This confusion has led to an inappropriate combining of all sensory approaches including those that do not have evidence to support their use. Importantly, this confusion led to misinterpretations, faulty assumptions, and subsequent policy decisions based on these faulty assumptions (e.g., the exclusion of sensory modulation disorder from the DSM-5 and the subsequent policy statement by the AAP that sensory-based treatments including Ayres Sensory Integration®) should not be recommended because of insufficient research to support their use. The end result for individuals with ASD and other individuals with sensory issues that interfere with their occupational performance will not have access or funding for a treatment which has been found to be successful in reducing anxiety and stereotypical movements in individuals with ASD (Ayres, 1969, 1972; Baranek et al., 2005; Miller, Anzalone, 2007; Miller, Coll, 2007; Parham et al., 2007; Parham et al., 2011; Schaaf, 2014; Schaaf et al., 2012a; Schaaf et al., 2013; Schaaf et al., 2012b; Schaaf et al., 2014; Schaaf & Miller, 2005; Schaaf et al., 2011; Watling, 2010; Watling et al., 2001).

Chapter 3 presented the methodology and offered a rational for use of Moustakas's (1994) transcendental phenomenological approach. Attention was given to the ethical and research standards of the occupational therapy profession, as well as the process and compliance with Nova Southeastern University's Health Provisions Division

Institutional Review Board for ethical human subjects research. Specific transcendental phenomenological procedures were explained.

Strict adherence to these specific phenomenological procedures, assuming the phenomenological attitude–open mind, and use of extensive bracketing strengthened the trustworthiness of the research study. Strengths of the research design and limitations were described. Threats to the rigor were discussed as were multiple procedures for addressing these threats to rigor, including a member check with the participating mothers. In addition to adherence to these procedures, a peer reviewer conducted an independent secondary analysis of the data. This peer reviewer then conducted a peer-review session to challenge the interpretations of the principal investigator (PI) and to check the PI's adherence to specific procedures including bracketing and maintenance of a phenomenological attitude.

Chapter 4 presented the findings of the study emphasizing the following six major themes that emerged from the mothers' data: (a) feeling judged in their occupational roles as mothers: The paradox of support services; (b) restricted freedoms and occupational deprivations as a family; (c) feeling unfairly judged as mothers; (d) fears about their families' well-being; (e) occupational injustices revealed through mothers' feelings about placement considerations; and (f) spiritual aspects of childhood placement considerations. For a more extensive and detailed table of the mother's significant statements see Appendix J, Summary of Mothers' Responses to the Interview Questions.

Occupational Therapy Lens and Vision of Health and Justice

Figure 1 below illustrates the occupational lens and vision of health and justice, which was developed as a means to conceptualize the discussion section and to illuminate the connections derived through data analysis using Law et al.'s (1996) PEO model and Sen's (1999) CA. In Figure 1, the participating mothers are denoted within the center of the eye with her children and family in their lifeworlds. The participating mothers live in the contexts of home, family, and community. To the left of the eye are four aspects influencing the mothers' considerations. Beginning with the top, moving downward these aspects include (a) interdisciplinary research, Sen's CA, WHO's public health policy, National Institutes of Health (NIH)'s, Deinstitutionalization Phase 1; (b) historical contexts of the evolution of mental health and occupational therapy (Minnesota Governor's Council on Developmental Disabilities, 2013); (c) mother contexts and lived experiences; and (d) contemporary forces influencing placements and health decisions with implications for population health–Deinstitutionalization, Phase 3 (Kaufman, 2007; Koyanagi, 2007).

These broader contexts also influenced the mothers' placement considerations. To the right of the eye is the occupational therapy lens with which the occupational therapist envisions the most comprehensive and holistic, yet sustainable path to health, well-being, and occupational performance. Occupational therapy views freedom of choice as essential to meaningful and motivating choice. This meaningful path to well-being contributes to living a full life and sustaining well-being despite challenges to mental and physical health along the way. Sustaining this well-being comes with the freedom to choose what is particularly meaningful to that particular individual during that particular time and place, considering all aspects that comprise or influence occupational performance (AOTA, 2014).

Figure 1

The Occupational Therapy Lens and Vision of Health and Justice

The occupational therapy lens and vision of health and justice reveals the essence and power of occupational therapy to address the occupational needs of this vulnerable group of mothers and their families and to expand its own vision of the curative power of occupation. This expanded vision addresses, yet goes beyond, treatment of the children with ASD and their families. An expanded vision also opens occupational therapy's potential to effect change at organizational and institutional levels to unleash the power of occupation and its vision of occupational justice. Through this expanded vision, occupational therapy will assert and establish its value and place on the primary care core health team. The full shift from institutional to health in the community offers the profession an opportunity to affect the mothers' and their families' real lives and freedoms, and to address health and economic disparities while taking a step closer towards occupational and economic justice.

Discussion and Interpretation of Results in Context of Problem Statement

The problem is that despite high service utilization rates, families of children with ASD consistently report dissatisfaction with obtaining adequate support services, receiving referrals, and care coordination (Kogan et al., 2008; Siklos & Kerns, 2006). Federal policies require states' active avoidance of out-of-home placements (Wulczyn & Orlebeke, 2006). However, forced premature placement may occur due to circumstances that are beyond parents' control (Parish & Lutwick, 2005). In other words, families who wish to raise their children within their homes may be unable to do so due to circumstances beyond their control. Conversely, the families who continue to raise their children with ASD and intellectual disabilities at home without sufficient support are at severe risk for social and economic marginalization (Koyanagi, 2007; Lucenko et al., 2008; Nankervis et al., 2012; Peacock et al., 2012; Parish et al., 2012a; Parish et al., 2012b). For those who can no longer be able to care for their loved ones at home, there will be fewer placement options to do so due to Deinstitutionalization, Phase 3–rights and recovery, shifting from institutional to community health, a compromised economy with high unemployment rates (Bureau of Labor Statistics, 2012), increasing diagnoses of ASD, and an evolving health insurance plan that has exceeded all budget projections.

Occupational perspectives from PEO and economic perspectives based on Sen's (1999) CA will be integrated into the following topic areas: (a) How do the mothers get there; (b) occupational therapy's role in supporting mothers and families of children with ASD and intellectual disabilities; (c) Leadership in community health–occupational therapy's role in community health, mental health, participation and economic stability; (d) occupational justice–freedom as a means to achieve agency and occupation performance as a measure of achievement.

Understanding Mothers' Placement Considerations and Decisions

A pilot study conducted as a precursor to this dissertation resulted in rich emotional content and unanticipated data which left the PI with the sense that there were other mothers who shared this experience. Mothers of children with ASD and co-occurring intellectual disabilities may be struggling to hold onto their children until their mental, physical, and economic resources are exhausted. As a society, there is much to learn from these mothers' experiences. Recognizing that recruiting mothers for this dissertation could be challenging, the mothers' experiences were compelling and the urgency of their situations seemed to warrant immediate attention to be brought to light for others who may be of help to the mothers and their families.

A transcendental phenomenological approach (Moustakas, 1994) was used to complete a pilot study to this dissertation to explore the lived experiences of two mothers who placed their young children (ages 11 years and 6 years) into residential care. The themes that emerged from the data in the pilot study were (a) urgent quest for a diagnosis–the need for answers; (b) coping with self-blame, guilt, and punishment; (c) ASD influence on family occupations; (d) feeling overwhelmed–things spinning out of control; (e) fighting for services; (f) inconceivable trauma of placing your child, and (g) what mothers need others to know about their lived experiences.

The research questions for the current study were revised to read,

- What are the lived experiences of mothers of young children with ASD and intellectual disability in regard to the decision-making process for out-of-home placement?
- What are the contextual aspects influencing mothers' placement considerations and decisions?

Occupational Therapy Practice Framework

The *Occupational Therapy Practice Framework [OTPF]: Domain and Process* 3rd edition is the official document of the American Occupational Therapy Association (AOTA, 2014). This document and its earlier versions have been the profession's official guide to occupational therapy evaluation and practice, and the means of defining and explaining occupational therapy to other professionals. Both the domain and process of occupational therapy are encompassed in the following overarching statement: “Achieving health, well-being, and participation in life through engagement in occupation” (AOTA, 2014, p. S2).

In the OTPF (AOTA, 2014), occupations include

- activities of daily living (ADL) or basic ADL (BADL);
- instrumental ADL (IADL);
- the person or client factors (values, beliefs, and spirituality);
- performance skills (motor, process, and social interaction);
- specific mental functions (affective, cognitive, and perceptual);
- global mental functions (consciousness, organization temperament, and personality);
- body functions (sensory, neuromusculoskeletal, and all other body systems involved including cardio, nervous system, and skin), and other systems related to function;
- performance patterns (habits, routines, rituals and roles);
- occupations (work/school, leisure/play, rest, and sleep which support well-being); and
- contexts and environments (cultural, personal physical, social, temporal, and virtual).

There is a complex interplay between the person, environment, and the occupational being’s occupations. Occupational therapists’ interventions with young children with ASD and intellectual disabilities often focus on development through play, activities of daily living, and school. Impacts of disorders such as extreme sensory disturbances and behavioral responses to various environments and situations can be unpredictable and challenging for children with ASD and their families. In the context of daily life occupations, household management, maintaining schedules, and running errands associated with motherhood and childrearing, these sensory disturbances can interfere with the individual's development and learning. State regulation (or calming down a child who is overstimulated)–regulation of the person's state to promote sleep and rest, can be achieved through Ayres Sensory Integration® intervention and other therapeutic techniques as well as through environmental means (Ayres, 1972; Baranek et al., 2005; Miller, Anzalone, 2007; Miller, Coll, 2007; Parham et al., 2007; Parham et al., 2011; Schaaf, 2014; Schaaf et al., 2012a; Schaaf et al., 2013; Schaaf et al., 2012b; Schaaf et al., 2014; Schaaf & Miller, 2005; Schaaf et al., 2011).

Occupational therapists promote adaptation and development through engagement in necessary and meaningful occupations. They do this by providing access to opportunities for participation in occupations that provide the just right fit between the person, the environment, and the occupation. Special skills in grading occupations, adapting environments, and fabricating splints and adaptive tools to support participation, allow occupational therapists to promote engagement and inclusion of individuals with disabilities in mainstream communities. The occupational therapist's role in the community is also to educate.

Occupational therapists' role with the family caregivers is to assess individual occupational performance and the occupational performance of the family as a functioning unit. A therapeutic goal in supporting caregivers is to help mothers and families establish adaptive strategies to carry out the necessary routines for manageable households, which provide a sense of security and well-being for the family. Another goal in supporting caregivers is to help the mothers and their families to promote engagement in health-promoting activities by establishing strategies to restore balance to their lives and to facilitate their engagement in meaningful occupations. These shared meaningful occupations may include spiritual, cultural or family rituals and celebrations, or other events and community outings which enhance the families' sense of identity and belonging, and contribute to the families' well-being and quality of life.

Occupational therapists work with the family based on the family's particular circumstances, strengths, resources, and needs as defined by the mothers and their families to develop adaptive strategies for participation and to advocate for access. From an occupational perspective of health, engagement in occupation is necessary for health and survival. Occupation is the means and the end to health promotion, providing a mechanism for adaptation and transformation across the lifespan, in everyday occupations of being and doing for the purpose of becoming (growth, development, and transformation). Because of a top-down approach beginning with the occupational being through the administration of the occupational profile, interventions are designed to be meaningful to the particular individual; therefore, more likely to be incorporated into the individual's life and sustained (AOTA, 2014).

It is the occupational being who inspires the intervention based on their desired goal. The therapy process uses the end goal throughout the therapy process as the individual engages in the desired occupation at various levels of participation. Occupational therapists collaborate with clients to establish mutual goals and developing useful strategies for sustained participation in the desired occupation. Compliance is rarely an issue in occupational therapy. Importantly, the likelihood of sustained post-intervention engagement in meaningful occupation is increased.

The following example conveys an occupational intervention for an artist who has arthritis. The occupational therapist takes an occupational profile of the artist and then collaborates with the artist to see what occupation has meaning. The artist chooses painting which provides a sense of identity, calmness, and competency. While the artist is engaged in the occupation of painting, the occupational therapist observes the artist to identify any movements or sustained grasps or postures that may exacerbate the artist's arthritis. The occupational therapist would help the artist to self-identify movements, postures, or time segments to observe during the occupation. The occupational therapist educates the artist on joint protection, pre-painting stretching and mobilization, splinting options, and adapted painting tools which may be used when symptoms are exacerbated. The artist who is drawn to painting incorporates the strategies that will protect his or her joints and the necessary pre-painting stretching protocols, because the artist desires to continue their meaningful occupation of painting. Having been educated as to what is necessary for the artist to continue painting, the artist incorporates therapy goals into his or her daily meaningful occupation. It is this recognition by occupational therapists that honoring the occupational beings freedom to choose what comprises a full life is what promotes the individual's engagement in and agency in the sustained health-promoting occupation.

In the case of a child with ASD and intellectual disabilities, the same principal applies, and a major occupation of children is play. Even Ayres Sensory Integration® protocols, which are specific in length and content depending on the sensory issue, tap into the child's innate exploratory and sensory nature and motivation the child to engage in the occupation of play; yet, these treatments are based upon the sensory modulation deficits that are specific to that particular child (Ayres, 1972; Baranek et al., 2005; Miller, Coll, 2007; Parham et al., 2007; Parham et al., 2011; Schaaf, 2014; Schaaf et al., 2012a; Schaaf et al., 2013; Schaaf et al., 2012b; Schaaf et al., 2014; Schaaf & Miller, 2005; Schaaf et al., 2011).

Occupational therapists could potentially play a greater role in assessing the occupational performance of the family and collaborate with social workers so that respite options could be accessed. Then, focus could be shifted to assessment of individual family member's health status for secondary illness or disabilities (mental/physical), participation level, and the occupational performance of the family as a functioning unit.

Services for the family could be centered on individual and family participation in healthful occupations to energize and renew each family member as well as the family as a unit. Occupational therapists could assist families in developing sustainable occupations that would allow mothers and families to scaffold activities for completion of necessary goals and the means for enjoying time together. Family-centered occupational therapy services could assess the options for the families to build the necessary networks of family, friend, and community supports to enable the families to engage in occupations as a family and increase their community participation to prepare for the child with ASD's potential return home. There may be cases in which the impacts of the ASD are beyond the mothers' and families capabilities. Families still require humanistic placement options that allow their families to remain engaged in the children's lives, despite the conditions that lead to the placement. Occupational therapists could consult with the builders of these community facilities to enhance the environments and equipment relevant to sensory issues, safety, engagement, and occupational performance.

Occupational Therapy Model: PEO

The focus in of the PEO model used in this study focuses on occupational performance. These elements transact with each other over time and space. The greater the congruence or fit between the person, the occupation, and the environment, the better the occupational performance. A family-centered approach to pediatric therapy services and occupational performance difficulties are identified by the family as issues for intervention. Interventions are specifically targeted towards changing the person, the environment, or occupation. The model allows for individual or group interventions, or strictly for environmental changes at any level.

Expanding Occupational Therapy's Roles to Broader Contexts

Sen's (1999) CA provided a sensitizing framework for understanding the interdependence of the mothers and their families on broader community, society, institutional, and political systems. Sen stated that "the relevance of disability in the understanding of deprivation in the world is often underestimated" (Robeyns, 2006, p.

352). Sen proposed five instrumental freedoms to be useful in understanding and facilitating individual and societal agency, human capabilities, and human and economic development. These instrumental freedoms are (a) political freedoms, (b) economic facilities, (c) social opportunities, (d) transparency guarantees, and (e) protective security (Sen, 1999, p. 38).

Based on the conclusions of this current study, it could be argued that occupational justice belongs on Sen's list of essential instrumental freedoms, as Sen's proposed instrumental freedoms all take place in context of occupations in which the occupational being engages. The same principle applies to populations, communities, societies, institutions, and organizations as multiple elements of the environment, the person, and the occupation transact with each other over time and space. *Occupational Therapy's Code of Ethics Standards* (AOTA, 2010) restated the profession's grounding in and commitment to AOTA's core values and attitudes including the seven core concepts of (a) altruism, (b) equality, (c) freedom, (d) justice, (e) dignity, (f) truth, and (g) prudence. A hallmark of occupational therapy practice is the concept of freedom and personal choice in which the occupational being or entity served must guide our interventions (AOTA, 1993).

For the mothers in this study, the interconnectedness to larger systems was necessary to promote the mothers' access to and engagement in opportunities to improve their occupational performance. The relationship between disability and poverty can be better understood through a contextual understanding of the mothers' situations as their opportunities for engagement in the work force were either reduced or inaccessible due to child care issues. In addition, their medical expenses were approximately 10 times that of caring for a child without ASD and intellectual disabilities, and more than twice as high as caring for a child with ASD without intellectual disabilities (Peacock et al., 2012). The interconnections between freedom and agency are also illustrated in this study, as restricted freedoms had a negative impact on the mothers' freedom to participate in obligatory occupations, to maintain households and schedules, and to sustain family life. These restricted freedoms in their instrumental ADLs compromised the mothers' health and the entire families' well-being, quality of life, and the occupational performance of individual family members and the family as a functioning unit.

The mothers' freedoms were also restricted from participating in desired occupations, special rituals, cultural and spiritual, or other meaningful occupations including work and civic participation. This is a significant restriction for the mothers and families as the research reviewed found spirituality as the only one of nine aspects of quality of life measures in which the parents of individuals with ASD experienced a higher quality of life than comparison groups (Brown et al., 2006).

Informed with a better understanding of the inter-connectedness of larger systems to health and occupational performance, the relationship between disability and poverty, and the relationship between freedom and agency, society can begin to contemplate how to build inclusive, sustainable societies and institutions. The PI asserts that occupational therapy provides a potential means or mechanism to both operationalize and measure the effectiveness of Sen's (1999) CA. The PI also asserts that occupation is the critical missing element in the current configuration of socio-economic determinants of health. This is because the medium for economic or social transformation is occupation. A job is an occupation and a social event is also an occupation. Engagement in occupations is both a medium and a catalyst for adaptation and improved occupational performance. Wilcock (1998, 2006) posed a three-way link that exists between occupation, health, and survival. The occupation allows for human adaptation as activities are embedded in human occupation. Facilitating occupational freedom to meaningfully engage in activities and thus improve health, well-being, and occupational performance.

Occupational therapists facilitate engagement in occupation to promote health, well-being, and quality of life, as well as to prevent illness, secondary illness, and disability. Occupation provides a mechanism to facilitate adaptation and a means by which to measure change and transformation by assessing occupational performance. Using occupation as the mechanism for promoting change also expands individual, societal, and institutional freedoms. Occupation is broad, and it is everywhere, encompassing a wide range of occupational choices to resolve the issues related to Sen’s argument against proposing a basic prescribe list of what would qualify as list of specific choices.

Occupational therapy may have a viable solution to solution to operationalizing Sen’s (1999) CA using the Law et al.’s (1996) PEO model of practice and its measurement tool–the Canadian occupational performance and measure (COPM). The *American Occupational Therapy’s Philosophical Base* (AOTA, 2011) asserts that all individuals have an innate need and right to engage in meaningful occupations throughout their lifespan. The AOTA’s philosophical base also asserts that engagement in these occupations can influence their growth, development, and well-being across the lifespan; therefore, “participation in meaningful occupation is a determinant of health” (AOTA, 2011, p. 565).

Based on a review of the literature, multiple disciplines, professions, policy and law documents in corroboration with this study’s findings from its participating mothers, the PI asserts that occupational therapy’s unique contribution to health—occupation—may offer a viable solution to both operationalizing and measuring Sen's CA. With occupation as a determinant of health, Sen’s resistance to proposing a predetermined list of which variables could be upheld in evaluating quality of life. The same principles may be applied to organizations, institutions, persons, communities, or populations. Occupational preferences of the person or other entity are honored and integrated into the therapeutic and transformational processes. Agency could be promoted through practical occupational goals in relevant contexts. The means an end of engagement in occupation would be promoted through the occupational therapy domain and process to produce the measureable outcome of improved occupational performance in the stated goal and expected outcomes (e.g., inclusion, tolerance, and engagement in occupation). Occupational performance and capabilities can be considered and evaluated, and interventions can be provided and evaluated in individual’s or groups’ particular context(s) and preferred choice of occupations.

Leadership in Community Health

Expanding Occupational Therapy’s Roles

In the past 20 years, AOTA has strengthened and increased every level of its educational programs and contributed quantitative and qualitative research on the effectiveness of its treatments. The profession has reflected on its epistemologies and interdisciplinary foundations and redirected the professions central focus on occupation and adaptation, conveying its professional identity through the language of the OTPF (AOTA, 2002, 2008, 2014).

The timing is both critical and optimal for AOTA to assert its advancement as a unique contribution to health to weigh in on the interdisciplinary panels and legislative issues relevant to individual and community. The current environment and the previously discussed conditions for the *perfect storm* exist, threatening the economy and population health. Occupational therapists have a number of strengths that will serve the profession well in seeking leadership in community health initiatives.

Occupational therapy founders included a partially trained social worker, an art teacher, a nurse, a physician, a psychiatrist, and an architect with a disability. Each believed in the healing powers of occupation. Occupational therapy adapted over the years to a medical model, until its freedoms became restricted and the profession’s identity was shaken. A period of reflection and connection to the profession’s earlier roots in mental health allowed the profession to reclaim its roots and integrate the medical aspects achieved during the postwar rehabilitation phase. The 2002 OTPF allowed for a renewed sense of the professions epistemologies and the means to integrate its roots in mental health and its medical expertise into an occupational perspective of health (AOTA, 2002). The OTPF (AOTA, 2002; 2008; 2014) that guides occupational therapy evaluation and interventions articulates the profession’s central focus on occupation and provides a means for practitioners to articulate the value of occupation for other professions and for those who use its services.

Occupational therapists can support the mothers in this study by assuming leadership roles in the protection of the mothers' rights and freedom to choose where their children shall live. Forced, premature, or pressured placement decisions made out of desperation cannot be considered freedom of choice. Placements to access necessary services for the child, to protect the child or siblings, or to avoid the social or economic marginalization of the family are not based on freedom of choice (Lucenko et al., 2008; Nankervis et al., 2012; Parish et al. 2012a; Parish et al., 2012b; Peacock et al., 2012).

Occupational therapists are equipped to promote socioeconomic and occupational justice simply by stepping down to fight barriers to participation that lead to socioeconomic deprivation and marginalization in addition to emotional deprivation, along with emotional deprivation and protecting mothers' freedom of access to necessary services and supports as Linda described "that allow their families to function." Mothers and families in similar situations need feasible options to raise their children at home and the protection of their rights to choose where their children shall live. In some cases, permanent placements are necessary; in these cases, humane and local community placements should be available. To protect mothers' freedom of access to necessary services and supports as Linda described "that allow their families to function," policy makers and communities are left with the following questions: (a) Who shall pay for these services, and (b) can we afford the services that are necessary to protect the families' freedoms?

The AOTA *Code of Ethics and Standards* supports advocacy to increase access to health services for those in need, decrease barriers to full civic and social participation, and to provide reasonable accommodations to access community activities (AOTA, 2010). Participation in occupation is viewed as necessary to health and well-being; conversely, barriers to or the absence of participation is viewed as detrimental to health and well-being. From this viewpoint, community inclusion is necessary (AOTA, 2014; Wilcock, 1998, 2006).

Occupational therapy clients include individuals, families, groups, communities, societies, institutions, and organizations with services geared towards engagement in occupation to improve occupational performance of these entities. For example, a community seeking to become more inclusive might seek occupational therapy consultation services to offer affordable ways to better accommodate its community members with disabilities. Inclusive communities value the presence and participation of all of their community members, demonstrating attitudes of tolerance, hospitality, and concern about the accessibility of buildings, parks, transportation, and activities (AOTA, 2010). Occupational therapists can be instrumental in promoting sustainable inclusion and community health programs. Occupational performance for inclusion of persons, communities, and populations can be developed and strengthened through the philosophical and science driven evidence-based principles of occupational therapy. Action-oriented inclusive approaches can be used to inspire new attitudes towards the value of inclusion.

Community inclusiveness might be measured by the absence or the presence of the community's most vulnerable individuals and groups, or by the level of participation in play, leisure, work, social, and political activities. Understanding families' occupational performances in multiple and diverse contexts may help occupational therapists to identify and intervene in eliminating multiple barriers to participation or what Sen (1999) describes as unfreedoms. Inclusion might be measured in the agency gained through the accessible that are offered, and the person's capability to convert this opportunity to improved occupational performance, strengthened capabilities, and increased agency for transforming opportunities into functionings and capabilities.

For the mothers in this study, their participation within the community was sometimes restricted by social barriers such as judgmental looks, unsolicited advice, or even chastising the child with ASD. The children's meltdowns in public places were particularly disturbing for the mothers. Each mother reported that they had experienced people staring at them, as if they thought they were bad mothers when their children ran away, misbehaved, or had a tantrum. What made things even more difficult for the mothers was that no one ever reached out to them to offer help when they were overwhelmed. A few of the mothers including Linda reported that she was very aware of this when she sees a mother who is having difficulty, and she always tries to offer a helping hand. The mothers all agreed that it is best to offer help, and if the mother does not need the help, she will let you know. Elise, whose child has severe behaviors, and unpredictable moments of aggressive or inappropriate behavior cannot take her child with ASD out with her other two children unless Elise has another adult to help; therefore, her freedoms have been severely restricted.

Occupational therapists serving on interprofessional and interdisciplinary panels making distributive decisions about service funding and community health are positioned to collaborate for the broader community supports for the mothers within their communities. These interdisciplinary interprofessionals contribute their knowledge, skills, and perspectives to build Healthy Communities, 2020 panels work together so that the resulting creation of healthy communities and community programing offer broad understandings of best community practices. Occupational therapists contributions to such interdisciplinary panels by bringing the occupational perspective of health into the community for full inclusion, and by offering health benefits that are personally meaningful and economically sustainable.

Occupational therapists will be challenged to a gain broader understanding of the environmental forces that influence placement decisions. Family-centered and occupation-centered practice is critical for improved occupational performance, health, well-being, and quality of life. The OTPF provides a means for practitioners and IPs to better understand how occupational therapy interventions can best contribute to the occupational performance of individuals, caregivers, families, communities, societies, and institutions in context (AOTA, 2014).

The PI of this study asserts that occupational therapy provides a potential measurement solution to Sen’s CA and proposes that occupation may be the critical missing element in the current socioeconomic determinants of health. Occupational therapists promote engagement in occupation to prevent illness, secondary illness and disability, and to promote health, well-being, and quality of life. Occupation provides a mechanism to promote adaptation and a means by which to measure change and transformation by assessing occupational performance. Using occupation as the mechanism for promoting change also expands individual, societal, and institutional freedoms to resolve Sen's argument against proposing a basic prescribed list of what would qualify as list of context of the occupational preferences of individuals, communities, and organizations.

A basic assumption of this study was the complex nature of occupational performance and its interdependence with larger contexts that influence access, participation, and occupational performance including distributive decisions, community planning, service delivery, inclusion, and human understanding. An assumption of the PI is that the needs of individual's families, communities, societies, institutions, and organizations as informers, and the needs of the governmental institutions and policies established to protect them, need to be congruent. This congruence must be understood through a deeper understand what mothers of children with ASD and intellectual disabilities and their families are going through.

With this study, the PI intends to inform others about occupational therapy's unique contribution to health and well-being in helping mothers improve their occupational performance. By engaging in everyday ADL and in meaningful occupations, the mothers and families begin to adapt to complex mothering roles and to decrease barriers to meaningful family activities at home and in the communities. The phenomenological account of the meaning of the mothers' experiences viewed characterizations of the mothers as having "given up on their children." Exploring the mothers' situations in larger contexts will highlight the importance of context in designing relevant and effective interventions for the children with ASD and their families.

Reflection to Prediction

Understanding the combined influences of historical and current contexts and emerging trends positions the informed researcher, professional, and policy maker to envision potential futures. Errors of past policies are examined to inform current and future decisions and for the purpose of predicting and reducing risks as professional and ethical responsibilities. Valuable insights gained from reflection are used to provide essential protections for the mothers of children with ASD and their families, as well as other vulnerable groups. Occupational therapy's preparation over the past 20 years has well prepared its members to take the lead in a potential and emerging community health challenge.

At this pivotal time in United States, several critical events are converging to create conditions for a potential perfect storm. Current ASD rates are significantly rising at a time of economic crisis, increased unemployment, and an evolving and debated Affordable Care Act that has exponentially exceeded all budget projections. Evidence to suggest trust in government institutions which were created to protect citizens is rapidly eroding evidenced by the increase in vaccine refusals and waivers for vaccine exemptions. The above conditions align with Phase 3 of Deinstitutionalization's rights and recovery and the full transition from institutional to community health (Koyanagi, 2007).

Health professionals, economists, educators, and policy makers face uncertainty about the future of health care, the stability of the economy, and concern about the significant rise in the rates of children diagnosed with ASD (CDC, 2008, 2012; Bureau of Labor Statistics, 2012; Orient, 2010). Just when it is critical for professions to collaborate and combine their collective understandings and services, the looming economy has also spurred some unhelpful rivalry and professional posturing for a place in the emerging health environment.

Meanwhile, mothers of children with ASD are watching to make sure that their children do not lose their support services. The mothers in this study who depended on these services and supports, not only for the child with ASD and intellectual disabilities but as a means for the family to survive, were wondering what this all means for their children with ASD and intellectual disabilities and their families.

Phase 1, the implementation of the Deinstitutionalization policy and closing of institutions (Koyanagi, 2007), was developed under the faulty policy assumption that families and communities would assume all caregiving responsibilities and associated expenses in regards to caring for individuals that were released with the closing of mental institutions in the United States. The repercussions and costs of this ill-fated policy still exist as evidenced by drug-use, crime, overcrowded jails, and homelessness.

Although states have been preparing for this shift to community health for years, state allocation of funds for and investments in preparation for this shift vary substantially among states. In addition, funding for community health has not kept pace with funding for medical institutions. States responded differently to the devastation of Deinstitutionalization’s first phase, adding resources and supports for family caregivers and community agencies. Some states are underprepared for a full shift to community health.

According to Koyanagi (2007), the Deinstitutionalization Phase 3 rights and recovery goal, as first articulated in 1993, was for full community integration. Mothers in the study who experienced disparities between state funds for community health questioned why such disparities exist, and voiced their frustration with the variance of services and supports among the different states. Five of the six mothers in the study moved at least once to secure services for their children; in some cases away from friends and relatives. As the economic and social impacts of full community inclusion become clear and placement options are further reduced, mothers of children with severe ASD who are currently at severe risk for placements will require support.

Current economies, rapidly changing technologies, and new ways of knowing, communicating, and decision-making when combined with Deinstitutionalization Phase 3 and evolving and uncertain health environments pose risks as well as opportunities. As society advances into the next level of technology, new cultures and ways of knowing, communicating, and decision-making as well as new economic environments, individuals at risk for social or economic marginalization are likely to require community support.

The history of Deinstitutionalization in the United States tells a cautionary tale as the country approaches conditions for a perfect storm (Koyanagi, 2007). Currently, the United States is in the midst of a major transformation in its health care system that has exponentially exceeded all budget projections, while the country is also experiencing an economy crisis with high unemployment rates. The Phase 3 goal of Deinstitutionalization is anticipated to make this full shift from institutional to community health. At the same time, the numbers of diagnosed cases of children being diagnosed ASD is rising at an alarming rate, which is certain to increase competition for already limited services and supports including respite services.

Contemporary influences have shifted the balance of power as mothers seek out information on the Internet, as in the immunization controversy and increased vaccine refusals which has implications for protection against the spread of serious diseases that threaten population health. Further contributing to these precarious conditions are emerging trends and popular or pop culture, new ways of knowing, communicating and information-seeking, and decision-making which also have implications for public health (Kaufman, 2007).

The influence of social media and pop culture has also created a shift in the power base between doctor and client relations as mothers are beginning to rely on the Internet for knowledge and making health decisions for themselves and their children. Some of these decisions could potentially threaten population health, as in the vaccine refusal waivers. Recent pockets of outbreaks were prevented due to high herd immunity in surrounding areas; however, if herd immunity drops, the potential public health risk for major outbreaks may be imminent (Omer et al., 2009).

Healthy Communities, 2020 is based on best practices in community health and Deinstitutionalization's recovery philosophy requires strengthening community capacities and promoting self-determinacy. Strengthened relations between professionals and community members are also part of building community capacities. Professional input, which honors the freedom of community members and views all members as a critical participant in the development of healthy communities, may find compliance to be less of an issue. Occupational therapy's interdisciplinary foundations, philosophical base and epistemologies are in agreement with WHO-ICF, NIH, Healthy Communities 2020, and recovery philosophies. The profession's knowledge, diverse skills, and commitment to freedom and self-determinacy strengthen the profession's capabilities for leadership in community. Occupational therapists are prepared to lead efforts in the creating and designing of livable communities with well-designed environments and occupations that naturally foster inclusion. Within these well-designed community environments, occupational therapists can organize broad efforts and specific training to community members and organizations, and volunteer organizations and groups to protect and serve the mothers in this study and other marginalized groups.

Occupational Justice

The OTPF defines occupational justice as access to and participation in a full range of meaningful occupations afforded to others. Social inclusion and the resources to satisfy personal, health, and societal needs would be examples of occupational justice (AOTA, 2014; Townsend & Wilcock, 2004). According to Sen (1999), freedom is a requisite to attaining economic and social justice. According to occupational therapists and occupational scientists, occupation is the means and mechanism to adapt, develop, and transform; occupational performance provides the means to measure this transformation. The participating mothers experienced major restrictions in their freedom to carry out their mothering occupations. These restricted freedoms affected their occupational performance in basic and instrumental activities of daily living and their meaningful engagement in roles, routines, and rituals as individuals and as a family.

Implications for Practice

Several implications for practice emerged from this phenomenological study. As mentioned earlier, occupational therapy is the third most requested service for children with ASD. Since the children are often referred for developmental concerns, many children are evaluated and receive services at home before the children receive the diagnosis of ASD; therefore, occupational therapists are often in a supportive role to the mother as the diagnosis is made.

There are many individualized areas such a sleep disorders and Ayres' Sensory Integration® research to establish the presence of sensory modulation disorder based on the latest and most rigorous studies, so that children who need these services have this option available to them (Ayres, 1969, 1972; Miller, Coll, 2007; Parham et al., 2007; Schaaf, 2014; Schaaf et al., 2012a; Schaaf et al., 2013; Schaaf et al., 2012b; Schaaf & Miller, 2005; Schaaf et al., 2011). Most of the mothers had experienced meltdowns with their children.

In regard to mothers' placement considerations and decisions, occupational therapists have an opportunity to support the mothers of children with ASD and intellectual disabilities who will face placement decisions. This role may include helping the mothers assess their capabilities in raising their children at home and helping them to discern the supports and services necessary to achieve this.

The occupational therapist may need to engage in advocacy for community respite services and community supports, which protect the well-being of mothers and families, and help them to avoid social and economic marginalization. The results of this study also suggest that occupational therapists might assume consultant roles in designing local respite centers for crisis intervention and for temporary or permanent residential placements for when placements are necessary. These respite centers need to be designed to consider the needs and quality of life for the child with ASD and their families, and the means for the families to remain connected. Since mothers of children with ASD and intellectual disabilities are at severe risk for economic and social marginalization, expanded occupational therapy leadership and advocacy roles will be needed in community and mental health.

This study also highlighted the significant changes occurring at this point in time, and the implications of all of these changes for the mothers in this study. A shift to full community health may give the mothers the opportunity to connect with others and to begin to build networks of support. However, if services become more competitive, some mothers are likely to be at even greater risk for their children's placement outside of the home, despite their desired choices. The convergence of deinstitutionalization, evolving health environments, compromised economies and increased ASD prevalence rates, places the mothers in this study at even greater risk for pressured placements, despite their desired choices.

The mothers in this study expressed that fighting for the already limited support services that help their families to survive was also one of their greatest sources of time consumption and personal, as well as family, stress (Ekas et al., 2010;

Magasi, 2012; Nankervis et al., 2012). This study also highlights the importance of occupational therapy becoming a member of the primary care core health team, due to the evolving health systems of care.

The more traditional roles of occupational therapy based on this study would include collaborating with mothers of children with ASD to sustain family life in the area of IADL. The mothers of children with ASD and intellectual disabilities throughout the literature review and also in this study, reported difficulties in carrying out their occupational roles and occupations for raising families, running errands, making and keeping up with family and therapy schedules, shopping, and their children's activities.

The extensive impacts of ASD on the mother and family can potentially leave mothers exhausted and feeling overwhelmed. Occupational therapy services can provide support for both the mother and her family's occupational performance as a functioning unit. Because of occupational therapists' diverse skills and knowledge about the complexities involved in individual as well as group occupational performance, occupational therapists' services have broad utility within the home including knowledge, skills, and means to adapt environments and grade activities as needed for the best fit for improved occupational performance.

Collaborating with the mother in regard to what specific roles or occupations are most challenging, the occupational therapists may work with the child with the disorder, or the family as a unit to improve the family's performance skills. Everyday ADL provide valuable learning opportunities for developing young children.

Occupational therapists have unique and diverse skills for adapting environments as well as special interventions to help children achieve a calmer state or to achieve the optimal level of arousal for successful participation. Helping mothers to create sensory comfort spaces within the home that are designed to tap into the children's interests and skills may be calming to children who cannot monitor their responses or convey their needs, pain, or anxiety.

Occupational therapists have special skills for grading skills and adapting occupations for the best fit between the individual, the occupation, and the environment. Mothers' household occupations and co-occupations can be enhanced through scaffolding the mothers' household routines and their children's play activities. In doing so, the mothers can learn to create safe play spaces that engage their children with ASD and siblings with developmental challenges for growth and adaptation as the mothers complete their household routines.

Occupational therapy offers valuable services ideal for helping not only the child with ASD, but helping the mother to perform her occupational roles and BADLs and IADLs in a way that is therapeutic for the child with ASD, without adding additional tasks for the mothers. Occupational therapists work closely with children with ASD as they are one of the most requested services for children with the disorder. Occupational therapists have an extensive repertoire of occupation-centered treatments which can be easily integrated into the daily routines and rituals of daily living. Occupational therapists can play a critical role in helping the children with ASD and their mothers and families individually and as a family unit to strengthen and refine their occupational performance at home.

Implications for Occupational Therapy Research

The implications for future research are multiple and broad due the breadth of the mothers' health risks, their needs related to mothering their children with ASD, and their needs and in relation to the well-being and participation needs of the entire families. Further exploration of maternal health issues related to reduced hours of sleep and interrupted sleep is needed. For those cases in which children can no longer remain at home, exploratory research needs to be conducted to assess current and potential community options for local and humane permanent placements, so that families can remain connected to their children.

Studies on wandering will need to be conducted as this diagnosis is associated with higher rates of mortality from drowning and accidents. The combination of sleep disorders and wandering places a child with ASD and intellectual disabilities at even higher mortality risk. Both sleep disorders and wandering need to be studied in relation to the level of maternal stress. All but one mother in this study cited wandering behaviors as a major area of concern for their children's safety and as a contributor to decreased community participation. Environmental design considerations for both the purposes of inclusion and safety will also require research.

Continued research will be needed to support occupational therapy/Ayres Sensory Integration® intervention for children or individuals with sensory issues including individuals with ASD and intellectual disabilities. These sensory issues interfere with learning, fine and gross motor coordination, behaviors, and reduction of stereotypic movements. Occupational therapy/Ayres Sensory Integration® may have potential implications for interventions for research and interventions for sleep and wandering disorders.

The occupation of caregiving and the role of the secondary caregiver in supporting maternal health require further exploration. Findings from a review of the literature found that mothers first turn to their spouses for support, indicating the importance of the father's role in supporting maternal health. The supportive role of the secondary caregiver or spouse and the intervener or professional who mediates during times of crisis could provide additional insights to supporting mothers or caregivers in their primary caregiver role (Harper et al., 2013; Neely et al., 2011).

Social networking needs to be explored in depth and through population studies to determine the extent of its influence in health decision making. The literature reviewed for this study conveyed a growing mistrust of government and its institutions designed to protect its citizens' health, specifically immunization programs which have protected the population from threats of disease and the potential for death or disabilities. The impacts of social networking, pop culture, and social media need to be better understood in regard to their potential threats to, as well as their potential benefits for, population health (Omer et al., 2009).

Cason (2012) and others have proposed that technology and telehealth offer opportunities for occupational therapy. For instance, offering mothers and citizens the abilities to connect with local and trusted community health and mental health professionals who are more likely to be recognized and accepted, particularly under the current atmosphere of mistrust and uncertainty in remote government institutions (Kaufman, 2007). Technology and telehealth offer increased opportunities to disseminate the results of critically appraised, peer-reviewed studies to mothers and other caregivers in parent-friendly terms. Using locally-based community health professionals to disseminate findings and answer questions about competing theories, parents could gain access to scientific evidence upon which to make important health decisions for themselves and their children, and a place to articulate their concerns about the vaccines and receive evidence-based information.

Limitations and Delimitations Based on Results Interpretations

A limitation of this study was the small number of participants. A purposive selection using narrow criteria could be considered a limitation; however, there was geographical diversity. The participating mothers came from Kentucky, Arizona, Florida, and three different regions in New York State. Because state funding varies from state to state as noted in the Theme 1 subtheme including the need to live in the right state, all but one of the mothers had moved at least once to secure services for their children. One of the mothers moved from South Korea to New York State. Including the states from which the mothers moved expanded the geographic location to New Jersey, South Carolina, and North Carolina. Transcendental phenomenology is qualitative research; therefore, the results are not generalizable. However, from the rich, thick descriptions of the mothers’ experiences, others may relate to certain aspects of the mothers experiences for potential transferability.

The recruitment of the mothers was extremely difficult due to the narrow criteria, and because the mothers are difficult to locate because they are rarely part of the typical autism spectrum disorders groups whose focus is geared more towards the cure than survival. Another delimitation of the study was that the mothers had great difficulty finding childcare and frequently had to respond to crises, which led to frequent cancellations. The mothers were eager participants in the research process once they had a chance to speak with the PI, and felt confident that they would not be judged. A final delimitation of phenomenological research is the potential for substitution of the PI's views for those of the mothers, or misinterpretation during the data analysis; however, strict adherence to phenomenological procedures were applied to avoid these threats to the study's rigor.

Recommendations for the Occupational Therapy Profession

This study brought to light the importance of occupational therapists' understanding of the occupational implications for placement considerations and decisions. Although placements have not traditionally been an area of practice for occupational therapists, it is clear that placement prevention for families who are trying to keep their families together can be viewed as a promising emerging area of practice for occupational therapists. Conversely, the AOTA could advocate for humane, quality, community placements for crisis intervention, temporary respite care, and permanent placement for caregivers.

Occupational therapists could also advocate for the appropriate design of these placements and respite facilities for safety, consideration of sensory reactions, and occupational performance. The findings regarding the absence of occupational therapy literature in interdisciplinary research could point to the need for increasing cross-publications. It could potentially be sign of unhelpful professional posturing; however, occupational therapists have a unique contribution that brings value to their role in interprofessional forums which must be avoided as a shift to community health is dependent on interdisciplinary and interprofessional communication and collaboration, each bringing forward their particular strengths and expertise.

Personal Reflexivity

As a prelude to the recommendations based on this study, it is necessary to begin with a word about transcendental phenomenology. In the process of reviewing the mothers' transcripts repeatedly, I was steeped in the mothers' insights until the themes seemed to arise from the transcripts giving me a sense of a new discovery. The phenomenological epoche process of assuming a phenomenological attitude, bracketing, and journaling my own knowledge, values, and beliefs to keep them separate from the participants', also stimulated intense moments of internal insights. It was necessary to journal these insights to remain faithful to the data, and a post analysis retrospective review of these reflections influenced a new way of looking at the mothers' situations. An idealist at heart, I imagined a utopian society, grass roots efforts to provide safety nets and a welcoming society. The realities expressed by the mothers and supported by the literature including economic, legal, and policy documents led me to other considerations.

In journaling about the question of how to help the mothers, I reflected on my past. My father was born on a farm in Roscommon, Ireland. He was the sixth of seven children. His father traveled to America seeking the means to support his growing family. My father came to New York at the age of six years old. As Irish immigrants, my father and his family faced ridicule, job discrimination "Irish need not apply," and hunger while waiting his turn on the long bread lines. My father valued my mother first, then family, honesty, education, and work. His background influenced his work ethic, his value of education, and his sense of loyalty and gratitude to the country that helped him and his family to survive and eventually thrive.

When the company he worked with for many years went out of business, my father did not rest until all 12 men under his supervision were employed by other companies. He was not a risk taker and he avoided any risk of poverty. He was a great believer in insurance as well, influenced by his fear of poverty. When his beloved new country was attacked at Pearl Harbor, he left his first son’s christening to enlist in the Navy. He returned from the war an educated American veteran having completed his high school GED at sea.

My mother’s family emigrated from Ireland and also moved to New York City. Her father was a well-paid engineer and her mother was the president of the Kerry Ladies, a high society charitable group dedicated to raising funds to help other Irish immigrants. She attended a private girls' high school in Manhattan. My mother remembered people knocking on her door for food and her mother made sure that every visitor had something to eat. Her background influenced her values which were family, love, peace, and service. My mother lived her life fully, feeling rich and blessed, despite the reality of our middle class, sometimes financially struggling, status. She never seemed to feel deprived in any way. When my father died, she was in her early forties with four children and no out-of-home work experience. She got a job with benefits and left within two weeks, knowing that she could never settle for a life without meaning just for the benefits. My mother found her meaningful occupation in working as Director of Religious Education at several churches and eventually became the Tri-State representative for New Jersey, New York, and Connecticut. She completed a graduate certificate program in pastoral counseling.

I thought about why my grandparents came to this country. They valued the ideals of freedom and opportunity. To the Irish, America represented a golden opportunity. To the American settlers, it was a chance to escape oppression and to gain religious freedom. So, freedom is deeply rooted in American culture, a culture of immigrants in one united country. The English language united the different cultures into a new diverse culture with a single language that allowed immigrants to communicate with each other but allowed each group to celebrate the uniqueness of their original culture. Religious freedom was allowed and there were provisions that prevented the government from imposing any religious affiliation on American society. There was a united experience of a melting pot or integration of many cultures. There was a deliberate avoidance of a monarchy; republic was established with a democratic system. Two parties were established which reflected different views, so that ideas could be more carefully deliberated and debated, and the vote eventually became a privilege and right for all citizens. The two-party system was created not as a means to divide the country, but as a means to allow for free expression of opposing views, with the understanding that truth is a product of the diverging of multiple viewpoints.

Characteristics of the United States include a fighting spirit against oppression and a protective stance on freedom. A free society and capitalist economy greatly contributed to America’s growth, development, creativity, and innovation. A generous spirit of giving in the American culture was initiated by Benjamin Franklin who scheduled his work life around his volunteer activities which he regarded as primary responsibilities. This spirit of volunteerism is continuously evidenced in the outpouring of volunteers, resources, and personal contributions following events such as the terrorist attack on the Twin Towers on 9/11 and the work that is still going on to support victims of Hurricanes Katrina and Sandy.

As a first generation American on my father's side and second generation on my mother's side, I reflected on why I felt uneasy about how the mothers would fare under the current health, economic, and sociopolitical environments. Participation of all societal members at whatever level they can achieve can strengthen the health, well-being, and occupational performance of the individual and contribute to the country's economic sustainability.

I envisioned a model based on the occupational profile of America. The three basic assumptions for this model would be (a) that freedom is a prerequisite for agency and occupational performance; (b) that a country's policies must be congruent with the culture, values, and goals of its members; and (c) that all potential policies would protect the freedoms and rights of all citizens to achieve.

I reflected on a potential model that might protect the mothers and their families to facilitate enhanced freedoms and eliminate unfreedoms or barriers to participation. This model would emphasize freedoms and the development of human potential. Such a model would highlight the positive aspects of a diverse culture of immigrants seeking opportunity, the heart of volunteerism, and a fighting spirit to protect freedom. It would preserve the freedoms of its people, institutions, and organizations. This proposed vision of an occupational justice model would guide the current republic with a democratic society in its capitalistic system to promote both human achievement and the necessary capital achievement for sustainability.

The culture would be that of immigrants and seekers of freedom and opportunity, empowered with a vote in a democratic process and an opportunity to achieve. The values would include industry, gratitude, empathy, and a spirit of volunteerism derived from a deep understanding of deprivation of freedom and opportunity, reflected in American history. There would also be fighting spirit against injustice or breaches of freedom or any encroachment in self-determinacy. This model would support the notions of freedom, access to opportunities, and inclusion which are congruent with American society and occupational justice.

I envisioned a model that used the strengths of the America's occupational profile to build a sustainable model of health and occupational performance. Despite America's past and on-going injustices as new groups integrate into its culture, America has its strengths. America is a free country largely comprised of a melting pot of diverse cultures, united under one language. This diversity of American culture, as a land of immigrants seeking freedom and opportunity, has contributed to the richness of America's heritage and its progress as a nation. Capitalism, sometimes diminished as a weakness of the country, has also been a strength by contributing to the country's economic growth, and economic stability. Evidence of this strength can be seen in the individuals with the lowest economic status who still fare better when compared to those in similar positions in other countries in the word.

At first I imagined a society where a grassroots effort would support the mothers and their families through volunteer efforts, but it became clear through the mothers' interviews that the literature revealed that this model would not be realistic nor would it be sustainable. Were higher taxes and redistribution of the wealth the best way to support the mothers? That consideration impinges on the freedoms of those who achieve the highest earnings, and on those in the middle who have to work hard to sustain their families from paycheck to paycheck. So, there is the potential for an undercurrent of resentments, hidden income or tax evasion, and frustration for achievers affecting incentive of the high and middle financial achievers and potentially affecting the low financial achievers. This system is also an older concept that was left behind as America created a new model which had surpassed this older model in relation to industry, human development, and economic growth.

A third possibility was influenced by Sen (1999), a staunch promoter of freedom to facilitate development and agency. Sen was a believer in free markets and free choice, although there are other aspects of capitalism which Sen did not support. Rather than impinging on anyone's freedoms, Sen proposed the elimination of unfreedoms that prevented access to opportunities for functioning and achievement, beginning with those at the lowest ends of achievement. From an occupational justice standpoint, this would mean removing barriers to full inclusion and accessible opportunities to participate in health-promoting occupations. Promoting this engagement in meaningful occupations would enhance occupational performance.

This concept based on Sen's CA and also on the principles of occupational justice sounded congruent with the United States founders and culture, as a nation of immigrants looking for opportunity and a better life. In order to sustain such a system and protect the freedoms of all groups, each member of society would contribute to an economic base at whatever level of participation possible. All would be taxed a choice gaining the benefit of the flat percentage in exchange for enculturating a calculated percentage of individuals at the lowest end of the economy into the high-achieving bracket.

Based on each of the occupational performance of the institutions or organizations in meeting this outcome, they would gain the advantage of a flat tax percentage rate; if this outcome was not achieved, the higher tax rate would apply. This concept, though not absolutely equal, would allow for freedom of choice and opportunities for individuals, groups, communities, societies, institutions and organizations to achieve. Rewarding actions that advance individuals, groups, institutions, and organizations which struggle may potentially dis-incentivize corrupt processes that occur while attempting to meet economic goals. For example, hidden income, tax evasion, and setting up overseas operations where worker protections do not exist may be reduced.

In reflecting upon America's past, one group that did not experience the freedoms of America were Africans who were taken from their country, sold into slavery, separated from their families, and made subject to unthinkable injustices. For years this group struggled to overcome these injustices and for some, the scars of these injustices continue to block their achievement. This important aspect of American history illuminates the impact of restricted freedoms on individuals and their achievements. Although America has had its struggles and there have been some grave justices throughout its development, even the groups at the lowest ends of achievement have fared better when compared to those of other counties. Sen (1999) reminded us that no free country ever suffered a substantial famine or genocide.

Summary

This transcendental phenomenological study was conducted to elicit essential understandings of mothers' perceptions of their entry into the decision-making process for out-of-home placement of their young children with ASD and intellectual disabilities. Families of children with ASD rely upon a wide range of support services (Blacher & McIntyre, 2006; Kogan et al., 2008; Siklos & Kerns, 2006). The problem is that despite high service utilization rates, families of children with ASD consistently report dissatisfaction with obtaining adequate support services, receiving referrals, and care coordination (Kogan et al., 2008; Siklos & Kerns, 2006). Federal policies require states' active avoidance of out-of-home placements (Wulczyn & Orlebeke, 2006). However, forced premature placement may occur due to circumstances that are beyond parents' control (Parish & Lutwick, 2005).

Before the Deinstitutionalization Act of 1955 as described earlier, and into the early 1960s, children with ASD and intellectual disabilities were often placed into institutional care (Koyanagi, 2007; Minnesota Governor's Council on Developmental Disabilities, 2013). Along with Deinstitutionalization came a vast amount of social, health, and community consequences that still exist in society today, and the burden of cost and devastation has remained. Deinstitutionalization's Phase 1 failures included a policy decision based on a faulty assumption and premature implementation without the necessary community services and supports in place. Phase 3 of Deinstitutionalization is the rights and recovery phase (Koyanagi, 2007).

Recovery refers not to full symptom remission, rather it is the right to self-determination and to live a full a life in the community, despite disability (Deegan, 2005; Koyanagi, 2007).

This research study was initiated to explore the lived experiences of the mothers so that others may understand what they are going through, particularly under the current economic, health, and environments as influenced by other environmental aspects. The research questions addressed in this study were (a) what are the lived experience of mothers of young children with ASD and intellectual disability in regard to the decision-making process for out-of-home placement, and (b) what are the contextual aspects influencing mothers' placement considerations and decisions? An IRB-approved interview guide (Appendix A) was used when needed to delve further into the topic; however, in phenomenology, it is the participants who describe their own meanings of their experiences and most of the mothers spoke to the items on the interview guide in their accounts.

Six mothers participated in this study. All six mothers had children with severe ASD and intellectual disabilities. Mary and Dorian placed their children, Lisa faced an undesired placement decision due to safety factors, but they were resolved before the decision was made by a change in medication. Of the three remaining mothers, Denise and Soo were adamant in their positions against placing their children, considered from their perspectives how other mothers might potentially decide to place their children. Elise was desperate to get her child the help necessary to keep her son at home, but she was becoming fearful of having to face an undesired placement in order to protect her other children. Her situation was complicated by her husband’s and son’s medical situations, and a realization that she felt exhausted, sleep deprived, and decreasing in health and strength to sustain her family life under the current situation.

A review of the literature uncovered a gap in the occupational therapy literature about the placement considerations, placements, and placement prevention. This gap in the literature needs to be addressed if the mothers of children with ASD and intellectual disabilities are to benefit from occupational therapy services that enable them to live, work, and play within their homes and communities.

With Phase 3 of Deinstitutionalization, the full shift from institutional to community health is an expectation. This means that people will be expected to work, live, and play in their communities despite mental or physical disabilities. This also means that there will be fewer options for placements of loved ones when families’ capacities to provide care or their finances are not sufficient to continue to provide care.

Humane options for local community permanent, temporary, or respite placements need to be available to relieve caregivers from their 24/7 responsibilities, for crises intervention, and for families who need a temporary placement for their loved ones, while they recover their strength and work on a plan for reintegrating their loved ones into less chaotic home environments. For some, such as Dorian’s daughter Katie, a placement is necessary due to the unsafe, uncontrollable, and unpredictable violent behaviors making conditions in the home unsafe for all including Katie herself and due to the family’s growing economic, occupational, and social marginalization.

Preparation for the full shift from institutional to community health as well as funding towards a smooth transition has been uneven among states, which potentially places vulnerable groups such as the mothers in this study at risk for forced placements or potential social and economic marginalization. Occupational therapists can advocate for these groups and for appropriate community placement options when the families can no longer care at home for their loved ones.

To assert its role and value on the primary care core health team and to strengthen its role as mental health professionals, the occupational therapy profession and its practitioners need to delineate for other professions the unique contribution occupational therapy has to health promotion and illness prevention. In transitional times, the occupational therapy profession has demonstrated its flexibility and adaptability. The occupational therapy profession will also have opportunities to convey the results of the profession's 20-year renaissance in all areas of education, theory, practice, research, professional competencies, and professional standards.

The literature review also highlighted that the holistic nature of occupational therapy practice and its wide range of services do not seem to be clearly understood. Occupational therapy's unique contribution to health may be better understood through this current study in which the needs of mothers and families were substantial and vast. The complexities of the mothers' situations illustrate the occupational perspective and approach to health. Through this study, the profession's role in illness prediction and prevention, remediation and adaptation, and health promotion was contextualized for others who may be able to help of their mothers and their children. Mothers' placement considerations were explored for a deeper understanding of the environmental and occupational aspects that influenced their placement decisions.

Conclusions and Reflexivity

This study identified a gap in the research on out-of-home placement, and a notable absence of occupational therapy citations in interdisciplinary literature on mothering occupations, roles, routines, and recent evidence to support a diagnosis of sensory modulation disorder. In studies from other disciplines, areas for future research often suggested topics that had been studied and used in occupational therapy practice for years. These areas included mothering roles, routines, occupations, and co-occupations as well as specialized interventions such as ®Ayres Sensory Integration Therapy. These finding suggest that occupational therapy may need to highlight and promote its recent research and professional progression to a wider readership. The literature review also uncovered that misinterpreted occupational therapy study results were used in a policy decision which had implications for funding and access to specialized intervention found to be effective in reducing anxiety, stereo-typical movement, and behavioral responses that impede occupational performance. For the mothers in this study, interventions that kept their children calm were regarded as important for the entire family.

A review of the literature also found that the holistic essence of occupational therapy is not fully understood, rather occupational therapy appears to be better understood within its specific areas of practice. In other words, the core concept of occupation as a means and an end does not appear to be fully understood by others; however, the AOTA (2002, 2008, 2014) OTPF has strengthened the profession in its ability to articulate its central focus on occupation as a means and an end to health, well-being, and quality of life.

This transcendental phenomenological study explored contextual aspects of the mothers' placement considerations and found that the mothers' placement decisions were influenced by environmental and occupational contexts. Current economies, evolving health environments and policies, technologies, economic policies, societal attitudes, and new ways of knowing, communicating, and decision-making have implications for public health.

The AOTA has prepared its occupational therapists to bring forth their valued service in traditional and expanding roles to meet the occupational needs of a changing society. From expanded roles and leadership positions, occupational therapists will be empowered to advocate in broader institutional, organizational, and community contexts to implement the environmental and occupational changes that will support full community inclusion. Expanding occupational therapy community health, mental health, and eventually primary health roles, will empower the profession to revolutionize current approaches to inclusion of its most vulnerable members as a step towards occupational justice.

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Appendix A

Interview Guide – Data Collection Tool

Appendix A

Interview Guide – Data Collection Tool

"Decision for Out-of-Home Placement of Young Children with Autism: The lived experience of Mothers." (original dissertation title)

Title was later changed to the current title of : "*Contextual Aspects Influencing Mothers' Placement Considerations for their Children with Autism"*

INTERVIEW GUIDE 1 Version 1

For Mothers Who Placed or Considered Placing their Children

What were your feelings about decision-making process for out of home placement of your child?

What about your experience of raising a child with autism influenced your entry into the decision-making process for out-of home placement?

As a mother of a child with severe autism how did you feel about your experience with family and community life (participation, occupational needs, family, going out as a family, home routines)?

What meaning/s did you derive from this decision-making experience? (Pre/Post Placement Perspectives)

What would you like mother's who have shared or may face your experience to know?

What would you like others to understand about your experience of the decision-making process that led to the placement of your child outside of the home? (General Public, Occupational Therapists/ Other Professionals, Policy Makers)

Could you share your perspectives of what would be helpful for mothers who raise children with severe autism within their homes?

"Decision for Out-of-Home Placement of Young Children with Autism: The lived experience of Mothers." (original dissertation title)

Title was later changed to the current title of: "*Contextual Aspects Influencing Mothers' Placement Considerations for their Children with Autism"*

A. *Interview Guide - Version2*

For At-Risk Mothers *Who Have not Placed or Do not Plan* to Place their Children

What are your Feelings and considerations for out-of -home placements for children with Autism Spectrum Disorder and Intellectual Disabilities?

What do you think, based on your experiences of raising a child with the ASD might influence a mother to consider placing her child?

As a mother of a child with severe autism, how do you feel about your experiences when you participate as a family, in your home and in your community life? (participation as a family in family community outings, home routines, social events)?

What would you like mothers who have shared or may face your experiences of raising your child with severe autism to know?

What would you like others to understand about your experiences, and to help them understand what could potentially lead a mother in your position to have to consider placing her child outside of the home?
(General Public, Occupational Therapists/Other Professionals, Policy Makers)

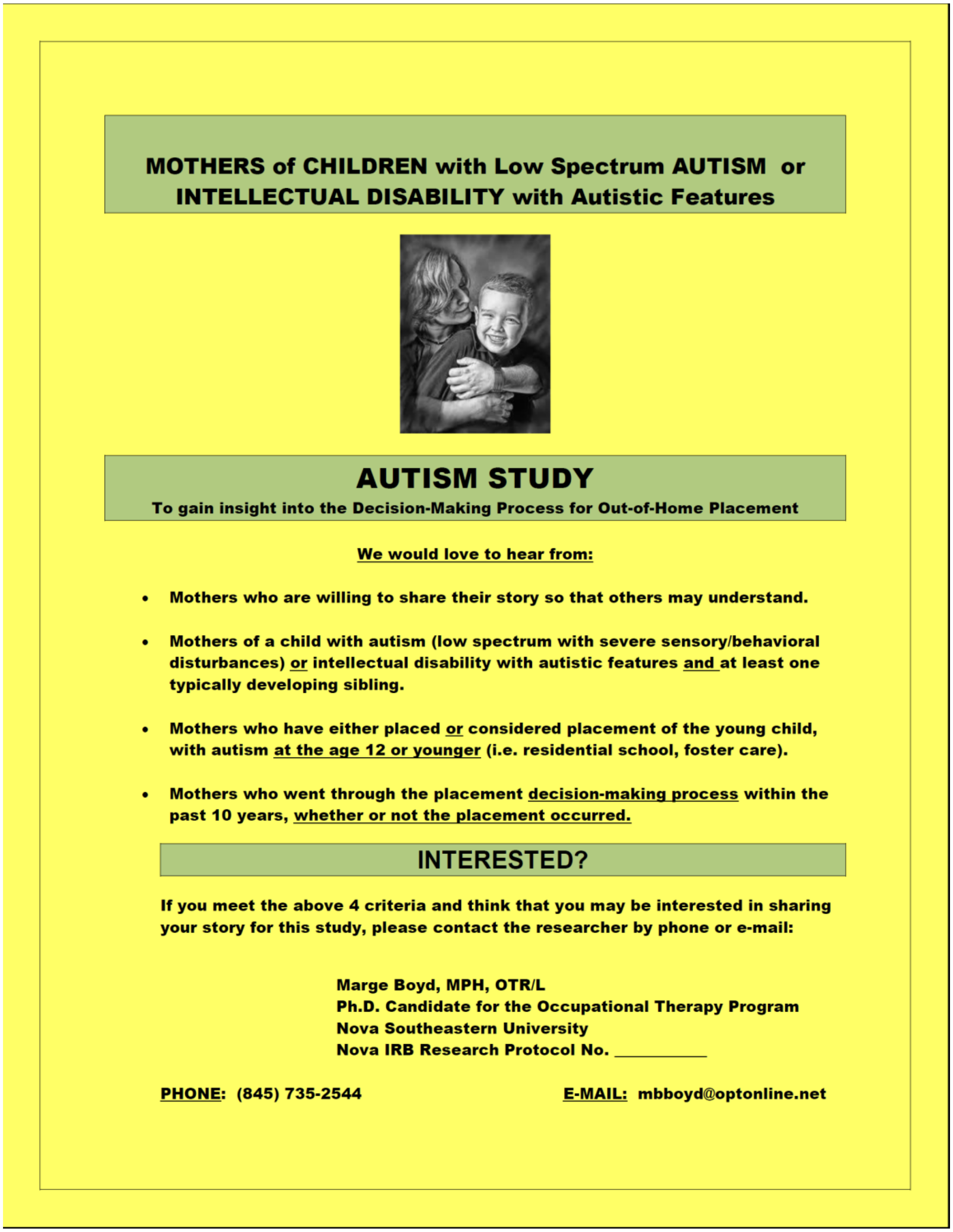
Could you share your perspectives on raising a child with sever autism, that may be helpful to other mothers in similar positions, raising their children with severe autism at home?

Appendix B

Recruitment Flyer Listing the Study Inclusion and Exclusion Criteria

Appendix B

Recruitment Flyer Listing the Study Inclusion and Exclusion Criteria



MOTHERS of CHILDREN with Low Spectrum AUTISM or INTELLECTUAL DISABILITY with Autistic Features

AUTISM STUDY

To gain insight into the Decision-Making Process for Out-of-Home Placement

We would love to hear from:

- **Mothers who are willing to share their story so that others may understand.**
- **Mothers of a child with autism (low spectrum with severe sensory/behavioral disturbances) or intellectual disability with autistic features and at least one typically developing sibling.**
- **Mothers who have either placed or considered placement of the young child, with autism at the age 12 or younger (i.e. residential school, foster care).**
- **Mothers who went through the placement decision-making process within the past 10 years, whether or not the placement occurred.**

INTERESTED?

If you meet the above 4 criteria and think that you may be interested in sharing your story for this study, please contact the researcher by phone or e-mail:

Marge Boyd, MPH, OTR/L
Ph.D. Candidate for the Occupational Therapy Program
Nova Southeastern University
Nova IRB Research Protocol No. ___________

PHONE: (845) 735-2544 **E-MAIL: mbboyd@optonline.net**

Appendix C

Initial Phone or E-Mail Script for the Researcher's Recruitment Follow-up

Appendix C

Follow-up Phone /E-mail Script to Potentially Interested Participants

Hello ________________________________.
Name of interested potential participant

Thank you for your interest in participating in my study about mother's "lived experience" with the decision for out-of-home placement. My name is Marge Boyd, a Doctoral Candidate in the Occupational Therapy Program at Nova Southeastern University.

You are being invited to participate in this study because you met the criteria of being a mother of a child age 12 or younger with severe autism with at least one typically developing child, who experienced the decision-making process for out-of-home placement within the past ten years. Research plays an important role in providing evidence to support decisions that are made in regard to providing support for individuals with disabilities and their families.

In conducting this research study, I expect to gain a better understand the impacts and needs of mothers and families of children with severe autism. As an occupational therapist who has worked with children with autism and their families for many years, I appreciate how the autism disorder can impact families. I also value the perspectives of mothers who have directly experienced this decision-making process for placement.

If you are still interested in participating, I will mail or e-mail a consent form in advance, that contains a detailed explanation of the research project and what will be expected of you if you agree to participate. The consent form will also provide detail about the procedures that will be in place to protect your confidentiality at all times. If you have any questions I can be reached at margboyd@nova.edu or (845) 735-2544 or mbboyd@optonline.net.

If you decide to participate after reviewing the consent form, I will call next week to schedule your first interview, and you will be requested to sign the consent form before the first interview begins. Thanks for your time and I will look forward to speaking to you next week.

Marge Boyd, MPH, OTR/L
Nova Southeastern University
PhD Student, Occupational Therapy

Appendix D

Adult/General Consent Form and Consent for Audio Recording

Appendix D

Adult/General Consent Form and Consent for Audio Recording

Nova Southeastern University
Health Professions Division
College of Allied Health and Nursing
Occupational Therapy Department
International Institute for Leadership in Occupational Therapy

(Original was submitted to the IRB on Blue Nova Letter Head)

Consent Form for Participation in the Research Study Entitled

Decision-Making Process for Out-of-Home Placement: The Lived Experience of Mothers of Young Children with Low Spectrum Autism and Intellectual Disability with Autistic Features

Funding Source: **None.**
IRB approval # 08161017Exp.

Principal Investigator
Marge E. Boyd, MPH, OTR/L
Ph.D Candidate Occupational Therapy
College of Allied Health & Nursing
3 Adams Court
Pearl River, NY 10965
(845) 735-2544

Co/Investigator
Dr. Sandra Dunbar, Dissertation Chair
Professor and Chair
Occupational Therapy Department
Health Professions Division
Nova Southeastern University
3200 South University Drive
Fort Lauderdale, Florida 33328-2018

Co Investigator:
Dr. Ferol Ludwig, Professor Emeritus
Dissertation 2nd Member
Professor Emeritus
Occupational Therapy Program
College of Allied Health & Nursing
Nova Southeastern University
3200 S. University Drive
Fort Lauderdale, Florida 33328-2018

Co-Investigator:
Dr. Sandra Countee, Dissertation 3rd
Professor and Division Director of Allied Health
Director of Occupational Therapy
Dominican College
470 Western Highway
Orangeburg, NY 10962
Contact phone number:
(845) 848- 6039

Institutional Review Board

Nova Southeastern University
Office of Grants and Contracts
(954) 262-5369/IRB@nsu.nova.edu

Contact phone number:

(954) 212-1240

Site Information: Private location that is acceptable to you.

What is this study about?

This study involves research. The purpose of the study is to gain a greater understanding of mothers' lived experiences of the decision-making process for out-of-home placement of their young children (at the age of 12 or younger) with low spectrum autism or intellectual disability with autistic features (sensory and behavioral deficits).

Why are you asking me?

Approximately eight mothers will be recruited for this study. You were invited to participate in this study because you met the criteria of being a mother of a child with low spectrum autism or intellectual disability with autistic features, and at least one typically developing sibling. You also met the criteria of being a mother who experienced the decision-making process for out-of-home placement of a child at the age of 12 years or younger within the past ten years, even if the placement never occurred. Finally, you met the criteria because you were willing to tell your story so that others could understand.

What will I be doing if I agree to be in the study?

Your participation will involve between two to three one-hour interviews conducted by the researcher, at a time and private place that is convenient for you (your home, investigator's office or other private setting of your choice), and a follow-up visit or contact. The purpose of the follow-up will be to discuss whether the themes that emerged from the data accurately represent your experience and for an opportunity for you to offer changes. The interviews and follow-up can be conducted according to your convenience, either by in-person visits, by phone or skype. If longer interviews with fewer visits/contacts are more compatible with your family schedule, this can also be arranged. The interviews will consist of open-ended questions, with flexibility as not to limit your perspective or responses. Although this procedure is not expected to cause any unpleasant reaction, due to the sensitive nature of this topic, contact information for licensed counselors will be provided at the beginning of the first interview, in the event that you feel the need to talk to someone at your own expense. If you feel that you would like refrain from answering a question, end the interview, or withdraw from the study you are free to do so at any point, without prejudice even though you signed the consent form.

Is there any audio or video recording?

To ensure accuracy, your interview about the decision making process for out-of-home placement of your young child with low spectrum autism or intellectual disability and autistic features. will be digitally audio-recorded or possibly video recording (skype). This audio or video recording will be available to be heard by the researcher, the IRB, and the dissertation committee (research study mentors). The recording will be encrypted and sent to a Professional Transcriptionist who has signed a letter of confidentiality to protect participants. The recording will be kept securely on the hard drive of the hard drive of a password protected computer, used only by the researcher. The recording will be kept for 36 months following the completion of the study and deleted from the hard drive after that time. Because your voice and image will be potentially identifiable by anyone who hears and sees the recording, your confidentiality for things you say (or do) on the recording cannot be guaranteed. These digital audio recordings will be available to be seen or heard by the researcher, the IRB, and the dissertation committee (research mentors), who have completed training in Human Subject Research.

What are the dangers to me?

It is not expected that you will experience any discomfort, however, due to the nature of this research study topic, a list of available professional counselors in your county will

be provided to you at the beginning of the first interview, in the event that you feel the need to speak to someone, at your own cost. The expense for this, or any other future counseling will be at your own expense. There could be a loss of confidentiality and your recorded voice or image could be potentially identifiable, however all efforts will be made to protect your confidentiality as outlined in this section and in the privacy section below. If you have any concerns about the risks or benefits of participating in this study, you can contact Marge E. Boyd, MPH, OTR/L or Dr. Sandra Dunbar, or the IRB office at the numbers indicated above. "If you have any questions about the research, your research rights, or have a research-related injury, please contact Marge Boyd, Dr. Dunbar, or Dr. Ludwig at the contact numbers provided on page one. You may also contact the IRB at the numbers indicated above with questions as to your research rights."

Are there any benefits for taking part in this research study? There is no direct benefit or payment to you for participating in this research.
An indirect potential benefit of participating in this study is that others, including mothers experiencing similar experiences: people in the community families with children with low spectrum autism and intellectual disability with autistic features and professionals who work with them and their families, and organizations that special disability services may better understand your situation.

Will I get paid for being in the study? Will it cost me anything?
There will be no payments made to you, or costs to you for participating in this study.

How will you keep my information private?
All information obtained in this study is strictly confidential unless disclosure is required by law. The IRB, regulatory agencies, Principle Investigator's (student researcher) dissertation chair may review research records. It is conceivable that your story could be published for educational purposes, however your confidentiality will be protected at all times.

To keep your information private, the following procedures confidentiality measures will be implemented:

- The digital interview recordings will be encrypted for secured transmission to a professional transcriptionist who has signed a letter of agreement to protect participant confidentiality. Recordings will be labeled using numbers instead of names.

- Transcripts will be labeled by numbers instead of names and securely housed in a locked file in the office of the researcher, along with the consent forms, and list of names with number codes. The number coded recordings and transcripts will also be saved on the hard drive of a password protected computer used only by the researcher. Number-coded recordings and transcripts will kept for a minimum of 3 years following the completion of the research project.

- If you choose to do the interviews over Skype, Skype may collect information about you including (but not limited to) your name, address, phone number, email address, age, gender, IP address, etc. You can visit the Skype privacy policy website (http://www.skype.com/intl/en/legal/privacy/general/) if you would like further information. While Skype may not know that you are participating in this study, they may be collecting identifiable information.

- Three years after the completion of the research project, all coded digital recordings of the interviews will be deleted from the principal investigator's password-protected hard drive and all consent forms will be shredded.

What if I do not want to participate or I want to leave the study?

You have the right to leave this study at any time or refuse to participate. If you do decide to leave or you decide not to participate, you will not experience any penalty or loss of services you have a right to receive. If you choose to withdraw, any information collected about you **before** the date you leave the study will be kept in the research records for 36 months from the conclusion of the study.

Other Considerations:

If significant new information relating to the study becomes available, which may relate to your willingness to continue to participate, this information will be provided to you by the investigators.

Voluntary Consent by Participant:

By signing below, you indicate that

- this study has been explained to you
- you have read this document or it has been read to you
- your questions about this research study have been answered
- you have been told that you may ask the researchers any study related questions in the future or contact them in the event of a research-related injury
- you have been told that you may ask Institutional Review Board (IRB) personnel questions about your study rights
- you are entitled to a copy of this form after you have read and signed it
- you voluntarily agree to participate in the study entitled *Decision-Making Process for Out- of-Home Placement: The Lived Experience of Mothers of Young Children with Low Spectrum Autism and Intellectual Disability with Autistic Features*

Participant's Signature: ____________________________ Date: ____________________

Participant's Name: ______________________________ Date: ____________________

Signature of Person Obtaining Consent: ________________________________

Date: ____________________________________

Appendix E

Contact Information for Licensed Counselors

Appendix E

Contact Information for Licensed Counselors

Woodmere, Queens – Contacts of Licensed Professionals

PENINSULA COUNSELING CENTER

124 Franklin Place
Woodmere, NY 11598

516-569-6600

Provides outpatient mental health and alcoholism treatment services for children, adults and elderly. Services for residents of Nassau County.

MENTAL HEALTH ASSOCIATION OF NASSAU COUNTY

186 Clinton Street
Hempstead, NY 11550

516-489-2322

www.mhanc.org

Provides free information, referral and counseling services for all family problems and concerns.

A. *Westchester County, NY - Crisis Intervention – Licensed Professional's Contacts*

THE HOME PROGRAM Behavior management consultation services, in-home training to address sleeping, toileting, mealtime, compliance and community behavior.

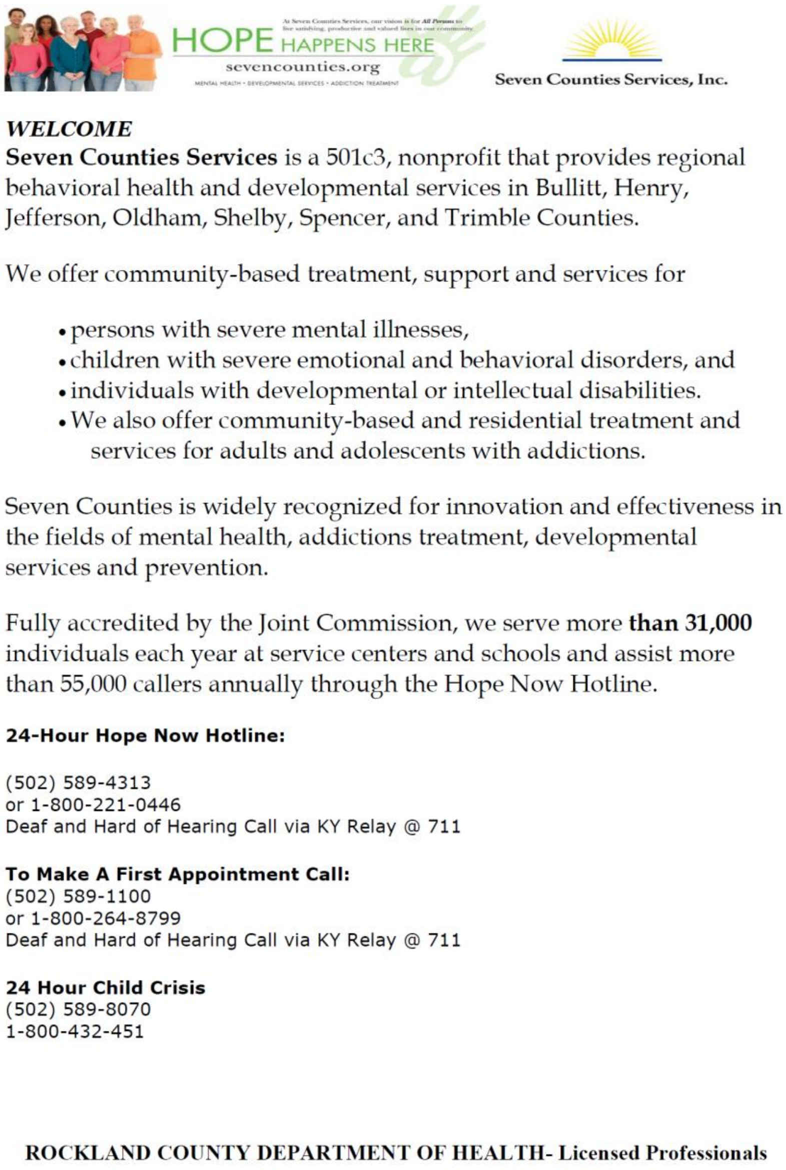
34 South Broadway Suite 411 White Plains
949- 3751 | thehomeprogram.org

HUDSON CENTER FOR PSYCHOTHERAPY A group of experienced and expert mental health professionals in independent practice, offering psychotherapy for adolescents, adults, couples and families as well as psychoanalysis and psychopharmacology.

25A Main St., Hastings-on-Hudson | 478-1511.

HUDSON VALLEY BEHAVIORAL SOLUTIONS
845-897-1788 | behaviorsos.com

Louisville, Kentucky Contacts of Licensed Professionals



WELCOME

Seven Counties Services is a 501c3, nonprofit that provides regional behavioral health and developmental services in Bullitt, Henry, Jefferson, Oldham, Shelby, Spencer, and Trimble Counties.

We offer community-based treatment, support and services for

- persons with severe mental illnesses,
- children with severe emotional and behavioral disorders, and
- individuals with developmental or intellectual disabilities.
- We also offer community-based and residential treatment and services for adults and adolescents with addictions.

Seven Counties is widely recognized for innovation and effectiveness in the fields of mental health, addictions treatment, developmental services and prevention.

Fully accredited by the Joint Commission, we serve more **than 31,000** individuals each year at service centers and schools and assist more than 55,000 callers annually through the Hope Now Hotline.

24-Hour Hope Now Hotline:

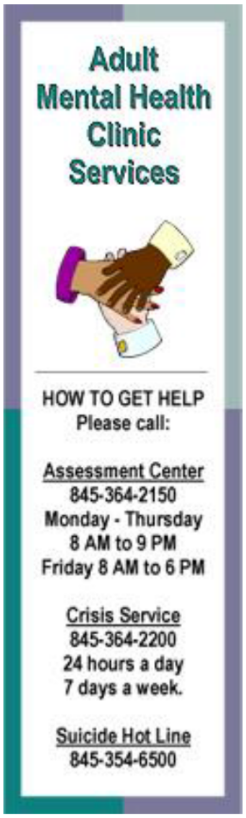
(502) 589-4313
or 1-800-221-0446
Deaf and Hard of Hearing Call via KY Relay @ 711

To Make A First Appointment Call:
(502) 589-1100
or 1-800-264-8799
Deaf and Hard of Hearing Call via KY Relay @ 711

24 Hour Child Crisis
(502) 589-8070
1-800-432-451

ROCKLAND COUNTY DEPARTMENT OF HEALTH- Licensed Professionals

Department of Mental Health



Adult Mental Health Clinic Services

HOW TO GET HELP
Please call:

Assessment Center
845-364-2150
Monday - Thursday
8 AM to 9 PM
Friday 8 AM to 6 PM

Crisis Service
845-364-2200
24 hours a day
7 days a week.

Suicide Hot Line
845-354-6500

Adult Mental Health Clinic Services

Why Come To Adult Mental Health Clinic Services?

Problems in living can arise at any time in life, especially during adulthood. At these times it is often helpful to talk with family and friends.

Many different kinds of problems affect people dealing with the stresses of everyday life in a fast paced world. People may feel depressed or anxious. Other people may have problems with their families, with their partners, or with people at work.

A family member may have a drug or alcohol problem, a serious illness, or an emotional problem that affects everyone in the family.

In these situations, it is helpful to talk with a professional who is attentive, objective, and wants to listen and understand.

The Clinic serves a varied socioeconomic, ethnic population with staff members who have language expertise in many languages including Spanish, French, Creole, Yiddish, Hebrew, German, Russian and Hindi.

The Clinic specializes in solution-focused, time

Services Provided

Assessment Of Individuals.
Psychiatric Evaluations.
Individual, Marital, Group, & Family Therapy.
Medication Evaluations & Monitoring.

Common Problems Treated

Depression.
Anxiety.
Panic Attacks.
Bipolar Disorder.
Posttraumatic Stress Disorder (PTSD).
Family Issues.
Relationship Problems.
Work Concerns.
School Problems.
Obsessive Compulsive Disorder (OCD).
Attention Deficit Disorder (ADD).

What Will Happen When You Make An Appointment?

When you call the Assessment Center, you will be scheduled for an initial appointment.

You will be asked about your concerns and the current circumstances that contribute to them.

You and your family will be treated with respect and confidentiality.

After the assessment appointment, the interviewer will recommend appropriate treatment, which may include psychotherapy and / or medication evaluation.

effective treatment through individual, marital and family therapy, psychiatric evaluations and medication management.

The Clinic also offers health education and health assessments and referrals for medical follow-up when necessary.

Our Staff Includes

- NYS Licensed Psychologists
- NYS Licensed Nurse Practitioners
- NYS Licensed Clinical Social Workers
- NYS Licensed Board Eligible & Board Certified 364-2150.Child Psychiatrists

We offer comprehensive care by working with other community agencies.

Our Fees

The Rockland County Department of Mental Health accepts a full range of insurance coverage including managed care plans, Medicaid & Medicare. If you do not have insurance, fees are based on your ability to pay.

To schedule an appointment please, call the Assessment Center at (845)

Appendix F

CITI and NIH Certificates of Completion for Human Research Training

Appendix F

CITI and NIH Certificates of Completion for Human Research Training

Primary Investigator’s Human Research Curriculum Completion Report

COLLABORATIVE INSTITUTIONAL TRAINING INITIATIVE (CITI)

HUMAN RESEARCH CURRICULUM COMPLETION REPORT
Printed on 09/25/2013
LEARNER
Marge Boyd (ID: 301582)
3 Adams Court
Pearl River
NY 10965-1502
DEPARTMENT Occupational Therapy
PHONE (845) 848-6033
EMAIL margboyd@nova.edu
INSTITUTION Nova Southeastern University
EXPIRATION DATE 09/24/2016
1. CPS
COURSE/STAGE: Basic Course/1
PASSED ON: 09/25/2013
REFERENCE ID: 9355112
REQUIRED MODULES DATE COMPLETED SCORE

Avoiding Group Harms - U.S. Research Perspectives	09/25/13	3/3	(100%)
Introduction	09/25/13		No Quiz
History and Ethical Principles - SBE	09/25/13	5/5	(100%)
Defining Research with Human Subjects - SBE	09/25/13	5/5	(100%)
The Regulations – SBE	09/25/13	5/5	(100%)
Basic Institutional Review Board (IRB) Regulations and Review Process	09/25/13	5/5	(100%)
Assessing Risk – SBE	09/25/13	5/5	(100%)
Informed Consent - SBE	09/25/13	5/5	(100%)
Privacy and Confidentiality - SBE	09/25/13	5/5	(100%)
Records-Based Research	09/25/13	2/2	(100%)
Research with Prisoners - SBE	09/25/13	4/4	(100%)
Research with Children - SBE	09/25/13	4/4	(100%)
Research in Public Elementary and Secondary Schools – SBE	09/25/13	4/4	(100%)
International Research - SBE	09/25/13	3/3	(100%)
Internet Research - SBE	09/25/13	5/5	(100%)
Research and HIPAA Privacy Protections	09/25/13	5/5	(100%)
Vulnerable Subjects - Research Involving Workers/Employees	09/25/13	4/4	(100%)
Conflicts of Interest in Research Involving Human Subjects	09/25/13	5/5	(100%)
Nova Southeastern University	09/25/13		No Quiz

For this Completion Report to be valid, the learner listed above must be affiliated with a CITI Program participating institution or be a paid Independent Learner. Falsified information and unauthorized use of the CITI Program course site is unethical, and may be considered research misconduct by your institution.

Paul Braunschweiger Ph.D.
Professor, University of Miami
Director Office of Research Education
CITI Program Course Coordinator

Peer Reviewer/Debriefer’s Human Research Curriculum Completion Report

COLLABORATIVE INSTITUTIONAL TRAINING INITIATIVE (CITI)

HUMAN RESEARCH CURRICULUM COMPLETION REPORT
Printed on 09/30/2013
LEARNER Nadine Revheim (ID: 268976)
140 Old Orangeburg Road
Room 235g
Orangeburg

New York 10962
USA

DEPARTMENT	Life Sciences (PICNAS)
PHONE	845-398-6543
INSTITUTION	Nathan Kline Institute for Psychiatric Research
EXPIRATION DATE	02/01/2015

SOCIAL AND BEHAVIORAL RESEARCHERS AND STAFF : Do the required modules for your group and then complete at least 9 additional modules of your choosing.

COURSE/STAGE: Basic Course/1
PASSED ON: 02/02/2012
REFERENCE ID: 7317451

REQUIRED MODULES	**DATE COMPLETED**
Introduction	01/25/12
History and Ethical Principles – SBE	01/25/12
Basic Institutional Review Board (IRB) Regulations and Review Process	01/27/12
Informed Consent – SBE	01/30/12
Conflicts of Interest in Research Involving Human Subjects	01/30/12
Nathan Kline Institute for Psychiatric Research	01/30/12
ELECTIVE MODULES DATE COMPLETED	
Defining Research with Human Subjects - SBE	01/31/12
The Regulations - SBE	01/31/12
Assessing Risk - SBE	01/31/12
Privacy and Confidentiality - SBE	02/02/12
Internet Research - SBE	02/02/12
Avoiding Group Harms - U.S. Research Perspectives	02/02/12
Research and HIPAA Privacy Protections	02/02/12
Vulnerable Subjects - Research Involving Workers/Employees	02/02/12
The IRB Member Module - 'What Every New IRB Member Needs to Know'	01/31/12

For this Completion Report to be valid, the learner listed above must be affiliated with a CITI Program participating institution or be a paid Independent Learner. Falsified information and unauthorized use of the CITI Progam course site is unethical, and may be considered research misconduct by your institution.

Paul Braunschweiger Ph.D.
Professor, University of Miami
Director Office of Research Education
CITI Program Course Coordinator

Appendix G

Participant Characteristics Table

Appendix G

Participant Characteristics Table

<table>
<tr><td colspan="4">**PARTICIPANT CHARACTERISTICS**
Contextual Aspects Influencing Mothers' Placement Considerations for Their Children With Autism</td></tr>
<tr><td colspan="2">**6 - Children have (severe) autism spectrum disorders and intellectual disabilities**
Placement Considerations
1 - Placed child temporarily (safety issues -3 years) Back home now
1- Placed (safety issues)
1 - Almost placed (safety issues)
2 - Adamant about not placing
1 - Family is In crises at severe risk for placement (safety issues -severe behaviors)</td><td colspan="2">**Placement Predictors –all at sever risk**
Caregiver Risk (Maternal Stress)
Autism + behavior problems combined
Assault/Injury/Severe Behaviors
Supervision need level- line of sight/at earshot
Intellectual Disability
Line of sight supervision/or at an earshot
No or minimal ADL
Seizure acuity
http://www2.dshs.wa.gov/RDA/</td></tr>
<tr><td colspan="4">***Contextual Aspects Influencing Mothers' Placement Considerations for Their Children with Autism***</td></tr>
<tr><td>**Participants 6 Mothers of children with autism spectrum disorders + intellectual disabilities**</td><td>**Children with autism spectrum disorders + intellectual disabilities Age at time of placement considerations**</td><td>**Husband + Other Children + Ages at time placement considerations**</td><td>**None of the mothers had planned to place their children – Each placement was crisis and safety driven**</td></tr>
<tr><td colspan="4">***Contextual Aspects Influencing Mothers' Placement Considerations for Their Children With Autism***</td></tr>
<tr><td>**#1 Mary**</td><td>**Helen (11)**</td><td colspan="2">Matt
Stephanie (8)
Ellen (2)
Family reached Crisis Point-Aggressive Behaviors Sibling Safety Issue-Child for Placed in Residential School and returned home after 3 years</td></tr>
<tr><td colspan="4">Mary was married to Matt, a protestant pastor, and they lived in a suburban neighborhood of Kentucky. Mary's and Matt's' first-born daughter Helen, age 11 years old, had ASD and intellectual disability. Helen's sisters Stephanie (age 8 years) and Ellen (age 2 years), had typical development at the time of the placement. The family moved from South Carolina to North Carolina to a neighborhood that was welcoming and where they felt at home. Helen was placed in a special education program. Friends encouraged Mary to push for Helen to attend an integrated school program. While the special program was more</td></tr>
</table>

<table>
<tr><td colspan="4">restrictive, the integrated program was not a fit for Helen who was then bullied. Matt and Mary were dissatisfied with Helen's school placements. At the process for placement, Helen was just under the age of 12 years and by that time, the decision-making behavioral problems escalated enough to cause safety concerns for her and for her two younger siblings. Mary and Matt found a residential school for Helen in Kentucky; however, the weekend visits were too draining, so the family relocated to Kentucky to be closer to Helen. Matt’s and Mary's parents helped with the expenses for this residential school.
After three years, Mary and Matt brought Helen back home. With the structure of the residential program, Helen's behaviors became more manageable and becoming accustomed to living in a non-chaotic household, the family was in a better state to firmly renegotiate Helen's terms of reintegration into the family once more. Helen and her family are doing much better. The family missed the sense of community that they had in North Carolina where they felt more accepted by the community. Mary and Matt had never lived close to their families and found it difficult to attend social events where Helen was accepted. Matt and Mary were happy to have Helen at home again; however, they had few options for social participation and Helen did not have friends that called her. They appeared to accept their circumstance in a spiritual way. Since the interview, Mary and Matt moved to Virginia due to a change of employment.</td></tr>
<tr><td>#2 Elise</td><td>Kenny (7)</td><td>Ned
<u>Fraternal Twins</u>
Nicole (5)
Evelyn (5)</td><td>Family is in Crisis Elise wants to raise child in their home
Struggling to secure sufficient services and supports to keep her son at home. Fearful that she may need to consider a placement.</td></tr>
<tr><td colspan="4">Elise lived with her husband Ned and their three children, Kenny (age 7 years) with ASD and intellectual disability, Nicole (age 5 years), and Evelyn (age 5 years). Elise’s family was in crisis. Elise wanted to raise the child in their home, but struggled to secure sufficient services and supports to keep her son at home. Elise was fearful that she may have needed to consider a placement due to Kenny’s aggressive behaviors towards himself and others, and his tendency to wander or bolt, placing Kenny and his sisters at risk. Kenny's language skills were insufficient for a conversation. Kenny was recently potty trained, but he did not always indicate when he needed to use the potty. Kenny had a seizure disorders and he also had certain nutritional deficiencies for which he was given supplements. Kenny had two younger sisters, Evelyn and Nicole, who are five-year-old fraternal twins. Evelyn had ASD, however, her she attended school with her twin sister, Nichole, who had neurotypical development. Evelyn sometimes had behavioral meltdowns.
Elise and Ned moved their family from North Carolina to Florida when Kenny's special services were dropped. Elise stated that her son’s services were dropped due to his "limited rehab potential." Elise relocated to Florida after researching, then finding, a special school for Kenny. Elsie, Ned, and their family had no friends or family in Florida, except for Elise’s mother who was elderly and could not be around Kenny. Ned was in poor health and in need of an organ transplant, however, he was still able to work from home. Elise was a stay-at-home mom who spent any free time completing forms and writing grants in an attempt to access special services to help Kenny. Elise was desperate to keep her son at</td></tr>
</table>

home, but she was concerned for her other two children’s safety and well-being as she could not manage all three children by herself outside of the home, without the assistance of an aide.

Without sufficient support, Elise feared that there may come a time when she would be unable keep Kenny at home. Elise believed that immunizations caused her two children's autism disorders and she expressed anger and frustration with the government-mandated immunizations and government’s reluctance to help her with a problem which Elise believed they caused. Elise was skeptical of the research studies that refuted the claim that immunizations caused autism. Elise was physically exhausted and mentally stressed attempting with very little support and limited sleep to raise her family in a new community. Elise and her family were in survival mode at this time with limited resources, and with no back-up caregivers for support. Elise expressed that she was catholic and wanted to find a church to join in her community, but she had been under pressure of deadlines to submit applications for government support and grants to help her children at this time.

#3 Linda	**Mattie (6)**	Gary Jeremy (3)	Did not want to place her child Almost had to do so because of safety issues which resolved after a medication change- Parents were Relieved when they did not have to place Mattie.

Linda and Gary lived in a suburb southeast of New York City with their two children Mattie (age 6 years) who had ASD and intellectual disability and Jeremy (age 3 years) who had neurotypical development. Mattie was a social child and she had language. Linda and Gary had no previous intentions of placing Mattie until she began to exhibit unsafe and increasing aggressive behaviors which placed both Mattie and her brother at risk. Linda and Gary considered placing Mattie due to these safety issues which resolved after a medication change. Both parents were relieved when they did not have to place Mattie. The idea of placing her child was extremely stressful to Linda, who felt conflicted between her feelings about placing her daughter outside of the home and her concern for the safety of both of her children. Linda expressed the trauma she felt in having to face such a decision as a mother.

Linda reported that she and her husband Gary enjoyed a social life with friends, family, and neighbors. They had some family support and they could afford to secure occasional respite services and qualified babysitters. Linda also sought out appropriate community activities in which Mattie could participate. Linda felt that many people could be judgmental and intolerant, particularly when Mattie had a tantrum or meltdown in a public place.

#4 Soo	**Michael (7)**	Kim Grace (5) Eugene (4)	Adamant that she would never place her child It would not relieve her, it would make her worry about him even more than now

Soo was born in South Korea. She and her husband, Kim, moved to a New York suburb approximately 25 miles northwest of New Jersey. They had three children. Their firstborn child Michael was 7 years old and had ASD with co-occurring intellectual disability–limited language development. Soo and Kim had two other children, a 5-year-old daughter Grace and a 4-year-old son Eugene, both had neurotypical development. Michael had a serious seizure disorders when he was very young, which appeared to be under control at the time of this study. Soo and Kim had no family in the United States, and they had no time to socialize or make friends. Soo mentioned that they enjoyed being connected to a church and that they were looking for a church in the area. Soo stated that the services they received for Michael would never have been possible had they remained in South Korea. She explained that in South Korea, her son would not have received services and he would not have been accepted by society, adding that she was grateful for the services she received. Soo stated that she was adamantly opposed to placing her child outside of the home, and believed that placing her son would cause her more stress than relief, as she would not know what was happening to her child. Soo respected the fact that other parents' situations and feelings about placements could be quite different from hers, and she would not judge others in their placement decisions.

Michael's language was limited and although he exhibited difficult behaviors and was subject to behavioral meltdowns, his behaviors had never been aggressive. Soo believed that all children needed to behave, and although she recognized Michael's problems, Soo still expected him to at least try to gesture to communicate his frustrations. Soo and Kim focused on raising their families and meeting their educational and career goals, so they did not notice the absence of social support as much.

#5 **Dorian**	**Katie** **(10)**	Richard Divorced Ashley (11)	Had to seek placement because of safety issues- had to wait 5 years due to appropriate options for her in Arizona- Katie’s assault on her mother in a public place and her arrest facilitated a placement for Katie.

Dorian was a single mother at the time of the placement decision-making process with two daughters, Katie (age 10 years) with ASD and intellectual disability, severe aggressive, violent behaviors, and no language skills and her daughter Ashley (age 11 years) with neurotypical development. Dorian lived in Arizona with her second husband, Doug. Dorian and her first husband Richard had lived in New Jersey with their two daughters. Dorian moved from New Jersey to Arizona to be closer to her mother and brothers, following the breakup of her marriage to Doug. At the time, Ashley was 6 years old and Katie was 5 years old. Dorian’s mother expressed to her that she believed Katie should be institutionalized and Dorian was shocked at this suggestion. Dorian's brother apparently concurred, but avoided getting involved. Dorian's mother and family distanced themselves from Dorian and her daughters; therefore, Dorian was lived in another state without any support. Although placement became necessary given the escalating severity of Katie’s aggressive and dangerous behaviors towards her mother, sister, and towards babies and small children when in public, Dorian decided to place her child by the age of 10 years.

Dorian sought placement for her daughter because of significant safety issues for her daughter Dorian and her older sister. Because of substantial budget cuts to disability services in Arizona, Dorian was unable to secure a placement until Katie was arrested at the age of 16 when she assaulted Dorian in a public place. Dorian refused to bring Katie back home out of fear for her other daughter’s safety, which facilitated the placement. Dorian met Richard, a man from her neighborhood in Arizona, and they got married. Dorian and Richard visited Katie regularly and they also took her on outings, this was extremely difficult.

<table>
<tr><td>#6
Denise</td><td>Albert
(11)</td><td>Robbie
Charlie (9)
Susan (4)
Ann Marie (0)
Born 2-weeks post-interview</td><td>Adamant that she would not place her child – It scares her when she sees her friends placing their children who are older than hers.</td></tr>
<tr><td colspan="4">Denise and her husband Robbie lived in a suburb of Northern Westchester with their children Albert (age 11 years), Charlie (age 9 years), Susan (age 4 years), and Ann Marie born two weeks post-interview. Denise was adamant that she would not place her child; it scared her when she saw her friends placing their children who are older than Albert. Robbie worked as a school administrator and the couple lived in a two-family house with Denise's parents. Her parents sold their home and bought this two-family house so that Robbie and Denise could afford to live in the town, based on the reputation of its school district’s special services. Denise’s and Robbie’s extended family were extremely supportive and they had sufficient resources.
At the time of the interview, Denise was pregnant and her due date was in three weeks, with a high risk pregnancy. Nevertheless, Denise was anxious to participate in the study because she believed that it was important to share her experience. Denise delivered her fourth child, a healthy baby girl, Ann Marie, two weeks following her interview. Albert was her firstborn son. Albert had ASD and intellectual disabilities. Albert also had a severe allergy to gluten, so the entire family was kept on a gluten-free diet and all visitors were expected to wash their hands entering the home. Albert also tended to wander and get himself into trouble, so he required 24/7 line-of-site care. Albert was fairly calm, with limited expressive language; however, he still had a fair amount of behavioral meltdowns. Denise reported that Albert slept for exactly seven hours at night, so she had to keep him up until at least 11:00 p.m., or he would get up during the middle of the night.
Denise's children had significant food allergies and Susan developed autistic-like symptoms when she was exposed to milk. Once milk was removed from Susan's diet, her symptoms disappeared and she appeared to be developing normally. Denise was suspicious of immunizations, and believed that they may have caused Albert's autism. She felt obliged to warn other mothers. Denise and Robbie worked together as a team. They had a well-developed system to manage household tasks. Denise could not imagine placing Albert outside of the home, yet she recognized how a mother could feel the need to place her child in a different situation. Denise worried about Albert's future in the event that she become unable to care for him in the future. Albert was being home-schooled at the time of this study.</td></tr>
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Appendix H

Transcriptionists' Letter of Agreement to Protect Participant Confidentiality

Appendix H

Transcriptionists' Letter of Agreement to Protect Participant Confidentiality

CONFIDENTIALITY AGREEMENT

This Confidentiality & Non-Disclosure Agreement ("Agreement") made as of This ____day of _________by and between _________("Client") whose e-mail address is _____________and **Transcription HUB** ("Company") with office address at New # 402 Old # 764 Poonamallee High Road, Kilpauk, Chennai-600010, Tamil Nadu organized and existing under the laws of India.

WHEREAS, Client and Company wish to disclose to each other, and each party wishes to receive and accept from the other party, under all of the terms and conditions of this Agreement, Confidential Information, as hereinafter defined, pertaining to the Client's and Company's capabilities:

NOW, THEREFORE, in consideration of the promises hereinafter set forth, Company and Client acknowledge and agree as follows:

Section 1. Definitions

"Affiliated Entity" shall mean any company or other legal entity directly or indirectly owned by controlled by or under common control with Client.

"Authorized Representative" of either party shall mean an officer of Client or Company of at least the level of Vice-President.

"Confidential Information" shall mean any information proprietary to either party or any other third party or which is designated as Confidential Information by either party at the time such information is provided to Company or within a reasonable time thereafter. Confidential Information includes all information related to all campaigns or projects shared/provided by the Company to the Client.

Section 2. Non-Disclosure of Confidential Information

Each party acknowledges and agrees that the Confidential Information is confidential, proprietary, and trade secret to the other party and is disclosed to each party on a confidential basis under this Agreement, to be used only as expressly permitted by the terms and conditions of this Agreement.

Each party agrees that it and any person to whom they grant access to the Confidential Information will at all times hold the Confidential Information in trust and strictest confidence and shall not except as herein permitted use, exploit, duplicate, re-create, display, decompile or reverse assemble, modify, translate, or create derivative works based upon or disclose or otherwise reveal the Confidential Information to any other party or permit or suffer any other party to do so. Each party hereby agrees to assume responsibility for all acts, omissions and breaches of this Agreement by its employees, agents and independent contractors.

Section 3. Breach

Company and Client recognize that the unauthorized disclosure, duplication, reproduction ruse of the Confidential Information would cause irreparable harm to Client and/or Company and that monetary damages will be inadequate to compensate either party for such breach. For that reason, Company and Client further agree that in any court of competent jurisdiction each party is entitled, as a matter of right, to injunctive relief including a preliminary injunction and an order of seizure and impoundment based upon an ex parte application to protect and recover the Confidential Information and Company or Client will not object to the entry of an injunction or other equitable relief against it on the basis of an adequate remedy at law or other reason. Such relief shall be cumulative and in addition to whatever other remedies Client or Company may have.

Section 4. Non-Solicitation

Before and during the period e24 Technologies and “Client” enter into any venture or transaction together, if any, and for one (1) year after the conclusion of the last such venture or transaction, and in any event for no less than five (5) years from the date of this agreement, neither party shall, directly or indirectly, either for its own account or as a partner, officer, employee, agent or otherwise solicit for business or employ any employee and/or subcontractor of the other, or any candidate, presented by one party to the other party.

Section 5. Termination

This agreement shall remain in effect for a period of five (5) years from the date of disclosure of Confidential Information, except as otherwise provided in section four (4)

Section 6. General Provisions

This Agreement shall be governed by and construed, and the legal relations between the parties shall be determined, in accordance with the laws of the India, without giving effect to the principles of conflicts of laws. This Agreement supersedes all prior' understandings and negotiations, oral and written, and constitutes the entire understanding between the parties on this subject. This Agreement and any of the rights or obligations hereunder are not assignable without Clients prior written permission. No waiver, modification, or amendment to this Agreement shall be binding upon the parties unless it is in writing signed by an Authorized Representative of the party against whom enforcement is sought.

IN WITNESS WHEREOF, the parties have caused this Agreement to be signed by their Authorized Representatives on the date and year first above written.

Name:____________________________
Name: ____________________________

Title: ______________________________
Title: ______________________________

Date:____________________________
Date:______________________________

Primary Investigator's Transcriptionist Confidentiality Letter

NOVA SOUTHEASTERN UNIVERSITY
Office of Gants and Contracts
Institutional Review Board

Re: Signed Confidentiality Agreement for study by Marge Boyd:
*"Decision for Out-of-Home Placement of the Young Child with Autism and Intellectual
Disability: The Lived Experiences of Mothers.*"

Researcher
Marge E. Boyd, MPH, OTR/L.
Candidate in the Occupational Therapy PhD Program at
Nova Southeastern University, Fort Lauderdale, Florida
Pediatric Occupational Therapist - New York State

Dear Professional Transcriptionist at Transcription HUB,

This letter of agreement relates to the above study. My name is Marge E. Boyd, a Candidate in the Occupational Therapy Ph.D Program at Nova Southeastern University and a New York Licensed Occupational Therapist who has been worked with children with autism and their families for over 20 years as a pediatric occupational therapist and Occupational Therapy Faculty and Administrator at Dominican College, NY. Upon IRB approval I will be conducting a study as partial fulfillment of a PhD in Occupational Therapy program. As the principal investigator for this study, I have assured the participants by way of a signed consent form that every effort will be made to ensure their confidentiality.

The participants' digital audio transcripts are labeled without names and uploaded on your website where they will also be retrieved once processed, to ensure confidentiality. As a professional transcriptionist, in accepting this assignment, you are agreeing to protect the confidentiality of each participant. Although the transcripts have no names, I am requesting that you delete the audio files by August of 2013. Thank you for agreeing to protect the confidentiality of my study participants. Please sign and date this letter below and e-mail marge.boyd@dc.edu it or upload it with the transcripts.

Sincerely
Marge Boyd, MPH, OTR/L

____ ________________

Professional Transcriptionist’s Signature Date

Appendix I

Principle Investigator’s Pre-Action Bracketing

Appendix I

Principle Investigator's Pre-Action Bracketing

"Decision for out of home placement: The lived experience of mothers of young children with autism"

Investigator: Marge Boyd, PhD Student, Occupational Therapy Program at Nova Southeastern University

Pre-Action Bracketing

Twenty four years of Pediatric Occupational Therapy Practice, over 20 years of academic and administrative experience in an occupational therapy program, a Masters Degree in Public Health, and scholarly pursuit of a PhD in Occupational Therapy from Nova Southeastern University have led to this point in the dissertation process. Having had an opportunity to consider the topic of my dissertation from my life roles of mother, grandmother, faculty, administrator, fieldwork coordinator, occupational therapist, student researcher, and occupational being, I realize that I enter this research endeavor with certain assumptions. These assumptions will need to be addressed openly through the process of pre-action bracketing.

In my role as a pediatric therapist, I have worked with children with autism and their families in multiple contexts (school, hospital, community, home). I have provided individual and group occupational therapy services for children with autism, collaborated with teachers, and spent time with many mothers and families of children with autism. From my perspective as a grandmother and mother, I empathize with these mothers in their concern regarding their children. As a new therapist in a hospital setting there was a great deal of attention focused on the child with autism. In the home setting, the role of the family became acutely apparent. As a doctoral candidate I come to this research project with a broadened sense of maternal and family needs including the need for social, family and community participation when raising a child with autism. In speaking to different mothers, on two separate and coincidental meetings, occurring within about one month of each other, I was introduced to the concept of out-of home placement of the young child with severe autism, and struck by the mother's stories. Recognizing how little I knew about out-of home placement even though I worked with children with autism and their families for so long, I felt compelled to study this topic. I also desire to share findings of this study with others, so they can also understand more about the lives of these mothers, children with severe autism, and family experiences leading to the decision for out-of-home placement. It is my belief that these mothers need to tell their stories, so that others can better appreciate their situation.

In a phenomenological pilot study to this dissertation, the topic of placement of the young child with severe autism was explored through the perspectives of two mothers who had experienced this phenomenon. It became clear that the greater issue was the decision-making process that led to the placement. A sense of feeling overwhelmed, isolated or restricted from typical family and social interactions and occupations was articulated by the mothers in this pilot study. Through my public health perspective, I believe that federal, community, and local supports and resources can indirectly contribute to maternal and family health. In conducting phenomenological research, purely from the mother's perspective, I expect an authentic representation of the mothers' lived experiences of the decision-making process for placement of their children outside of the home to emerge from the data. My administrator and faculty roles contribute to my understanding that to strengthen a program, administrative support is necessary and that to elicit the appropriate supports, others with differing roles, perspectives and agendas must understand. Thus, the mothers' perceptions of the decision-making process for out-of-home placement of their children, reduced to the essence of all their experiences, may serve as a powerful mechanism to elicit the understanding and support that they need.

Currently, there is a strong legislative push for prevention of out-of-home placement. My personal feeling on this issue is that for some parents, placement may be the most appropriate option, and that parents who wish to raise their children with autism within the home should be given the appropriate support and *real* opportunities to do so. My belief is that parents of children with autism need particular services for a particular situation. The issue is the to understand more deeply about the type of services the child/family families and their potential to enhance capabilities, while presenting real opportunities to raise the child at home without compromising the family unit , maternal and family well-being or their occupational freedom.

If parents are afforded *real* opportunities to raise their children at home, and make the decision for out-of-home placement of their children, then I believe that the placement is the right choice. When parents have not been afforded real opportunities to raise the child within the home, and choose to place the child out of desperation, then human cost may be too great for all.

Appendix J

Summary of Mothers' Responses to the Interview Questions

Appendix J

Summary of Mothers’ Responses to the Interview Questions

“Contextual Aspects Influencing Mothers’ Placement Considerations For their Children with Autism”

Summary of Mothers’ Responses to the Interview Questions

What are/were your feelings about the decision-making process for out-of-home placement of your child?

Mother #1 *Placement*	I had many feelings…it’s all so complicated…Here is what you are not supposed to say to people, the overall feeling was incredible relief and initially I struggled with myself [in] how much relief… I was feeling…And so as you know, as a mother what I was supposed to be feeling was incredible sadness, incredible, which I did feel the sadness, but I was supposed to be feeling just horrible that… I was placing my child…it was a struggle for me [conflicting feelings between sadness and relief]…I was thinking about my other (two) children...(I felt) resentment that this is what I had to do to make our family be able to function, to help Ellen (child with autism) to function….(it was) hard and painful in that, this is what our life had become, and that you have taken the first baby of yours and having to send her away is very painful." Mothers just don’t do that. That was my message to myself. Now I went away to boarding school, my God, you don’t need all those personal philosophies, but I went away to boarding school, my dad was in politics in my small town where I grew up. The schools were really bad…it was a small Tennessee town, and so my

Mother #1 cont'd.	mom really wanted me to get a good education. So, I had a great experience. In one sense, Helen was young, but in another sense, I thought well it this is not the worst thing. So this is the bliss side. We had checked lots of therapists… over her life, so it [was] not that we weren't getting a lot of input...she has always taken 4 types of meds, we [had] tried 23 medicines for her…So now, Matt thought it [Helen's placement] was the worst thing. He wasn't used to boarding school or anything like that and so to him it was…yeah a different experience… and what I kept saying to him was...you are not the one taking care of her all day. We agreed about the plan. His plan was to get her home as soon as possible. In other words, if we could find a different school placement. This was a temporary setting for him…My view was, oh my god, I can probably breathe, and I don't really care how many years this lasts, if I am breathing. So...we went through [with] it. So, [Helen was] seven hours away and so it was hard to see her and every time we went on the weekends, it was just horrible…she would hold on the car seats and God, you know it was awful…I mean…it was awful…She would just scream…don't leave me and so it was terrible and then at the same time she was becoming more independent…I heard her teachers say…[it was a] big difference. [The family had been] babying her, which you do a lot in a household to keep the peace… Matt started looking for jobs in Kentucky, and I agreed with that…to be closer to [Helen]. Helen was doing a lot better. We thought we would try to bring her home and so we did. So she has been at home for almost three years now…I think that there is something internalized in her brain…it's amazing that…she doesn't get like there are four quarters in a dollar, she still doesn't get that…but the thing that she does get [is that I] need to watch myself if I am going to stay at home and to her it was worth everything. We got the therapist and we all said, if you are going to stay at home, then you can't fall apart, you can't do all these things…So she

	seems to understand that enough that she can get some control [over her behavior]. We have [Helen's bedroom] in the basement which a lot of people think is mean, that she is in our basement. It is a finished basement…but it works better…it's quiet…she can isolate herself when she needs to.
Mother #2	As long as I am emotionally and physically capable, I will do anything I can to keep our family unit together." I thought about placing Kenny in a residential home one day, but the thought of letting him go brings me to tears. I don't know what Kenny's future holds, but he may one day have to transition out of the home and I hope God will give me the needed strength…I am still thinking that I could never put my beautiful baby boy in a group home.
Mother #3	Heartbreaking…Heartbreaking. Very painful. Very…I mean…If I was talking with my spouse, it was just very difficult… where he was more practical… he could see things that might be necessary… realistic in looking into the future…I'm the mom, you know, and that's my baby. "Situations in our home were dangerous… Hitting, pinching, being unsafe…running around, being destructive. She had a younger sibling [Jeremy, age 3 at the time] , so that was a big, big, big issue". [Mattie was] running out of the house into the street." [We] "spoke about it [the potential placement] for about a week and a half". "It was a very stressful period of time…what felt bad was that I couldn't do anything to help my child, that I felt hopeless…or not even hopeless, just really helpless…that I couldn't do anything to make her feel more comfortable. And then I felt like if I had to place her in a home, I would be a bad Mom, like I was just giving up." "[Mattie's behaviors had become] very dangerous. She hurt herself badly and had to hospitalized." It was medication related…Things improved… on a better system, so we took a step back… she went to school and…things

	improved a little…things improved slowly and she is much more stable now."
Mother #4	I would not be able to handle having my child placed at a residential home. I [would] find it more difficult not to know what is happening to my child. It would not relieve me, but that's just me. Each child and each parent's family circumstances differs… [maybe] the parent becomes ill, or divorce, economics, or the other children's safety in jeopardy…
Mother #5	It's very emotional. Something you never think you'll ever do…it got to the point of, it's a necessity. You feel so guilty because you're like this is my child, I should be the one caring for her… my mother is a little bit elderly and could not be around Katie. Well, since I moved to Arizona, Katie was five, and since my mother saw how she, she was, she said you know she needs to be institutionalized and I was like what? ... And of course, my brothers were on that same note and they just didn't want anything to do with that. [Katie] was six at that time, she was almost seven and her care provider …married to an older man and she said, hey, I will take her as a foster child, and so we talked with the of State of Arizona and they said, yeah, just this is a temporary thing and we'll figure out the logistics later .
Mother # 6	In my mind, I have made a pact with my child and I do not think that anything could break it. I mean even my own marriage. That's one of my fears, that I would be in that position [To be placed in a position to have to place Albert]. So…parents who have decided to put their kids…I can understand why because there comes moments in time for instance just like the bowel accidents, the urine accidents, like when things are going bad, that's what happens to Albert you know. So it's control like right now he is going through puberty, so we are having more accidents as night, not in the day. But that's the stressful part, it's like you know you are up at night, you are bathing, changing the beds… your lights are

	on in the bathroom, you are doing laundry because it's going to ruin the clothes… So you do it right away or else, so you are doing it [laundry] at 2 o'clock, 3 o'clock in the morning. Now you went to bed at 3 and you are getting up at 5 and now you have an hour in the middle where you're like….and you do it four nights in a row, and you feel like you are going to die. And so that's - I can see why they would say that…it is very difficult for me.
What about your experience of raising a child with autism influenced/could influence your entry into the decision-making process for out-of home placement?	
Mother #1 Mother #1 cont'd	When we were living in North Caroline, Helen had all these issues in school…It was hard for her, any kind of change in her schedule. …she just constantly melted down over changes in schedule. It was just horrible and by melting down, that was you know, typical autism behaviors, screaming kicking, hitting, grabbing and throwing… constant. From the time of being a baby, Helen could not be seized. She was always, always…so aggravated and one day [going to elementary school]. This is before she could ride the bus, the bus was just too much for her to handle. It was too loud and…she had separation anxiety. So Matt was driving her to school and he did no have his priest clothes on because he was going for a [medical test]. And I was in the car because I had to drive him home and that was not the routine…Helen got so upset over this change that she unbuckled her seatbelt and she crawled from the back, while Matt was driving …and she grabbed off his glasses and I mean, he couldn't see and he was driving…and I am trying to grab her…it was so horrible. Just as in any child's life, you have these pivotal moments…you know, sort of despair and in an Autistic child's life and so it was just this horrible moment and we sent her to a camp for autistic children one summer and it was only like a three week camp and it was such…not having to deal with the day-to-day was so incredible. The sense…that I couldn't breathe, when went to this camp, it was so remarkable to me and the guilt that went along with that you know, it was ridiculous, and so when she came back from this camp she apparently hated it. She hated the whole camp experience and it was a therapeutic camp and they knew what they were doing, but she hated it.

She hated being out of the routine and the day she got back, she was so angry that Stephanie, my middle child was standing around her room…in the door frame, and Helen just knocked the hell out of Stephanie, it was very dangerous and Stephanie hit her head and it was bad. And I was so angry at Helen for, I couldn't believe the anger I felt towards my own child and that's another thing that you [mothers] are never supposed to say about this child. You are supposed to just sort of internalize this aggressive behavior. Helen had, at one time broken a mirror in her room, which scared us for her own safety and we had to, of course remove every single thing from her room. There wasn't much in there to begin with, but you know we started feeling like we needed a rubber walls….she couldn't have anything in there. And finally, she had a wooden hairbrush and she got mad at me over something and threw that hairbrush when I turned around to walk away, and she has always hated, you know…so many therapists say, you need to walk away when she is….

Well, the way she dealt with that was I mean threw the hairbrush as hard as she could and it hit me, I am just, as I am talking…I realize we have a head theme…she hit my head as hard as she could…and I had a huge bruise and it was just painful and again that anger swelled up in me…Well to be treated that way…I grew up in a very peaceful home where you just didn't do that kind of thing. My brother and I never hit each other, there was just not that…we were probably repressed and that has its own issues which my husband [would] point out. But still that was just so foreign to me and so mean that it was hard to take. So those were some of the behaviors leading up…all that occurred in South Carolina…then Matt got a job in North Carolina…and we loved it there, but the middle school Helen was in was awful. The teacher was young…she was already burned out…The school was overcrowded and I went against, there are many cultural norms. What people kept saying to me is …she needs to be mainstreamed… I tried to mainstream Helen, the whole time we were in South Carolina and I saw[that Helen] was totally distracted by the other kids…she [couldn't] keep up…she was anxious even with a personal assistant…she just couldn't function. I was going to place her in a classroom that had fewer kids and …this classroom was still overcrowded. Her teacher was not showing up. She was taking off days at a time and the assistants were running the class which…they weren't qualified to run the class. I was going over there

	every…it was just ridiculous…And so one day Helen came home, on the bus, she was getting her glasses knocked off on… the special needs bus and I am thinking, you guys can't handle this, you can't protect a kid who has got, it was just amazing and then they called me from school one day and a regular Ed. Kid had knocked her head against a door frame and she came home with a big knot on her head. So there were…these signs…this is a terrible placement and I was looking for other [placements]. There was a private school, but Helen at that pointed hated to ride in a car and I would have at least a 40 minute commute twice a day with the kid who hates to be in a car. I asked the doctor in a developmental disabilities clinic…I said maybe I need to home school her and…he said I think if you do that, your marriage will fall apart and the rest of your family will not be able to sustain in such a way, because… you are going to be exhausted. My parents have always been very supportive as much as they can …from a distance, because we moved so much. And my dad said he would help us financially. We just started to talk, we just started thinking what are we going to do? She was having meltdowns all the time and it was really affecting my middle daughter, Stephanie who was about nine…and this is for your next study… Hospital, [Ohio] and it was nothing…Stress. So God, that was, that's been a hard piece. So we just started looking at the possibilities and that is when we came up with the school in Kentucky and just started researching and talking about it.
Mother #2	I will not be here forever…I may not be able to care for him one day…My body is breaking down and I am exhausted…due to all of the physical challenges and endless sleepless nights." "If it gets to the point where we can no longer handle my son and he is endangering his sisters, then I will look into out- of-home placement."...but if I can get some strong arms/aids, to work with him in the home, then I think that is preferable, and will cost less for the government to pay for"

Mother #3	[Mattie's behaviors had become] very dangerous. She hurt herself badly and had to hospitalized. "It was medication related…Situations in our home were dangerous… hitting, pinching, being unsafe…Running around, being destructive. Mattie, [age 6 at the time] had a younger sibling [Jeremy, age 3], so that was a big, big issue".[Mattie was] running out of the house into the street." [We] " spoke about it [the potential placement] for about a week and a half".
Mother #4	I could not imagine mothers placing their children outside of the home "I find it more difficult not to know what is happening to my child. I would not be able to handle having my child placed at a residential home. It would not relieve me, but that's just me. Each child and each parent's family circumstances differ."
Mother #5	"It was safety. I have another daughter who is a year older than Katie. Katie would push her sister and myself into traffic. She would throw things…dishes, shoes, silverware…try to rip things off the wall, like a TV that was mounted, you know mirror. There were lots of things like that." "grab my arms when I was driving…throw things at her sister in the car"
Mother # 6	One of my darkest fears is that Albert will have an epileptic seizure and die. You know, he doesn't have seizures right now, but in puberty that's going to begin for a lot of these children with autism. My greatest fear is that I will lose him. My only hope that I ever had after he was diagnosed is that he still has longevity, he did- nothing has been cut away from him you know like children with Down Syndrome don't live past a certain point…Friends [have put] their kids in placements. But….from my perspective with each time I have had a child it is like a vow that I take to each of them. And it means that no matter what, I'm going to be there. And if I were to put him in a place, first of all would he be sick every day? Yes, because [he would] be exposed to gluten and he has celiac disease…it

	leads to cancer…it leads to onset diabetes. And for his own physical safety, I mean but besides that emotional well-being. You know it's my job to make sure that his life is as smooth as possible, now… That being said, I'm going to die one day and so I'm hoping I live [till] 90, you know then Albert will be like 60 something…So I can give most of his life at my home. But then…do I expect my kids to take on this responsibility? I don't know what to expect. I've seen siblings want to take on this responsibility, because they are so attached. That's why I had to prevent the resentment between the kids based upon the fact that Albert has autism…I try to make everything fair so he would be even. I want to make sure they love each other. And that's the most important thing to me. Now they go on in life, will he be in a placement? Maybe, maybe when he is in his 60's. I don't even – sometimes I have fear, I have friends of mine who are now placing their kids in placements and I say to myself, they are ahead of me…Albert is 11, their children are 20. What will I feel like when he is 20? Here I am big and pregnant, and I'm going to be 40…39 this …July. And I'm bent over [the] tub cleaning up my child's accidents and I'm exhausted…Am I going to live [to] 60…am I going to be physically able to your know…I am not in their shoes what makes them feel like they have to do this? Maybe I'll feel that way later on….So that cause me a lot of fear…that I will feel that way…but I do know myself…I'm a person that is rigid. So when I decide something, I don't really change that much, I really don't, you know …I did think of that…Albert, even when he was diagnosed, that it was me and him…[mother cries] So sorry…I didn't want to cry…You have kids, you don't give up, so….
As a mother of a child with low spectrum autism how did you feel about your experience with family and community life (participation, occupational needs, family, going out as a family, home routines)?	
Mother #1 *Household Routines*	They envelop you with their routines…Helen has never liked TV, she will not sit and watch a movie …she is very, very intense. She has to be constantly stimulated.
Self-Care	When she started her period and I tried to explain it, but you just, how much of that goes in…And I was showing her the pad and how to put it in and she ripped the pad off, I just wrote a big story about that, that's why I am smiling and she put through so mad, she put

	the pad in her mouth and just ripped it apart into little shreds, you know, and then she spit it out in my face and you know, there was this kind of dual nature but I thought, yeah, that's probably how all of us feel, you know, and I said her, I said Helen I understand, it's horrible, it's the pits. But you can't spit that on my face. You can't spit that on my face. So I was furious because she is spitting at me and then I am passionate… I left. [went out of house]…and called Matt to come home. I was pretty mad though, I left because she was screaming which always, which scares our dog, which scares Ellen and Stephanie and that makes me mad, that's when I get mad. And I actually left her. I took the other girls to a movie and I called Matt and I got him out of a meeting and I said you need to come home, and he did, but that's the only time I have left her, because I just couldn't, I thought I was going to hit her.
Mealtime-Cooking	
Bedtime Routines-Sleep	
Family Outings and Occupations	
Community Inclusion Tolerance Hospitality	I've been on the board [disabilities] and it's a policy group and an advocacy group…I actually had to take a break from it because I decides to go back to school … sort of… something for myself and also to be involved in the schools of my other two children and the council has not liked that decision because they think I am abandoning the cause…Oh gosh…it's so loaded. You know, I think that what you were on a local level, I would say…and this a…I come from a spiritual understanding…I would say that there is a real lack of hospitality towards people with autism and people with disabilities. And by lack of hospitality… *Willful Hospitality* … I mean…[being in a store with all your children and the child with autism has a tantrum as you are on the

	check-out line]. And I think the situation…arouses so much fear in people and panic…and it's much easier not to do anything. But I think that's what I would ask for on a local level. It's just a "willful hospitality" towards these people…and that's something that they [people with disabilities] don't get. The feeling of being included and asked to be included, I did a lot of workshops on… incorporating people with disabilities into faith communities which is something I speak about a lot. You've got to have a huge network and I hate to be, you know…part of my cynicism I think on a policy level is those networks are fewer and fewer. Unless you have endless funds, those networks…you really have to seek them out…and you have to be in the right state. the worst, worst part is you know, Helen has no friends and part of it is that she doesn't know how to be a friend and we tried to train her and teach her…but I think that social aspect, the relational aspect is just this huge missing piece, and it is really sad and nobody deserves to live in a world, you know, and…they shouldn't have to live in a home with their parents, that's no fun. But that's what they do because that's safe and because there is nowhere else to go and because parents are scared. So, I am speaking to you sort of just where I am at my life stage. Those are just two of the big pieces…[community inclusion, and life transitions].
Wandering-Elopement Bolting	
Shopping	*Shopping?* Never ever, never ever, never ever! [mother avoided shopping with Helen]One of the boys in [Helen's] class asked her to go to the prom. So [Helen, now age 17] got a dress and we took her to the alterations place. She was with her sister, [Stephanie now age 14], and she put on the dress. It didn't fit and she [Helen] was just furious and she started screaming at the top of her lungs and there are all these people in there getting stuff.…and she grabs the straps and they start ripping…and I am like no, and I grab her hands and this is when [the woman who does the alterations] came in, and she

	has this most calming demeanor, and she said…"I make you beautiful" and it was just…[so] effective…[she said, "okay, let me get you dress up, let me get you dress up". Just to have her calm down, the woman[said]"Helen, you are going to look like a princess and I am going to help you" and she just pinned it up really fast and as soon as the pins were in it, Helen…was okay…and I was so…grateful
Movies	Helen has never liked the movies. Now she will go and fall asleep which is good…we call it the best expensive nap that there is.
Park	No friends…The first time we had friends is when we moved to North Carolina. That was kind of the first time we were really honest and just said, you know, this is our family, this is who we are and they just embraced that, because that's the kind of community they are.
Restaurants-Eating Out	Horrendous-even now God, Dinners were so awful, going out to dinner. We could not go out to eat…Stress. So God, that…has been a hard piece, we couldn't do anything
Vacations Travel/Hotels	No none of that…it makes me laugh because you think you know, people talk about going to Disney World or something like you just….but it's a lifetime, yeah. We have figured now… how to go on vacation. My parent's keep Helen and that's just been in the last three years that we gave ourselves permission, you know…to go on vacation.
Spirituality Religiosity Culture	I come from a spiritual understanding…I would say that there is a real lack of hospitality towards people with autism and people with disabilities. And by lack of hospitality…… I mean…[being in a store with all your children and the child with autism has a tantrum as you are on the check-out line]. And I think the situation…arouses so much fear in people and panic…and it's much easier not to do anything. But I think that's what I would ask for on a local level. It's just a "willful hospitality" towards these people…and that's something that they [people with disabilities] don't get. The feeling of being included and asked to be included, I did a lot of workshops on…incorporating people with disabilities into faith communities which is something I speak about a lot.

	I probably need to live in New York, because nobody here [town where she lives] talks, but you know, and I had a mom come up to me and say there is a child with [a] disability and [the child] is very loud and the mom stopped bringing her to church. [this mother, being concerned about the mother, reached out to the other mom out of concern when she did not see the mother and child in church anymore.] The mother told her that she stopped bringing her [child] to church because people were staring…she said that nobody has ever asked who we are or you know… what's going on and so that kind of thing just incorporating [that kind of concern].
Holidays Special Events Family Celebrations	
Going out with Friends	Helen has no friends and part of it is that she doesn't know how to be a friend and we tried to train her and teach her…but I think that social aspect, the relational aspect is just this huge missing piece, and it is really sad
Family and Social Support	My family was two and half hours away which is the closest they had ever been. But I had never lived in the same town as my family during my married life we've been married for 22 years…So we've pretty much done it all. The autism groups are a lot of times focused on kids who don't have low IQs and it's a whole different ballgame.
Sibling Impacts	<u>Negative Impacts</u> [Stephanie] had to have whole lot of therapy. What she started doing was internalizing everything to her stomach and two years ago, her stomach started hurting so bad that she could not go to school, it was just constant and so we …took her to Children's Hospital and it was all stress And I was grateful to Stephanie, my middle daughter who showed for the first time…she felt like it's hard, it's hard for Helen. So, she had moved from a point of embarrassment to compassion and that's a huge leap for a sibling. *<u>Positive Impacts</u>*

	Oh, without a doubt and then she did a mission trip this year and she went down to New Orleans and helped to do some Katrina work and came home and said that was the best experience of her life and then she was talking about it, she had, you know, from living with Helen, you know, people's, you just know that people's lives are hard and I am not sure that would come, that wouldn't necessarily have come. So I think that's, nothing good. There have been two big pieces of Stephanie's life that we have seen when she is in eighth grade and she is a teenager and she has all that self-centered thing that teenagers are suppose to have. But they had a big project they had to do this year and it's called Capstone and it's a year long project, it's a presentation, and she chose to do autistic kids and so her whole presentation and she is so proud of it, is on her experience with Helen, and two years ago she didn't even talk about it. She could not even talk about it. It was so embracing, it was so…
Life Transitions	I think that social aspect, the relational aspect is just this huge missing piece, and it is really sad and nobody deserves to live in a world, you know, and…they shouldn't have to live in a home with their parents, that's no fun. But that's what they do because that's safe and because there is nowhere else to go and because parents are scared. So, I am speaking to you sort of just where I am at my life stage. Those are just two of the big pieces…[community inclusion, and life transitions] I think that…autistic family members need places to live…that show where we [the grown children with autism] are in our life stage. I think they need to be in an apartment with other autistic people and have caregivers…So they *Life s* have some social [life]… Where do they go next and what's next and how do we incorporate them into our communities because that is something they [need to incorporate] And part of going to a school, is that their life is sort of [in the norm].
Isolation/ Marginalization	I think that…autistic family members need places to live…that show where we [the grown children with autism] are in our life stage. I think they need to be in an apartment with other autistic people and have caregivers…So they have some social [life]…

Maternal Stress and Health	
Marital Stress	Then for your third study…the marital stress is ungodly…clergy life has its own stresses, but people always talk about how the death of a child affects a marriage and in some ways…[with an] autistic child, you experience a lot of loss…what you expect from…being a mother…from your stories and your dreams forever…So, I think there is a lot to be said about how you are living in loss.
Split Families	We have figured now… how to go on vacation. My parent's keep Helen and that's just been in the last three years that we gave ourselves permission, you know…to go on vacation.
Occupations: Necessary and Meaningful and Time Use	*<u>Necessary Occupations</u>* *<u>Meaningful Occupations</u>* *<u>Time Use</u>*
Participation Facilitators/ Barriers	
Environments Enabling-Disabling	
Economic Status Finances	
Employment	
Medical Expenses	
Vaccine	
Mother #2	Following routines are extremely important because he gets upset by change. He will bite, pinch or flop down

Household Routines	because he can't process why the routine has changed. When things remain predictable he feels more secure. "We are constantly struggling with how to maintain a "normal" family life. In SC, we had lots of in-home help which was a godsend yet it was hard to have a normal lifestyle with outsiders constantly in our home. I could not have survived the first few years after 2 children were diagnosed with autism without the help but always having people in our home caused different stresses & disruptions for our family life. In Florida, we have absolutely no help which is much worse.
Self-Care	It is challenging at home and out in public because Kenny just got potty trained at age 7 yrs. and [he] is still not fully trained to wipe or tell us he has to go. I am worried that I am too tired to cook his special GFCF, brush his teeth or give him the supplements he needs.
Mealtime-Cooking	We are unable to get our son to sit at the dinner table and eat with us without an aide so we let him eat alone in front of his computer while the rest of us eat together. I am worried that I am too tired to cook his special GFCF foods.
Bedtime Routines-Sleep	We never get a good night of sleep. Kenny is prone to waking up unexpectedly in the middle of the night. This requires that I sleep in the same room. I sleep lightly, waking every time he moves or coughs. I cannot remember the last time I slept for more than 3 or 4 hours straight.
Family Outings and Family Occupations	I am unable to take the children out as much and as a group of siblings. Without an aide, I hardly take Kenny out in the community to teach him safety, learn how to act appropriately and get socialization. We try to only attend activities sponsored by autism foundations or special needs organizations. We always have to worry about Kenny escaping, disrupting or becoming aggressive to others, masturbating in public or melting down. So we are very careful about where we go. Since we moved to Florida, without an aide I am unable to take my kids out as much, even to autism-friendly events.

	Our lives are hectic and chaotic, always putting out fires or worried that Kenny will figure out how to get out the doors and get lost or run over by a car. My husband can't go fishing or play baseball with him because he doesn't "get it" & he will run off.
Community Inclusion Tolerance Hospitality	I have to constantly be an advocate, develop a thick skin & shrug off disapproving looks when Kenny is wreaking havoc in public, have patience of a saint when dealing with him at home… [Kenny]frequently throws tantrums because he can't speak in sentences & continually repeats words or phrases and speaks immaturely so people are always staring at us or asking me what is wrong with him. Our lives are hectic and chaotic, always putting out fires or worried that Kenny will figure out how to get out the doors and get lost, or run over by a car. Without an aide I am unable to take my kids out as much, even to autism- friendly events. I have little in common with parents of neurotypical children & the differences in development are so obvious that I tend to only make play dates and associate with other special needs families because I don't have to explain or apologize for his behavior.
Wandering-Elopement Bolting	*High Risk* He can too easily get out of the door, pull fire alarms, run out emergency doors setting off those alarms and flicks lights on and off everywhere we go. [I have to] implement safety equipment & locks. Meltdowns happen more frequently in airports & restaurants because he gets overstimulated by the noise And the lights & negative behaviors increase the longer we are away from his usual routine. [I want] coverage for GPS tracking bracelets for all autistic children who elope since the waiting list is 19,000 people long and about a 7 yr. wait. I was told that it was next to impossible to be bumped ahead of the list as a crisis situation unless your child gets hit by a car or severely injures himself or someone else. I would like to see Medicaid transfer from state to state, GPS tracking bracelets for all elopers, in-home behavioral therapy programs and other therapies available and respite for parents.

Shopping	[Shopping] is a stressful event so avoided as much as possible. I can't stop to go to the bathroom or buy a loaf of bread when I have all the kids in the car. We always have to worry about Kenny escaping, disrupting or becoming aggressive to others, masturbating in public or melting down.
Movies	Movies are stressful events so avoided as much as possible. He got kicked out of a movie theater simply because he was laughing too loud.
Park	Just a simple trip to a park requires preplanning and scheduling an aide, splitting up the family or my husband to agree to go with all of us. Taking Kenny to a park requires being on top of him so he doesn't hurt another child or himself on the equipment because he is not completely aware of where he exists in space and does not know how to take turns or play appropriately so he may sit at the top of the slide blocking it so the other children cannot go down so they will give up or they will try to step over him. Then they ask me what is wrong with him. He may take his pants off, urinate or play with himself in public. He may suddenly grab a person's glasses off their face, pinch, bite or choke. He may get on top of a toddler in a jumpy house and not know he is suffocating them.
Restaurants-Eating Out	Customers may give us pitiful stares; complain about him or just move away so we always try to get a table far off in the corner so we bother the least amount of people. Meltdowns happen more frequently in airports & restaurants because he gets overstimulated by the end the lights & negative behaviors increase the longer we are away from his usual routine. Going to restaurants [is a] stressful event…so [it is] avoided as much as possible. We always have to worry about Kenny escaping, disrupting or becoming aggressive to others, masturbating in public or melting

	down
Vacations Travel/Hotels	Meltdowns happen more frequently in airports & restaurants because he gets overstimulated by the noise and the lights & negative behaviors increase the longer we are away from his usual routine.
Spirituality Religiosity Culture	We can't attend church because they [the three children] can't sit still or stay quiet.
Holidays Special Events Family Celebrations	Our elderly parents are becoming more & more intolerant of his messes & unpredictable and uncontrollable behaviors& prefer that we don't bring him over to their homes or go out to eat with us.
Friends	He has never had a friend and has no idea how to make one. He is so low functioning he is not even aware that he doesn't have any friends. I doubt he could even participate in special Olympics unless he had 2 aides.
Family, Friends and Social Support	[moved 3 times - 3 different states - living in current state for only 1 year] Our elderly parents are becoming more & more intolerant of his messes & unpredictable and uncontrollable behaviors & prefer that we don't bring him over to their homes or go out to eat with us.
Sibling Impacts	We are always separating the family because I can't take all 3 children anywhere without an aide accompanying us. Without an aide I am unable to take my kids out as much, even to autism- friendly events. I have little in common with parents of neurotypical children & the differences in development are so obvious that I tend to only make play dates and associate with other special needs families because I don't have to explain or apologize for his behavior. Emily, who is high functioning autistic, resents him because we allow him more time on the iPad simply to keep the peace in the house, go out less because he is too hard to manage and may run off & we are too tired to do much else but clean up his messes and put out fires that he causes. We are always stressed & frazzled

	and don't have the energy for more. I have not been able to schedule his sisters for brownies or a gymnastic class because I have not been able to afford or train a babysitter. Our preoccupation with Kenny's needs has taken away from the girl's social friendships and school & sports activities that they and we should attend. We are overworked and overburdened & his siblings are also under a great deal of stress. I worry about the future of his sisters. I am afraid he will seriously hurt them one day. I wonder if his sisters will feel comfortable bringing their friends over to our house when he has violent outbursts, meltdowns or just flaps around like he is mentally retarded? Will they be embarrassed about the condition of the house? How will this affect their social friendships and ability to participate in school activities? Will I be able to get them to outside activities so they are well-rounded?
Marital Impacts	We are trying hard to help our autistic kids but it takes a toll on our marriages, jobs and mental health. We need a lot more than what is being offered. The ultimate goal is that Kenny will get enough appropriate medical help to lead a pain-free & functional life no matter where he lives.
Split Families	We are always separating the family because I can't take all 3 children anywhere without an aide accompanying us. I usually leave him behind and only take his twin sisters to visit my parents, go to birthday parties or functions.. If we do try to attend a function or event, we take 2 cars knowing my husband will have to leave early with Kenny.
Life Transitions	I don't know what Kenny's future holds but he may one day have to transition out of the home and I hope god will give me the needed strength. I would make sure it was a program where he would get the necessary medical treatments, therapies, special diet and could learn how to properly behave and adjust in society. I would never consent to psychotropic medications. If I am able to be involved in his residential program and I see that he is healthy, happy & moving forward toward reaching his full potential and the rest of the family is able to grow and heal, then that is what is important. Hopefully, there will be more options for him as an adult as far as autism high schools, colleges and

	vocational training after he graduates. Placement in a group home setting may be inevitable if it is in the best interest of our family. But as long as I am emotionally and physically capable, I will do anything I can to keep our family unit together. I will move to New York or another state to get the help he needs if I find that there really are NO services in Florida. I believe with the right kind of supports, accommodations and assistance I can keep my son home and get him significantly better.
Isolation/Marginalization	I have not been able to afford or train a babysitter. We can't attend church because they [the three children] can't sit still or stay quiet.
Maternal Stress and Family Well-Being	I have not had 1 hour of respite or help since August making it impossible to fill out the piles of applications necessary to get on the painfully long wait lists for services so I don't feel like a prisoner in my own home. I don't understand how services can vary so much from state to state. When we moved from SC to FL in August, my son lost his Medicaid Tefra pan and it was not transferrable to a different state so I am starting over from scratch trying to figure out how to get services. I left behind over $100,000 of services for a move to Florida to enroll both autistic children in an excellent autism public charter school. The cost to educate a child at this school is $60,000 because of the individualized curriculums and high student to teacher rations. Thankfully, the tuition is free because it is a public charter school but parents are asked to help with fundraising and volunteer their time. My body is breaking down and I am exhausted. I am sure I am aging faster than my peers due to all of the emotional and physical challenges and endless sleepless nights. The stress has taken a toll on both of our health, especially my husbands. He is at end stage liver failure and needs to get on a list for a new liver but he doesn't want one because living with autism is difficult, expensive & overwhelming so what is the point prolonging his life.
Marital Stress	We fight about everything from financial problems to what protocols to do or not to do.

	My husband has left us on several occasions because of the stress & my son was so distraught he would bite me because he could not express himself any other way.
Isolation/Marginalization	I realize raising Kenny is a life-long challenge but it is also a labor of love. As long as there is a breath in my body, I will continue to surround my son with the right doctors, therapists & schools that are equipped to deal with autistic children who see his potential because he is capable of great progress.
Occupations: *Necessary/* *Meaningful* *and* *Time use*	*Necessary Occupations:* In SC, I spent most of my time attending IEP meetings, taking the kids to their therapies and managing, training & scheduling all of the personal care aides and behavior therapists. In FL, I am chauffeuring the kids back and forth to school because the charter school is not providing transportation. There are always doctor's appointments, supplements and special protocols to follow. Life is always stressful with an autistic child much of which results from the cost of therapies, cost of attorneys & advocates to advocate at IEP meetings, time involved with driving to therapies, decisions on which protocols to follow & who is going to administer them, fights with insurance companies over service denials, credit ratings going south, constant debt, expensive moves to get better services, etc. [I have to] stay up to date on new tests & treatments. I have not had 1 hour of respite or help since August making it impossible to fill out the piles of applications necessary to get on the painfully long wait lists for services so I don't feel like a prisoner in my own home. I don't understand how services can vary so much from state to state. When we moved from SC to FL in August, my on lost his Medicaid Tefra pan and it was not transferrable to a different state so I am starting over from scratch trying to figure out how to get services. I left behind over $100,000 of services for a move to Florida to enroll both autistic children in an excellent autism public charter school. The cost to educate a child at this school is $60,000 because of the

	individualized curriculums and high student to teacher rations. Thankfully, the tuition is free because it is a public charter school but parents are asked to help with fundraising and volunteer their time. *Meaningful Occupations:* *Time Use* I have not had 1 hour of respite or help since August making it impossible to fill out the piles of applications necessary to get on the painfully long wait lists for services so I don't feel like a prisoner in my own home.
Participation Facilitators-Barriers	I have not been able to afford or train a babysitter. I have not had 1 hour of respite or help since August making it impossible to fill out the piles of applications necessary to get on the painfully long wait lists for services so I don't feel like a prisoner in my own home.
Environments Enabling-Disabling	Meltdowns happen more frequently in airports & restaurants because he gets overstimulated by the noise and the lights & negative behaviors increase the longer we are away from his usual routine. The only time he is calm is when we are in the car driving down highways where he can stim on the evenly spaced out electric poles which can entertain him for hours on end.
Economic Status Finances	We are going further in to debt paying for after care which we wouldn't need to do if we had personal care aides and behavior therapists at home working with them after school. I have not been able to afford or train a babysitter.
Employment	I am unable to work because of all of their [the children's] special needs. Many times my husband has to leave work early or take time off to help me. If the government would provide [support for] caregivers, it would give us the opportunity to become more effective parents.
Medical Expenses	We are going further in to debt paying for after care which we wouldn't need to do if we had personal care aides and behavior therapists at home working with them after school.

	Without medical insurance coverage our efforts to resolve Kenny's medical issues have been put on hold. Unfortunately, the states that mandate autism coverage only help a small percentage of people who have state job insurance or don't work for a company with self-insured insurance plans. I would like to continue seeing his DAN doctor for his GI, neurological & gastrointestinal issues but that cost out of pocket. His vaccine injuries caused interstitial seizure activity and he needs to be monitored by his DAN doctor but we haven't been able to afford to see him.
Vaccines	I want the American Academy of Pediatrics and CDC to eliminate unnecessary vaccines, stop adding more vaccines to the schedule and remove all neurotoxic ingredients from the vaccines. I want to government to stop brainwashing the public into thinking that vaccines are safe when they are causing a whole generation of our children neurologic & nervous system damage. I want the government to take responsibility for creating this epidemic and take action to try to end it and assist those families who have been affected. His vaccine injuries caused interstitial seizure activity and he needs to be monitored by his DAN doctor but we haven't been able to afford to see him.
Eroding Institutional Trust-Anger-Resentment	Kenny has severe medical issues and the government is ignoring his plight. I wish the CDC, AMA, AAP would focus on approving effective treatments and reduce the number of vaccines on the schedule, green the few that are left on the schedule, reduce amount of environmental toxins we are exposed to and stop wasting money researching & sidetracking people to believe there is a gene causing this unprecedented epidemic. No epidemic increased at this rate is due to genetics. I wish that the FDA would approve & the most effective treatments that parents are finding are working for their autistic kids & make it mandatory that insurance companies cover them.
	[has housekeeper and babysitters]

Mother #3	
Household Routines	You know what that has made all the difference I think, the extra set of hands for anything and everything makes huge difference. There were times where I had an -- like an older experienced woman and then there were times right now where I have like a younger person, college aged…Going for…Special Ed. or that sort of thing. [Without help] I may not get anything done.
Self-Care	
Mealtime-Cooking	It is very difficult. If she is not occupied, I can't cook dinner. There were times were I couldn't even do anything because I had to sit or be with her. Cooking dinner and doing – it's like she couldn't see me in the kitchen between the dine and stuff, very difficult.
Bedtime Routines-Sleep	Mattie thrives on routines, you know like anything else, when your child is tired and they don't feel like doing anything …it's difficult to get them to comply to what you want to do. [Mattie] has sleep issues so that's difficult. She could be up anywhere from 10 times at night…and she can run out of the door, down the stairs you know…I asked for everything… now she has a night nurse, so that's a big help, so somebody that's there at night to watch her. But I think it's also sleep deprivation and also it's a quality of life for my son if I wanted him to have like a typical like friends sleepover that sort of thing. I have to get -- I don't know if it could happen you know if she is here. I can't do that. She has to be you know either at my mom's house or something else or you know. Well, like she used to run into my son's room and wake him up, he'd be scared to death.
Family Outings and Occupations	[SON] plays baseball and basketball. You know it would be very difficult if I had to bring her [Mattie]. And she sat in it with her. She had a book with her which is great, and she says one, two, three, and as a family we were like this fit. You know so that I mean just feel like we can do certain things.
Community Inclusion Tolerance	I'm very aware of other moms with other situations that I will do anything and everything to help them, but I've also been in a situation where just recently actually I

Hospitality	was in a restaurant and I was dining with my husband and my son, my daughter was at a program and there was another disabled child there with her parents just having breakfast and a couple that was sitting next to them was really rude and purposely got up to move so he wouldn't have to look at this child. It was disgusting. It was just really and like you're kidding you know it was just really just and she was just sitting there, she just looked different. She was having breakfast with her parents and it was heartbreaking to me, because if anybody did that I would open my mouth and I have to say something. I'm very quick to take her and remove her from the situation [meltdowns/tantrums]. I don't think I even realize what's around me unless somebody or some situation is really obnoxious you know…Where I've overheard comments and I've had to say something, but otherwise I would just remove her from the situation and get in the car, try to breathe and move on. I never -- I've never had anybody to reach out and help me like a stranger with -- when I was with my daughter… like I can't even tell you. Don't judge first of all and take a moment and really if you don't have that situation you really should -- it's hard to say. It's like step out of your comfort zone a little bit. If you see somebody struggling and that's just human nature you see somebody struggling don't be so mean, go and try to help out and ask just ask do you need any help. And it's up to you to say like yes or no, thank you I'm okay, but I appreciate it.
Wandering-Elopement Bolting	*High Risk* [Mattie] is a flight risk. Mattie is very social, so she…has to say hello to everybody. She doesn't know stranger anxiety and danger.
Shopping	[Mattie] is a flight risk, so [shopping] is a very hard thing to do. As far as the supermarket, Mattie, I've tried, when she was younger it's easy, can put her in a car and go and do everything. When she got older she is more of like a flight risk. So, we'd have …one person…chasing her and one person…[shopping]It takes two or three times as long. Mattie is very social, so she…has to say hello to everybody. She doesn't know stranger anxiety and danger, so it takes

	long[er}…could be like 20 minutes-different things happen if she is not secure, you know if I don't put her in a cart or something.
Movies	We've tried taking her to the movies before…when she was younger, but not so much as she [Mattie] has gotten older. She doesn't have the patience…it's too long…she will be up and up…it doesn't work.
Park	
Restaurants-Eating Out	We can take her to get a slice of pizza, you know but that's fast and fun and fabulous that four of us can do that… If we go to a restaurant…it's too much…too overwhelming.
Vacations *Travel/Hotels*	And there are certain things if you know if we're thinking about a vacation or something like that there are certain things that I know we can't do as a family unit you know. Oh for example -- like a cruise, I would feel really uncomfortable having my daughter on the cruise for a sake of running around. It's too open of an area. I just would not feel safe you know like could I take her to let's say like Disney or a place where it's more contained and I could have like you know we could bring a stool or something like that that's a little bit…what we did. She handled that. We took her to the zoo in November when we were away. We were in Texas and we took her to the zoo and we had these -- it wasn't like we've rented a carriage and it wasn't like a baby kind of thing. It's like for like little toddler things…
Spirituality *Religiosity* *Culture*	[Goes with husband and son] When I have…an extra set of hands like a babysitter or something to help out. That's to [take the] edge off …But otherwise I feel like I am perched ready to go in a moment's notice afraid that something will happen,…and other times I feel… maybe she doesn't realize that she is missing. So some people say like if God…didn't want you to have this child…you couldn't handle this child, you wouldn't have had this child. I mean it's presentable, but it's hard to think or believe that somebody would intentionally do this to somebody you know…and like

	okay when you are the chosen parent that you're going to be the patient one and you're going Family events, holidays are very difficult. It helps to be like…this is your purpose in the world…I find that to be a bunch of b. s…or like angry with God [for giving me more than I could handle] …Yeah, I feel like that a lot…I think I'm past the point of questioning. It's so funny, I don't feel comfortable [I] can't lean on anybody else for my situation, you know, or like people asking for help from like a Rabbi or a priest. When she is able to go to these different places and she is able to and I have the resources of the community and even if it's from my, you know religious background there are certain groups that she can go to and participate in… So, she gets that little bit of flavor which I want her to have.
Holidays *Special Events* *Family Celebrations*	Family events, holidays are sometimes very difficult. It helps when I have like an extra set of hands like a babysitter or something to help out. That's to edge off but otherwise I feel like I am perched ready to go in a moment's notice afraid that something will happen, yeah and other times I feel it's maybe she doesn't realize that she is missing you know on something. So, it's probably easier for our peace of mind to keep her at home where I know that she is safe with a sitter or something like that and we can go you know like the three of us.
Friends	I happened to have a lot of close friends that I've known for a long time and close friends here… That I met. But it's very difficult to really go there because they don't -- they're not in my shoes. They don't have kids that have an issue. They might have an issue with other things, but it's not as intense or as deep.
Family and Social Support Mother # 3 *Family and Social Support, cont'd.*	When she was…younger [at] school, they had moms'…group that would meet every week and I would participate in that and that was really helpful. But I'm so involved in like her school and with all her therapists and stuff that I'm pretty like I'm running. I'm really involved with her professionals or teachers or therapists. I mean I don't know how [I was] functioning before, but I if you don't have anybody to help you are to just give yourself a break. You could lose your mind.

	Well, there was a time I didn't [have the support] and it's… I don't know how I was functioning to be honest. But it's very difficult to really go there because they don't -- they're not in my shoes. They don't have kids that have an issue. They might have an issue with other things, but it's not as intense or as deep. But there are sometimes where like you just meet somebody that really gets it. To understand… Like I had it whatever… I mean I can say I had a tough day, you know.
Sibling Impacts Mother # 3 *Sibling Impacts, cont'd.*	It's my daughter, who's disabled loves her brother more than the things. He is the greatest thing. She loves him so much. She hugs him a lot. My son on the other hand I think tolerates her. He is younger first of all…And so I think it's also very difficult for him to be with her, or relate to her or that sort of thing…so he just runs… He is like no, no, no. I definitely think so. I definitely think especially siblings, I think that's a big thing. I think especially from my son I was very concerned you know how he is going to grow. He is…you know… he doesn't have a typical situation whereas his other friends might have very typical situation. So, he questioned you know…he is able to talk to me and I constantly tell him you know this is your sister. This is her issues and this is what we got and we'll do the best of whatever we're doing, but I think for him not having other friends that he knows first-hand of siblings that have other kids with us or… it's hard for him. And doesn't get certain things, so that's very when he is a past her you know… And he is three years younger. So that's a big deal. What I'm hoping that he -- as he gets older he'll understand and he'll appreciate and he'll be a little bit more sensitive and he will grow up knowing that you know there are differences in the world and there it's okay to be different or whatever. But he doesn't get it now, but I try to make you know so that he is I mean as best as we can that he…That he tolerates his sister, he is nice to her and [if] he is not, if he says anything mean or does anything you know …like I nip it in the butt I won't have it.

	But I think it's also sleep deprivation and also it's a quality of life for my son if I wanted him to have like a typical like friends sleepover that sort of thing. I have to get -- I don't know if it could happen you know if she is here. I can't do that. She has to be you know either at my mom's house or something else or you know. So, he can't just have his like friends, so that's another that what they have...That's a huge… He cannot. I do not. I think purposely for him, but I do not have play dates unless I have somebody here specifically for her or if she is at a program and I can have as many kids as I want over for him, so he feels easy and comfortable can come and go and that sort of thing that worrying about her. Or he can go someplace… out you know.
Life Transitions	
Isolation/Marginalization	Well, there was a time I didn't [have the support] and it's… I don't know how I was functioning to be honest. You know like you have issues like you've to worry that she could run.
Maternal Stress-Health Family Well-being	Well, there was a time I didn't [have the support] and it's… I don't know how I was functioning to be honest. You know like you're not sleeping. You're very stressed. You are constantly doing anything and everything for your child and you're not taking care of yourself. You're not taking care of your spouse or your other children it's just…
Marital Impacts	You know like you're not sleeping. You're very stressed. You are constantly doing anything and everything for your child and you're not taking care of yourself. You're not taking care of your spouse or your other children it's just…
Split Families	So, it's probably easier for our peace of mind to keep her at home where I know that she is safe with a sitter or something like that and we can go you know like the three of us.
Occupations Necessary/Meaningful Time Use	*<u>Necessary Occupations</u>* *<u>Meaningful Occupations</u>* *<u>Time Use</u>*
Participation	

Facilitators-Barriers	Right, well I have issues about that any time she goes anywhere and like…
Environments Enabling-Disabling	
Economic Status Finances	
Employment	
Medical Expenses	Life is always stressful with an autistic child much of which results from the cost of therapies, cost of attorneys &advocates to advocate at IEP meetings…
Vaccines	
Eroding Institutional Trust Anger-Resentment	
Mother #4	
Household Routines	Lots of pre-planning.
Self-Care	
Mealtime-Cooking	
Bedtime Routines-Sleep	
Family Outings and Occupations	
Community Inclusion Tolerance Hospitality	
Wandering-Elopement	

Bolting	
Shopping	
Movies	
Park	
Restaurants-Eating Out	
Vacations Travel/Hotels	
Spirituality Religiosity Culture	
Holidays Special Events Family Celebrations	
Going out with Friends	
Family and Social Support	My family is not here [in this country}.
Sibling Impacts	
Life Transitions	
Isolation/Marginalization	
Maternal Stress and Health	
Marital Impacts	
Split Families	
Occupations; Necessary/Meaningful and Time Use	*Necessary Occupations* *Meaningful Occupations* *Time Use*
Participation Facilitators-Barriers	This is the right fit. Is this -- can these people handle it, are they trained right you know like this…But you have to deal with…all these anxieties.
Environments Enabling-Disabling	

Economic Status Finances	
Employment	
Medical Expenses	
Vaccines	
Eroding Institutional Trust-Anger-Resentment	
Mother #5	
Household Routines	
Self-Care	I'll go there [to the residential facility] and I'll say, do not let her where clothes like this. It's peace of mind and just different things like I'll say, you know she needs her hair combed or she'll need you have to help her improve through because she had a lot of central issues that she doesn't want like scrub her scalps. So you have to help her, right. She is not going to do it because you really have to help her and you're going to encourage her when you want… but …she needs her hair, she needs her scalp scrubbed….I kept saying, this is a hygiene issue and I am sure this state doesn't want hear that you're not making toilet paper available…. and it's not they didn't have it available, it's just that she does weird stuff. If you leave her alone with that [roll of toilet paper] she'll pick the whole roll…and stuff it down this toilet and have the toilet overflow. So you just have to [do some] monitoring…just give her little bit…time her, you know …you have to stand there, you can't leave her in the bathroom by herself.
Mealtime-Cooking	

Bedtime Routines-Sleep	
Family Outings and Occupations	
Community Inclusion Tolerance Hospitality	
Wandering Elopement Bolting	
Shopping *Shopping, cont'd.*	I mean like, I tried to have her out in public, we're trying to do the – I was a single at that time and I was trying to get some groceries and she is biting my arm as I was trying to pay for the things and then it just gotten really, really bad and so I'd just about had it…If you go into a hardware store and they have toilets on display, she pulls her pants down and tries to go to the bathroom. And she is not trying to be bad, it's just she …the social part of it, she just doesn't get it.in the store, she ended up biting, she is biting your arm and all that was going on.
Movies	
Park	I would take her to playground up until the age she was may be 11 because she started attacking people at playground. At first, I take her to playground where there were no children and I would you that opportunity to sit with and I would have little treat stuff and I'd make her use her sign language to get them, you know. And if somebody brought their kid, I knew I was in trouble and she do anything she could to try to get that kid and try to separate her from them and she'd even, if the parent picked up the kid, she tried to grab the kid and snatch them away from the parents and I mean I've ripped her clothes and everything trying to hold her back off from this kid. Till this day, we don't trust her, we'll take her places that we guard and we do a lot of like manipulation, my husband and I to keep her away from other kids. [Katie] had this thing for smaller people, like children

	and babies and she pushed them and threw them down to the ground and I really don’t think that she was trying to be mean…I don’t know if she really thought that they were real…she was really smart…she can’t write or anything, [but] she would spell with her finger…I am trying to play.
Restaurants-Eating Out	
Vacations Travel/Hotels	
Spirituality Religiosity Culture	
Holidays Special Events Family Celebrations	
Friends	
Family and Social Support	There was no support system. My brother, he was local at that time had small children and didn’t want to have a chances to any kind of physical you know problems and my other brother, he had a very new baby and when [the baby] was like a year old he brought her around Katie and she got physical with the baby and he hasn’t seen her…And that was like seven years ago.
Sibling Impacts	
Life Transitions	
Isolation/ Marginalization	Like this mom that I was talking to, she has found that she is getting more and more isolated from people that she used to be friends with and socialize with and family friends and relatives and whatever because it’s not doable.
Maternal Stress/ Health and Family Well-Being	
Marital Impacts	

Split Families	
Occupations: Necessary/ Meaningful and Time Use	
Participation	
Participation Facilitators-Barriers	
Environments Enabling-Disabling	
Economic Status Finances	
Economic Status Finances	
Employment	
Medical Expenses	
Vaccines	
Eroding Institutional Trust-Anger-Resentment	

Mother #6	*Morning Routine* I start with the laundry. I make the beds. …So, I wake them up really late at 8 o'clock and beat it to the bus by 8:50 [a.m.]. So, I have 50 minutes to you know--I do everything. *Mom and Dad's Evening Routine* Once the kids go to bed this whole place has to come back together like me and my husband, we're like a team. My husband is amazing and so he'll …do dishes and take care of the kids, their beds…I'll [pick up] the toys, scattered all over the place… vacuum. We don't sit down. I mean my husband is really cool because…he knows [what] I'm dealing with all day long, so he lets me have my shows at night. So, I'll watch one or two shows on the couch you know and then he joins me, like last night was an easy night, so he joined me. *Laundry* just for instance things were so chaotic here that we didn't fold laundry, so we used to have all these big plastic bags, and heap them in my bedroom full of clean clothes, so ithe morning we would have to hunt through the bags…[that] might include last season's clothes…So, we got into a routine of…prioritizing what's important I a home, it used to be all about what we could…fix….And now what can we do to make things better. So new went through all of the black plastic bags, about 23 of them…gave away stuff that we .no longer use and now we're folding every single day. Is there a therapy we're missing, and we would strategize that kind of stuff.
Self-Care	I get the kids in the bathroom. I brushed their teeth. I you know wipe down their hair. I dress them.
Mealtime-Cooking *Mother #6 Mealtime-*	*Breakfast* we eat breakfast and I [provide] one breakfast. Today I was late because I wasn't feeling well, so I'm giving them cereal, but normally it's waffles, the maple syrup warmed on the stove, or something warm…and they have like literally 12 minutes to eat and we're out of the door to the buss…so it's literally a whirlwind, you know.

Cooking, cont'd.	*Dinner* It is really hard because you know…I have therapists here …sometimes till …6:00 at night. And when those therapists are here that late, they need my help sometimes. Albert will not want to do his therapy...he is rolling on the floor, refuses to get up. I'm the only one that really has control over him [Albert] to get him back to therapy…it's not just that *Mealtime-Cooking* though…asking me where supplies are…signing bills I don't start cooking until 7:00 o'clock in the evening, so…we're eating at 8:00, 8:30 and we realize the chaos of it all…and we're trying to fix it all…
Bedtime Routines-Sleep	I…didn't really want to be a mom…where I was a drill sergeant. Albert never slept really well and when he was an infant he barely slept. He screamed for six hours and I had to hum into his ear to keep him calm…he began to sleep, but it was like two-hour clips, so I would be up all night with him. Now, he can sleep a good solid seven hours, but if I put him to bed too early, then he is up too early. So, with my kids unfortunately [they] go to bed really late and that is a big problem. I can get them in the bath tub by 10:00 and in the bed by 11:00 p.m., but that's [a] crazy thing for kids. I'm up really late. I'm up till 2:30 in the morning.
Family Outings and Occupations	
Community Inclusion Tolerance Hospitality	People will make comments… [one person] said that you know, they had a child or a grandchild like that that didn't speak and really all they need[ed] to do is be spanked. And I remember thinking you're insane…Due to being spanked, you know ….you just discipline them… smack them out of it. I'm like…This is my disabled child who spins in circles and you know [since] he was 3…. But… another good example…I have so many [laughing]
Wandering-Elopement Bolting	

Shopping	
Movies	
Park	
Restaurants-Eating Out	
Vacations *Travel/Hotels*	*Vacations* We go on vacations all the time. We don't avoid vacations. Last summer we rented this… home…[it had] several alarm systems…they had children's gates [at the top of the stairs] and everything is set up…I can know that Albert would be okay…And that was a great vacation…When we come home, we unpack and for a week, Albert will take the bags and put them at the top of the stairs, to remind us to pack again… So, we have to keep putting away the bags…so Albert has lots of qualities that make our lives easier in many ways. And I have lots of friends with autism, and it is not like that for them. Albert wants to be part of the group, so I always think that's one of his strengths. *Hotels* We try to pick places that are easy to go because Albert would actually try to escape hotel rooms. I don't know if he is trying to escape. We don't know what to expect from Albert because he always…goes to the door in a hotel room…It's almost like you are in a war zone or something. You're going away for a week, but you don't have any sleep, because the whole night Albert is awake. He comes out of the bed and he crawls across the floor so we won't see him…so it is like sneaking in a war…and we're jumping over [the bed] and it's more like barricading the door of the hotel, so we'll put all of our bags against the door and the chair, everything we have. Move the furniture, which is going to be a fire hazard, but I think at the same time, we can't lose him in a strange city. Some hotel locks…[can be opened just by opening the door]…there is no unlock [like a bolt that would require one to manually unlock it]…Albert just keeps on going.
Spirituality *Religiosity* *Culture*	
Holidays	

Special Events Family Celebrations	
Going out with Friends	
Family, Friends and Social Support	And I have lots of friends with [children with] autism. Albert wants to be part of the group, so I always think that's one of his strengths.
Sibling Impacts	
Life Transitions	
Isolation/ Marginalization	
Maternal Stress and Health	
Marital Impact	At the beginning, part of the problem of having a child [with] autism is the fighting that you do as a couple over every decision that you make for that child, so ages three to four, we, me and my husband fought like dogs. I was worried because everybody tells you [the] divorce rate for special needs parents is like 85%. So, you get scared you know…my husband is amazing…he was like every decision we have to have two yeses…if it is a big decision…if it was not such a big decision, we'll have to listen to each other and all the different reasons. It is a very good system. We came together even more so, because after that…we have strategies that back us a little more as we've never experienced it [raising a child with autism] together. So it was like we came together as a team and our marriage has strengthened after that. It was more solid-I mean we're amazing. There is a lot of stressing so we are trying to figure out how to calm that stress because of all the things we do at night.
Split Families	
Occupations: Necessary/	By Friday, when I have to get up and do my morning routine again, I'm done, I'm like so done. I can't wait for Saturday comes when Lenny and I can almost we

Meaningful and Time Use	can do our things which like one of our rituals is we go – we get up, we go to the gluten-free bakery in Briarcliff, it's all gluten-free the whole bakery. We don't go inside and there is a table that we can sit, just too chaotic, we take all the stuff into the car, the kids get all their goodies and then we go get coffee at Starbucks and then we take a ride through all the rich expensive areas around here. And we look at the horses, and look at the houses and children are always like when are we going to have a mansion? … So, you know we just day dream basically and the kids love the ride, we love the ride and it's a chance for me and Lynd to talk because the kids occupy themselves…and it keeps us sane. My mother always jokes because my grandparents, my mother's parents had 10 children…So their date was they would leave the house and they would sit in the car, in front of the house together. While all the kids were in the house, bigger kids, watching the little kids, and then they would be able to have a date and talk to each other and actually be a husband and wife, like to talk.
Participation Facilitators-Barriers	"If you have nothing (to look forward to) and you're just desperate…you don't have any choices to make. I think it would help these parents if they get respite care where [the respite workers] were actually paid money. Because $8.00 an hour isn't going to… [pay for the service]. If the State could do something for [people raising children with autism who have no support], like have an hour off once a week, I mean to do something…any-thing…any kind of break… to be able to say-oh my God, we came to Friday. You know because we are going out.
Environments Enabling-Disabling	
Economic Status Finances	
Employment	

Medical Expenses	
Vaccines	
What meaning/s did you derive from this decision-making experience? (Pre/Post Placement Perspectives)	
Mother #1	*Pre-Placement* I think that the pre-decision what it meant was…you are sort of existing in this little family….with all this dysfunction and it's sort of your own reality… and you…believe that…maybe this isn't real…maybe…you will ..wake up from the dream and there is that kind of feeling that every day you think…ok, well that was just yesterday…I mean it's crazy how your mind and your heart [are] just sort of hoping internally that today I will wake up and it will be totally different, and it's not. When [your child enters] a school setting it becomes so real. It's almost like you've joined this club that you didn't really want to join…like you are professing to the world in a sense that I've got this child and she is autistic and this is the way it is and it's not changing because you are sort of coming out of the closet in a way… You are acknowledging to everybody that this is really real. This is who my child is, this is who our family is, this is what we are dealing with [where before], you could sort of protect yourself. *Placement* [Once you] make the decision [to place your child], people are really standoffish in a way. I think [that people] think, wow, [your child] must be really bad or she must be really weird and there is always, what did you guys do? You know I had several mothers who danced around the fact that…if I had done something different, you know... if I had been more… or whatever…that I could have done this… Actually everyone has gone there, so there was a lot of that before. At the point…of making the decision is like you get to the absolute lowest point and the other thing is the expense. I mean, oh my God, this place is so expensive, and we were fortunate enough that my dad was able to help us… and you know…It is amazing how many people said to me and how many people have since we have been here like…well it must have been nice to be able to, you know, send your child there and I just can't believe that

somebody would say that and I thank they are talking about the expense and I said….No…it was horrible…But I had a therapist say to me after we made this decision, you know what you have done for once is to put your other children before Helen…I mean in a sense…what she was saying was …I think she was trying to help give me permission to be okay with this decision, because…Helen has always been the focus, the control, the everything…and so it's okay to be able to take care of the other children…and its okay to be able to enroll them in something instead of riding around, following Helen to OT and speech and…but that's what happens in an autistic family.

Post Placement
Then, [after the placement], I felt like I was okay with that club, that this is where we are and that's alright…and then I just sensed that [this] decision…is I sort of post that decision. I felt like, I was okay with that club that the, that okay, this is where we are and that's alright and then I just sense that decision, I think she is coming home and it has been so much more clear to me, that normal is just this….illusion

Oh, without a doubt and then she did a mission trip this year and she went down to New Orleans and helped to do some Katrina work and came home and said that was the best experience of her life and then she was talking about it, she had, you know, from living with Helen, you know, people's, you just know that people's lives are hard and I am not sure that would come, that wouldn't necessarily have come. So I think that's, nothing good.

There have been two big pieces of Stephanie's life that we have seen when she is in eighth grade and she is a teenager and she has all that self-centered thing that teenagers are suppose to have. But they had a big project they had to do this year and it's called Capstone and it's a year long project, it's a presentation, and she chose to do autistic kids and so her whole presentation and she is so proud of it, is on her experience with Helen, and two years ago she didn't even talk about it. She could not even talk about it. It was so embracing, it was so…

Well, now going back to your child developing this compassion…I think that the children that have been through this experience...things…or I think they are different than other children. I think they are… older than other children.

Mother #2	
Mother #3	
Mother #4	I would not be able to handle having my child placed at a residential home. I [would] find it more difficult not to know what is happening to my child. It would not relieve me, but that's just me. Each child and each parent's family circumstances differs… [maybe] the parent becomes ill, or divorce, economics, or the other children's safety in jeopardy…
Mother #5	
Mother #6	One of my darkest fears is that Albert will have an epileptic seizure and die. You know, he doesn't have seizures right now, but in puberty that's going to begin for a lot of these children with autism. My greatest fear is that I will lose him. My only hope that I ever had after he was diagnosed is that he still has longevity, he did- nothing has been cut away from him you know like children with Down Syndrome don't live past a certain point…Friends [have put] their kids in placements. But….from my perspective with each time I have had a child it is like a Vow that I take to each of them. And it means that no matter what, I'm going to be there. And if I were to put him in a place, first of all would he be sick every day? Yes, because [he would] be exposed to gluten and he has celiac disease…it leads to cancer…it leads to onset diabetes. And for his own physical safety, I mean but besides that emotional well-being. You know it's my job to make sure that his life is as smooth as possible, now… That being said, I'm going to die one day and so I'm hoping I live [till] 90, you know then Albert will be like 60 something…So I can give most of his life at my home. But

	then…do I expect my kids to take on this responsibility? I don't know what to expect. I've seen siblings want to take on this responsibility, because they are so attached. That's why I had to prevent the resentment between the kids based upon the fact that Albert. Has autism…I try to make everything fair so he would be even. I want to make sure they love each other. And that's the most important thing to me. Now they go on in life, will he be in a placement? Maybe, maybe when he is in his 60's. I don't even – sometimes I have fear, I have friends of mine who are now placing their kids in placements and I say to myself, they are ahead of me…Albert is 11, their children are 20. What will I feel like when he is 20? Here I am big and pregnant, and I'm going to be 40…39 this …July. And I'm bent over [the] tub cleaning up my child's accidents and I'm exhausted…Am I going to live [to] 60…am I going to be physically able to your know…I am not in their shoes what makes them feel like they have to do this? Maybe I'll feel that way later on….So that cause me a lot of fear…that I will feel that way…but I do know myself…I'm a person that is rigid. So when I decide something, I don't really change that much, I really don't, you know …I did think of that…Albert, even when he was diagnosed, that it was me and him…[mother cries] So sorry…I didn't want to cry…You have kids, you don't give up, so….In my mind, I've made a pact with my child and I don't think that anything could break it. I mean even my own marriage.
As a mother of a child with ASD and intellectual disability and (a) typically developing children/child, what do you want others (community members/leaders, family members, professionals, religious leaders, policy makers, funders of services) to know about how they can best help you and your family in your situation ?	
Mother #1	*<u>Policy Makers</u>* *Fighting for Services* You know…that's such a loaded question. I sat [with] a hospital transition team that helps with the transition to adulthood, and they looked at me and said, here is what we would recommend… move from Kentucky…go back to North Carolina, close to your parents, go to New York State, but you should move from Kentucky, because the residential options are so low and the support is so low. You've got to have a huge

Mother	network and I hate to be, you know…part of my cynicism I think on a policy level is those networks are fewer and fewer. Unless you have endless funds, those networks…you really have to seek them out…and you have to be in the right state. I loved our occupational therapy experience when Helen was young. You know I distinctly remember the day…I felt so sorry for her occupational therapist. We…[are] done with your case because she can cut with scissors now…which was…our last goal. Helen is doing well in school and she has gotten to a point where she is stable….And I said you are kidding me and she said no, [it was] like a killer…because she can cut with scissors and that was sort of the last goal. When you talk about occupations, that-to me is what the world is…It's [the world] is going to end… cutting with scissors… it's not enough…I came up with all kinds of things…that were out of the school domain. I've been on the board [disabilities] and it's a policy group and an advocacy group…I actually had to take a break from it because I decides to go back to school … sort of… something for myself and also to be involved in the schools of my other two children and the council has not liked that decision because they think I am abandoning the cause…Oh gosh…it's so loaded. *Life Transitions* I think that…autistic family members need places to live…that show where we [the grown children with autism] are in our life stage. I think they need to be in an apartment with other autistic people and have caregivers…So they have some social [life]…they shouldn't have to live in a home with their parents, that's no fun. But that's what they do because that's safe and because there is nowhere else to go and because parents are scared. So, I am speaking to you sort of just where I am at my life stage. Those are just two of the big pieces…[community inclusion, and life transitions] Religious Leaders and Community Members Attendance at Religious Services I probably need to live in New York, because nobody here [town where she lives] talks, but you know, and I had a mom come up to me and say there is a child with [a] disability and

#1	[the child] is very loud and the mom stopped bringing her to church. [this mother, being concerned about the mother, reached out to the other mom out of concern when she did not see the mother and child in church anymore.] The mother told her that she stopped bringing her [child] to church because people were staring…she said that nobody has ever asked who we are or you know… what's going on and so that kind of thing just incorporating [that kind of concern]. Community *Willful Hospitality* You know, I think that…on a local level, I would say…and this a…I come from a spiritual understanding…I would say that there is a real lack of hospitality towards people with autism and people with disabilities. And by lack of hospitality…I mean…[being in a store with all your children and the child with autism has a tantrum as you are on the check-out line]. And I think the situation…arouses so much fear in people and panic…and it's much easier not to do anything. But I think that's what I would ask for on a local level. It's just a "willful hospitality" towards these people…and that's something that they [people with disabilities] don't get. The feeling of being included and asked to be included, I did a lot of workshops on… incorporating people with disabilities into faith communities which is something I speak about a lot. *Social Exclusion* the worst, worst part is you know, Helen has no friends and part of it is that she doesn't know how to be a friend and we tried to train her and teach her…but I think that social aspect, the relational aspect is just this huge missing piece, and it is really sad and nobody deserves to live in a world, you know, and…

Mother #2	Policy Makers *Fighting for Services* I left behind over $100,000 of services for a move to Florida to enroll both autistic children in an excellent autism public charter school. The cost to educate a child at this school is $60,000 because of the individualized curriculums and high student to teacher rations. Thankfully, the tuition is free because it is a public charter school but parents are asked to help with fundraising and volunteer their time. I have not had 1 hour of respite or help since August making it impossible to fill out the piles of applications necessary to get on the painfully long wait lists for services so I don't feel like a prisoner in my own home. I don't understand how services can vary so much from state to state. All parents of special needs kids need some respite and many of our kids are elopers & need project lifesaver GPS tracking bracelets. They all need therapies but the state of Florida has not given me a service coordinator or any hope of any help since the waiting list is 19,000 people long and about a 7 yr. wait. I was told that it was next to impossible to be bumped ahead of the list as a crisis situation unless your child gets hit by a car or severely injures himself or someone else. I would like to see Medicaid transfer from state to state, GPS tracking bracelets for all elopers, in-home behavioral therapy programs and other therapies available and respite for parents. Without an aide, I hardly take Kenny out in the community to teach him safety, learn how to act appropriately and get socialization. As soon as I moved to Florida I should have been assigned a service coordinator through the agency for persons with disabilities who should have approved me for respite hours & helped me fill out all of the endless paperwork and applications required to get on long wait lists for services. If Medicaid had transferred to the new state there would not have been any lapse of services. I am told that the Medicaid in Florida is income based so that would most likely disqualify us and the Med waiver which is not income-based has 19,000 people on the list. At the very least the state of Florida should have sent me temporary respite to give me time to fill out the applications & try to get approved for Medicaid, the Med Waiver or find a church, grant or foundation who can provide

Mother #2, cont'd.	me some assistance. I would beg the state of Florida to consider our case a "crisis" and bump us ahead of the other 19,000 applicants so we can get a Project Lifesaver GPS bracelet, therapies & respite. I wish I had insurance & funds to get my son the medical help for his gastrointestinal issues which are causing many of these impulsive behaviors. I wish I had the money, time and assistance to implement the proper protocols to help my son with all of his gut & brain issues. I can't believe our …health insurance plan through my husband's company excludes every service or therapy for autism which means my son had to stop cold turkey all of his physical, speech, occupational therapy and behavioral therapies when we moved to Florida. Without medical insurance coverage our efforts to resolve Kenny's medical issues have been put on hold. Unfortunately, the states that mandate autism coverage only help a small percentage of people who have state job insurance or don't work for a company with self-insured insurance plans. *Government Institutions* It's about time the government takes responsibility for this condition and allows our children to get the treatments they need. You pay now or a lot more later. I want the government to make it mandatory for insurance companies to cover autism therapies and autism doctor specialists such as GI, Defeat Autism Now &neurologists. I want hyperbaric oxygen therapies to be FDA approved as a therapy for autism…[I want] coverage for GPS tracking bracelets for all autistic children who elope.
Mother #2 cont'd.	*American Association of Pediatrics and Center for Disease Control.* Vaccines I want the American Academy of Pediatrics and CDC to eliminate unnecessary vaccines, stop adding more vaccines to the schedule and remove all neurotoxic ingredients from the vaccines. I want to government to stop brainwashing the public into thinking that vaccines are safe when they are causing a whole generation of our children neurologic & nervous system damage. I want the government to take responsibility for creating this epidemic and take action to try to end it and assist those families who have been affected. Community

Mother #3	<u>Policy Makers</u> I think it's really hard when you're doing a…whole policy… I think you have to generalize…and kids with autism spectrum disorders, there are all different types, all different kinds of things and each child is individual so it is a very hard thing to say… everybody should be entitled to this…I think there should be very strict evaluations for each individual and they should be paid for by the school or whatever…that's my theory. And then from there to get the appropriate services…it's hard to say. If you are a parent and you know your child you know what's best for your child and I wouldn't just sit back …you know it's best for your child, so I wouldn't just sit back and let somebody dictate to me what they feel is necessary when I feel that this is going to help her and here are the reasons why and that sort of thing. <u>Community</u> *Don't Judge* Don't judge first of all I think that some people are very judgmental. I think some people will give you the look like you know, this mother is not taking care of her child. This child is a brat or they don't understand and they're very quick to judge and very quick to give you …[a] what are you doing kind of look.…and take a moment and really, if you don't have that situation you really should…[not judge]… asking. I am very aware of other mom's with other situations, that I will do anything and everything to help them, but I've also been in a situation where just recently…in a restaurant I was dining with my husband and my son…my daughter was at a program and there was another disabled child [at the restaurant] with her parents, just having breakfast, and a couple that was sitting next to them was really rude and purposefully got up to move so he wouldn't have to look at this child. It was disgusting.
Mother #4	When my child behaves inappropriately in a public setting, I get upset when people judge me, and on the other hand it makes me think, that they feel he is "normal" and should know better."
Mother	*<u>Policy Makers</u>* *Fighting for Services* My understanding and I don't get really involved in politics

#5	and all, but at least in the State of Arizona, the budgets have been cut so drastically that the decision makers.. Policy makers are looking strictly at the dollars and they don't understand the situations that people are in. At one point, they wanted to take my other child out of the house and put her in a foster home to give her a safe place to live and I was like, you're going to totally ruin my other child's life. If they continue to cut these budgets, the agency that Katie is with right now may not even be able to survive. *Community* One thing I Keep stressing because people keep telling you, "I can't give up message," I am not giving up on this yet. I will never give up on Katie. [I am] just trying to present and environment that is best for everybody. Like this mom I was talking to, she has found that she is getting more and more isolated from people that she used to be friends with and socialize with and family, friends, relatives, and whatever because it's not doable. *Lend a helping hand* And there are people…it was at a busy intersection and I am on the phone with the police and the police officer says or you know the dispatcher says we have the police coming out but get in your car and lock the door, so she can't continue to do this. And I said I can't, she has no fear, in a quite busy intersection. There is a fast food place right behind me where people are coming in and out of the drive way, I got the key perspectives and she continued to do it and not one person, she pushed me down to the ground, she broke my watch, she was ripping my shirt off of me. And not one person even came over to say what's going on here.
Mother #6	*Policy Makers* *Fighting for Services* "And these kids are too low functioning for services…that's ridiculous, even if the kid is not making academic strides, you also have to think about the dynamics of the family and the household…the services have to be in place in order for these. Maybe you have done something that will be important for that family and that child".

	“Most of the stress you have is getting the services that they [your children] need.” *Community*
What would you like mother’s who have shared or may face your experience to know?	
Mother #1	If you decide to try an out-of-home placement it is not the end of the world. It is absolutely not the end of the world…And sometimes it’s really the beginning and I think that was the case for us. We were able to start going to family therapy after Helen left and we had done family therapy before, but it was much different and there was a lot more freedom to say things. And so, in a sense when Helen left, some things began. And when she came back home, I think we were all a lot healthier. You have an idea when [Helen taking over the whole house] it’s happening…and you can be a little more assertive with saying. I won’t have it. But I think there is fear that like…as if we had this old version of what residential facility means, like they are going to be locked in a… you know, and that’s really not the way it is. I would definitely share how much independence Helen gained from being away from us. I…saw with surprise that she could do things that I never thought she could do, because she was away from us and I think that’s reMattable. There are times right now that she has really gone back to being super dependent on us in a lot of ways…it’s a challenge. You’ve got this concept that God gave you this child and you have to sell yourself to be able to have this child…And that is a really hard message and I think it’s ongoing with [moms with] autistic kids. "It's okay to be able to take care of your other children" It doesn’t have to be final…It can be a step along the way.
Mother #2	Give yourself some credit and down-time to recharge. If you are in a state which offers no services or inappropriate education research other locations and prepare to move. Apply for grants and charity to get safety equipment and services which your insurance does not cover.

	Don’t be afraid to apply and ask for help.
Mothe#3	I think that if you are a mother of a disabled child…you need a team of people…to help, because it is overwhelming.
Mother #4	I look at things positively and take a deep breath to survive it all, without losing my mind like so many mothers have. There are many moments even in a single day when I just have to take a deep breath, tell myself that it is ok, that I can do better, that it is gradually getting better, and that it could be worse.
Mother #5	But, the one thing… I kept stressing this…because people keep telling you, [the] “I can’t give up message”, I am not giving up on this yet. I never will give up on Katie. It’s just that you’re trying to present an environment that is the best for everybody.
Mother # 6	It used to be all about what we could do to fix…to make him [Albert] better…is there a therapy we are missing? And we would strategize that kind of stuff…[but then] everything else kind of went to the wayside…We would actually be shopping on the computer all day long, what kind of things are best…tuition…Supplements…best doctors…look at studies…We bring him to a holistic pediatric neurologist. She is really great trying to figure now. But we…kind of lay back a little bit…on the quest [for the] cure, because right now until we find a cure, that’s not happening…A lot of parents .before your kid is like five…You know that your child might still speak… I remember his [Albert’s] fifth birthday, I was so depressed that he wasn’t speaking…You know he speaks, but speaking you know. And I knew his progress was dimmer and I was so depressed and I was just like, that’s it. I was depressed from age 3 to five, because he was diagnosed at three, and I remember thinking I’m not going to be depressed on the day of his birth…I’m just not going to do it…And there was kind of a decision making point right there, where it was deciding not to let this kills us…your know like our happiness…that despite this, we’re going to find a way to figure out [how] to be happy as a family.
Could you share your perspectives of what might be helpful for mothers of children who raise children with ASD and Intellectual Disability within their homes?	
Mother	I would say if you want to keep your child at home that’s wonderful. You need a huge network [of support] and if you have that, that’s great. You need to make sure that you are

#1	comfortable with asking [for help] and tapping into it [network of support]...you need to build [it] in time, if you have other children… that would be the main thing…it's really easy to forget that they [your other children] have needs. What I did was turn [to] my middle daughter…I put all my hopes on to her and I had to have a therapist come and look at me and say… she [Stephanie] is not perfect, she cannot be perfect, and I didn't even know I was doing that. I think I am [a] pretty open mom…but I had no idea that I was doing that, but Stephanie was so afraid of disappointing me because of all she had seen…They are kids… they go all alone..."It's okay to be able to take care of your other children" So I would say, just make sure that you are comfortable with building that network for yourself…and the other thing is… Unless you just have endless funds, you really have to seek out [Networks of support] and you have to be [live] in the right state.
Mother #2	Respite is important and crucial to the journey to get your child to the most functional level he can be. Stay involved in your child's program, continue to advocate and don't be afraid to move on to new therapists, schools or caregivers if they are not qualified or hold your child back.
Mother # 3	You need a support system. I think that if you are a mother of a disabled child…you need a team of people…to help, because it is overwhelming. Especially if you have other children in your household, you can't devote all of your time to your disabled child… you have to divide and conquer…I think the more help you have, the better you feel, the better you are able to deal with life and all its stuff.
Mother #4	To the extent that they are physically and cognitively capable, all children after the ages of 2 or 3, depending on the child should be held accountable for certain actions. At around 3, for instance, they should clean up after themselves after they play. After 1 year of age, a child should not be allowed to just cry and scream without attempt-ing to communicate what is wrong, in the case of my child who is very limited in communication skills and can only primitively gesture, I still require him to at least try and gesture, instead of acting out or getting mad. Every child needs to be told what is acceptable and what is not. I look at things positively and take a deep breath to survive it all, without losing my mind like so many mothers have. There are many moments even in a single day when I just have to take a deep breath, tell myself that it is ok, that I can do better, that it is gradually getting better, and that it

	could be worse.
Mother # 5	I think that for young kids, I think my biggest thing was try to help them [be] around typical kids as much as possible when they're young….Don't overdo it with the therapies…the more they an be in a typical environment the better and I think another thing for mom and dad is that you need time away. [If] You have other children you need time with those children. You know even with my husband, I'll say to why don't you go pick Katie up, I am off doing a grocery shopping and then we'll hook up…spend time together and then we both take her back home. You know, but to ask for help. But to ask for help because I think too often we don't wanted…to…get to the point where we just so… like we're dying…overwhelmed.
Mother # 6 Mother # 6 cont'd.	I think that it is really important to surround yourself with people who are going to help you and be there for you…true friends. It's your siblings, moms, brothers. I am lucky [but] people who don't have these relationships with their family…I would think that you need to figure out ways…they could be a support system for you. If I [didn't] have a support network…I think [I'd] crumble and die… You know some of these moms are single moms, their husbands have left them. They don't have anybody in the family…some of their families are in other states. Some families are afraid. "The earlier [the child with autism] gets early intervention, the better." "If you have nothing (to look forward to) and you're just desperate…you don't have any choices to make. I think it would help these parents if they get respite care where [the respite workers] were actually paid money. Because &8 an hour isn't going to it [pay for the service]. If the State could do something for [people raising children with autism who have no support], like have an hour off once a week, I mean to do something…any-thing…any kind of break…to be able to say-oh my God, we came to Friday. You know because we are going out. There are lots of variables that come in and slam together and that makes that woman have to make a decision… I feel very fortunate to have an incredible support network. At the beginning, part of the problem of having a child [with] autism is the fighting that you do as a couple over every decision that you make for that child, so ages three to four, we, me and my husband fought like dogs. I was worried because everybody

	tells you [the] divorce rate for special needs parents is like 85%. So, you get scared you know…my husband is amazing…he was like every decision we have to have two yeses…if it is a big decision…if it was not such a big decision, we'll have to listen o each other and all the different reasons. It is a very good system. We came together even more so, because after that…we have strategies that back us a little more as we've never experienced it [raising a child with autism] together. So it was like we came together as a team and our marriage has strengthened after that. It was more solid-I mean we're amazing. There is a lot of stressing so we are trying to figure out how to calm that stress because of all the things we do at night. My husband goes to bed [at] 1:30 in the morning and gets up at 5:30 and goes to work. He is at a really high level job and a lot of pressure. It is just too much to expect him to function that way so we're trying to figure out how to get the most out of the full day.