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# A Parent Consultation Group For Parents of Children With Autism Spectrum Disorder: A Mixed Methodological Study

Cassandra Catherine Clark
*Eastern Kentucky University*

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By

Cassandra Clark

Thesis Approved:

Peggy Watt

Chair, Advisory Committee

Dana Howell

Member, Advisory Committee

Dudley O'Brien

Member, Advisory Committee

Dean, Graduate School

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Date 6\30\2011

# A Parent Consultation Group for Parents of Children with Autism Spectrum Disorder: A Mixed Methodological Study

By

Cassandra Clark

Bachelor of Science

Eastern Kentucky University

Richmond, Kentucky

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# DEDICATION

This thesis is dedicated to my mother,
Barbara Clark for her unwavering support.

# ACKNOWLEDGMENTS

I would like to thank my mother, Barbara Clark who has shaped my values and instilled dedication into my way of life, my brother's, Nathan and Kyle Clark for teaching me to laugh at myself and helping me to live my life one day at a time. I would also like to thank my colleagues in the Occupational Therapy program who have inspired me to be a part of a great profession and demonstrate passionate in all that I do. A special thanks to my advisor, Dr. Peggy Wittman for believing in me and providing me with strong support and guidance. I would also like to thank Dr. Dana Howell and Dr. Shirley O'Brien, also on the committee for providing me with academic guidance and inspiration to keep progressing in my personal and professional goals, after the academic world.

# ABSTRACT

Parents of children with Autism Spectrum Disorder (ASD) are known have higher levels of negative stress than parents of children without a chronic illness. These parents' roles and routines are also impacted since the many demands made by their children put them at greater risk of occupational injustice as they are less likely to participate in occupations of their choice. Despite multiple studies examining stress in parents of children with ASD, there is little to no recent published research on the effects of a parent consultation group on parents of children with ASD and their sense of competency and attitudes toward therapy. In this study three mothers chosen using a convenience sample participated in a weekly parent consultation group. A mixed methodology study was implemented to discover what these mothers perceive as the challenges and/or needs of their children, stressors concerning their child's and family's lifestyle, and how effective a parent consultation group was to them. These three parents' perceived their most challenging areas as their child's difficulty with routines, their dissatisfaction with school system, daily exhaustion, and their child's social participation. It was also found that there is an increase in parent sense of competency after participation in a parent consultation class when therapy is perceived as a positive experience. Occupational therapists can provide tools to parents of children with ASD to assist them in increasing levels of competency and decreasing stress in order to live a more occupationally balanced and satisfied life.

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# CHAPTER I

## INTRODUCTION

### *Background and Need*

### Families of Children with ASD

Families are unique and dynamic systems made up of individuals that may share experiences, values and beliefs. Townsend and Wilcock (2004) suggest, "Humans are occupational beings who need and want to participate in occupations to develop, thrive, and reach their potential" (p.262). Families often relate to one another by participating in each other's chosen occupations.

### Occupational Injustice

Autism Spectrum Disorder (ASD) is a chronic condition that may cause negative disruptions in the occupational roles and routines for the individual with autism and his or her family members. DeGrace (2004) found, "Families expressed the feeling that the demands of autism are nonstop, where they expend so much energy and time dealing with the child and autism" (p.545). The roles and routines of families with a child with ASD are planned around the needs of this child. Since these needs are so demanding, parents often do not have the opportunity to participate in occupations of their choice. According to Fiddler and Peerla (2009) "To be deprived of the right to participate in chosen occupations means there is an occupation injustice" (p.10). The entire family may experience occupational injustice as they are deprived of this privilege. Parents of children with ASD are especially at greater risk of occupational injustice, as they are responsible for the entire family unit, and must meet the needs of their child before their own.

## Negative Stress

Since the families of children living with ASD must meet so many demands, negative stress is a common feature. High levels of negative stress can have a negative effect on the parents' occupational balance. Past research (Baker-Ericzon, Brookman-Frazee, and Stahmer, 2005) shows that parents of children with ASD have the highest level of stress even compared among parents of children with other chronic illnesses. DeGrace (2004) suggests that families of children with severe autism may have difficulty engaging in daily occupations that hold positive meaning as the routines and habits revolve around the child with ASD.

## Parent Education Programs

While occupational engagement of these families may be impacted negatively; parent education programs can support healthy occupational engagement. For example, Brookman-Frazee (2004) found parents of children with autism reported feeling more positive affect, a reduction in stress, and more time for leisurely activities after participating in an educational program for parents. Other contributing factors to stress, such as the parent's sense of competency, attitude towards therapy, social support, and non-constructive coping strategies can also be addressed through parent education programs

*Problem Statement*

Despite multiple studies examining stress in parents of children with ASD, there is little to no recent published research on the effects of a parent consultation group on parents of children with ASD and their perception of parental competency before and after participation in an educational parenting class. Nor is there any published research about the satisfaction with the process and outcome of therapy for parents of children with ASD. There is a need for further investigation of the effects and satisfaction of participation in a parent consultation group for parents of children with ASD. One way to address the needs of parents of children with ASD is through family-centered practice. The occupational therapist can assist the parent's with individual needs as well as the child's to promote improved functioning and satisfaction in their participation in daily activities. One approach that can be utilized to do this is offering parenting educational courses. An educational class for parents should focus on what parents perceive as a challenge in their parental capacity; a positive change in their perception of parenting skills may lead them to feeling a sense of empowerment in their parenting role. Mahoney (1999) reports that "Recently, parent and family empowerment have been increasingly mentioned as both a goal and an important outcome of child mental health services which includes parent education programs" (as cited in Brookman-Frazee, 2004, p. 195). Brookman-Frazee also found that an empowered parent will feel more competent in managing stressors and child behaviors which will likely increase quality of life as well as participation in leisurely activities. Additionally, parent consultation groups often have a positive influence on the child's symptoms. These findings imply that participation in a parent consultation group focusing on what parents perceive as most stressful could lead to an increased sense of parenting competency. This could play a role in empowering the parent and allowing him or her to feel less stressed which could consequently enhance occupational performance.

### *Statement of Purpose*

Since the parent's perceptions of their child's strengths and needs form the basis for the content of the parent consultation group, this study was designed to address both the children's needs and the effectiveness of the group in assisting parents feel more effective in meeting these needs. Many studies have examined the effect of a professional social support system, but Benson (2006) argues "Parent perceptions of the helpfulness of professional sources of social support was not found to be a significant factor in reducing stress" (p.692). A parent consultation group must offer additional training other than just providing a support group for the parents. Twoy, Connolly and Novak (2007) suggest that many parents believed that that they did not have the ability to alter the outcomes of the child's disorder. (p. 258). Professional support should focus more on addressing the issues seen by the family, such as child behaviors, in order to be more helpful to the participants involved. A parent consultation group can provide skilled services to the parents aimed at what the parents perceive most distressing

In order to effectively assist parents of children with autism manage stress and decrease occupational injustice it should be determined what the parents of children of ASD perceive as most stressful so that these specific issues can be addressed. It was also found that parents of children of autism with more severe symptoms are at a greater risk for poor mental health outcomes which significantly correlates with parent depression (Benson, 2006). Since research has shown that child symptom severity is correlated with stress proliferation, it is important to address a child's behavior symptoms in the parent consultation group. Addressing these issues could result in less stress, higher quality of life, and increased occupational engagement for the entire family unit.

The parent consultation group at Eastern Kentucky University followed a curriculum that focuses on tracking behavior, understanding a child's behavior, encouraging positive behavior, using social rewards, nonsocial rewards, and setting clear expectations. There were a total of six classes offered and each class focused on one of these topics. Further research is needed to examine the effectiveness of this subject matter on the parents' perception of competency and discipline practices.

*Research Objectives*

This mixed methods research study seeks to investigate the following questions:

1. What do three mothers of children with ASD perceive the challenges and/or needs of their children?

2. What do three mothers of children with ASD perceive as stressors concerning their child’s and family’s lifestyle?
3. How effective was a parent consultation group to the three mothers sense of competency?
4. How satisfied are the mothers about their participation in a parent consultation group?

### *Definition of Terms*

To ensure understanding of this discussion, the following definitions are included for use in the interpretation of the review.

Autism Spectrum Disorder (ASD): a neurodevelopmental disorder characterized by qualitative impairments in social interaction and communication skills, along with a restricted repetitive and stereotyped pattern of behavior” (APA, 2000, p 59).

Child: For the purpose of this study the child is an individual birth to twelve years of age who has a diagnosis of Autism Spectrum Disorder.

Empowerment: A complex, participatory process aimed at achieving greater societal justice and equity through enabling groups with disadvantages to exercise power and influence. (Christiansen & Townsend, 2004).

Family Unit: For the purpose of this study, a family unit includes the child with autism spectrum disorder, their parents or caregivers, and siblings that reside within one home.

Leisure: Freedom or opportunity to do something (Christiansen & Townsend, 2004).

Leisure Pursuits: Occupations or activities that are freely chosen. (Christiansen & Townsend, 2004).

Negative Stress: Stressors that contribute to the development of other problems. This type of stress can lead to stress overload which is excessive amounts and types of demands that require action. (Lunney, 2006).

Occupation: Everything people do to occupy themselves, including looking after themselves (self-care), enjoying life (leisure), and contributing to the social and economic fabric of their Communities (productivity)" (CAOT, 2002, p.34).

Occupational Habits: Recurring largely automatic patterns of time use within the context of daily occupations. (Christiansen & Townsend, 2004).

Occupational Injustice: To be deprived of the right to engage in chosen occupations (Fiddler & Peerla, 2009).

Occupational Engagement: Client's doing, thinking, and feeling under certain environmental conditions in the midst of or as a planned consequence of therapy. (Keilhofner, 2008).

Occupational Participation: The engagement of the individual's mind, body, and soul in goal directed pursuits. (Christiansen & Townsend, 2004).

Occupational Performance: The task-oriented, completion or doing aspect of occupations, often, but not exclusively, involving observable movement. (Christiansen & Townsend, 2004).

Occupational Routines: Recurring sequences of time use, such as the regimen repeated upon waking daily. (Christiansen & Townsend, 2004).

Occupational Therapy: The therapeutic use of everyday life activities (occupations) with individuals or groups for the purpose of participation in roles and situations in home, school, workplace, community, and other settings. Occupational therapy services are provided for the purpose of promoting health and wellness and to those who have or are at risk for developing an illness, injury, disease, disorder, condition, impairment, disability, activity limitation, or participation restriction. Occupational therapy addresses the physical, cognitive, psychosocial, sensory, and other aspects of performance in a variety of contexts to support engagement in everyday life activities that affect health, well-being, and quality of life (AOTA, 2008, p.673 )

Parent: For the purpose of this study, a parent is the legal guardian who has custody of one child with Autism Spectrum Disorder.

Rhythm: A regular and recurring pattern of living or occupational behavior. (Christiansen & Townsend, 2004).

Role: The part played by a person in society or life. (Christiansen & Townsend, 2004).

Routine: A regular, predictable way of acting; a recurring pattern of occupational engagement or time use. (Christiansen & Townsend, 2004).

Social Participation: Mosey (1998) defines, "Organized patterns of behavior that are characteristic and expected of an individual in a given position within a social system" (as cited in AOTA, 2008, p.675 )

### *Assumptions*

This study was based on the following assumptions:

1. Parents of children with Autism Spectrum Disorder are typically at higher risk for occupational injustice.
2. A Parent Consultation Group can assist parents in feeling empowered, which will allow more room for engagement in meaningful occupations.

These assumptions were based upon the researcher's personal experiences, values, and beliefs about families, and how they experience stressors together as an entire family unit.  Since a major symptom of autism includes the child having issues with social skills, families will often have to alter or decrease their social participation as the child with autism may not always be able to tolerate these contexts.  Children with autism also sometimes require a strict routine, which alters the occupational routine of each family member, but especially the parents. It is believed that parents of children with Autism Spectrum Disorder will have fewer opportunities for engagement in occupation of their choice due to the high demands of the child with autism.  It is a researcher's bias that most occupational engagement of these parents will be spent on productive occupations especially those activities involving caregiving.  These additional productive occupations will leave less time for the entire family to participate in leisurely pursuits or restorative occupations, putting the family at risk of not achieving occupational balance or harmony.  The occupational therapist can assist the children with ASD as well as the parents of the children with ASD through various services. Through family-centered care the occupational therapists can obtain information on what the parent's perceive as stressful and work with the parent's to improve overall functioning and satisfaction for the entire family unit.  If parents can address what they perceive to be most stressful by seeking professional support through a parent consultation group, this may lead them to feel more empowered and therefore allow them the opportunity to participate in more chosen occupations with their families. This feeling of empowerment can help the families enhance their lifestyle by increasing their quality of life, and reducing the negative affect that may result from the occupational injustice experienced before seeking professional support.

# CHAPTER II

## LITERATURE REVIEW

A literature review of relevant materials was conducted to determine the current level of understanding of families of children with Autism Spectrum Disorder (ASD). The literature discussed in this review is separated into three areas; stress and families of children with autism, occupations of families of children with autism and family-centered practice. In addition, a summary is included to provide information regarding the implications for occupational therapy practice.

### *Stress and Families of Children with Autism Spectrum Disorder*

The American Psychiatric Association (2000) defines autism as, "a neurodevelopmental disorder characterized by qualitative impairments in social interaction and communication skills, along with a restricted repetitive and stereotyped pattern of behavior" (p 59). A diagnosis of ASD influences the individual's life in great way but it also has the potential to introduce many changes in the family system. Twoy, Connolly and Novak (2007) report, "Stress for families of children with ASD is considerable and chronic" (257). Chronic illness of one family member has been known to cause multiple stressors for an entire family unit. Parents especially are under much stress as they manage their own lives as well care for their children. This is especially true of parents of children living with autism. Past research (Baker-Ericzon, Brookman-Frazee, and Stahmer, 2005) shows that parents of children with ASD have the highest level of stress even compared among parents of children with other chronic illnesses. They define a stressor as a constraining force or influence placed on the family unit that produces, or has the potential to produce, changes in the family's existing equilibrium. The diagnosis of Autism has been known to be a powerful stressor in the family unit as it impacts many different aspects of the family's routine.

With such negative levels of stress the overall health and quality of life of these families are expected be much lower when compared to families with children who have not been diagnosed with autism. Davis and Carter (2008) report, "Although some parenting stress is considered to be normal and adaptive for all parents, studies of parents raising children with ASD clearly document elevated stress levels" (p.1278). Stress has immediate consequences on the person's occupational engagement. Through their critical review, Law, Steinwender and Leclair (1998) report that high levels of stress and perceived control have been associated with a negative relationship between occupation and health.

Research has shown that parents of children with ASD have also been known to display other negative symptoms, affecting the overall health of the individual. Benson (2006) expresses that parents of children with autism are at greater risk for depression. Poor mental health outcomes are also associated with negative consequences on the individual's participation in occupation. Occupational therapists have the knowledge and skills to direct parents in their health and wellbeing. It is not the type of activity but rather the characteristics of the activity such as choice, control, and intrinsic motivation that lead to increased quality of experience and flow (Law, Steinwender, and Leclair, 1998). Occupational therapists can help direct parents to find purposeful and meaningful activity.

Negative parental affective symptoms experienced by parents of children with autism have been highly correlated with parenting stress and are considered important components of parental well-being (Davis & Carter, 2008, p. 1284). There are also several other studies which show that parents of children with autism often display symptoms of depression and anxiety.  Davis and Carter (2008) found that mothers and fathers both felt depression and anxiety after learning of their child's diagnosis. Mothers had slightly more affective symptoms, although the difference between mothers and fathers was not significant, this research points to the negative consequences of living with high levels of stress.  Davis and Carter (2008) also examined both mothers' and fathers' perspectives of parent and child functioning. Information was gathered through various standardized assessments to measure the parent's perspective of core autism behaviors and child competency as well as the parent's feelings of stress. Results indicate social relatedness deficits are most stressful for parents of children with ASD. (p.1289).  These findings highlight the need for family interventions to take into consideration what mothers' and fathers' identify as being most stressful to them.

Multiple research projects have found that negative symptoms of depression and anxiety are a direct result of high levels of stress brought on by characteristics of a child's limitations. Benson (2006) found that, "child symptom severity and stress proliferation both significantly correlate with parent depression" (p. 690). This study helps justify the need for treatment services that not only address coping strategies of parents but also address the behavioral issues of the child that are causing much of the distress. Although social support is often a much needed adaptation during a family's time of need, informal social support may be all that is necessary. "Parent perceptions of the helpfulness of professional sources of social support were not found to be a significant factor in reducing stress" (p.692). Professional support should focus more on addressing the issues seen by the family, such as coping strategies and child symptomology.

Sivberg (2002) studied stress on the family system as well as coping patterns of the parents of children diagnosed with ASD and parents of children not diagnosed with any condition or illnesses. As expected, parents of children with ASD were found to have much higher stress levels than parents of children of the same age and similar demographics without any diagnosed condition. Sivberg also discovered families experienced less strain when the parent's utilized higher levels of coping. Parents of children with ASD and parents of children without a condition or illness use different coping patterns. For example, parents of children with ASD often use the negative coping pattern of distancing or escape. These parents also identified themselves as having a lack of support. These non-constructive characteristics are likely contributors of higher strain on the family. In conclusion, Sivberg (2002) states, "the results emphasize the importance of efforts to help parents with a child diagnosed as having

ASD to develop and employ more adequate coping behaviors, so as to reduce the strain on the family system and to enable them to better meet both their own needs and those of their children" (p.407).

Like the previous studies' Estes, Munson, Dawson, Koehler, Zhou and Abbot (2009) also focused their attention on higher levels of distress on families of children with ASD. This study compared parents of children with ASD to parents of children living with other developmental delays (DD). Parents of children with ASD may experience more stress because of their child's impairments in social relatedness which has been identified as the largest contributor of stress to mothers in past research. Estes and colleagues set out to discover if child problem behaviors are more strongly related to maternal parenting distress than child daily living skills within both the ASD and DD group. This study supported the researchers' hypotheses; mothers of children with ASD reported higher levels of stress and the children in the ASD group demonstrated higher levels of problem behaviors. Social participation is a key objective in occupational therapy, since these behaviors are causing much distress they should not be overlooked by professional support. Estes et al suggest, "Targeting these behaviors may reduce parenting stress, improve psychological functioning, and ultimately increase the effectiveness of interventions designed to enhance child development" (p.385).

### *Occupations of Families of Children with Autism Spectrum Disorder*

According to Law (2002), “Participation is a vital part of the human condition and experience – it leads to life satisfaction and a sense of competence and is essential for psychological, emotional, and skill development” (p.641). Participation is vital to the individual but also to the success of the family unit. Many modern families stay involved in one another’s life by sharing their individual experiences with the family unit. Happiness, sadness, and stress experienced by one family member are often experienced by every member. Fiese (2007) reports, “families are healthier overall when routines are used in the service of effective management strategies and when they incorporate planning and offer some structure” (p.43). Every family is unique as each individual member has their roles and routines which influence the routines and rituals of the family unit. DeGrace (2003) found, to ‘be’ a family requires the unit to establish a sense of connection and to acquire a sense of inner satisfaction in their daily patterns of doing. Thus, ‘being’ a family implies being able to derive a sense of meaning from engagement in daily living experiences (p. 348).

As evidenced in the literature review, parents of children with ASD experience elevated levels of distress. These negative levels of stress impact the roles, routines, and rituals of the family. For instance, parents often take on additional roles that parents of children with autism do not. Parents who want to see their child get the best intervention possible often welcome opportunities to be their child’s case coordinators and treatment overseers but this also places a heightened burden on the parents or family system (Schwictenberg and Poehlmann, 2007). The extraneous demands of families of children with autism interfere with family's engagement in occupation. Gray (1997) argues that families of children with autism may experience more difficulty orchestrating smooth, functional family routines (as cited in Larson, 2006).

One study interviewed parents and found, "Families expressed the feeling that the demands of autism are nonstop, where they expend so much energy and time dealing with the child and autism" (DeGrace, 2004, p.545). The needs of a child with autism are plentiful and often control the lives of the families as the family's day revolves around these needs. "When routine activities are disrupted, there is either a sense of rigidity or a chaotic flow to daily life and a sense of resentment toward doing chores. These interactions create feelings of alienation, exclusion, and an unwillingness to express emotions freely" (Fiese, 2007 p.42). The stress and occupational disruption that families of children with autism experience puts them at higher risk for occupational injustice which could consequently affect their quality of life. DeGrace (2003) reports, "understanding and being able to impact the occupations of the family unit has the potential to influence not only the children we work with, but also their families and society at large" (p. 547). Since these occupational disruptions may lead to occupational injustices it is the role of the occupational therapist to work with the family in establishing or reestablishing participation in roles, routines, and leisure pursuits of their choice.

### *Occupational Therapy in Family Centered Practice*

Children with autism usually receive a variety of services in different contexts including school, outpatient, and the home. The stress that the family is under is not always addressed in these services. Since autism affects the entire family, occupational therapy services should be designed for the family unit. Price and Miner (2003) discuss how occupational therapy practice supports a parent's relationship with his or her child and promotes being a family. "These elements are often embedded in our interactions with families" (as cited in Case-Smith, 2009, p. 50). The needs of the parents should be addressed during services as well as the needs of the child. Parent support can benefit the interactions of all family members.

Case-Smith and Arbesman (2008) "it is important that occupational therapists become informed about the interventions with the best evidence for effectiveness" (p.416). In order to meet the needs of the parents and the children, family-centered practice should be considered as the focus of professional support. Racino (1998) argues that in order to effectively provide parent support, the services provided should focus on family-centered interventions. "Supporting families, means starting first with the family's views, beliefs, and world views and working in partnership to figure out what role, if any, the organization might play" (p.441). The practitioners who provide support for families of children with autism must support the self-perceived issues recognized by the families. One method of addressing the issues seen by the family is using occupational performance coaching. Occupational performance coaching is recently identified intervention strategy designed by occupational therapists working with families to enable occupational performance. Graham, Rodger and Ziviana (2009) discuss how providing occupational performance coaching for parents helps the families' occupational engagement. This type of intervention was found to enable the therapist to be both family- and occupation-centered while being evidence-based in their choice of intervention. "Occupational performance coaching focuses specifically on the enablement of children and parent's participation in occupations in home and community contexts through parent identified solutions to performance barriers" (p.16). Occupational therapists can help families of children with Autism Spectrum Disorder better their lives by providing family-centered services which promote engagement in meaningful occupation. Graham, Rodger and Ziviana (2009) found that there was significant improvement in child's occupational performance and parental wellbeing when occupational performance coaching was implemented.

### *Summary*

The childhood condition of Autism Spectrum Disorder has continually been identified in research as a stressful condition to not only the child but to the whole family unit. Parents are often bearers of much distress usually due to the child's social behavioral impairments. There are also other contributing factors such as the parent's sense of competency, attitude towards therapy, social support, and non-constructive coping strategies. Twoy, Connolly and Novak (2007) state that "Active coping strategies are generally thought to be a more positive ways of dealing with stressful events as an individual attempts to change the nature of the stressor or how one perceives the stressor. (p.258). Occupational therapists can provide parental support by providing family centered services focusing on what the parents perceive to be most distressful and assisting them with active coping strategies, especially participation in meaningful occupation. Engagement in meaningful occupation can replace parent's negative or passive coping strategies by providing an outlet for their stress and promoting normalcy in their routine and lifestyle. (SOC and PIL-R) "Emphasizes how important it is that parents of a child with an autistic spectrum disorder develop and employ as many well-functioning coping strategies as possible. This could involve, for example, balancing their attention sufficiently between the child with ASD and their other children; being careful not to expect an undue amount of help, in caring for the child with ASD, from his or her siblings; taking a consistent and mutually coordinated approach to the child with ASD; and being careful not to view that child as the sole source of strain within the family" (as cited in Sivberg, 2002, p. 406). By implementing occupational engagement into the families' routine this could be used as a more effective and healthy coping strategy to the daily stressors that are experienced. The evidence demonstrating the influence of mediating factors supports one of the most basic premises of occupational therapy, in that the experience of occupation enhances the effect of occupation on health (Law, Steinwender, and Leclair, 1998). Occupational engagement can be promoted to parents of children with autism by helping them to feel empowered. This research project seeks to study the parent's sense of competency before and after participating in a Parent Consultation Group. An empowered parent will be more likely to engage in meaningful occupations, which will benefit the well-being of the family unit

Children with ASD exhibit a wide array of problematic symptoms and behaviors which can adversely affect parent and family well-being" (as cited in Benson and Karlof, 2009, p. 350). While each individual experiences stress in their own unique way; there are many similarities among what parents of children with ASD perceive to be stressful. Gadow et al. (2004) found, "One variable that has been extensively studied as a possible predictor of parent distress is child symptom severity. A parent who seeks support for what they identify as most stressful may lead to parent empowerment which will influence the amount of chosen occupations they engage in (as cited in Brookman-Frazee et al, 2006, p. 183). Brookman-Frazee (2004) found an empowered parent will feel more competent in managing behavior and will likely increase participation in leisurely activities. It is possible that participation in the Parent Consultation Group at Eastern Kentucky University may help the participating parents gain competency allowing them to feel empowered which will likely lead to engagement in chosen occupations benefitting the well-being of the family unit. Due to these past finding this research project seeks to find:

1. What do three mothers of children with ASD perceive the challenges and/or needs of their children?
2. What do three mothers of children with ASD perceive as stressors concerning their child's and family's lifestyle?

3. How effective was a parent consultation group to the three mothers sense of competency?
4. How satisfied are the mothers about their participation in a parent consultation group?

# Chapter III

## METHODOLOGY

### *Research Design*

A qualitative design was the initial research approach taken for this study; however after careful selection among team members a mixed method design was chosen. A more in depth review was essential to assess the implications of participation in a parent consultation group. Amaratunga, Baldry, Sarshar, and Newton (2002) discuss how the combination of methodologies draw focus to the relevant strengths of the study and further suggest, “Researchers produce a final product which can highlight the significant contributions of both methodologies” (p.23). This approach was chosen since the research project added the quantitative aspect in addition to the already established qualitative portion of the study allowing the quantitative and qualitative results to be collected independently and interpreted later in the research process. Creswell, Creswell and Clark (2007) describe this method as, “an efficient design in which both sets of data can be collected and analyzed independently using the techniques associated with each data type. This approach is supportive of team research, in which the team can include individuals with quantitative and qualitative expertise” (p.17). The experienced research faculty members on the parent consultation group team include those with strong quantitative and qualitative backgrounds. The occupational therapy student conducting this particular study was guided by these professors in the occupational therapy and psychology departments allowing for guidance and knowledge in both methodological approaches. By taking a mixed methodology approach the results associated with participation in a parent consultation group will be better understood. This mixed methodology study seeks to understand the following research questions:

1. What do three mothers of children with ASD perceive the challenges and/or needs of their children?
2. What do three mothers of children with ASD perceive as stressors concerning their child's and family's lifestyle?
3. How effective was a parent consultation group to the three mothers sense of competency?
4. How satisfied are the mothers about their participation in a parent consultation group?

## Qualitative Research Design

The qualitative portion of this study was put into effect with the focus on the first two research questions. Through use of a semi-structured interview, the parents were asked to identify goals for their children, discuss anxieties and hopes that they have, and identify strengths and challenges of their family and/or child. The semi-structured interview was also used to shape goals and curriculum for the child group that took place separately but at the same time as the parent consultation group

## Quantitative Research Design

A quantitative approach was implemented to investigate the third research questions. Creswell, Fetters and Ivankova (2004) state, “Quantitative results might help researcher’s select qualitative cases so they can examine the results in greater depth” (p.8). The quantitative data for this study is used in conjunction with the qualitative data to further asses the effectiveness of participation in a Parent Consultation Group as classes are designed to focus on what participants identified as most stressful. To collect this data the Parent Sense of Competency Scale was implemented as a pre and posttest. Also, a Therapy Attitude Inventory assessment was utilized to further enhance the quantitative outlook and to gain insight as to how satisfied the mothers were with their participation in the parent consultation group.

### *Participants*

All parents who participated in the parent consultation group were involved in this specific study; three parents were included using convenience sample with some inclusion criteria. These mothers were chosen from a group of fourteen parents, twelve mothers and two fathers who were paired with the child’s mother. These fourteen participants are parents to a total of thirteen children with an ASD related diagnosis; Autistic Disorder (5), Asperger Syndrome (5), or PPD-NOS (2). It was a requirement that all parents be over the age of 18 years, the age range for these participants being twenty eight to forty one. The inclusion criteria included parents with children with an Asperger’s diagnosis, mothers and biological parents to child with ASD.

*Setting*

The Parent Consultation Group (PCG) takes place at Eastern Kentucky University (EKU). This is an annual group that occurs on campus in the psychology building during the spring semester. This group was originally designed in 2005 by a psychology professor and her graduate students.  Wittman stated, “The parenting group was formulated based on evidence which showed that a skills-based cognitive-behavioral approach dealing with specific concerns of parents who had children with ASD were found more effective than just a more traditional support group” (personal correspondence, February 28, 2011).

The parents in this 2010 study participated in a 7 week parent consultation program. The average Parent Consultation group class lasted approximately one and a half hours and included a PowerPoint lecture on the curriculum for that day. The topics for the parent class were introduced to focus on what has been found to be most distressful to parents of children with ASD in past studies. The curriculum was adapted from Rex Forehand’s (2002), “Parenting the Strong Willed Child” and focused on tracking behavior, understanding child’s behavior, encouraging positive behavior, using social rewards, nonsocial rewards, and setting clear expectations. By addressing these topics of concern, we are investigating the assumption that parents may gain empowerment from participating in a parenting class which will decrease the amount of occupational injustice that a family units experiences when one member is living with a chronic illness, such as autism.

### *Instrumentation*

Each participant participated in a semi-structured intake interview and completed the following assessments:

Qualitative Pre-Group Assessments:

1. Semi-structured Intake interview (See Appendix 1) This is a semi-structured interview given to parents before attending the parent consultation group. Parents were asked to discuss some of their child's likes, dislikes, and fears, what they would like to achieve from attending a parent consultation group, and what goals they have for their child. This was used as a pre-test assessment only as it was used to obtain information about what the parent's perceived needs are. The information obtained was used in customizing activities in the already pre-determined curriculum to match the mother's needs. The three mothers being studied in this review were interviewed and audiotaped by the psychologist and graduate occupational therapy student who collaborated in facilitating the group sessions for the parent consultation group.

Quantitative Pre-Group Assessments

2. Parent Sense of Competency Scale (See Appendix 2): This is a 17-item scale developed to measure parent's perceived efficacy and satisfaction in parenting. This questionnaire is answered on a 6-point scale ranging from

strongly disagree (6) to strongly agree (1). Gibaud-Wallston and Wandersman reported internal consistencies of .82 for the Value/ Comforting scale and .70 for the Skills/Knowledge scale, and test-retest reliability coefficients over a 6-week period ranged from .46 to .82. These authors also reported evidence for concurrent validity as Psoc scores were correlated with the parents' perceived difficulty with the infant, social support, and psychological well-being (as cited in Ohan, Leung, Johnston, 2000).

### Quantitative Post-Group Assessments

1. Parent Sense of Competency Scale
2. Therapy Attitude Inventory (TAI) (See Appendix 3): This is a parent-report scale of satisfaction with the process and outcome of therapy. This will allowed for information to be obtained on client satisfaction with the therapy process. This self-report measure consists of 10 items and each item is answered on a 5-point scale from not satisfied (1) to very satisfied (5). The TAI is known to have high levels of validity and reliability. A disruptive Cronbach's alpha for the TAI was excellent (.91) and the stability coefficient across a 4-month period was also high (.85) (Brestan et al, 1999).

### *Educational Approach*

The occupational therapy and psychology departments collaborated together to integrate unique skills and services using a variety of educational approaches. The classes for the parent consultation group were directed by a licensed psychologist whom is also a professor of psychology at Eastern Kentucky University. In partnership with the psychology instructor, an occupational therapy graduate student and psychology graduate student contributed to the class through observation and participation in discussion. Graduate students from both departments partook in the role of leading the classes for both groups. Occupational therapy graduate students contributed to leading the parent and child groups as part of their service learning requirement for their inquiry teams. Wittman explains the role of occupational therapy for both the parent and children consultation courses is, “to increase the ability for social participation” (personal communication, February 28, 2011). Racino (1998) states, “ It is the job of the occupational therapist to figure out which areas are suffering and how we can assist that person in performing these activities in a more functional, successful and independent way” (p.1). Since parents of children with ASD are found to demonstrate decreased participation in chosen occupations secondary to high levels of stress the role of occupational therapy in this setting is to implement activities that will help parents manage their stress levels and increase their participation in chosen occupations as well as social participation for themselves and the entire family unit.

The occupational therapy student fostered the ability for social participation in the parent group by offering opportunities for discussion about specific topics of concern and activities for the parents and their family to do outside of the classroom. The occupational therapy graduate student also provided short discourses; five to ten minutes in length introducing “make and take” activities for the parents to use with their children at home. The two “make and take” activities used a positive token economy approach which awarded the child for appropriate behavior. The make and take activities were designed to meet the needs and challenges identified by the parents during the intake interviews. The occupational therapy student presented these activities for the parent’s to use with their children while at home. All activities promoted participation in an identified area of need through a reward system. These activities could be graded as needed and parents were given verbal instructions on how to do so.

The non-social reward “make and take” activity (See Appendix 4) was presented in the form of a chart. It was designed to focus on routines since the parents in the study had identified participation in routine as a challenge for their children. When a child satisfactorily performed a set of assigned duties for their daily or weekly routine they would receive a non-social award. Forehand (2002) describes non-social rewards as “material or desirable objects such as toys or special treats. These types of rewards are sometimes useful when you start teaching a new behavior” (91). Each parent was given a laminated chart that included two parts; Duties and Rewards. This chart was laminated so that chores and rewards could be documented with a marker. This method allowed for the chart to be adapted as routines changed over time or as the child progressed with this reward system. The parent’s filled out which chores they wanted their child to do, essentially which routine they wanted to establish and used a special marking or symbol such as a star in the rewards section to keep track. Once a child received the goal amount of markings for routine completion then they would receive a special non-social award. Parents were instructed to change the goal for markings as needed; for instance as children became more established in their routine with completing chores then the amount of stars needed to obtain an award should be increased so that the routine would be instilled into the child's way of life more effectively. Some of the nonsocial awards chosen by parents included; a new toy/collector's item, a new video game, or free time spent for video games, computer, or television.

The social rewards make and take activity (See Appendix 5) was also presented as a chart but the children received a more immediate reward for their behavior. "Social rewards can be verbal, physical, or activities" (Forehand, 2002, p.87). It is suggested that all social and non-social awards be rewarded with verbal praise for the most effective outcomes; parents were instructed to practice this with their children.. The social rewards for this activity were given not for doing well with routines but for specific behaviors that parent wanted to concentrate on. Examples of behaviors parents in this study focused on include; helping another child, not throwing a tantrum in a certain situation, getting a good report from school/caregiver, or not displaying distracting behaviors during a movie, at the grocery store, etc. This 'make and take' activity provided children with a choice in the reward they were to receive, all reward choices encouraged social participation. Each parent was given a chart with six Velcro pieces that included the social activities that the child could choose as a reward for their behavior. The choices were presented on the Velcro pieces in words and illustration. The social rewards choices presented to the parents were included based on feedback from the intake interviews and discussion during the parent consultation group. The rewards include; Being outside with someone, Caring for a pet, Playing a game with someone, Dancing with family/friends, Receiving a hug, or Making a craft/gift for someone, These rewards focus on a fun activity which draws attention on others; they were chosen specifically to encourage initiating social participation as it was identified as a challenge among the parents of children with ASD. Parents were also given blank pieces with Velcro so that they could personalize their social rewards to fit their own child's/family's needs. Parents were instructed to pick two to three rewards and let the child pick from that smaller selection rather than having six choices of rewards.

As mentioned earlier, discussion among parents and professor and student class facilitators played a large part in this study. The discussion's intent was not to serve as a social support group but to have a cognitive behavioral approach. The parents addressed children's behavior by tracking their child's behavior and including in the discussion. The parents tracked their child's behavior using Albert Ellis's Model of REBT: The ABC Model of Psychotherapy. Ellis & Dryden (1997) explain how this method, "discourages unhealthy negative feelings by showing clients their functional and dysfunctional beliefs (behaviors) about their unfortunate antecedents and by teaching them how to maximize the former and minimize the latter" (p. 102). In this case, parents are becoming familiarized with when their child’s negative behaviors occur as a result from what unfortunate antecedent, so that they can direct their child’s behavior to be more positive. The parents were given multiple copies of behavior tracking charts that included a space for an antecedent, behavior, and consequence. The concept of the ABC approach was discussed with the parents during the parent consultation group and was also explained in written words on each parent tracking sheet.

It was the parent’s homework assignment to bring in one or more of these forms filled out to be discussed in the next parent group. The parents were asked to fill these out as soon as possible after the event; however this was not always possible and many times parents were completing the forms as the parent group began. This being noted, the parents were more apt to bringing these in filled out as the classes went on. Each week, every parent would get the opportunity to discuss what issue they were addressing with their child and the other parents and the psychologist facilitating the group would all provide feedback and suggestions on how they could address that issue.

Another focus of the parent consultation was promotion of a skill called attending which is used to assist parents in increasing positive behavior. The concept of attending was also adapted from the book, P*arenting a Strong Willed Child.* Attending refers to, “describing your child’s appropriate behavior, and at times, imitating what your child is doing” (p.73). Parents were instructed to watch their child closely and seek out times when their child was not displaying negative behaviors and to focus on the positive behaviors being displayed at the moment. “The parent gives no directions and asks no questions. The parent simply describes exactly what the child is doing" (p.74). Parents were asked to make attending statements with positive emotion and enthusiasm so that their children would feel a sense of reward for their positive behavior. This skill was role played several times throughout the seven weeks. Parents were instructed to use attending with their child at home and report their progress with this skill and progress with their child's positive behavior. Forehand also reports, "When parents use the attending skill, it communicates that they do notice and are interested in their child's appropriate behavior which will increase the likelihood that he will behave more appropriately more of the time" (p.75).

### *Data Collection*

The data collection process began in February of 2010, shortly after receiving Institutional Review Board approval in January 2010. The qualitative data was collected following a convenience sample in which three parents of children with ASD participated in intake interview two weeks before the parent consultation group began. The psychology professor and occupational therapy graduate student worked together interviewing two of the mothers; due to an interruption the third mother was interviewed only by the occupational therapy student. The intake interviews were recorded through audio taping and were transcribed to find codes and themes to use in this study. The occupational therapy graduate student researcher transcribed verbatim.

The quantitative data was collected in two parts; the pre-tests and post-tests. The pre-test; Parent Sense of Competency Scale was given to the three parents to fill out during the intake interviews. The parents were placed in an individual room with a file of paperwork including consent forms, confidentiality notice, and the Parent Sense of Competency Scale. The parents were left alone to complete the paperwork and this pre-test in private. The post-tests; Therapy Attitude Inventory and the Parent Sense of Competency Scale were administered on the last day of the Parent Consultation Group. The last twenty minutes of the class was set aside for the parents to fill these two forms out. The parent's completed the post-test assessments in the same room as one another. They were encouraged to complete every question independently. After completing the paperwork parents were awarded with a fifteen dollar gift certificate to a local bookstore for their participation in the program. These gift cards were made available through general funding of the psychology department.

### *Data Analysis*

#### Qualitative Data Analysis

The semi-structured intake interviews were transcribed verbatim from audio recording by the occupational therapy graduate student. These transcriptions were thoroughly examined by color coding similarities with post-it notes. Creswell (1998) reports, "researchers analyze their data inductively to establish patterns or themes. The final report provides for the choices of participant , a reflexivity of the researchers, a complex description and interpretation of the problem, and a study that adds to the literature or provides a call for action" (p.51). Six different categories were identified through this inductive process as the researcher placed similar codes onto color coded post-it notes that represented similarities. These codes were later narrowed down into three themes of the study. Creswell & Fetters (2004) support this process, "Qualitative inquiry can improve the description and explanation of complex, real world phenomena pertinent to health services research" (p.9).

### *Trustworthiness*

Trustworthiness was founded in this study through use of triangulation and reflexivity. A multi research method of triangulation was implemented for this study to better focus on the implications of parenting a child with ASD to those who participate in a parent consultation group. Triangulation was implemented in this study through use of the mixed methodology. By having a mixed method study, three types of data were used; interviews, two assessment scales, and peer debriefing during data analysis. Peer debriefing was used to establish triangulation for this study by having experienced qualitative researcher and professor in the occupational therapy department reviewed the graduate student's transcription, codes, and themes then provided guidance and feedback. Sharing responses with other team members helped to establish reliability and consistency in the qualitative results. Also contributing to this study was a record of the work completed forming an audit trail during data analysis. Literature of previous parenting classes for parents of children with ASD were also used to support the findings of this study. By bracketing assumptions and beliefs during the course of this study, the primary researcher was able to validate trustworthiness through reflexivity.

### Quantitative Data Analysis

The total scores for the pre-tests and post-tests were gathered and summarized in the table format below. The psychology graduate students scored this data and shared results with all team members. The Parent Sense of Competency pre-tests and posttests were reviewed for each parent; these scores were then compared to parent's Therapy Attitude Inventory score to investigate if there is any relationship to a parent's sense of competency before and after participation in a parenting class and their attitudes toward therapy. One way in which reliability was established for the quantitative portion of this study was through demonstrating instrument reliability. The findings from past research, Ohan, Leung, Johnston (2000) and Brestan et al. (1999) were used to support trustworthiness for the quantitative portion of this study. Both quantitative assessments are self-report measures and were found to show good interrater reliability, test/retest reliability and validity; as referenced in the instrumentation section of this review. Also, the therapy attitude inventory assessment was used as a post-test only to help eliminate changes associated with multiple testing. This study also had good mortality because the three participants remained active in the PCG from beginning to end and attended each parent consultation class.

# Chapter IV

## RESULTS

The results discussed in this study are obtained from three parents who participated in the Parent Consultation Group at Eastern Kentucky University. These participants were selected for the study using a convenience sample with inclusion criteria requiring that the participants were biological mothers; their children had received a diagnosis of ASD and had availability to interview. The three mothers' selected for this study children's ages ranged from nine to twelve years old, were all males, and IQ scores ranged from 100 to 120. Two of the three parents had never participated in a Parent Consultation Group or similar experience prior to this study. One parent was a returning participant who had been involved in the program one year earlier.

### *Qualitative Data*

The qualitative data for this study was obtained through a semi-structured intake interview. Four themes were found. These include; difficulty with routines, parental dissatisfaction with school system, parental exhaustion, and social participation. These themes are presented in alphabetical order as none have been found to be more significant than another.

### Difficulty with Routines

All three mothers identified difficulty with establishing routines as a challenge for their child. The parents expressed their concerns about their child needing reminders in order for them to help them. One mother (Parent 1: AA) reported, “He is a very good helper. He has to be reminded of the steps to do it but he is always eager to help”. Later she again reiterated this when asked how her son did with helping around the house. She replied, “When he is reminded of them he does very well”. This mother explains how her child does well with the task of completing chores but these routines are not established as he requires cuing and reminders in order for them to be completed. The second parent interviewed (Parent 2: LJ) also identified this challenge, “He is usually pretty good at helping if you ask”. Another mother, (Parent 3: AI) states, “It’s really hard to establish routine. He loses interest. I don’t know how they become established for him. It’s like I don’t know what the key to that is”. This mother expressed her challenge in helping her child to achieve this goal. Since all three mothers reported their child needing reminders as being an issue it was included as a theme for this study and was included in the course content of the parent consultation group.

### Parental Dissatisfaction with School System

Another theme found among all three parents was their dissatisfaction with their child’s school system. All three mothers explained how their children did not receive proper services at school. One parent (Parent 2: LJ) discussed her experience with her son’s school, “[Employee’s name] the counselor said you know I don’t know what to with him, I don't have an idea of what to do with him. His grades are good, his test scores are good. He obviously doesn't belong in a special ed class, but you know we have a child at school who is autistic, through stereotypical autistic and he's in the FMD room, you know [child's name] doesn't need to be in the FMD room. They just didn't know what to do with him, they just really didn't". The children of the three mothers in this study were not receiving services outside the school and considered the services offered in school to be fundamental to their child's progress so the lack of services offered in their child's school was seen as a threat to their child's growth. In fact two of the three mothers had taken their child out of the school system. One mother (Parent 3: AI) stated, "We took him out of the school, he is now home schooled. I pushed them [special services] for a while but they just didn't work out".

## Parental Exhaustion

Another common theme among these three mothers was the feeling of exhaustion. Much of this exhaustion is reported as resulting from the wearying requests or necessities their children place on them unknowingly on a daily basis. One mother (Parent 2: LJ) described this as, "I've told him 50 times and why am I having to tell them a 51st time, and they just really don't get it they really don't". All three mothers expressed feeling exhausted by their child's everyday demands. Another mother (parent 1: AA) described her experience, "He is going to be 10 in July and I think the steps of what you have to do after the bathroom need to be hanging up and I'm at the point where I just shouldn't have to do this anymore". This feeling of exhaustion is a major factor interfering with the routines of the parents of children with autism. When the children display behaviors that the parents perceive as overwhelming or stressful then they are less likely to participate in chosen occupations because they may feel occupationally imbalanced while trying to meet the demands of their children. This was evidenced by this mothers account (Parent 3: AI), , "I would like to find a balance because he questions everything and I would like to try and answer all of those questions but there are days that I cant. I just don't have the energy to everyday". This feeling of exhaustion was included in the parent consultation group by addressing because it is a behavior identified as stressful or exhausting for the mother's involved.

## Social Participation

Finally, a theme focusing on social participation was included in this study as parents reported one their biggest worries was their child's challenge with social participation. The three mothers in this study distinguished two aspects of social participation that they wanted their children to gain more competency with this skill. These two challenges of social participation identified by the mother's in this study include; initiating appropriate social interactions and not understanding social rules.

The mothers in this study see their child's challenges in initiating appropriate social interactions as a problem because it hinders their ability to make friendships. The first mother interviewed, (Parent 1: AA) stated, "I would like for him to initiative conversation in a way that doesn't push people off immediately so he actually has a chance of making friends". The mothers of these children experience negative feelings, including stress and worry when they see their children having a difficult time making friends. This mother identifies her son’s challenge in initiating conversation as her son’s biggest challenge in social participation as well as a large source of stress for her. She elaborates on this, “I would love for him to say hello to someone. Just open up and initiate the conversation until he is able to do that there is not a lot of point in going beyond that because for right now he needs to start talking to someone that doesn’t immediately push him away. He needs to make friends; he would love that very much but he just doesn’t know how to talk to other kids at all”.

The second aspect of social participation, not understanding social rules was also recognized as large source of stress. This was mentioned as challenge for all three children in this study and was identified as a goal to address by the parents. One mother, (Parent 2: LJ) explained, “He just doesn’t get interested in the same types of stuff as other kids, I mean he likes kids but he only wants to talk about what he wants to talk about, and this upsets his friends”. Again these challenges are sources of stress for the parents and were identified as goals to address in both the child and parent groups for this study. Another mother, (Parent 3: AI) described her son’s challenge, “He really has trouble engaging with other people and the back and forth. If he is talking to you he will ask you a question but he won’t listen to the answer or he will just talk past you”. This theme was included in the parent consultation group to decrease the amount of stress and anxiety parents feel in helping their child to achieve this goal.

### *Quantitative Data*

The quantitative data was collected through the standardized assessments; Parent Sense of Competency Scale and Therapy Attitude Inventory. Table 1 listed below displays the pre-tests and post-test scores for the parent sense of competency scale, along with Therapy Attitude Inventory scores which was used as a post-test assessment only. The pre-test assessments were given to parents to complete individually in a private office room prior to beginning the PCG classes. The posttest assessments were completed by the participants during the final PCG course; the last fifteen minutes were left for parents to fill these out individually. Parents were encouraged to complete all questions and to not share responses with the other participants.

Table 1
List of Parent Pre and Post-Test Scores

| Parent ID | Parent sense of competency pre-test | Parent sense of competency post-test | Therapy Attitude Inventory |
|---|---|---|---|
| Parent 1: AA | 71 | 74 | 42 |
| Parent 2 : LJ | 83 | 81 | 27 |
| Parent 3 : AI | 75 | 77 | 42 |

The highest total score possible for Parent Sense of Competency Scale is 102. The parents of this study scored between 71 and 83 on pre-test assessments and between 74 and 81 on the posttest assessment. While the scores for this assessment did not show statistically significant changes there were some changes. Two of three parents did indicate a positive change in their sense of parenting competency after participation in the parent consultation group; one mother however rated a slight negative change in their sense of competency after participating in the parent consultation group.

The Therapy Attitude Inventory is also a self-report measure that uses a Likert scale. The highest possible score for this assessment is 50. The ranges of scores for this assessment are between 27 and 42 for the three mothers in this study. These scores indicate that two of the mothers rated participation in the PCG positively and one more indicated more of a neutral point of view not rating participation as positive or negative.

While the results are not statistically significant, Table 2 and Table 3 listed below show the relationship between the parent's perception of their competency and their attitude toward therapy.

Table 2
Pre-Test and Post-Test Scores for Parent Sense of Competency

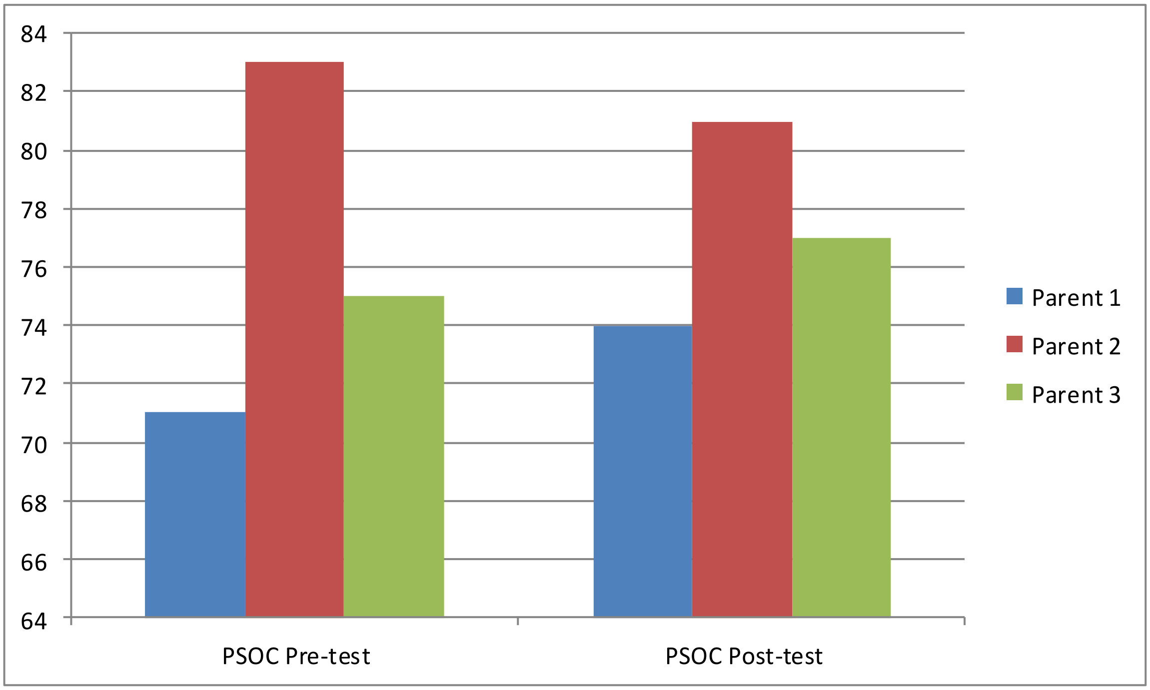
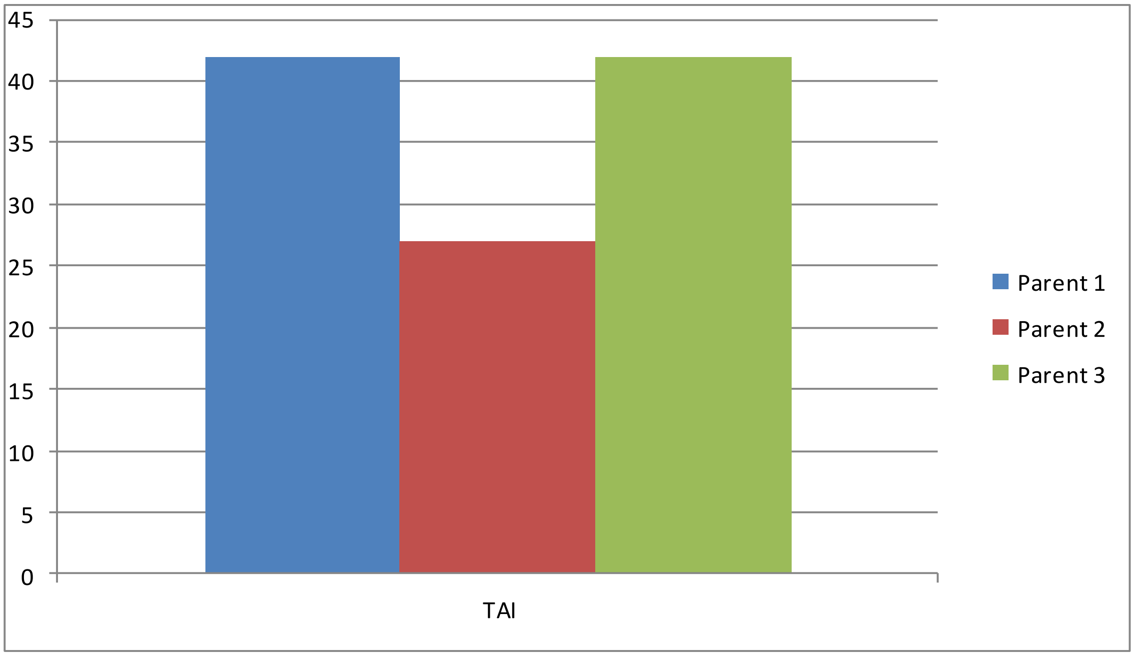


Table 3
Therapy Attitude Inventory Scores



The two mothers who rated themselves as having a positive attitude with the PCG using the TAI (As seen in Table 3) also showed a slight increase in their sense of parenting competency after participation in this group (As seen in Table 2).  Parent 2 in this study showed a decreased score in parent competency at posttest, and she did not rate herself as having a high positive feeling toward participation in the PCG.    The parents who viewed the Parent Consultation Group experience as more positive felt more competent in their parenting while the parent who viewed the Parent Consultation Group experience as less positive showed a decrease in their sense of competency.  It should be noted that parent 2 in this study was a returning participant to the parent consultation group, whereas parent's 1 and 3 had never participated in a parent consultation group prior to this experience.

# Chapter V

## DISCUSSION

The results of this study are separated by qualitative and quantitative data.

### *Qualitative Research Findings*

The qualitative results help to understand the research questions, what do three mothers of children with ASD perceive the needs and/or challenges of their children and what do three mothers of children with ASD perceive as stressors concerning their child's and families lifestyle? The findings gathered from the semi-structured interview discovered that the three mothers of children with ASD identified their children's challenges as: social participation skills and difficulty establishing routine. The support offered to the parents in this study is intended to focus on addressing the issues seen by the family. The three mother's identified stressor's to their lifestyle as; their child's difficulty in establishing routine, dissatisfaction with their child's school system, feelings of exhaustion, and their child's challenges in social participation. These perceived stressors were addressed in the 'make and take' activities since past research has shown, negative symptoms of depression and anxiety are a direct result of high levels of stress brought on by characteristics of a child's limitations (Benson, 2006, p.690).

### *Quantitative Research Findings*

The quantitative results assisted in understanding the research questions, how effective was a parent consultation group to three mothers who participated and how satisfied are the mothers about their participation in a parent consultation group? The results of this study found that three mothers of children with ASD feel more competent in their parenting skills after participating in a parent consultation group when they perceived the therapy services as more helpful. In fact a parent who perceives the therapy services as not having a positive influence may feel less competent after participation in a parent consultation group. Benson (2006) supports these findings as they found parents did not perceive professional sources of social support helpful but that "parents of children with ASD experienced positive affect from participation in a parenting class when the perceived needs were addressed" (p. 691).

### *Implications for Occupational Therapy*

The implications for occupational therapy in addressing the needs of parents of children with ASD became evident when analyzing the intake interviews of the three mothers that participated in this study. Based on this analysis it was determined that occupational therapists can assist parents of children with ASD in providing additional programming or services for children with ASD, assisting parents with feelings of exhaustion, and increasing social participation among children with ASD. Since the parents of children with ASD often do not have access to these services, occupational therapy services need to be made convenient and accessible to the families. DeGrace (2004) reports that families often do not participate in occupations of their choice because of these "non-stop" demands. The demands of ASD may also contribute to parent's participation in treatment Parents often are not able to participate in services for themselves because they must stay with their child instead of participate in educational services. The parent's in this study were able to participate because it was convenient as their children were receiving services at the same time. Also, occupational therapy services that are offered to the parents and children can assist parents in managing their perceived stress as both groups are receiving separate services to work toward common goal(s). For instance the intake interviews for this study were used to set goals for the child group based on what the parents identified as their needs. This information was also used to assist the parents as the make and take activities were graded to fit the needs of each parent based on the information they shared during the intake interview.

## Dissatisfaction with Services

The three mothers' in this study identified the need for their children to receive further services and to be involved in more group interaction. Having their children participate in the child group was recognized by the parents as one of the attracting factors to participating in this research study as they believed their children were not receiving these much needed services. This lack of opportunity is another contributing factor of the occupational injustice experienced by families of children with ASD. Christiansen and Townsend (2004) describe the occupational injustice related to decreased resources and explain that justice is, "required for occupational participation sufficient to satisfy personal needs and full citizenship" (as cited in AOTA, 2008, p.671). The three mothers' in this study do not feel that the current services being provided are appropriate for their children with ASD which suggests that occupational therapists should offer programming specialized for the needs of children with ASD. Occupational therapists are adept in their skills of providing group services and can address this need by providing social skills groups in after school programs or as part of inclusion programming so that the specific needs of these children are met

One mother in this study (Parent 2) reported lower satisfaction with the parent consultation group than the other two parents. This mother was a returning participant to the program. It is possible that this mother was less satisfied with the services offered because it did not meet her needs. The curriculum of the parent consultation group was the same curriculum as the year before. The make and take activities were a new addition to the program and these were customized to focus on what the parent's identified as their need but other than these two activities this mother may not have been exposed to new information consequently affecting her perception of how helpful the parent consultation group was.

## Parental Exhaustion

Another implication for occupational therapy is providing services to assist parents of children with ASD with their feelings of exhaustion. The mothers in this study felt exhausted by the everyday demands of their child's requirements for reminders to do something or behavior refinements. As evidenced in the literature review, parents of children with ASD experience much exhaustion as a result from the occupational disruptions in their routines and roles. Occupational therapists can work with parents to become skilled in actively changing their child’s behaviors. One way to help these parents is to train them in recognizing instances in which their children are not displaying demanding behaviors and to focus on these by providing them with social rewards.

Occupational therapy services can also be utilized to address parental exhaustion by assisting parents in attending to the sensory needs of their children. Jasmin et. al. (2009) state “Individuals with autism have difficulties with processing and modulation of sensory input” (p. 234). By educating parents on how sensory modulation affects their child’s behaviors, social participation, and occupational performance is another way that occupational therapists can have a positive effect on parental exhaustion. Furthermore, occupational therapists can provide children with sensory profiles and train parents on specific sensory integration techniques that will help their child modulate their sensory input.

## Roles and Routines

Parents of children living with a chronic illness may experience many exhausting factors other than the added responsibilities. Lee et al (2001) report, “In trying to deal with some of the ramifications of a chronic illness, many caregivers will develop an emotional state known as chronic illness” (p.48). Parents of children with ASD may also feel a sense of exhaustion due to a decrease in roles as the role of caregiving becomes engulfing. Lee, Strauss, Wittman, Jackson, and Carstens (2001) report, “In trying to deal with some of the ramifications of a chronic illness, many caregivers will develop an emotional state known as chronic illness" (p.48). Parents of children with ASD may also feel a sense of exhaustion due to a decrease in roles as the role of caregiving becomes engulfing. Lee et al also discovered, "The hobbyist role of the caregiver disappears over time" (p.59). The caregiver's hobbies and participation in occupations outside of caregiving are greatly impacted by the demands and chronic sorrow of caring for a family member with a chronic illness. There is opportunity for occupational therapists to create opportunities for participation in hobby or leisure for promotion of a more balanced set of occupations.

## Social Participation

Occupational therapists can also aid parents of children with ASD by working with them to improve their child's social participation. In this study, occupational therapy sought to assist parents in feeling more competent in addressing their child's challenges with social participation. The social reward "make and take" activity was implemented to encourage parents to reward their children with social rewards. Providing social rewards could teach children to initiate appropriate social interactions or can help them in showing interest in another person. Occupational therapists can also facilitate simulated scenarios for role play for parents and children to address this challenge of children with ASD.

## Addressing Parenting Competency

Parents of children with ASD necessitate feelings for more positive self-efficacy and competency in their parenting skills. In addition to assisting parents in enhancing specific skills, occupational therapists should also strive to assist parent's in feeling more competent about their most consuming role, parenting. Occupational therapists should persist in discovering what parents lack confidence about and address these issues in detail. Occupational therapists can address the needs of the parents by gaining an extensive understanding of the parent's needs and by taking a family centered care approach.

Another suggestion for occupational therapy in serving parents of children with ASD is to team with other professionals to achieve desired goals. Law (2006) explains, " When working with children with ASD, occupational therapists look at the interaction of the child/youth within their environment which includes the family, school system, community programs, and other health professionals" (p.2). Since autism is a fast growing condition with rates expected to increase there is much opportunity for occupational therapists to collaborate with other professionals in a variety of settings. Howell and Wittman (2011) found that occupational therapy and psychology students working together with children with ASD had, "opportunity to learn and practice appropriate intervention with children with autism, to make connections between what they were learning in classes with actual clinical work, and finally, to learn about the role of the other profession". Interprofessional work leads to many learning opportunities about communication and roles of different professions so that every profession involved can advance their skills in addressing the needs of parents of children with ASD.

### *Implications for Occupational Therapy Education*

Wittman and Bundy (2008) state, "Given the growth in diagnoses of autism, the probability that occupational therapy practitioners will work with both children and adults with this condition also is increasing. Practitioners working in school systems, private pediatric practices, home health, and mental health programs increasingly will be asked to provide occupational therapy assessment and intervention for persons with autism" (p.1). Because of the increasing opportunity for occupational therapists to work with adults and children with autism there are many implications for education in occupational therapy. First, education should focus on equipping occupational therapy students with the skills to assist individuals with autism across the lifespan. Adults with autism continue to have needs after childhood and occupational therapists should be prepared to confront these needs on an individual and community level.

When a child is diagnosed with a disability or chronic illness the whole family, especially the parents are affected. Parent's also often experience depression (Olson & Hwang, 2001). Depression is another condition that needs to be addressed. Brown & Stoffel (2011) explain how parents of children with ASD may experience depression, "depression is related to considering the future. The person is grieving for dreams that no longer seem possible coupled with fear or anxiety" (p.51). Occupational therapy education should include addressing the mental health needs of parents of children with autism into their curriculum and practice.

Finally, Family centered practice should also be promoted in occupational therapy education. It is important to keep in mind that every family is unique when compared to others, and even though experiences are often shared among members of a family each person's experience is exclusive to that individual. Despite these unique differences it has been known for an entire family to be impacted by one family member's illness. Children with ASD and their parents have insufficiencies in their lifestyle that occupational therapy services can enhance. Each family member's needs should be confronted when seeking professional support. In order to meet these needs, family centered practice should be considered as the focus for those studying occupational therapy.

### *Limitations*

. An effort was made to establish trustworthiness by having two interviewers present during the intake interviews. However, due to interruptions, the third parent was interviewed by only one researcher. Participants were interviewed only one time and follow-up interviews were not done. The principal researcher is a novice with little experience in planning and conducting a study of this kind. There are also some limitations to internal validity. While the assessments used were found to have good interrater and test/re-test reliability the assessments are not standardized as there are no norms for these two scales. Construct validity was challenged when measuring the effectiveness of enhancing parent's sense of competency. While a pre-test and post-test scale was used to measure changes before and after participation in a parent consultation group, the specifics of what parents felt less competent about were not considered. A general sense of competency was evaluated but parents were not asked if they felt more competent in any particular area. The exclusive skills addressed in the PCG were also not taken into consideration when evaluating parent's sense of competency before and after participation in the parent consultation group.

The external validity of this study was challenged as only mothers of children with Asperger's were included. Father's may perceive strengths, challenges and stressors differently than mothers of children with ASD. Likewise, the children of the parents in this study all had diagnoses of Asperger's; parents of children of other ASD diagnoses may also hold a different perception. The results of this study cannot be generalized to fathers or parents of children with ASD related diagnoses that are not Asperger's.

### *Future Research*

There continues to be a need for future research in the effectiveness of parenting classes for parents of children with ASD. Future research in this area should seek to include a greater number of participants and include mother and fathers as their needs and perceptions of stressors may differ. A more specific evaluation of what parents feel less competent about could also be useful when working with parents of children with Autism. Some specifics were addressed in this study however a more in-depth review could have been beneficial to parenting skills and parent's perceptions toward therapy.  Future research can take a participant action research approach in which a collaborative effort is made to meet the needs of these families.  Stolerman (2009) supports this type of research stating, "Participatory Action Research (PAR), rooted in the scholarly traditions of critical inquiry and action research, does just that. To borrow from revolutionary parlance, it is research for the people, by the people. Participants collaborate with researchers to formulate the research question, design the project, and develop specific actions that benefit their communities" (p. 253).

Research should also focus on addressing the needs of the children as they grow.  Since the children are continually challenged by their social limitations and other symptoms of ASD, the parents can be trained in addressing these needs so their children are better prepared with the life skills to live more independent and satisfying lives. One way to address life skills is by addressing the challenges children face in social participation.  Duncan and Klinger (2008) researched social participation services in group settings, school, and in the community. They report that individuals with ASD "will likely benefit more if they are provided with the opportunity to build their social skills and learn how to interpret various social cues in different contexts" (p.181). By providing services that focus on assisting individual with recognizing social cues in a variety of contexts, they may be better prepared to learn new life skills and be successful in a variety of contexts.

### *Conclusion*

This mixed method study about a parent consultation group for parents of children with ASD provides support for occupational therapists working with parents and families of children with ASD. There are many opportunities and implications for occupational therapy to work with this population. Occupational therapists can provide tools to parents of children with ASD to assist them in increasing levels of competency and decreasing stress in order to live a more occupationally balanced and satisfied life. Further research is needed to determine the effectiveness and generalizability of related studies.

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# APPENDIX 1:

## Semi-Structured Interview

## EKU Parenting Group
## Pre-screening Questions

**General:**

1. Have you attended any groups (social skills or therapy groups) before? If yes, please describe:
    a. What you liked about the group.
    b. What you learned from the group.
    c. What you would change about the group.
2. Do you have an email address? If yes, please provide your email address below.

**Child:**

3. What is your child's age and diagnosis?
4. Could you please give us an estimate of your child's IQ? We ask this because we want to know the different types of children that are involved in the group.
5. Is your child currently receiving services anywhere? (Occupational, Counseling, etc.)
6. What are your child's favorite snacks? Does your child have any food allergies?
7. Does your child have any special fears we should know about
8. We incorporate a social therapy dog and her owner into our group activities. How does your child respond to dogs?
    - Does your child have any allergies, specifically to dogs?
9. What are your child's personal weaknesses or areas of difficulty
10. What types of approaches from adult caregivers are helpful to your child?

**Parent:**

11. What are your children and family's personal strengths or abilities?
12. What sort of skills would you like to focus on most for yourself or your child in this group?
13. What do you think will be most challenging for you (your biggest problems) during the group?
14. What do you hope to get out of this group?

**Child Goals:**

These are the four different areas of concern your child will address. Devise a goal for each areas listed below for your child.

a. **Having fun by myself**
b. **Getting along with others**
c. **Taking care of myself**
d. **Helping**

Use the following Questions to gather more information/explain what area measures:

**Having Fun by Myself:**

- What things does your child enjoy doing alone?
- What are his/her favorite play activities?

**Getting Along with Others:**

- Who does your child most enjoy doing things with in your family, at school, or in other places?
    - Who are his/her favorite people?
    - Does he/she have a pet and if so, how does he/she relate to him/her (the pet)?
- What environment does your child enjoy being in the most (home, school, church, indoors, outdoors, etc.)?
    - What is his/her least favorite environment?
- Our group is designed to help facilitate social skills, especially friendship skills among our participants. How does this goal fit your child? What goals would you like to see us work on together?

**Taking Care of Myself:**

- What kinds of things does your child do for him/herself in terms of dressing, grooming, eating, etc.?

**Helping:**

- Does your child have any household chores? If so, what are they?
- How well does he/she do them?
- Does your child do anything else for others? If so, what do they do?

# APPENDIX 2:

# Parent Sense of Competency Scale

PSOC

**<u>Please rate the following items on a scale of 1 (strongly agree) to 6 (strongly disagree)</u>**

1. The problems of taking care of a child are easy to solve once you know your actions affect the child. This is an understanding I have acquired.

   (Strongly agree) (Strongly disagree)
   1 2 3 4 5 6

2. Even though being a parent can be rewarding, I am frustrated while my child is at his/her current age.

   (Strongly agree) (Strongly disagree)
   1 2 3 4 5 6

3. I go to bed the same way I wake up in the morning, feeling like I have not accomplished a whole lot.

   (Strongly agree) (Strongly disagree)
   1 2 3 4 5 6

4. I do not know why it is, but sometimes when I am supposed to be in control I feel more like the one being manipulated.

   (Strongly agree) (Strongly disagree)
   1 2 3 4 5 6

5. My mother/father was better prepared to be a good mother/father than I am.

   (Strongly agree) (Strongly disagree)
   1 2 3 4 5 6

6. I would make a fine model for a new mother/father to follow in order to learn what he/she would need to know in order to be a good parent.

(Strongly agree) (Strongly disagree)
1 2 3 4 5 6

7. Being a good parent in manageable, and any problems are easily solved.

(Strongly agree) (Strongly disagree)
1 2 3 4 5 6

8. A difficult problem in being a parent is not knowing whether you are doing a good job or a bad one.

(Strongly agree) (Strongly disagree)
1 2 3 4 5 6

9. Sometimes I feel like I am not getting anything done.

(Strongly agree) (Strongly disagree)
1 2 3 4 5 6

10. I meet my own personal expectations for expertise in caring for my child.

(Strongly agree) (Strongly disagree)
1 2 3 4 5 6

11. If anyone can find the answer for what is troubling my child, I am the one.

(Strongly agree) (Strongly disagree)
1 2 3 4 5 6

12. My talents and interests are in other areas, not being a parent.

(Strongly agree) (Strongly disagree)
1 2 3 4 5 6

13. Considering how long I have been a mother/father, I feel thoroughly familiar with this role.

(Strongly agree) (Strongly disagree)
1 2 3 4 5 6

14. If being a mother/father of a child were only more interesting, I would be more motivated to do a better job.

(Strongly agree) (Strongly disagree)
1 2 3 4 5 6

15. I honestly believe I have all the skills necessary to be a good mother/father to my child.

(Strongly agree) (Strongly disagree)
1 2 3 4 5 6

16. Being a parent makes me tense and anxious.

(Strongly agree) (Strongly disagree)
1 2 3 4 5 6

17. Being a good mother/father is a reward in itself.

(Strongly agree) (Strongly disagree)
1 2 3 4 5 6

# APPENDIX 3:

# Therapy Attitude Inventory

Mother ____________________ Father ___________________

## THERAPY ATTITUDE INVENTORY*

(Please circle the response for each question which best expresses how you honestly feel.)

I. Regarding techniques of disciplining, I feel I have learned

1. Nothing 2. Very little 3. A few new 4.several useful 5. Very
many useful techniques techniques techniques

II. Regarding techniques for teaching my child new skills, I feel I have learned

1. nothing 2. Very little 3. A few new 4.several useful 5. Very
many useful techniques techniques techniques

III. Regarding the relationship between myself and my child, I feel we get along

1. much worse 2. somewhat 3. The same 4.somewhat 5. Very much
than before worse than more confident confident
before

IV. Regarding my confidence in my ability to discipline my child, I feel

1. much less 2. somewhat 3. The same 4.somewhat 5. Much
confident worse more confident more
confident

V. The major behavior problems that my child presented at home before the program started are at this time

| | | | | |
|---|---|---|---|---|
| 1. considerably worse | 2. somewhat worse | 3. The same | 4.somewhat improved | 5. greatly improved |

VI. I feel that my child’s compliance to my commands or requests is at this time

| | | | | |
|---|---|---|---|---|
| 1. considerably worse | 2. somewhat worse | 3. The same | 4.somewhat improved | 5. greatly improved |

VII. Regarding the progress my child has made in his/her general behavior, I am

| | | | | |
|---|---|---|---|---|
| 1. very dissatisfied | 2. somewhat dissatisfied | 3. neutral | 4.somewhat satisfied | 5. very satisfied |

VIII. To what degree has the treatment program helped with other general personal or family problems not directly related to your child in the program

| | | | | |
|---|---|---|---|---|
| 1. hindered much more | 2. hindered slightly | 3. neither helped nor hindered | 4. helped somewhat | 5. helped very much |

IX. I feel the type of program that was used to help me improve the behaviors of my child was

| | | | | |
|---|---|---|---|---|
| 1. very poor | 2. poor | 3. adequate | 4. good | 5. very good |

X. My general feeling about the program I participate in, is

| | | | | |
|---|---|---|---|---|
| 1. I disliked it very much | 2. I disliked it somewhat | 3. I feel neutral | 4. I liked it somewhat | 5. I like it very much |

# APPENDIX 4:

# Non-social Rewards ‘Make and Take’ Activity

## Rewards for Completing Chores
### Duties

Reward your child with a special symbol each day they successfully complete an assigned duty.

Week/month:

| | Sunday | Monday | Tuesday | Wednes-day | Thursday | Friday | Saturday |
|---|---|---|---|---|---|---|---|
| | | | | | | | |
| | | | | | | | |
| | | | | | | | |
| | | | | | | | |

### Rewards

Let your child know how many symbols they must earn in order to get a specific reward. This can be changed as adaptation is needed.

| | |
|---|---|
| _______ symbols | |
| _______ symbols | |
| _______ symbols | |
| _______ symbols | |
| _______ symbols | |

# APPENDIX 5:

## Social Rewards ‘Make and Take’ Activity

(Actual document had cut-out pieces with Velcro attachments)

## Rewards for Good Behaviors

My Choice goes here!

## My Choice of Rewards

Play outside with someone

Caring For a Pet

Playing a game with someone

Dancing with family/friends

Receiving a Hug

Make a gift for someone