EXPLORING THE FACTORS RELATED TO PARENT INVOLVEMENT IN THE INTERVENTIONS OF THEIR CHILDREN WITH AUTISM

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Abstract

EXPLORING THE FACTORS RELATED TO PARENT INVOLVEMENT IN THE INTERVENTIONS OF THEIR CHILDREN WITH AUTISM

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This thesis explores the factors of parental involvement in the behavioral interventions of children with autism. Parental involvement in behavioral intervention is crucial to child success. Urie Bronfenbrenner’s ecological model suggests there are environmental factors that influence child development. A child’s development can be affected when individuals with the most influence and who are closest to the child are affected by environmental or societal factors. It is important for therapy professionals and social workers to understand these factors so they can provide parents with the necessary support to assure successful development and learning of the child. This study was conducted in Sacramento, California. The participants were recruited through a local resource center called WarmLine, which provides support to families with children who have special needs. A parent questionnaire was distributed to participants using an online survey system. Participation was anonymous and voluntary. Fifteen parents of children with autism between the ages of three to five who were receiving behavioral intervention participated in this study. Participants indicated the major factors that made it easier for them to be involved included: financial resources, frequent communication with
providers, support from family and friends, and the initiative of staff to provide parents with information regarding interventions and resources. Involvement is potentially more difficult when those needs are not met. The results of parental involvement found in this study cannot be applied to the particular population at large because the participants were already receiving services from this resource center, and because most of the participants indicated a significant level of involvement already. However, the results are significant nonetheless because they help to inform professionals who work with this population of the potential challenges and strengths parents can have and to help the professionals build on them to encourage parental involvement. Recommendations for future research are to collect a larger number of responses and explore the effect of utilization of resource centers on parental involvement in interventions of their children with autism.

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Chapter 1

Introduction

The number of children diagnosed with autism spectrum disorder (ASD) has rapidly increased over the past 20 years (Carey, 2009). In year 2000 it was estimated that 1 in 300 children had this diagnosis, in 2007 that number doubled to 1 in 150 children, and in 2009, an article in the New York Times magazine referenced a large study that estimated that more than 1 in 100 children in the United States may have Autism (Carey, 2009). The rising prevalence of ASD calls for greater clinical attention to effective methods of intervention for children with such diagnoses as well as their families (Burrell & Borrego, 2012). Parent involvement in the intervention efforts of their children with ASD is crucial for the success of the intervention as research suggests that “parental involvement in treatment improves the generalizability of skills and increases the amount of intervention the child receives” (Burrell & Borrego, 2012, pp. 423-432). Research shows that in order for intervention efforts to be effective, parents or close caretakers of children must be involved in the intervention process. The issue is that there are many obstacles parents face that prevent them from being fully involved in the intervention efforts of their children which hinder the parent-child outcomes and put further strain and stress on the family dynamic (Kern, 2000). This study explores parental involvement in the interventions of their children with autism and examines the factors that contribute to that involvement or the lack thereof.
Background and Significance of the Problem

ASD is a serious lifelong neurodevelopmental disorder with onset prior to the age of three years and is characterized by “qualitative deficits and impairment in social interaction and communication, restricted, repetitive, and stereotyped patterns of behaviors, interests, and activities” (Morsello, 2005). Though direct causes of autism have not yet been determined, scientific research shows that the etiology of autism is strongly linked with genetic and environmental factors in early development (Lai, Lombardo, & Baron-Cohen, 2013; Volkmar & Pauls, 2003). Over the last quarter of the 20th century and continuing through the 21st century, much scientific research and government support has gone into the improvements and advancements in treatment and education of children with disabilities (U.S. Department of Education, 2007).

Since the enactment of the Education for All Handicapped Children Act in 1975 that supported states in developing programs and resources for children with disabilities and their families, there have been great strides in development of various types of help to help improve outcomes of person with developmental disabilities. This law was amended in 1997 and became the Individuals with Disabilities Education Act (IDEA). Before this law came into effect, individuals with disabilities were often accommodated rather than assessed, educated and rehabilitated (U.S. Department of Education, 2007). Since the passage of this law, significant advancements have been made “toward meeting major national goals of developing and implementing effective programs and services for early intervention, special education, and related services” (U.S. Department of Education, 2007). Based on the information provided in articles on the US
Department of Education website, between the years of 2012 and 2014, a total of over 161.4 million dollars have been granted to institutions all over the United States in support of early intervention of children with autism ranging from interventions such as assistive technology, personnel development, research, parent training, to inclusion and economic self-sufficiency in adulthood (U.S. Department of Education, 2015, http://www.ed.gov/). Because there is much support from the government focused on providing assistance to children with autism and their families, parents and professionals must be aware of the ways that they can be involved to positively affect the outcomes of their children’s lives and help children reach their fullest potential.

Although a cure for autism does not yet exist, since the 1960’s many approaches and methods of intervention have been proven to be successful in treatment of autism (Deisinger, 2011). Much information about various intervention methods focusing on behavior modification for individuals with autism currently exists, however, professionals agree that parent involvement is crucial for the success of those interventions (Lai, Lombardo, & Baron-Cohen, 2013; Burkens, Hobson & Hobson, 2013; Solomon & Chung, 2012; Benson & Carlof, 2008). Though the cause, the prevalence, and intervention methods of autism are widely researched, this author believes that more focus should be drawn to parental involvement, and how to support parents in their involvement.

This is especially important because “in California, infants and toddlers presenting with suspected developmental delays from birth to three years of age receive early intervention services though the federally sponsored early intervention program
known as Early Start” (Cavagnaro, 2007). Once considered rare, according to the Department of Developmental Services, the amount of individuals with autism being served increased twelve – fold between 1987 and 2007, just in California, and the numbers of families with children with autism served by government organizations continues to rise in California and throughout the United States. Because this disorder has a serious lifelong impact on individuals and their families and requires costly lifelong interventions and services, it is important that parents and professionals understand why parental involvement is important and how to use available resources to promote child success.

**Purpose of this Study**

Providing early intensive behavioral intervention to children with autism is crucial to the developmental success of the child. However, raising a child with developmental disabilities such as autism can cause parents to experience many life challenges including increased stress which can prevent parent involvement in the interventions of their children and negatively affect child outcomes, which will be discussed in the following review of the literature section. With appropriate support from professionals as well as interactions with the community at large, parents and their children can realize the benefits of those interactions. It is hoped that the benefit of understanding all the factors that prevent parents from being involved in the intervention of their children with ASD, will help clinicians develop an approach to help and support parents in their participation in the intervention efforts of their children.
The first objective is to determine if parental involvement in the interventions of their children with autism is important and what challenges parents may experience that may be preventing them from being involved in the intervention methods. Next, using the collected survey responses, the study will identify to what extent parents are involved in the interventions of their children, and what factors may contribute to their involvement or the lack thereof. The last objective is to provide recommendations to professionals and parents regarding how they can collaborate better with parents so that children can benefit.

Theoretical Framework

The framework that will be used to show the potential factors involved in parental involvement is Urie Bronfenbrenner’s ecological model (Rosa & Tudge, 2013). Throughout his life, Bronfenbrenner was a world-renowned child psychologist who explored the field of human development and called attention to all environmental factors that influence child development including immediate people surrounding the individual as well as cultural forces nationwide (Brendtro, 2006). His ecological model is often referred to in child development and helping professions. He believed that a child’s successful development in essential aspects of life including intellect, morality, and social and emotional skills, depends greatly on the people who are closest to the child, with whom he or she develops strong attachment, and are committed to his or her well-being throughout life. Thus, he believed that “every child needs someone who is irrationally crazy about him or her” (Brendtro, 2006, p. 162).
In his ecological model, Bronfenbrenner suggested that individuals and their environments are shaped and altered by their reciprocal interaction with one another (Brendtro, 2006). His bioecological theory further supports the ecological theory stating that the genetic material one is born with interacts with the environmental experience, and produces the developmental outcomes of that individual (Bronfenbrenner, 1994). Therefore, while children with autism are born with certain traits that display the characteristics of the disorder, environmental factors such as interactions with parents, parent participation in therapy, as well as direct behavior intervention services, can have a significant effect on the outcomes of those interventions.

Bronfenbrenner’s ecological theory includes four interconnected spheres called microsystem, mesosystem, exosystem, and the macrosystem, each representing various environments that influence the development of an individual (Turnbull, Blue-Banning, Turbiville, & Park, 1999). The innermost sphere is the microsystem that represents the factors in the child’s immediate environment that affect him or her directly such as who he or she lives with, and the extended family (Turnbull, Blue-Banning, Turbiville, & Park, 1999). The next sphere contains the microsystem and connects it to other systems. An example of a mesosystem for a child with autism receiving intervention services would be professionals’ such as therapists, teachers and nurses interactions with parents (Turnbull, Blue-Banning, Turbiville, & Park, 1999). The next sphere is the exosystem which does not involve the child as an active participant but interacts with mesosystems in which he is involved such as parent employment organizations. The outermost sphere is the macrosystem which is the government leaders, the culture, and the society in which
the child lives that has a cascading effect on the smaller systems that surround the child (Turnbull, Blue-Banning, Turbiville, & Park, 1999).

While all the spheres of the ecological theory affect the child directly and indirectly, this research will mostly focus on the occurrences in the microsystem and the mesosystem, although the effects of the exosystem and the macrosystem will also be explored. Although children and parents can greatly benefit from the vital resources that are provided by the intervention staff, parents can also be a vital resource for professionals and other community organizations who work together to enhance the child’s and family’s quality of life, because individuals across all four levels of the ecological model have “strengths and resources that complement professional expertise” (Turnbull, Blue-Banning, Turbiville, & Park, 1999). This statement is directly related to this study, as it suggests that a strong connection between parents and their children, as well as parents and their children’s intervention programs provides a greater potential for positive effect on their children’s development.

Although caring for a child with ASD can be stressful for many parents, professionals can help parents to overcome those challenges and minimize as much as possible the potential barriers that may come with raising a child with autism using the strengths perspective. The strengths perspective does not devalue that challenges families may face, but rather “demands a different way of looking at individuals, families, and communities” (Saleebey, 1996). This perspective will be discussed in this paper suggesting ways it can be used by professionals to positively affect family’s lives. In addition, the Resiliency Model of Family Stress, and Adjustment (Hall, Neely-Barnes,
Graff, Krcek, Roberts, & Hankins, 2012) will also be discussed as a tool that can be used to help families realize enhanced sense of purpose in raising a child with autism. This framework focuses “(a) individual to family systems: ways a family internally handles problems or difficulties between its members and (b) family to community: ways in which the family externally handles difficulties or problems through interactions between the family and the community” (Twoy, Connolly, & Novak, 2007).

Using Urie Bronfenbrenner’s ecological and bioecological models as well as the framework of the Resiliency Model of Family Stress, and Adjustment, and the strengths perspective, this thesis will explore some of the most common stressors parents of children with autism are faced with in raising their child, and will explore potential factors that help them overcome those challenges.
Chapter 2

Review of the Literature

Autism Spectrum Disorder (ASD) is currently a widely studied developmental disorder due to its growing prevalence worldwide. Autism is a pervasive disorder that presents itself in qualitative impairments in social interactions and communication, restricted patterns of behavior and interests with onset before the age of three years (Spreckley & Boyd, 2009). Many theories exist on the potential causes of autism such as hereditary, genetic, medical and environmental factors and researchers continue to explore these potential causes (Twoy, Connolly, & Novak, 2007). Autism presents itself with specific behaviors such as impaired eye gaze and lack of social reciprocity with limited and/or absent joint attention. Communication impairments may be portrayed in lack of or absence of language, echolalia, or lack of appropriate imaginative play. Furthermore, restricted patterns of behavior oftentimes present themselves in ways of abnormal preoccupations, interests and activities, stereotyped mannerisms, or having difficulty with change (Volkmar & Pauls, 2003).

In addition to the aforementioned characteristics, children with ASD may also exhibit challenging behaviors such as anxiety, sleeping and eating problems, temper tantrums, and aggressive behaviors toward self and or others (Spreckley & Boyd, 2009) and extreme difficulty learning essential human behaviors (Twoy, Connolly, & Novak, 2007). Furthermore, between 50 and 70 percent of children with ASD also have an intellectual disability. The fact that ASD is a spectrum disorder indicates that the severity of characteristics of this disorder vary in individuals. Some individuals may attain some
functional language and become affectionate with certain individuals; others may remain aloof and not gain any effective communication (Spreckley & Boyd, 2009).

The Diagnostic and Statistical Manual of Mental Disorders (DSM) which is “a classification of mental disorders with associated criteria designed to facilitate more reliable diagnoses of these disorders” (American Psychiatric Association, 2013, p. xli), provides criteria for diagnosing various disorders such as autism. According to the most current DSM, the DSM 5, autism symptoms are typically recognized in the second year of life between 12 and 24 months. Delays and symptoms may even be seen earlier than 12 months in some individuals (American Psychiatric Association, 2013, p. xli).

**Importance of Early Diagnosis**

Research shows many benefits of early detection of autism symptoms, and professionals of the American Academy of Pediatrics (AAP) have developed strategies such as the A.L.A.R.M. acronym (autism is prevalent: listen to the parents; act early; refer; and monitor) as a guide for pediatricians to provide a prompt diagnosis and refer for intensive interventions (Twoy, Connolly & Novak, 2007).

Professionals have also developed highly reliable developmental screening questionnaires such as the Ages and Stages Questionnaire (ASQ) that looks at strengths and trouble spots and in children’s development. The ASQ is the ideal tool that allows professionals to collaborate with the parents of children and identify potential delays in areas such as social skills, communication skills, problem solving skills, as well as fine motor and gross motor skills early in the children’s development as young as one month of age to 5 and a half years of age. Other tools that are similar to the ASQ such as the
Modified Checklist for Autism in Toddlers (M-CHAT) and Baby and Infant Screen for Children with Autism Traits (BISCUIT) also help professionals identify developmental delays (Matson, Tureck, Turygin, Beighley, & Rieske, 2012) and refer for necessary services. Although these are not diagnostic tools, they are widely used by professionals to identify potential delays in a child’s development, provide an opportunity to educate parents on typical developmental milestones, provide tools for parents to use to help their children learn the skills they lack, and make appropriate referrals for needed resources (McKnight, 2014). Early detection of ASD symptoms is important because it can provide parents timely access to intervention services that are essential in treating and preventing the accumulation of deficits that can hinder later social and communicative functioning (Rodger, Cook, Keen, & Braithwaite, 2008).

**Early Intensive Behavioral Intervention**

Various interventions for individuals with autism exist including Greenspan Floortime (Thornton, 2006), the Early Start Denver Model (Vivanti, Dissanayake, Zierhut, & Rogers, 2013), Relationship Development Intervention (Gutstein, Burgess, & Montfort, 2007), and Applied Behavior Analysis (ABA) (Axelrod, McElrath, & Wine, 2012). A number of therapeutic methods including music therapy (Reschke-Hernandez, & Alaine, 2011), as well as play based occupational therapy (Rodgers, & Ziviani, 1999) are also common. Over the past 60 years however, behavioral intervention in the form of ABA has been most researched and proven to be most effective in treatment of ASD (Axelrod, McElrath, & Wine, 2012). Therefore, this thesis will focus on parent involvement in the ABA interventions of their children.
A set of operant conditioning therapy focused on behavior modification knows as Applied Behavior Analysis (ABA) is the most effective behavioral treatment for autism when compared to other treatments including medication and special diets (Spreckley & Boyd, 2009). ABA is a type of Early Intensive Behavioral Intervention (IBI) that can be applied to any population or any age group, and has made considerable contribution to the research involving populations with developmental disabilities (Axelrod, McElrath, & Wine, 2012).

Because children with ASD have difficulties with leaning and being able to learn through imitation, Ivar Lovaas developed ABA in 1987. It is based on the science of teaching appropriate behaviors by breaking down tasks into small steps and training each step in a systematic way for many hours per day, with a recommended time of 40 hours per week (Axelrod, McElrath, & Wine, 2012). Original studies by Lovaas were monumental as they showed that ABA intervention can increase cognitive functioning and contribute to gains in IQ scores in children with autism (Spreckley, & Boyd, 2009). The fact that the gains observed in this study were replicated and maintained in several follow-up studies, for the first time in history, produced encouraging outcomes for individuals with autism and helped them to live more fulfilling lives (Axelrod, McElrath, & Wine, 2012).

ABA is delivered through Discrete Trial Training (DTT) incorporating positive reinforcement, stimulus control, and fading prompts to shape and teach the intended behaviors across various settings (Matson, Tureck, Turygin, Beighley, & Rieske, 2012). Typically children with ASD receive the diagnosis between the ages of 2 and 3 and begin
to receive ABA interventions. Research has shown that children under the age of 30 months respond best to this intervention (Matson, Tureck, Turygin, Beighley, & Rieske, 2012). ABA was designed to address all the problems faced by individuals with ASD and has shown effectiveness in development of language and communication skills, self-care skills, as well as improvements in quality of life, productivity, and elimination of challenging behaviors including those that are life threatening (Axelrod, McElrath, & Wine, 2012).

Though there is no cure to autism, research has shown that some children “achieve a level of functioning that is indistinguishable from the typically developing peers” (Matson, Tureck, Turygin, Beighley, & Rieske, 2012, p. 13) or ‘best outcomes’ and are able to enter mainstream classes without additional support from the intervention staff. A study conducted in 2014 at the University of California, Davis, Medical Investigation of Nuerodevelopmental Disorders Institute (MIND Institute), which is an international research center for neurodevelopmental disorders, revealed findings that further emphasize importance of earliest intervention. Researchers found that six out of seven infants as young as 6 months of age with apparent ASD symptoms, who participated in this study and received therapy, had neither ASD or developmental delays by age 3 (Brown, 2014).

The therapy was implemented by the parents of those infants as the researchers recognize the effectiveness of therapy implementation by those who are most in tune with and spend most time with their children (Brown, 2014). Sally Rogers, the main researcher of this study stated that “it was the parents – not therapists- who did that…
parents are there every day with their babies. It’s the little moment of diapering, feeding, playing on the floor, going for a walk, being on a swing, that are the critical moments for babies” (Brown, 2014) and she was able to prove that in her work, essentially, preventing the diagnosis of ASD of those children. Professionals agree that early detection of potential symptoms of ASD is very important because treatment efforts can begin immediately, and the sooner intervention is received, the more the child will benefit (Matson, Tureck, Turygin, Beighley, & Rieske, 2012).

When children receive the autism diagnosis, parents can begin to work with professionals, determine an Individualized Education Plan (IEP) for their child, and begin receiving Early Intensive Behavioral Intervention (EIBI) to help their children learn skills and knowledge they lack. EIBI can be provided in a school based setting or in the home of the child 20-40 hour per week, depending on the needs of each child (Matson, Tureck, Turygin, Beighley, & Rieske, 2012). Research shows that children with ASD who receive intensive treatment show significantly more improvement in skills than those who receive less treatment (Burrell & Borrego, 2012).

**Importance of Parental Involvement**

Parental involvement has significantly influenced the research of the cause of autism and professional practices of treating autism over the past century, since the beginning of the wide recognition of this disorder (Langan, 2011). It was parental involvement that directed the focus of research away from the “refrigerator” mother theory that blamed parents for causing autism in the 1970s and 1980s, and redirected the focus of research on other potential causes such as vaccinations and environmental
factors in the 1990s (Langan, 2011). In the 2000s it was the vigorous action of parents that spearheaded the movement of acceptance of individuals with autism through advocacy for their children’s rights throughout history, and initiated a more collaborative, rather than confrontational relationship with professionals (Langan, 2011). Consumers of ABA and parent advocates have greatly contributed to significant impact in the legal system in effort to initiate the delivery of intervention services at home and at schools for their children with autism (Axelrod, McElrath, & Wine, 2012).

Activism in the forefront of policy and research is a very important part of parental involvement; however parental involvement in the daily face to face interventions is just as important, as it directly affects the child’s development and learning. Parents are most dependable, knowledgeable and stable people in the child’s life who can contribute greatly to the outcomes of the intervention (Burrell & Borrego, 2011). Furthermore, research on families of children with disabilities has found that when important stakeholders (such as parents) are included in ABA intervention of their children, both parents and children harvest the benefits of improved family functioning (Burrell & Borrego, 2011).

**What Constitutes as Parent Involvement?**

Parental involvement in the ABA interventions of their children can be observed in many forms. Parents can be involved by communicating directly with intervention staff or through communication notebooks, participation in their children’s intervention staff team meetings, attending workshops and trainings on strategies to use with their children, observation of their children’s therapy, and/or by conducting one-on-one
instruction and therapy with their children at home. However, research shows that more intensive parental involvement in treatment results in more positive treatment outcomes will be (Burrell & Borrego, 2011).

Parents’ active involvement in the intervention efforts is especially important because they are the ones who spend the most time with their children and have the most influence on them. Children who’s parents are involved in the intervention methods can receive an even greater amount of learning opportunities in addition to the intervention they already receive from intervention staff (Burrell & Borrego, 2011). Although one small study conducted at University of California, Los Angeles found that because of the greater knowledge of ABA that professionals have, interventions provided by professionals are more effective than when it is run by parents (Smith, Buch, & Gamby, 2000), there is evidence showing otherwise as well. According to the bodies of literature that have been researched regarding parent involvement, numerous studies have shown that parents can learn the techniques of interventions and effectively implement it with their children (Solomon, Ono, Trimmer, & Goodlin-Jones, 2008).

**Parent Implemented Intervention**

One of the ways that parents can participate in their children’s intervention program is by directly conducting formal sessions with their children. Parent directed interventions have shown to be successful in studies ranging from children of different ages and disabilities. Researchers have found that parents are indeed capable of implementing effective interventions themselves and have identified many benefits of this (Levy, Ae-Hwa, & Olive, 2006). Studies find that when parents act as intervention
agents, their children benefit from increased number of hours of therapy focusing on language and behavior, without increasing the costs of service providers with the ability to continue interventions as necessary throughout the child’s lifespan (Levy, Ae-Hwa, & Olive, 2006) and continue reduction of problem behaviors of their children with ASD as necessary throughout the child’s life (Levy, Ae-Hwa, & Olive, 2006).

Some research has suggested that parents acting only as ‘teachers’ of their children can negatively affect the parent child relationship (Turnbull, Blu-Banning, Turbiville, & Park, 1999). The message that parents must always act as teachers to their children may miscommunicate the idea of the parenting role to parents with children with autism and other developmental disabilities. Children with disabilities need to have a feeling of acceptance, appreciation, and love, especially from their parents, no matter the disability (Turnbull, Blu-Banning, Turbiville, & Park, 1999). The research attempted to hypothesize that this type of relationship between parents and children may cause children to feel unworthy of unconditional acceptance due to the subtle and not so subtle messages from parents that they must be changed before they can be accepted (Turnbull, Blu-Banning, Turbiville, & Park, 1999). The majority of studies and evidence based research however, disproves this hypothesis beyond reasonable doubt. The majority of literature that exist regarding parental involvement states that “parents of children with autism are critical components of the rehabilitation process, without whom gains [in skills] are unlikely to be attained” (Kern, 2000) and professionals among the behavioral science arena agree regarding the importance of parents’ direct involvement of therapy with their children with autism,
**Parent Trainings and Collaboration with Intervention Staff**

Because parents spend the most time with their child and know their child best, parents can offer much support to the intervention staff and because intervention staff is more knowledgeable in the interventions of the child, they can provide guidance to the parents (Turnbull, Blue-Banning, Turbiville, & Park, 1999). When parents follow through with the intervention plans of the child with ASD in the home and the community, in addition to the intervention already provided to the child outside of the home, the child has more opportunities to learn new skills in a consistent fashion (Volkmar & Pauls, 2003). Consistency in ABA intervention is important because it aims to generalize learned skills across environments to ensure mastery and maintenance of those skills. Generalizability of skills for children with ASD is essential because they have difficulty in displaying learned skills across settings and situations (Burrell & Borrego, 2011). Children receiving therapy must be able to apply learned skills in various appropriate environments outside of the therapy room without the help of the therapist.

Engaging in experiences and social interactions in varying situations with individuals who have the skills to help teach appropriate responses in all setting and environments is one of the most important aspects of successful outcomes (Burrell & Borrego, 2011). Therefore, therapy staff must work with parents and encourage parent implemented treatment in activities that parents and children engage in daily, such as playing, self-care, chores, shopping, etc.
In order for children with autism to gain the most out of their intervention, it is important for parents and professionals to collaborate and support each other. Parents must not only be aware of the therapy goals of their children, but must also work with therapy staff to help their child achieve that goal. For example, if parents are unaware of the intervention plan the staff utilizes to modify a child’s particular behavior problem and are not addressing this problem at home in the same manner as the staff does in the classroom, attempted behavioral modification will not be effective. Miscommunication between parent and therapy staff, or rather lack thereof may impede progress and make it more difficult for the child to achieve the goal. Furthermore, parents need specific instructions and useful techniques on how to deal with and how to modify their children’s problematic and destructive behaviors (Rapin, 1997).

Best outcomes are observed when clinicians and parents have supportive and understanding relationships that allow them to work together, share goals, expertise, responsibility, and problem solving (Burrell & Borrego, 2011). This can be done through that aforementioned strategies such as participating in intervention staff team meetings, continued communication in person as well as communication journals, and attending trainings on appropriate strategies they can use with their children (Burrell & Borrego, 2011).

Various types of methods exist to provide parents with the necessary training in the intervention and techniques of their children. Some programs stress importance on positive parent-child interaction to teach age appropriate communication and promote language development of the child (Burrell & Borrego, 2011). Other programs such as
Parent Child Interaction Therapy (PCIT) which involves providing in-vivo coaching to parents by observing parent and child through a one way mirror and providing immediate feedback to the parent through a hearing device, have also been used (Burrell & Borrego, 2011). Other parenting programs, under the supervision of the clinician, integrate parents into directly implementing the intervention skills they learned after observing the intervention provide by the therapist. This training technique is effective because it includes clinicians providing parents direct in–vivo training and guidance as well as feedback (Burrell & Borrego, 2011).

Another effective training technique used to provide ABA training to parents is the Treatment and Education of Autistic and related Communication-handicapped Children (TEACCH) home based model (Burrell & Borrego, 2011). The TEACCH model involves parents working with two therapists such that while the parent is observing one therapist implement therapy behind a one way mirror, the other therapist explains what is being done to the parents. The parent is then encouraged to implement those strategies at home (Burrell & Borrego, 2011).

Another in-home program approach includes parents in therapy from the start of the intervention program. In this approach the therapist and parent work together to identify areas that are most important for the child to learn and then teach the parent strategies to use to improve overall condition, prevent problem behaviors, redirect inappropriate behaviors, and effective implementation of consequences to problem behaviors. Following this, parents are left to implement them alone with their children
with the therapist remaining available to the parent for ongoing support, education, and strategy modification as needed (Burrell & Borrego, 2011).

Studies have shown that when parents are trained in the systematic therapy techniques of the therapy that their children receive, both parent and the child harvest the benefits of this interaction (Solomon, Ono, Trimmer, & Goodlin-Jones, 2008; Gilbert & LeBLanc, 2007). Parents gain confidence in providing effective intervention and children benefit from the increased interaction with their parents, as well as modified behavioral problems, learning awareness of emotion, increased self-esteem, and stimulated speech and language development and play skills (Solomon, Ono, Trimmer, & Goodlin-Jones, 2008; Gilbert & LeBLanc, 2007). Furthermore, when parents implement therapy themselves, they receive a sense of confidence and empowerment therefore reducing their feeling of depression and stress related to raising a child with developmental disabilities (Estes, Vismara, Mercado, Fitzpatrick, Elder, Greenson, & Rogers, 2014) as well as increased optimism and confidence in parenting ability, as well as (Solomon, Ono, Trimmer, & Goodlin-Jones, 2008)

Parent involvement strategies can be as intensive as providing parents opportunities to practice therapy guided by clinician coaching, or by providing parents with treatment manuals, videos, and other information. Although just a few of the many existing parent training approaches are described here, and more research needs to be done about the effectiveness of each method, options are possible and should all be considered when including parents in the interventions. Furthermore, regardless of the
methods used to involve parents in the interventions of their children, it is essential to the successful outcome of the intervention (Burrell & Borrego, 2011).

**Factors that Prevent/Contribute to Parent Involvement**

An important thing to consider when involving parents in treatment is making sure that parental involvement in treatment is possible for parents (Burrell & Borrego, 2011). The type of approach that professionals use in involving parents in the interventions of their children is an important factor. Research suggests that professionals neglect to initiate the involvement of parents in the intervention and do not provide them with the support and education they need to be consistent with the intervention plans of their children (Moh & Magiati, 2012), which can restrict the progress of the child. The problem may be that clinicians do not know how to appropriately involve parents or are not familiar with the various methods that can be used to involve parents such as including parents in the initial stage of treatment and/or collaborating with parents on developing goals and problem solving (Burrell & Borrego, 2011).

One study focused on potential factors that may inhibit parental training and found that the parent-clinician relationship may be a factor worth considering (Rodgers, Keen, Braithwaite, & Cook, 2008). This study was based on findings of another study that found that parents of children with autism display fewer strategies to coping with stress which may inhibit them from forming healthy working relationships with professionals and be dissatisfied with the services received from the clinicians (Rodgers, Keen, Braithwaite, & Cook, 2008). Through this study researchers found a few factors
that contributed to parent dissatisfaction with services. Parents that participated in the study reported challenges in building rapport with clinicians, feeling incompetent, and not being understood in the demands of parenting a child with autism (Rodgers, Keen, Braithwaite, & Cook, 2008). The parents stated that they would have liked to feel more valued and have their values understood, rather than being treated as a ‘case’ (Rodgers, Keen, Braithwaite, & Cook, 2008). Another study found similar findings stating that “communication between professionals and parents is one of the strong indicators for effective and successful partnership education” (Turnbull, Blue-Banning, Turbiville, & Park, 1999) along with respectful considerations of the culture of the family.

Another factor that is important to consider when encouraging parents to participate in the interventions of their children is determining how they perceive autism, their coping mechanism, and their belief in the potential effectiveness of intervention. A recent study that interviewed 16 parents ages 60 and older found that some parents who participated in the study did not see intervention services including behavioral management services to be useful because they did not believe that it would be effective in helping the children with their problem behaviors (Hines, M. Balandin, S., & Togher, 2011). Therefore, pursuing intervention was not worthwhile to those parents (Hines, M. Balandin, S., & Togher, 2011). The study found that some parents cope by adapting a view of autism as a tragedy that happened to their child, as a belief that their child being ‘buried’ by autism which may “conflict with constructions by professionals who adopt strength-based approaches to support individuals with disabilities” (Hines, M. Balandin, S., & Togher, 2011). It is important to learn about the preconceptions and beliefs of
parents in order to implement an intervention plan personalized for the needs of that family. The study suggests that in order to get a deeper understanding of personal needs and coping mechanisms of each family, it is imperative to take the time to establish rapport over time and to develop relationships with the families (Hines, M. Balandin, S., & Togher, 2011).

Other potential factors that may prevent parent involvement in intervention are aspects in the family dynamic that may make it difficult for parents to participate such as, other children to take care of, one parent households that may have additional responsibilities and stressors, or the techniques may be too confusing or difficult to understand in the way they are explained to them (Burrell & Borrego, 2011). Issues in the home of the family that are not addressed by the family may be impeding the child’s progress in treatment. Therefore, according to Burrell and Borrego (2011), clinicians should be able to assess the family dynamic and be able to address potential problems such as these by providing families with special attention to decrease the stressors in the family and the use of techniques should be explained to parents in way that they may be able to understand and be available to provide then with additional support as necessary.

Parent satisfaction of the early intervention programs as well as the professionals working with their children is essential for parents in understanding their role in the intervention efforts (Borrego & Burrell, 2012) as well as parent and professional collaboration in services (Rodger, Cook, Keen, & Braithwaite, 2007). According to Solomon and Chung, “there are likely to be interrelated presenting problems (overwhelming schedules, parental conflict secondary to exhaustion and grief, confusion
Parental stress of children with ASD “is primarily due to child dependency, physical limitations, cognitive impairment, caregiving responsibilities, interference in daily activities, and long term caring responsibilities” (Borrego & Burrell, 2012, pp. 423-432). In addition to these responsibilities, children with ASD exhibit disruptive behaviors that are difficult for parents to deal with, such as physical aggression, property destruction, defiance, difficulty transitioning between activities, and tantrums (Solomon, Ono, Trimmer, & Goodlin-Jones, 2008), which can impair the parent-child relationship.

Although problem behaviors may manifest differently in children with autism, they need to be carefully assessed and require strategic intervention (Solomon, Ono, Trimmer, & Goodlin-Jones, 2008). When parents do not know how to appropriately deal with the negative or disruptive behaviors of their child with autism they may inadvertently reinforce the problematic behavior which will cause those behaviors to increase and exacerbate in the future (Burrell & Borrego, 2011). This may cause the parent-child relationship to become hostile and negative (Burrell & Borrego, 2011) and decrease opportunities of learning and socialization when aggression and tantrum behaviors are present (Solomon, Ono, Trimmer, & Goodlin-Jones, 2008).

Because children with disabilities have more complicated needs there may be restrictions on events or activities that can be attended by the family and routines and traditions may be altered, which may place additional strain on the family and negatively effecting marital satisfaction in two parent households (Burrell & Borrego, 2011).
Furthermore, “marital quality has also been found to be related to parental depressive symptoms, parenting efficacy in mothers, and to depressive symptoms and parenting stress in fathers” (Burrell & Borrego, 2011 pp. 423-432) which can negatively affect the child with autism and as well as the entire family.

Research shows that high parent stress is related to an increase of child disruptive behaviors, suggesting that there may be a cycle between parental stress and disruptive behaviors in children and can negatively affect the sense of self efficacy in parents (Solomon, Ono, Trimmer, & Goodlin-Jones, 2008). The severity of the disorder in the individual child is also a factor that can contribute to parent high levels of stress which results in less satisfactory parent-child interaction (Beurkens, Hobson & Hobson, 2013).

Providing intensive and continuous behavioral intervention to children is oftentimes a difficult task for parents, especially those who work, have other children, or experience other stressors that may inhibit their mental health and interaction. For families, raising a child with ASD can result in significant psychological and mental health concerns including increased reduced opportunities for self-care and leisurely activities, disruptions in finances, work and family life, and increasing the risk of elevated levels of stress depression, and anger (Benson & Karlof, 2009). Furthermore, “stress proliferation (the tendency for stressors to create additional stressors) has been suggested as an important contributor to depression among caregivers” (Benson & Karlof, 2008, pp. 350-362).
Positive Factors of Raising a Child with Autism

Though most of the research that exists regarding raising a child with autism focuses on the challenges parents face when raising a child with developmental disabilities, some research explores the positive effects and personal growth that parents experience as well. A small study conducted in Canada surveyed and interviewed 8 married mothers who were primary caregivers of their children with autism (Markoulakis, Fletcher, & Bryden, 2012). The study found that “participants had life-changing experience and lost dreams, but viewed the possibilities that were ahead of them with a sense of hope, control, and empowerment “(Markoulakis, Fletcher, & Bryden, 2012). Although there were limitations in this study, there is a potential that these results may apply to many other parents of children with developmental disabilities.

Although caretakers and families of children with autism have many demands placed on them, according to this study, it is possible for caregivers and families to view their roles positively and maintain an enthusiastic attitude toward their experiences. Mothers who participated in the study reported experiencing social benefits as a result of new experiences they became involved in as a result of caring for a child with autism. Because caring for child with developmental disabilities is a threat to health, mothers reported a motivation and renewed focus on physical health, to prevent potential health costs. They also stated that they experienced benefits of new employment opportunities as they explored employment options. Furthermore, the study reported experiencing familial benefits and increased commitment in their marriages as a result of caring for a child with autism (Markoulakis, Fletcher, & Bryden, 2012). Many mothers also became
involved in formal and informal aspects of autism advocacy and shared this experience as being a benefit in their lives as well (Markoulakis, Fletcher, & Bryden, 2012).

Research has shown that parents of children with autism experience more parenting related stress, depression, and anxiety than do parents of children with other developmental disabilities (Solomon, Ono, Trimmer, & Goodlin-Jones, 2008) which can hinder the amount of involvement in intervention efforts of parents of children with ASD. However, benefits of raising a child with autism may also be realized by caregivers and families through appropriate support and educations from professionals (Markoulakis, Fletcher, & Bryden, 2012)

According to Kern (2000) “parent education programs, when implemented properly, can help to reduce parent stress while greatly improving communication” skills of children. Furthermore, it gives parents a sense of confidence and empowerment therefore reducing their feeling of depression and stress related to raising a child with developmental disabilities (Estes, Vismara, Mercado, Fitzpatrick, Elder, Greenson, & Rogers, 2014). However, to involve parents in the interventions of their children requires more than just providing the parents and primary caregivers with specific knowledge and techniques they can use to modify the behavior of their children (Turnbull, Blue-Banning, Turbiville, & Park, 1999). Research suggest that “in addition to enhancing the families capacity to help their child make developmental progress, these other family outcomes include enhancing the families perceived ability to work with professionals, to develop a strong support system, envision an optimistic view of the future, and to increase the overall quality of life” (Turnbull, Blue-Banning, Turbiville, & Park, 1999).
Theoretical Model Approach to Parent Involvement

To increase the likelihood of successful outcome of each child, all of the aspects that affect the child’s life should work together. In their figure titled Ecological Systems of Partnership Education, Ann Turnbull, Martha Blue-Banning, Vicki Turbiville, and Jiyeon Park (1999), the authors explain that children with autism and their parents are a small part of the ecological model and restricting the focus on them alone, limits their connections to necessary resources and quality of life for the child and the family. It is important to recognize that the child and family are a part of a larger ecological community which needs to be transformed to support children and families so that parents can experience the benefits of raising a child with disabilities, and children can reach the best outcomes as they interact with the other systems in the ecological model (Turnbull, Blue-Banning, Turbiville, Park, & 1999).

Rather than looking just at the microsystem, which includes the child, the parents, siblings and the extended family, using Urie Bronfenbrenner’s ecological model, which shows how environmental systems influences the family, professionals can consider the entire ecological system of the child and the family and ultimately connect them with the education and support that is needed (Turnbull, Blue-Banning, Turbiville, & Park, 1999). Furthermore, “ecological perspectives of child and family quality of life imply that not all of the expertise resides with the professionals on the early intervention team to make things happen across all four ecological levels, environments, and interactions… thus, professionals greatly need not only the expertise of parents but also the expertise of key community members” (Turnbull, Blue-Banning, Turbiville, & Park, 1999, p. 164). Using
this approach, service providing organizations and clinicians can better understand the various stressors, obstacles, and issues that parents may be facing that prevent them from effectively participating in the interventions of their children, and be successful in involving parents in the interventions of their children, and may be able to assist them in connecting with those resources.

Using the Resiliency Model of Family Stress Adjustment and Adaptation (Hall, Neely-Barnes, Graff, Krcek, Roberts, & Hankins, 2012), it is evident that parents of children with developmental disabilities who lack support from the beginning, are at a high risk of increased risk later on, “therefore, resources available and accessible to parents of children with disabilities become even more important to family resiliency” (Hall, Neely-Barnes, Graff, Krcek, Roberts, & Hankins, 2012 p. 32). Furthermore, it is important that members in the community and general public that interact with the child and the family in some way, need to be educated on developmental disabilities and their effects on the family which will support resiliency in families and alleviate some family stressors (Hall, Neely-Barnes, Graff, Krcek, Roberts, & Hankins, 2012). A study that looked at the coping strategies of stressed and non-stressed parents of children with developmental disabilities found that in order for families to be resilient against stress, they need to cope with the disability of the child in a positive way, they must be connected to resources, and they must be able to engage in problem solving (Hall, Neely-Barnes, Graff, Krcek, Roberts, & Hankins, 2012). This study suggests that professionals who work with families of children with disabilities must help families in reducing stress by following up with those families who lack resources and may be experiencing a pile
up of stressors, and connecting them to needed support or interventions (Hall, Neely-Barnes, Graff, Krcek, Roberts, & Hankins, 2012).

Furthermore, professionals must be familiar with the strengths perspective model and utilize it with families and empower them to overcome the challenges they face. Using the strengths perspective professionals who with families must form collaborative and mutual relationships and help the families acknowledge the resources, knowledge, talents and motivations they already possess and capitalize on them to overcome challenges (Saleebey, 1996). This will help families “recognize their innate resilience” (Saleebey, 1996), and use it to problem solve, cope with stressors, and realize the benefits of raising a child with a developmental disability for the ultimate benefit of their children.
Chapter 3

Methodology

The purpose of this study was to explore parental involvement in the intervention methods of their children with autism, and the factors that prevent or encourage that involvement. This study explored the idea that although raising a child with developmental disabilities can cause parents to experience more parental stress, with community support, parents with can overcome barriers and realize the positive factors of raising a child with autism.

Study Objectives

The main research question was based on the working hypothesis that there was a positive correlation between increased support to parents and their involvement in the intervention of their children. This research also contained sub-questions that were based on the information gathered from the literature review with the intent to be explored further through the findings from this survey. The first sub question was: is there a relationship between the availability of staff as well as trainings being provided to parents and the frequency of parent implementation of therapy with their children. The second sub question was: is there a relationship between parental involvement and the social support they have. The third sub question was: do parents with children with disabilities experience more challenges or positive factors by raising a child with autism and what type of support can make it easier for them to be involved in the interventions of their children.
The research design comprised the use of a survey questionnaire that was distributed to parents of children with autism. The development of the questionnaire was informed by the literature review and guided by the research question. This section will address the methodology used for this study including the study design, sampling procedures, data collection procedures, instruments used, as well as the data analysis approaches. This research was approved as exempt by the California State University, Sacramento, Division of Social Work Research Review Committee. The Human Subjects Research Application for this research project was submitted to the Institutional Review Board which approved the research after a thorough review. The human subjects protocol number granted for this study is 14-15-006.

**Study Design**

Using a descriptive research method the author decided on a population to focus on which were parents of children with autism; chose a technique for sampling the population, which was by using a survey questionnaire; then developed a means of distributing the survey. To the best abilities this research minimized the potential entrance of bias in the study. Then, as the descriptive method procedures continued, this author actually collected, recorded, organized, and analyzed the data gathered (Leedy & Ormrod, 2013, p. 220). The author then used that data to gain an understanding of the issue and determined if the hypothetical issue exists in reality and what the underlying reasons and prevalent trends are of this issue for most of the people surveyed for this project, and used the outcomes of this study to recommend a final course of action to address the issue in Sacramento.
This researcher used a cross sectional study design for this study, in which the information from the participants was collected without manipulation of the study environment. The cross sectional study design allows the researcher to use the collected data to compare different population groups at a single point in time. Using the cross sectional design allows this researcher to compare many different variables at the same time such as relationship to the child, employment status and the amount of time the individuals spend doing formal behavioral therapy with their child at home.

Next, the researcher used a survey questionnaire that included both open ended and closed ended questions to collect qualitative and quantitative data. This method combines the qualitative and the quantitative designs and allows the researcher to collect the data as well as analyze the data in an efficient way. According research text “mixed method designs with both quantitative and qualitative elements often provide a more complete picture of a particular phenomenon than either approach could do alone” (Leedy & Ormrod, 2013, p. 98). Using the qualitative approach was helpful in attempting to understand the issue and its complexities, and allowed the work to be exploratory in nature. Utilizing the quantitative approach this researcher was able to seek explanations to the issue and generalize her findings to other persons (Leedy & Ormrod, 2013).

**Data Collection, Instrument and Convenience Sampling Procedures**

This researcher utilized a written questionnaire as the survey instrument which was distributed electronically through a mass data base of e-mail addresses of participants of a local family resource center that serves families of children with developmental
disabilities in Sacramento California called WarmLine. WarmLine provides information and linkage to community resources, education and workshops to parents and professionals, advocacy, family events, and one on one support to families of children with developmental disabilities (warmline.com). This family resources center provided support for this research by approving the request to distribute the survey questionnaire (Appendix B) to its participants along with their monthly newsletter through mass email. The questionnaire was distributed two times in a two month period. The data collection process was set up such that only one response was accepted from each of the e-mail addresses that it was sent to. Only parents of children with autism ages 3-5 years old were asked to respond to this survey.

Participants of this study were informed through an informed consent letter provided at the beginning of the questionnaire discussing the purpose of the study as well as potential benefits and risks included in choosing to participate in the survey. Potential participants were informed that participation in this study was completely voluntary and posed no risk to the services they receive or their personal information. Participants were informed that the survey was completely confidential and did not ask for any identifiable information. By submitting their responses they implied consent to participate in the research. Participants were asked to self-report the data from their personal experience. Participants had the liberty of skipping questions they did not want to answer or choosing not to participate even after starting the survey.

This questionnaire was an important tool in the process of collection and analysis of the data collected from the participants as it helped this researcher extract the
necessary information from the responses of the participants in a timely manner. The survey questionnaire was designed with the intent to understand the potential factors that affect parental involvement in the interventions of their children with autism and give the answers to the research questions. The questionnaire had a total of 20 questions and was a mix of quantitative questions which included the demographic information such as relationship to child, parental employment, their involvement in the interventions of their children. The final page of the questionnaire included potential challenges and factors that make it easier to be involved in the interventions of their child with autism. All the questions in the survey questionnaire were informed by the literature. All the questions were multiple choices however for some questions participants were asked to choose one answer that they felt best applied to them and others asked parents to choose all answers they felt applied to them. The surveys were submitted by participants by clicking the ‘submit’ button at the end of the questionnaire.

**Data Analysis Approaches**

The data analysis included basic descriptive and inferential statistics that guided the researcher to a better understanding of parent engagement. Data analysis began immediately after the three month time frame that was allotted for the return of the survey. In this time frame, fifteen surveys were completed by participants. After the data has been collected, a software system, SPSS was utilized for data analysis. Leedy and Ormrod (2013) state that in quantitative research data is “numerically manipulated and statistically analyzed, followed by interpretations of those manipulations” (p. 158) and that the analysis of the data and the interpretation of that data are closely related. In this
research thesis aspects from both qualitative and quantitative data analysis will be utilized to ensure that all the information collected is analyzed to its full potential in helping to reach conclusions regarding this research topic.

**Sampling Procedures**

“The sample is a representative part, an extract from which to generalize back to the whole” (www.iwh.on.ca), and although this survey questionnaire was distributed to a large number of potential participants, and the researcher’s original target was 25 participants, only 15 were received because questionnaires tend to have a low return rate (Leedy and Ormrod, 2013, p. 220). The current study was able to collect data from a convenience sample of 15 participants. Because participation in this survey was voluntary and participants had the right of not responding to questions, some questions were skipped. Of the 15 questionnaires that were submitted, three were incomplete, with more than 75 percent of unanswered questions, therefore the results of this research may vary based on the information that is needed and the questions that were answered.

The validity and explanatory power decrease with larger sample sizes (www.iwh.on.ca). Because the convenience sample size of this research is so small and is focused on a population in one city in one state (due to the accessibility of the population), with a specific requirement to participation (parents of children with autism ages 3-5), the margin for error in this research is significant. The margin of error is further increased because the participants of this study were contacted through one family resource center which significantly decreases the probability of randomization. Furthermore, because the participants of this survey are already engaged with services
form this resource center; it is suggestive of participants being already involved in the interventions of their children. A larger sample size and randomization of the population targeted would give the results of this research significance and power. Though sampling methods are subject to error, (www.iwh.on.ca), this researcher attempted to obtain meaningful information about the population.
Chapter 4

Study Findings and Discussion

The purpose of this study is to explore the factors of parental involvement in the interventions of their children with autism. The research design comprised the use of a survey questionnaire that was distributed to parents of children with autism. The parent questionnaire was used to collect data from the answers they provided to each question. Although the survey questionnaire was distributed to a large number of parents of children with developmental disabilities, only parent of children with autism ages 3-5 years old were invited to complete the questionnaire. Furthermore, although it is unknown how many parents met participation criteria, the number of people who met the criteria and chose to participate in the questionnaire is 15 (n=15).

Because the questionnaire was completely voluntary, parents could chose not to participate at any time during the survey and were given the option to skip questions. Therefore, some questions did not have a total of n=15 responses. Each figure and result will specify the number of participants who did and did not answer particular questions. Results are further explained using illustrations such as graphs, charts, and figures. The survey questionnaire was designed with five separate parts focusing on different aspects of parental involvement including demographics, communication with staff, the frequency of parents’ implementation of therapy, challenges of being involved, what would make it easier to be involved in interventions, as well as the benefits of raising a child with special needs.
The first few questions focused on family dynamics which were answered by all 15 participants. Several questions pertaining to parent, family, and child characteristics were included in this part of the questionnaire, including participant relationship to child, marital status, and employment status and child abilities, with n=15 responses to these questions.

The following chart in Figure 1 shows that most of the people who chose to partake in the survey, 93% of them, or 14 people were mothers. Only 7% or 1 participant was a grandparent. Interestingly, no fathers participated in this questionnaire.

![Participant relationship to child chart](image)

*Figure 1: Participant relationship to child (n=15).*

It was important to know the relationship of the participant to the child because this would help the researcher know who most likely answered particular questions of the survey. Knowing this will help this researcher draw most appropriate conclusions of this study.
Next it was important to know the family status. This information is important because it would help the researcher know if participating individuals were single parents, which would indicate to the researcher potential barriers or stressors to parental involvement in the interventions of their children.

![Figure 2: Indicating family status (n=15).](image-url)

According to the results shown in Figure 2, only 20% of respondents or 3 individuals indicated that they are single parents. Out of the three single parent households, the participant who is the grandparent of the child indicated that he/she is a non-married or single caretaker. Seventy-three percent of respondents were married and one response indicated ‘other’ for their marital status which she explained with the explanation of “living with fiancé”. For the purpose of this study, this family is still being counted as a single parent family. Married status does not necessarily guarantee a fixed type of financial and time contribution and more information regarding financial
and time contributions toward care of the child is needed to make an appropriate
determination whether that fiancé takes a parental role in raising the child.

Next, this author inquired about the employment status of participants and their
partners. The employment status is an important factor in parental involvement in the
intervention efforts because employment can take away time and socio emotional
attention from the child as employment can cause extra stress on parents.

Figure 3: Family employment status (n=15).

As Figure 3 above indicates, 6 out of 15 participants are employed full time, 2 are
employed part time, and 7 are not employed. This indicates that 8 participants work full
time or part time while 7 are unemployed. Three out of the 8 participants who work full
time are a single parent household which indicates that 5 out of the participants who are
married work full time or part time. When considering partner employment it is the
contrary. The chart shows that 9 partners are employed full time, 2 are employed part
time, and only 1 is unemployed. Three participants indicated ‘not applicable’ as employment status.

This shows that more partners are employed than unemployed, however, this does not prove or disprove that parents experience stress at work and don’t spend time at home conducting therapy with their children. More information is needed, therefore, this author inquired about the abilities of the children (as shown in figure 4) and later inquired about frequency of involvement in certain intervention activities (as shown in figure 5).

The next item that this researcher considered was child’s abilities. The question in the survey asked parents to rate their child’s abilities choosing one of the given the options 1) nonverbal and delays in all areas, 2) some language and delays in many areas, or 3) verbal and some skills in par with children his/her age. Knowing the potential abilities or the severity of disabilities the child experiences may help the researcher know how much time of intervention a child may need considering that children with more disabilities need more time of intervention.

![Figure 4: Child abilities as rated by participants (n= 14).](image-url)
As Figure 4 above indicates, 14 participants answered this question. The results showed that most parents (50%) rated their children as having some language and delays in many areas, 40% rated their children as verbal with some skills in par with other children their age, and 7 percent of parents who responded to this questions rated their child as nonverbal and delays in all areas. This is especially important when considering the question about the type of intervention their children receive that is conducted by the therapy staff for a certain amount of time and certain amount of days out of the week. All 15 participants answered this question with a request to choose one of three options which are 1) home based therapy, 2) center based therapy or 3) ‘other’. The results showed that 5 of the children receive home based therapy, 3 receive center based therapy and 7 children receive therapy under the ‘other category’. This question did not provide a space for participants to specify what type of therapy the child received, but it is not center based or home based therapy.

Questions 7-12 (refer to Appendix B), dwelled into frequency of parents involvement in intervention methods with their children. The frequency questions are an important part of this questionnaire and this research because the results help the research understand to what extent parents are currently involved in the interventions of their children. The questions inquired about the frequency of parents communicating with intervention staff by phone, their frequency reading and writing in the communication book and observing therapy sessions. The frequency questions also inquired about parent participation in review meetings, being trained in intervention methods, and the frequency of actually conducting therapy with their child. The options of participation
included 1) frequently (more than once per week), 2) sometimes (more than once per month, 3) rarely (once per month or less). The n value varies in each question because some participants skipped some questions. All responses are indicated in Figure 4.

\[ \text{Figure 5: Frequency of parent involvement in intervention activities.} \]

The question inquiring about communication with intervention staff over the phone or in person was answered by 14 participants. This question is important because it inquires about the regular communication about child intervention between staff and parents. Eight of the participants stated that they communicate with staff frequently, 5 participants stated that they communicate with staff sometimes and 1 participant stated that she rarely communicates with staff. Although the frequency of communication between parents and staff is important, the quality of that communication is even more important as it shows to what extent professionals are helpful to parents and their inquiries and concerns. The question regarding the responsiveness of intervention staff to the inquiries of parents, out of the 12 participants that answered that question, the
majority of them, which is 7 participants, stated that the staff is extremely responsive, 4 indicated that staff is moderately responsive, and only one participant stated that the staff is not at all responsive to their inquiries.

The question inquiring about reading and writing in communication books of their children was answered by 14 participants. The communication book is an important tool of the intervention that is provided by the intervention staff because that is where child’s progress or regress and goals are documented. When parents read what is written in the communication book, they update themselves on what their child is working on in the intervention, and what the child is struggling with, which helps them be on the same page with the intervention staff. They can also give feedback and a suggestion regarding what is important for them that the children learns first, or suggest a way that may be easiest for a child to learn a particular task. The results of the responses to this question are indicated in the above Figure 4. As shown in the figure, 7 participants indicated that they read and write in the communication book frequently, 3 participants indicated that they read and write in it sometimes, and 4 participants rarely read or write in it.

The communication book is a way to track the progress of the child and a way for parents and staff to communicate with each other in written form. This can be a useful tool when used appropriately and based on the results from this survey; most people (10 out of fourteen) use it frequently and sometimes, which shows that it is indeed an effective and useful tool of communication.

The next frequency question inquired about how often parents observe the therapy sessions conducted by professionals with their children. This question was answered by
14 participants. The results of this question indicate that 50% (7) of participants frequently observe sessions, 14% (2) of participants sometimes observe therapy sessions, and 36% (5) participants rarely observe therapy sessions with a total of once a month or less. The question inquiring about attendance of review meetings and contributing input regarding goal setting was answered by 12 participants. The results of that questions showed that 5 participants (42%) frequently attend meetings, 6 participants (50%) sometimes attend review meetings, and 1 participant (8%) indicated that he/she rarely attends the review meetings. Similar results were observed for the question inquiring about the frequency that parents are trained in the intervention methods that their children receive. This question was also answered by 12 participants. The results of that questions showed that 5 participants (42%) are frequently trained in the interventions, 6 participants (50%) stated that they are sometimes trained in the interventions, and 1 participant (8%) indicated that he/she is rarely trained in the intervention methods of his or her child by the intervention staff.

The last of the frequency questions which inquired about the frequency that parents conduct formal therapy with their child at home was also answered by 12 participants. Five participants stated that they conduct formal therapy frequently (more than once per week), four participants stated that they conduct formal therapy with their child at home more than once per month (sometimes), and three participants indicated that they rarely conduct formal therapy with their child, which is once per month or less. Furthermore, a question that is not indicated in Figure 4, but is important nonetheless, is the question regarding the extent that parents handle problem behaviors of their child in
the same manner that the intervention staff handles them. Out of the 12 participants that answered this question, 6 participants stated that they try every time, 5 participants stated that they try when they can (sometimes), and one participant stated that he or she handles the problem behaviors in his/her own way. This question is especially important because it indicates the results of consistency in the way that problem behaviors are handled.

The purpose of the next question which asked about the perceptions of parents regarding the rate of difficulty of conducting formal therapy with their child was to potentially help explain the reason for the frequency or infrequency of parents conducting formal therapy at home with their children. The response options that were given for this question were 1) extremely difficult, 2) moderately difficult, and 3) not at all difficult and participants were asked to mark one option that applied to them the most. The results of this question are indicated in Figure 5 below and explained further in the explanation following the chart.

![Figure 6: Difficulty of conducting therapy (n = 12).](image-url)
Out of the 12 participants who answered this question, most of them, which was 58% (7) stated that conducting therapy with their child is moderately difficult, 17% or 2 participants indicated that it is extremely difficult to conduct therapy with their child, and 25%, which is 3 participants, feel that it is not at all difficult to conduct therapy with their child.

This researcher analyzed the results even further to evaluate if the severity of the child’s symptoms had an influence on the difficulty of conducting therapy with their child. The two parents who stated that it is extremely difficult to conduct therapy with their child indicated that their children verbal with some skills in par with other children their age, or that their child has some language and delays in many areas. The participants who stated that it is moderately difficult to conduct therapy indicated similar responses regarding the severity of their child disability. The participants who stated that conducting therapy is not difficult at all indicated that their child has some language with delays in many areas.

This survey questionnaire did not provide a sufficient amount of information to speculate whether marital status may or may not be a factor. The results of the questionnaire were that the two of the three participants of the single parent household indicated that it is moderately difficult to conduct therapy. The third participant who is a single parent did not answer this question.

In an attempt to further explain parental participation in the intervention of their children, or the lack thereof, the questionnaire asked participants to respond to the question about how much they feel their involvement in the formal therapy sessions with
their child makes a difference in the progress of their child. Twelve participants answered this question and the significant majority which is 10 participants (83%), answered that their feel that their involvement makes a big difference in their child’s progress. One participant stated that their participation makes little difference and one participant indicated that her participation does not make a difference at all in the progress of her child.

The following question had 7 possible options of answers and parents were asked to mark all that apply to them. The question asked parents to mark all options that apply to them as far as the challenges that they face that make it difficult for them to be involved in their child’s program. Only 9 participants chose to answer this question and the result are shown in Figure 6 and further explained below.

Figure 7: Challenges that make it difficult to be involved in interventions (n= 9).
As indicated in Figure 6, majority of participants who answered this question (5 participants) feel that time constraints and other stressful events at home are challenges that make it difficult to conduct formal therapy with their children at home. The option marked as ‘other stressful events at home’ did not provide a space for participants to specify examples of particular stressful events at home that make it difficult for them to be involved in the interventions of their child. Therefore, this is unknown to the researcher. Not being properly trained in the interventions, and lack of support from partners and other family members are not factors that make it difficult for parents to conduct therapy because that options were not marked by any of the participants. One participant indicated that the child does not need therapy and one participant expressed poor communication with the staff regarding the intervention methods of the child.

The following question that was asked of participants required participants to share what makes it easier for them to be involved in the interventions of their children. Knowing this information would help the researcher identify not only the actual factors that make it easier to be involved, but also identify even more potential challenges as well. This information also lets the researcher know the needs of parents and what professionals and service providers must keep in mind when working with parents with children with autism.

Figure 7 below indicates that responses of participants to the question of what factors make it easier for parents to be involved in their child’s program. The options given as potential answers to this question were 1) having financial resources, 2) having support from family and friends, 3) having frequent communication with providers and
staff regarding child’s interventions, 4) having the staff approach me with training, updates, and resources, 5) communicating with other parents. Participants were asked to mark all options that they felt apply to them and eleven participants answered this question.

Figure 8: Factors that make it easier to be involved in intervention (n=11).

The results to this question show that the major needs that most parents have are financial resources and having frequent communication with providers regarding intervention of their children with a total of 8 participants marking this option. The second most marked factors to this question were support from family and friends and staff initiating assistance with trainings, updates, and resources. The option of communicating with other parents was marked by only three of the 9 parents that answered this question.

The last question in the survey was also a ‘mark all that apply’ question that asked participant to state the benefits they have experienced by raising a child with special
needs. This question was an important question because it is the only one that focused on the benefits parents may be experiencing by raising a child with special needs, for as explained in the literature review, although it is very challenging to parent a child with special needs, there are various benefits that are involved as well. There were 4 options that parents could choose, although participants were asked to choose only those that apply to their particular experiences. This question was answered by 11 participants indicating that each participant marked at least one option he or she felt applied to their experience. The results are described in Figure 8 below with a further description following.

![Figure 9: Positive factors of raising a child with special needs (n = 11).](image)

The options that were provided to participants as answers to this question were 1) I have learned to speak out for my child, 2) I have made many close friends with people I would not have met otherwise, 3) I take better care of myself, and 4) my marriage has become stronger. All the responses that were provided in this question were observed in the literature review as benefits that parents reported in other studies. The participants
that were recruited to complete this survey were clients of the WarmLine family resource center that provides unique services to parents by connecting parents of children with special needs with each other, which helps parents overcome their challenges knowing that other parents have gone through them or are going through them as well.

The results of this question indicated that 90.91 percent of participants (10 participants) who answered this question feel that they have learned to speak out for their child. Seven out of the 11 participant (63.64 percent) who answered this question stated that they take better care of themselves. There were 6 participants (54.55 percent) who feel that their marriage has become stronger through raising child with special needs, and only 2 participants (18.18 percent), indicated that they have made close friends with people they would not have met if they were not raising a child with special needs. In relation to the research question, these may be some of the potential positive factors of raising a child with autism and makes it easier to be involved in the interventions of their children.

**Themes of Strengths**

The first strength is the fact that parents and caretakers who received the questionnaire in their email responded to the questionnaire and submitted it. Although taking a survey and participating in research is not a direct component of involvement in intervention that was researched in this study, the fact that these parents chose to participate indicates that that they care to a high extent about the effectiveness of the interventions of their children receive and took the extra step to contribute to this research. This is further shown by the fact that all the participants are a part of the
resource center from which they received the email in the first place, and most of them stated in the survey that they have learned to advocate for their child, which indicates that they may be already involved in the interventions of their children at the mezzo and/or macro levels. Above all, based on the participant responses, all participants indicated that they realize the importance of their involvement in the interventions of their children and understand that it makes a difference in the progress of their child.

Another strength that was observed is the functional, formal and informal support system including spouses/significant others, stable income, friends and others. It was observed in this study is that most of the parents are married or have a significant other and most of them are employed showing that they have some type of a support system and share the burden of attention and finances in raising a child with this developmental disability. However the key here is not the marital status but the strength of the support system and potentially a single mother who has a strong support network would do as well as the married couples. A large amount of participants (6) stated that their marriage has become stronger despite raising a child with autism. Furthermore, some participants (2) also indicated that they have formed new and close friendships with people they would never have met, which further confirms that they have social support. A large number of participants (7) also stated that they take better care of themselves, indicating that they are aware of the stress that raising a child with special needs can have and take better care of themselves to potentially prevent burnout.

The next strength that was observed is that there are more participants who frequently and sometimes are involved in communication with staff by phone and written
alternative methods than those who rarely communicate with the interventions staff of their children. More participants frequently observe therapy sessions than those who rarely observe therapy sessions and more participants frequently participate in their children’s review meetings than those who do so rarely.

Another strength of the participating parents was that more parents conduct therapy with their children frequently and sometimes (11 total) than the amount of parents who rarely conduct therapy with their children (1 total). For the most part, based on the responses collected using this survey, most parents (11 total) are very involved in the interventions of their children and most parents stated that they find conducting formal therapy with their child has a level of moderate to extreme level of difficulty and only 3 out of 12 respondents stated that it is not at all difficult. Most parents (11) communicate with the interventions staff frequently and sometimes, and feel that staff does communicate with them about the intervention methods and 11 participants stated that staff is responsive to them when they have questions or inquiries. Most participants also stated that they feel that they are properly trained by the staff in the intervention methods of their children and a significant majority of the participants stated that they try every time and sometimes to handle the problem behaviors of their child the way that intervention staff handles them.

The aforementioned results may be an indication that the parents who responded to this survey are the more active parents. The less active parents may not have responded to this study and they are not be represented in the findings. It is unknown exactly how many families this resource agency serves and how many received the
questionnaire, therefore, the conclusion is that the respondents of this survey are mostly active observers and participants.

**Themes of challenges.** When considering the options that were given to participants regarding the factors that make it difficult for them to be involved in the interventions of their children, some of the challenges that were offered by the literature, such as not being properly trained, or lack of support from loved ones or denying the fact that their involvement makes a difference in the interventions of their children, did not apply to the participants of this survey at all. Most participants stated that the primary challenges in their involvement are not having enough time and having other stressors at home.

All of the factors presented in Figure 7, which indicates the things that participants chose as factors that make it easier to be involved, can also be considered as challenges that are obstacles for parents to be involved in the interventions of their children because there aren’t any indications that parents have access to these factors. Financial resources are a challenge because working to receive financial resources to take care of bills and other things is necessary, but time consuming. With more financial resources for parents, they could perhaps have more time to spend with their children conducting therapy. Having frequent communication with provider staff can also be a challenge based on the availability and cultural competency of the providers. It is unknown how often staff initiates training and updates to parents, therefore it will be considered as a challenge because it is a need that parents have, that when its met, makes it easier for parents to be involved in the interventions of their children.
Summary of Findings

Although this study had a small sample size of one area in one state and the results cannot be applied to this particular population at large, the results have significance nonetheless because the data was collected directly from parents of children with autism. There were multiple personal strengths as well as weaknesses that participants portrayed through this study based on their responses that provide essential information that allows this researcher to better understand the degree of current involvement in the interventions of children with autism in and what resources are helping to encourage that involvement. It also aids in the attempt to provide a framework of the resources they are lacking and how therapy professionals and staff can best meet those needs to ultimately encourage involvement in the interventions of their children with autism.
Chapter 5

Summary, Conclusion, and Recommendations

The purpose of this study was to explore the factors related to parent involvement in the interventions of their children with autism. The main research question was based on the working hypothesis that there was a positive correlation between increased support to parents and their involvement in the intervention of their children. This study explored the idea that although raising a child with developmental disabilities can cause parents to experience more parental stress, with community support, parents of children with autism can overcome barriers and realize the positive factors of raising a child with autism. The purpose of this study was to identify the potential needs of parents and inform the professionals working in this field of these needs, with the ultimate goal of increasing the parent involvement in the interventions of their children with autism if it appears to be lacking.

Summary of the Study

This study was conducted with a total of 15 participants who were parents of children with autism between the ages of 3-5 in the greater Sacramento area who are participants of a family resource center for families of children with autism, WarmLine. A parent questionnaire was the main tool used for data collection and was distributed using a web based survey distribution system. While 15 total survey were submitted, 12 surveys were completed to the fullest. The study participants were all mothers and one grandparent, which was unintentional, but led he study to focus on this population.
One of the important results that emerged from the participants was the amount of activities parents engaged in. The majority of the participants stated that they already were frequently doing most of the activities provided on the questionnaire. Furthermore, although the participants had many of the characteristics the literature signifies as challenges that parents of children with autism typically experience, the results of the survey reflected that these challenges do not prevent parents from being involved. Most of the participants stated through their responses that if the listed challenges are met (challenges identified in the literature), then it would make it easier for them to be involved.

Another noteworthy result from this study is that many parents stated that they need support from family and friends indicating that social support is very important to parents of children with developmental disabilities; however it may not always be available to those whose relationships are strained by distance or other social factors, as well as daily stressors and responsibilities. This is a need that professional working in the field can help parents with.

**Implications for Social Work**

The diagnosis of autism is becoming more prevalent however; numerous intervention methods exist to help prevent the occurrence of symptoms as well as treat the disorder. Intervention efforts are most successful when people who are close to the children, such as their parents, implement therapy across settings and situations to help children generalize and maintain skills. Parent implemented intervention is considered evidence-based practice according to the National Professional Development Center on
Autism Disorders in the United States. Research shows that parents are indeed able to learn the intervention techniques and implement them correctly and help their children learn the skills they lack (relatetoautism.com). Parent training, education and involvement are important factors of successful behavioral intervention and meeting the needs of children with autism (Corsello, 2005).

Having parents implement the interventions will increase the amount of intervention children receive, without increasing the cost of therapy. Although parents of children with autism experience many struggles and obstacles that can make it difficult for them to be involved parents of children with autism also experience positive factors of having a child with special needs and social workers working across various settings can help families of children who need that support so that the children and parents can realize the benefits.

Knowing the typical challenges that families of children with autism experience, social workers can advocate for greater availability of services, financial aid, and other resources for this population. Increased knowledge and education about autism would be extremely beneficial and new policy initiatives should be put to be in place to effectively help children and families with autism. One of the things that social workers can do on a macro level is advocate for families of children with autism through policy change to provide financial assistance to parents of children with autism so that parents can have more time implementing interventions with their children and not struggle financially to support their families. Social Workers can also advocate for funding to much needed
resource centers that provide help to such families as well as developing resource centers aimed at helping parents of children with developmental disabilities.

Social workers can also partner with existing resource centers and agencies and help the staff working directly with the children by providing training about the importance of parental involvement and teaching professionals how to approach parents with trainings and suggestions, as well as recognize the challenges that parents may be experiencing and explain to them how the challenges may be affecting parental involvement using Urie Bronfenbrenner’s ecological system. Social workers can also provide resources to staff that they can provide to parents when they recognize needs of parents that can be met with community resources.

Social workers who are passionate about working with families of children with special needs may also work on a micro level that includes work with families directly. Social workers may choose to pursue this field as a specialty and provide home visitation to families of children with autism helping them learn skills to overcome their obstacles, connect them to much needed resources in the community, provide psychosocial therapy as needed and encourage and support parent implemented therapy. They may also utilize the developmental screening tools to identify potential delays in children, teach parents of early sign of developmental delay, and what to do as well as refer the families to necessary resources for assistance they need.

**Recommendations**

This study was aimed the importance of parental involvement in the interventions of their children and identifying the challenges that prevent them from being involved.
None of the challenges that were provided in the survey questionnaire were identified as significant challenges that prevent their involvement.

In the process of evaluation of the study, it is important to consider that the participants of this study were receiving aid from the WarmLine resource center. Although it is unknown to what extent parents received services from this center, it is worthy of note that there may be a link between their participation in the resource center and their involvement in the interventions of their children. Therefore, the results may have been skewed to some extent. Furthermore, this leads this researcher to question the effectiveness of the services provided by the resource center in educating, encouraging, and helping parents in being more involved in the interventions of their children. This researcher recommends that future studies focus on utilization of resource center and how it affects parent involvement in interventions. Also, because of the small sample size the results of the survey cannot be applied to the general population, therefore, this researcher recommends that future research on this topic recruits a larger sample size as well and be qualitative in nature to allow participants to elaborate on their answers and provide reasoning.

**Limitations and Recommendations for Future Research**

Due to the time allotted for this study, there were several limitations in the process of this survey. Although this researcher had a goal of 25 responses to the questionnaire, the end sample was significantly smaller. This may be a result of a few potential factors such as a limited target population and a potentially small amount of people that the survey was emailed to.
One limitation of this study is that it was quantitative in nature which did not allow participants to elaborate on their answers or add in a response if one they most related to was not provided. The survey did not provide a space for parents to explain their particular situation and why they chose the responses they did, which could have provided this researcher an opportunity to gather more information.

Another limitation is that this research was conducted online and parents could not complete this survey if they had limited access to the internet, which may have contributed to the submittal of the three incomplete surveys. The skipped responses may also have been the result of the fact that this was a voluntary questionnaire and participant were given the option to skip questions as they pleased. Another limitation related to the fact that this survey was voluntary and required self-reporting brings a potential that participants may have reported being more involved than they truly are to make a more positive impression despite the fact that this questionnaire was anonymous. On the contrary however, the fact that participants of this survey are receiving assistance through the resource center they received the email through, implied that they may already be involved in the interventions of their children.

Another limitation is that only the voices of the parents were reflected in this research and the study did not include other entities that are involved in the interventions such as therapy staff, case workers, and resource center staff. Including data from these entities would enhance the value of this study because it would provide more information to the study and help answer additional questions regarding parental involvement.
The final limitation of this study is that only the voices of female care takers were heard because no male figures participated in the questionnaire. This author recommends that future research focus on father stress, coping and involvement to better understand the importance of father’s involvement in their child’s interventions.

**Conclusion**

This study provided a unique perspective from parents about their engagement in the interventions of their child with autism. The study produced original strengths, challenges and suggestions for parent engagement in their children’s intervention methods to increase effectiveness of the therapy their children receive. This study provided a literature review of the importance or parental involvement in the intervention of their children, and presented the finding of previously conducted research on the challenges and positive factors that parents of children with special needs experience. Using the collected survey responses, the study identified to what extent parents are involved in the interventions of their children, and what factors may be contributing to their involvement or the lack thereof. Although the results were insignificant due to the small sample size and not enough information gathered, the information that was gathered can help social work professionals understand the needs of parents of children with autism and help them overcome the obstacles of being involved in the interventions of their children.
Appendix A

Informed Consent to Participate

California State University, Sacramento

If you are a parent of a child with autism who is 3-5 year old, please take a few minutes to take this survey.

About this study

Title: Exploring the Factors Related to Parent Involvement in the Interventions of Children with Autism.

This study is being conducted by Anna Kutsar, Master in Social Work candidate, under the supervision of Dr. Francis Yuen, Professor at the California State University, Sacramento. The purpose of this study is to identify ways that professionals can provide better services and support to parents with children with autism. In order to attain relevant data it is absolutely critical to gather the feedback directly from parents, which is why you are being asked to participate in this survey.

There are only 20 questions in this online survey and it should take no more than 10-15 minutes to complete. You may choose to skip any questions or stop at any time, although completing all the questions will be more helpful for the study. Your participation in this survey is voluntary and completely anonymous. They survey will not ask for your name or any other identifiable information and there is no way that your participation can negatively affect any programs or services you currently receive.

By participating in this survey, you will help provide information that may be used to develop programs that help other parents with children with autism. In addition, for every completed response that is submitted to this survey by February 15, 2015, WarmLine will receive a donation of $5 from the researcher.

This study has been approved by the Institutional Review Board of the California State University, Sacramento.

By clicking on the “NEXT” button, you consent to participating in this survey. If you have any questions, complaints, or concerns about this research, please contact the researcher, Anna Kutsar by phone (XXX) XXX-XXXX or email at annakutsar@csus.edu.

Thank you.
Appendix B
Parent Questionnaire

1. **What is your relationship to the child?**
   □ Mother  □ Male guardian
   □ Father  □ Female Guardian

2. **Please indicate your family status.**
   □ Married
   □ Single parent household

3. **Do you work outside the home?**
   □ Part time
   □ Full time
   □ Not paid employment

4. **Does your partner work outside the home?**
   □ Part time
   □ Full time
   □ Not paid employment

5. **What type of therapy does your child receive?**
   □ Home based
   □ Center Based
   □ Other

6. **Please rate your child's abilities.**
   □ 1 – nonverbal and delays in all areas
   □ 2 – some language and delays in many areas
   □ 3 - verbal and some skills in par with children his/her age

7. **How often do you communicate with your child's therapy provider or staff on the telephone or in person?**
   □ Frequently (more than once per week)
   □ Sometimes (more than once per month)
   □ Rarely (once per month or less)
8. How often do you read and/or write in your child's communication book?
   - Frequently (more than once per week)
   - Sometimes (more than once per month)
   - Rarely (once per month or less)

9. How often do you watch your child's therapy sessions?
   - Frequently (more than once per week)
   - Sometimes (more than once per month)
   - Rarely (once per month or less)

10. How often do you attend review meetings and have input into goal setting about your child’s intervention program?
    - Frequently (more than once per week)
    - Sometimes (more than once per month)
    - Rarely (once per month or less)

11. How often are you trained in the intervention methods used by the intervention staff?
    - Frequently (more than once per week)
    - Sometimes (more than once per month)
    - Rarely (once per month or less)

12. How often do you conduct formal therapy with your child?
    - Frequently (more than once per week)
    - Sometimes (more than once per month)
    - Rarely (once per month or less)

13. How difficult do you find it to conduct formal therapy sessions with your child?
    - Extremely difficult
    - Moderately difficult
    - Not at all difficult

14. How much do you feel your involvement in formal therapy sessions with your child makes a difference in his/her progress?
    - Makes a big difference
    - Makes a little difference
    - Does not make a difference

15. How responsive is staff to your questions and inquiries?
    - Extremely responsive
    - Moderately responsive
    - Not at all responsive
16. If your child has problem behaviors (tantrum, aggression, and self-injury), to what extent do you try to handle the problem behavior in the same manner as the intervention staff does.

- [ ] I try every time
- [ ] I try when I can (sometimes)
- [ ] I handle the problem behaviors in my own way

17. How has communicating with other parents of children with autism helped you with your own stress related to the parenting of your child?

- [ ] It has helped me a lot
- [ ] It has helped me somewhat
- [ ] It has not helped me
- [ ] I do not have an opportunity to communicate with other parents

18. How do you feel you have changed through the experience of parenting a child with special needs? *(Mark all that apply).*

- [ ] I have learned to speak out for my child
- [ ] I have made many close friends with people I would have never met otherwise
- [ ] I take better care of myself
- [ ] My marriage has become stronger

19. What challenges do you have in being involved in your child’s program? *(Mark all that apply).*

- [ ] Staff does not communicate with me about the intervention methods
- [ ] Not being properly trained in the intervention methods
- [ ] Not having enough time
- [ ] My child does not need therapy
- [ ] My involvement in therapy will not make a difference in my child’s outcomes
- [ ] Lack of support from my spouse and other family members
- [ ] Other stressful events at home

20. What factors make it easier for you to be involved in your child’s program? *(Mark all that apply).*

- [ ] Having financial resources
- [ ] Having support from family and friends
- [ ] Having frequent communication with providers and staff regarding your child’s interventions
- [ ] Having the staff approach me with training, updates, and resources
- [ ] Communicating with other parents
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