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# Interventions for Multicultural Children with Autism

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# Interventions for Multicultural Children with Autism

Submitted by Stephanie Kitzhaber  
May, 2012

## MSW Clinical Research Paper

The Clinical Research Project is a graduation requirement for MSW students at St. Catherine University/University of St. Thomas School of Social Work in St. Paul, Minnesota and is conducted within a nine-month time frame to demonstrate facility with basic social research methods. Students must independently conceptualize a research problem, formulate a research design that is approved by a research committee and the university Institutional Review Board, implement the project, and publicly present their findings. This project is neither a Master's thesis nor a dissertation

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## Abstract

This qualitative study examined the interventions that are helpful when working with multicultural children who have autism and their families. Data was collected through five semi-structured interviews (n=5) with professionals who work with children who have autism, which included a variety of psychotherapists, social workers, mental health practitioners, and counselors. Grounded theory methods and open coding were used to analyze codes in the data to record common themes from the interviews. Themes found from this study were separated into five categories: language, importance of play, family education, gender roles, and stigma. Findings from this study were consistent with some of the previous research on autism. Implications from this study suggest ideas for future research in this area, with hopes to improve the treatments and clinical interventions that are provided for multicultural children who have autism.

## Acknowledgments

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# **Interventions for Multicultural Children with Autism**

## **Introduction**

Autism is a development disorder that impacts children and their communicative and social functioning into adulthood. The most recent statistic indicates that childhood autism is diagnosed among approximately one out of every 88 children in the United States, and is the most commonly diagnosed among all developmental disabilities in the US (Center for Disease Control and Prevention, 2012). The disorder poses significant challenges and complexities, as *autism spectrum disorders* (ASD) are described as “deficits in reciprocal social interactions, communication, interests and behaviors,” and the age of onset is typically prior to the age of three (American Psychological Association, 2000). Autism is also more common among boys than girls at a ratio of four to one, respectively (Morrier, Hess & Heflin, 2008).

ASD is diagnosed across a continuum to include other disorders described as *pervasive developmental disorders* (PDD). PDD is an umbrella term that is used to describe the range of symptoms that are considered developmental in nature as well as long lasting, or pervasive, throughout a child’s life and into adulthood. Autism is diagnosed across this continuum in order to include and identify children with more mild symptoms and children with more severe and debilitating symptoms. Children with autism are typically considered to be on the more chronic end of the spectrum, and typically have symptoms that impact their functioning in a wide range of ways. The symptoms of autism are also generally more visible and require the most intensive interventions (Jensen & Spannagel, 2011).

There are two other disorders that are identified along the ASD continuum, Asperger's and PDD-not otherwise specified. *Asperger's disorder* is generally considered less severe and debilitating in comparison to autism, and manifests in ways that may suggest less functional impairments (Block, Block, & Halliday, 2006). Children with Asperger's syndrome maintain verbal competence, while struggling with social interaction. Children with Asperger's may also display repetitive behaviors and motions, but maintain cognitive functioning. *Pervasive developmental disorder-not otherwise specified* (PDD-NOS) is another disorder on the autism spectrum and is often referred to as "atypical autism." Children with PDD-NOS often have characteristics of autism, but do not meet the threshold for autism or Asperger's diagnosis due to certain factors such as delayed onset, range of severity of symptoms, or atypical symptoms that do not fit in either diagnostic category (Block, Block, & Halliday, 2006).

Autism is recognized more by society than other developmental disorders due to the increase in awareness and education about this disorder. The rates of children with an autism diagnosis have grown steadily over the last five years, and appear to be growing still (Jensen & Spannagel, 2010). This is partially due to the increase in public awareness of autism, as the signs of autism are being more accurately assessed among young children (Volkmar & Pauls, 2003). Autism is also more prominent in the media, as celebrities such as Jenny McCarthy, Toni Braxton, and John Travolta have announced that their children were born with this disorder (autismepicenter.com). This has prompted other parents to become more active with spreading awareness and education about this condition (Wolff, 2004). There is also more information provided to parents, teachers, caregivers, and other professionals who work with children, in an effort to increase the

knowledge base of how this disorder affects children and how this disorder “looks” (Wolff, 2004).

Autism impacts the family unit, particularly the primary caregivers of the child. While there is more information about the treatments available for autism, many parents want answers regarding the cause of this diagnosis, and how it can be prevented in the future. Science has not yet proven the exact cause of autism, which leaves many parents researching and trying to find their own explanations for how their child develops this disorder. Many parents feel that childhood vaccinations, coupled with a sensitive immune system, cause autism. Some parents have noticed that the first symptoms of autism started to appear after they brought their child in for their measles, mumps, and rubella (MMR) vaccines (Gihring, 2012). Gihring (2012) states the increase in autism, coupled by the lack of explanations in the medical world, has created a “refuser movement,” in which parents are refusing to listen to medical providers because they have a common distrust of medical experts. This movement has grown alongside the internet, as parents are able to research and connect with other parents across the country to find answers. Along with vaccinations, some parents also feel that autism could be explained by gluten or dairy intolerance, and some parents have altered their children’s diet in hopes that this helps to improve their child’s symptoms.

Children with autism are also subject to comorbidity with other diagnoses, which means that these children may have symptoms that are explained by other diagnoses such as anxiety, obsessive compulsive disorder (OCD), or attention deficit hyperactivity disorder (ADHD). Due to this comorbidity, children with autism often appear to struggle in ways that are both noticeable and persistent. Children with autism have severe

impairments with verbal skills and they often test at a lower IQ level, resulting in a diagnosis of mental retardation approximately 75% of the time (Block, Block, & Halliday, 2006). Children with autism may interact with others in ways that make them appear deaf or “mute” to a person who does not understand the disorder, as these children often struggle with limited communication or verbal skills. Some of these children never develop meaningful speech, even into adulthood, and continually have lifelong struggles with navigating the social world (Volkmar & Pauls, 2003).

Children with autism present unique vulnerabilities that could play out in the school, home, social, or therapy setting. The complex nature of autism affects each child differently, with a variety of symptoms that often require a combination of medical, educational and psychological therapies to help aid progress towards recovery (Jensen & Spannagel, 2011). Children with autism are often times at greater risk for being bullied and picked on by other children, due to their social deficits and inability to communicate needs effectively (Dyches, Wilder, Sudweeks, Obiakor & Algozzine, 2004). Due to the complexity of this disorder and the range of supported and available treatments, it is important to find early interventions that promote recovery.

Children with autism also present some unique strengths and capabilities. These children may have higher competence in non-verbal skills, and a small portion of these children present with savant skills, particularly in art, music, or data and memory skills (Volkmar & Pulls, 2004). Children with autism also have a range of possibilities in terms of their outlook and recovery potential. Some children with autism may never develop the full severity of the symptoms, and may require treatment for some aspect of their development, such as verbal abilities, but may have limited impairments or no noticeable

impairments in other developmental qualities of the disorder (Block, Block, & Halliday, 2006).

Children raised in families where English is not the primary spoken language at home face additional challenges when they are diagnosed with autism. These children face unique needs when they are diagnosed with autism due to the verbal component of this disorder (Morrier, Hess, & Heflin 2008). The meaning of an autism diagnosis is not always understood cross-culturally because of a lack of words in some cultures to describe the symptoms of autism. Some Asian and African cultures have no word for autism, and other languages have adapted the English word and the Western explanations to fit in within their own culture, while presumably never truly understanding the nature of the disorder or its effects on the child's wellbeing and future (Wilder, Dyches, Obiakor Algozzine, 2004). In Chinese culture, the character for disability translates as disabled (chan) and useless (fei), and carries a heavy stigma for children within this community (Coon, Cook, Tran & Tu, 1997). The absence of words in other languages for this disorder creates unique barriers for discussing care with the family and agreeing on a treatment plan that best fits the needs of the child and best reflects the child's cultural identity and framework for understanding illness.

The symptoms of autism can also be understood differently among cultural groups. For example, in Asian culture, children are taught to be silent and to avoid eye contact with an adult, which mimics symptoms of autism and could be misunderstood cross culturally (Coon, Cook, Tran & Tu, 1997). Additionally, in Somali culture, autism has an association with a mental illness. Mental illness in this culture can carry a significant stigma, which may result in the denial of symptoms and inability to recognize

symptoms due to negative responses from the community and lack of awareness of disabilities within the community (McGraw-Shuchman & McDonald, 2004). Cross-cultural differences may become a major barrier for helping children and their family access appropriate treatment, while also presenting opportunities for social workers to engage with these families and communities to help them understand the nature of this diagnosis and the recommended treatments.

When identifying interventions and treatments that are helpful in working with children who have autism, it is particularly important to understand the cultural nuances and the impact that this disorder has on children from culturally diverse or non-English speaking families. Children from culturally diverse families now constitute approximately one third of the population born in the United States, at rates that appear to be growing (Zhang & Bennett, 2003). Multicultural and immigrant children are often diagnosed with autism at a later age when compared to white children, and the language and social deficits are noticed at a much later stage in their development, leaving these children at a disadvantage in terms of treatment (Morrier, Hess, & Heflin, 2008). With autism, and most disorders, early intervention is crucial and increases the child's recovery potential.

There are several treatment methods that have been used by professionals who work with children who have autism. The best known and most highly researched treatments include Applied Behavioral Analysis (ABA), speech therapy, occupation and physical therapy, and social skills and play therapy. These treatments all draw on special education and behavioral psychology and many treatments share similar features and goals, but may focus on different aspects of the child's functioning as a treatment target

(Volkmar & Pauls, 2003). Treatment methods for autism typically focus on decreasing “problem” behaviors that the child is exhibiting, such as uncontrolled and inconsolable aggression or repetitive behaviors, while teaching skills and increasing communicative functioning (Jensen & Spannagel, 2011). The treatment goals are child-specific and are determined by assessing a child’s functioning level and what they are able to work on during their stage of development. Structure and routine are two key components to most treatment approaches, as this helps to decrease anxiety and helps provide the stability they need to make progress (Volkmar & Pauls, 2003).

Children with autism often work with a combination of social workers, teachers, psychologists, psychiatrists, and doctors due to the complex nature of the disorder and the range of services and interventions that may be required (Jensen & Spannagel, 2011). Established autism therapies focus on the same overall goals, but may focus on different treatment targets and outcomes in terms of how the child learns to communicate and relate to the world. Parents and caregivers of children who have autism are often required to complete extensive research in order to find out which interventions will be helpful for the treatment of their child. They are often times overwhelmed with psychological services that range in levels of intensity, and may include both the child and their family in the treatment process (Jensen & Spannagel, 2011).

In order to understand the needs of children who have autism, it is important to gather the insights and perspectives of the many professionals who work with these children. Professionals from these diverse educational backgrounds are key informants who can help shape understandings about autism among multicultural groups, and how to best work with these children and their families. These professionals and providers have a

unique vantage point when determining the needs of this population, as well as the interventions that are the most effective when working with children who have autism.

The purpose of this research project is to further understand childhood autism, and how it affects children from multicultural families by exploring the interventions that are being used with multicultural and/or bilingual children. Professionals who work with children who have autism will be interviewed in order to gain a better understanding of the many different behavioral and psychological treatments available, to determine if these treatments are appropriately meeting the needs of multicultural children with autism. The overall goal of this research is to answer the question: What multicultural interventions are helpful when working with children who have autism and their families?



## **Literature Review**

In order to understand the value of this study it is first essential to understand a few key points about autism such as the prevalence of this diagnosis, the impact on multicultural groups, and the barriers to care. This literature review will review how autism was first assessed and how this diagnosis evolved over time. The literature will review barriers to care for this population, and how autism treatment is understood and discussed in different cultures. This literature review will address the interventions that are used when working with children who have autism, the impact on the family, along with attributes of resilience that both children who have autism and multicultural populations possess. Lastly, the literature review will address social workers' understanding of autism, and how this understanding defines and influences interventions. For clarification purposes, *multicultural* will be used to define children who represent two or more cultures, with an emphasis on children from immigrant families or from families where English is a second language

## **History of Research**

In order to appreciate and understand current research on autism, it is important to have an understanding of the historical context of autism, and how this disorder was previously viewed. Several historical reviews of how autism became a diagnosis indicate that symptoms such as having repetitive motions, delays in communication skills, or being withdrawn and uncommunicative were viewed in the past as symptoms of schizophrenia. This resulted in school-age children being diagnosed with schizophrenia when they possessed “negative” symptoms, such as flat affect, poor social functioning, perceived apathy, and limited responsiveness to surroundings (Wolff, 2004). Swiss

psychiatrist Eugen Bleuler first introduced the term autism, which stems from the Greek word “autos,” meaning self. Bleuler first used this term in 1911 to describe these symptoms in the context of a schizophrenia diagnosis. It was not until 1938 when the term autism was no longer used to describe symptoms of schizophrenia. During this time, autism became recognized as symptoms associated with a childhood neurodevelopmental disorder instead of a psychiatric illness (Wolff, 2004).

As the understanding of autism has developed, so has the speculation regarding the causes of the diagnosis. In the 1950's and 1960's, children with autism were assumed to be a product of poor parenting and were often recommended for psychotherapy to work on their relationships with their mothers, which came at a great economic and psychological cost to the families and children who were learning to cope with this disorder (Wolff, 2004). The term “refrigerator” mothers was developed in the late 1960's to describe distant, cold mothers who were thought to have caused the disorder due to parenting deficits (Dyches et al., 2004).

Autism is no longer considered a byproduct of poor parenting, but there are still several unanswered questions regarding the causes of autism. Research is currently being done to determine potential environmental factors, such as food allergies or exposure to toxins in the air, but no causal link has yet been established (Block, Block & Halliday, 2006). Celebrity actress Jenny McCarthy has also brought attention to potential environment factors. She feels that when a child has a sensitive immune system and is then given childhood vaccinations such as the measles, mumps, and rubella (MMR), the child is more at risk for developing autism. The study linking vaccinations to autism was recently discredited, and scientific evidence does not support a link between autism and

vaccinations (Block, Block & Halliday, 2006). Research also suggests that autism is genetic, although it cannot be traced to one gene. Research is beginning to find that autism is partially caused by genetic mutations, which affects every embryo differently (autismspeaks.org). Autism continues to be an area of interest in the field of research, as this research will help determine how autism is caused and how it could be prevented.

### **Autism among Multicultural Groups**

Many large scale studies have focused on determining the population most affected by autism, and has included mainly quantitative measures to determine who is affected by this disorder and what the potential causes may be. Morrier, Hess and Heflin (2008) studied the ethnic and socioeconomic characteristics of children with autism with regard to their placement in school programs. A total of 185 teachers who work with children who have autism responded to a survey regarding strategies they used to work with children with an ASD diagnosis. The teachers were also asked, as part of this survey, to indicate the race and age of the children they were currently working with. This study also identified the ethnic characteristics among the teachers who were involved in the treatment and education of these students (Morrier, Hess, & Heflin, 2008).

The responses indicated a number of findings. This study found that most of the services being provided to children with autism were provided to boys rather than girls, at a ratio of approximately six to one, respectively, which is higher than the national average of four to one. The prevalence of boys having autism more often than girls is also reflected in existing research. Over half of the children being served were Caucasian, with approximately a third being African American, and a small minority who were

either Asian, Hispanic, or mixed race. These results indicate that autism affects minority populations, but the proportions of those being served in the school was lower than what was expected. It is generally accepted that autism does not discriminate, which means that autism affects everyone regardless of race or socioeconomic status. These results indicate that while autism does affect minority children, they are underrepresented in school programs that target children with autism.

Morrier, Hess and Heflin (2008) suggest that the under representation of children with autism from multicultural groups in this study could be linked to the limited amount of professionals who were available to work with this group. The strategies involved with the children did not appear to differentiate with regards to ethnicity, but a recommendation from this research is to identify the role of ethnicity and how this affects the treatment strategies that children with autism receive in a school setting (Morrier, Hess, & Heflin, 2008).

Another study by Thomas, Ellis, McLaurin, Daniels and Morrissey (2007) identified utilization rates of autism-related services within different ethnic and racial groups. The researchers interviewed 383 North Carolina families who had a child 11 years of age or younger with autism to determine which services were being utilized among different racial and economic groups. This study found that several disparities in service existed. More specifically, this study found that children of racial or minority families utilized a case manager less than half the time, and only a quarter utilized the services of a psychologist. Among minority families and those of lower levels of education, access to care was a major barrier to treatment for autism and was a major cause of concern within the study.

This study also found that higher income families had increased odds of utilizing speech and language therapy services, as well as services offered by a developmental pediatrician. Higher income families were more likely to consult with a neurologist regarding their child's condition and were more likely to utilize one of the major treatment approaches for autism. According to this study, children from a lower economic background and from ethnic groups utilized less of the recommended treatment options, which suggest that the treatment options available do not meet the needs of this population (Thomas et al, 2007). This discrepancy around service utilization among multicultural groups supports the need for this study, as children from multicultural groups should be represented equally among the services that are provided for children with autism. It is important to determine the interventions that are helpful when working with this specific population because children and their families are more likely to engage in services that reflect their cultural needs.

### **Barriers to Treatment**

Children from multicultural backgrounds face a variety of barriers when trying to access basic health care services. These obstacles to care often overlap with the already existing barriers that most families perceive when trying to access appropriate services. Kim and Keefe (2010) identified the barriers that Asian Americans have when trying to access healthcare in America, which helped conceptualize the obstacles that are faced by this population. This demographic ties in the concerns about the healthcare among multicultural and immigration groups, as children with autism often come from these ethnic groups and are affected by the barriers to healthcare. Asian Americans are one of the fastest growing groups in the US and have health needs that are not appropriately

being reflected in the services that are available for Asian minorities. As described earlier, symptoms of autism can mimic the values that Asian children are raised with understanding; avoiding eye contact, displaying minimal emotions, and limited engagement in conversation when in a school setting.

Kim and Keefe (2010) identified four major barriers to care that affect health outcomes among this population. These barriers include lack of providers who speak their language or understand Asian culture, the knowledge within the community about health concerns, the lack of affordable health insurance, and fear of trying to obtain services due to immigrant status. Language barriers are perceived as a major concern in this community. Many Asian Americans struggle with making an appointment, advocating their particular health needs, and understanding the recommendations or treatment options from the doctor (Kim & Keefe, 2010). Immigrant status is also a major barrier to care, as immigrants have several factors involved when they leave their country to find a new life in the host country. When an immigrant is “illegal” they may be unable to obtain health care or other services for their child, and fear being exposed for their illegal status if they try to apply for services. This article recommends that policy changes need to be implemented at the government level before any changes can make a substantial impact on the health and wellness of these populations.

There are several barriers for children needing autism services. When a family chooses to get help for their child with autism, they are faced with many major commitments. The first of these commitments includes the number of psychological, cognitive, verbal, and occupational and physical therapy assessments needed to determine the appropriate level of services that can meet the child’s needs (McLennan, Huculak &

Sheehan, 2008). Children with autism and their families face many barriers to finding effective, affordable treatment that meets their care needs and they often struggle with a number of obstacles when trying to access the recommended services. Families also struggle with applying for insurance and maintaining eligibility for insurance, due to all the complicated paperwork involved with this process.

A pilot study by McLennan, Huculak and Sheehan (2008) examined the services acquired by parents of Canadian children who had autism and were under the age of six. This study found several deficits in the assessment and service recommendations provided to children, along with several concerns among parents who were trying to navigate the system. When parents were asked to identify concerns they have about autism assessments, services, and treatment recommendations, over half of the respondents indicated that “navigating through the health and social services systems” “repeating the child’s story to different professionals” and “lack of information about the services available” were among the top most commonly perceived barriers to care (McLennan, Huculak & Sheehan, 2008). The responses of these parents indicate that the services that are available are too difficult and complicated to obtain.

This study also found that less than half of the children had psychological or genetic testing, which is a common practice guideline when determining if a child has autism (McLennan, Huculak & Sheehan, 2008). A large population of these children had speech and language therapy without the psychological or genetic testing beforehand, making it difficult to determine the cause of the child’s delays and the appropriate level of intervention needed to help the child recover.

One limitation of this study is that it relied on parental report post-care, which may not have always been accurate due to the array of professionals involved in the care and the difficulty any parent would have when trying to recall the type of assessment completed on their child. This raises an interesting concern regarding children with autism, as they could be treated for autism but are actually psychologically struggling with something else altogether. This means that a child could be treated for autism but is actually struggling with ADHD. Unless appropriately assessed, this would be impossible to determine and the child would essentially get lost in a world of treatment and services that may never be effective or relevant (McLennan, Huculak & Sheehan, 2008).

Another study, by Cook, Cook, Tran and Tu (1997) identified the barriers to rehabilitative care to children in Canada who belonged to the Chinese community. Using qualitative measures, this study interviewed a total of 94 people who were either caring for a child (ages one-20) with a disability or that belonged to the Chinese community, in order to gather information about culture perceptions. Focus groups discussions were held to facilitate this communication, and five key areas were identified as the focal points for the research. These focal points identified the specific supports and treatments needs of families who had a child with a disability, the barriers to receiving treatment, the various health sectors used to treat disabilities, the utilization of community support services, and the acceptance of children with a disability in the wider community.

The findings from this study indicate that children with a disability who belong to an ethnic group face several social and cultural barriers to appropriate care. They feel isolated, marginalized and stigmatized. Parents of these children feel shame that their child has a disability, particularly when the disability is cognitive versus physical, and



even avoid bringing their child in public in certain situations. This study also found that language barriers were a primary obstacle to accessing and utilizing adequate treatment, and several respondents felt that the lack of competent translators was a major aspect of this dynamic. Respondents in this study also felt that western medicine was more effective when treating acute illness, but that Chinese medicine was more effective when treating chronic conditions, such as autism (Cook et al., 1997). This study helps identify the needs among multicultural groups as well as children with disabilities, and helps identify potential barriers that may be present among several cultural groups. The research on the barriers to care within the general population as well as the multicultural population helps provide clearer need for interventions and treatments that are more accessible and culturally appropriate.

### **Impact on the Family**

When a parent has a child with autism, or any other disability, they often struggle with a number of barriers and difficulties when trying to accommodate for the child's unique needs. A study by Sen and Yurtsever (2006) identified some of these difficulties through interviewing mothers who had a child with one of three disability types: cerebral palsy, mental retardation, and autism, in order to identify the effects this has on the family unit. They interviewed 103 mothers who were primary caregivers to a child with a disability between the ages of three and 18 to determine the difficulties the family experienced and the support that the families needed. The results were then broken down by child disability type, and were compared and contrasted against one another.

This study found that a large population of the participants struggled emotionally, financially, and socially due to the demands of raising a child who has a disability. These

struggles intensified when the participants felt like they did not have enough knowledge about their child's condition. Mothers of children with autism felt the least supported financially of the three groups, and less than 50% of the participants felt that their financial needs were being met appropriately (Sen & Yurtsever, 2006).

Mothers of children with autism were also found to be the most emotionally affected of the three groups, and indicated that they felt overwhelmed, angry and lonely. Mothers of children with autism felt severe sadness that affected their work, social life, and family relationships. The participants also expressed concerns regarding external blame for their child's disability, with 11.8 percent of the mothers of children with autism indicating that they felt blamed by their husbands. Psychological support was expressed as a need among the respondents in this study, with mothers of children with autism representing the largest group who desire this type of support. (Sen and Yurtsever, 2006). This study represents the need for more appropriate interventions for the treatment of children who have autism and their families, as the families in this study were the most in need of support.

### **Interventions and Treatment**

Children from diverse, multicultural backgrounds may face a number of barriers when trying to get access to needed treatments, and require unique interventions that help guide them and their family through the process. Zhang and Bennett (2003) provided a theoretical framework regarding the specific needs of the family and how the facilitation of communication can help the child and the family access needed services. This article articulates which interventions are helpful when working with multicultural children, and

helped provide an understanding for how to model these interventions when working with a child who has autism and their family.

Understanding the cultural norms and implications that an autism diagnosis indicates is a key aspect when beginning to work with families. Zhang and Bennett (2003) emphasize the need for professionals to understand the families' reaction to hearing that their child is diagnosed with a disability, as this can help the professional understand the emotional reaction and to approach them with sensitivity. In any family, but particularly in multicultural families, establishing trust is an essential component before any progress can be made towards the child's care needs. The provider needs to take more time with these families in order to establish this trust, and needs to make an extra effort to reach shared meaning and agreement about the diagnosis, treatment, and recommendations. Introducing the family to the special education system takes time, particularly if the family does not speak English or if they have cultural views on the special education system (Zhang and Bennett, 2003).

Zhang and Bennett (2003) also emphasize the need for understanding the child's family structure, and who will be involved in the child's care. This could include extended family members, friends, or community leaders who are involved with the child and who helps the family make decisions for treatment. The decision-making process should include any of these important people in order to set up interventions that will likely be followed through.

It is also essential, according to Zhang and Bennett (2003) to develop goals that are considerate of the families' language and culture. This could be as simple as understanding the language used at home, so that parents can be active participants in

services and can support the child using learned interventions while at home. While this article highlights several interventions that can be helpful when engaging families in autism treatment, it does not indicate the treatments that are effective or the preference for different methods among multicultural populations.

There are several interventions that are recommended for the treatment of autism. A study by Callahan, Mehta, Magee and Wie (2010) used secondary data analysis to review the results of 187 surveys that were provided to teachers, administrators, and parents of a child with autism. The goal of the survey was to determine the preference for each individual treatment method and the effects they have on students who have autism. In order to determine the preference, participants were asked to express their opinions about the perceived importance of each specific intervention method using nominal “yes” or “no” variables.

Applied Behavior Analysis (ABA) and Treatment and Education of Autistic and Related Communication Handicapped Children (TEACCH), are two comprehensive models that were evaluated in this study. Both models are known for their national certification and established results with children from all cultural and economic backgrounds. Both methods utilize behavioral psychology to understand child development, and utilize a variety of interventions and methods when treating childhood autism (Callahan, Mehta, Magee & Wie, 2010). ABA focuses on behavioral analysis by using positive reinforcement to help the child to increase their useful behaviors and decreasing harmful behaviors. TEACCH, in contrast, relies more on visual learning and structured teaching methods and focuses more on accommodating to the child’s needs,

whereas ABA focuses on the child accommodating to the world around them and to societal norms (Callahan et al, 2010).

ABA and TEACCH have been known in the autism world as mutually exclusive treatments, and the equality of these programs in terms of outcomes has been difficult to assess. This study found that services providers did not have a preference between ABA or TEACCH treatments, but that they preferred a combination of the key components of each program. The participants indicated that a combination of these treatments provided the most comprehensive method for having an effective outcome. This was due, in part, to the balance of the treatments and the activities emphasized in each, according to the participants (Callahan et al., 2010).

While this study provided some interesting concepts that should be evaluated and understood further in order to help determine appropriate interventions for children with autism, it did not provide any information about the preference for these programs among multicultural groups. It would be beneficial to learn about the preference for these or other treatment methods within multicultural groups, in order to determine appropriate interventions for this population. This research study seeks to determine which interventions are appropriate by identifying the treatment modalities that are used for different ethnic groups, and if these treatments are culturally sensitive and specific to this populations' needs.

### **Attributes of Resilience**

When considering the barriers to care, the impact on children from multicultural groups, and the impact on the family, it is also important to consider a families' resilience, or ability to “bounce back” in the face of adversity. *Resilience* is described as

the “ability to stretch (like elastic) or flex (like a suspension bridge) in response to the pressure and strains of life” (Boss, 2006, p. 48). Attributes of resilience are protective factors that can help a child and their families pull together and navigate the many difficulties that a child with autism deals with on a daily basis.

A study by Bayat (2007) employed qualitative measures to further understand the role of the parents’ perceptions of their child’s autism diagnosis, and how this perception affects their view on the quality of life for their family. Initially, data was collected from 165 parents of children, ages two-18, with autism in order to determine the characteristics of the children being represented in this study. The participants were recruited from the Autism Society of Illinois’s mailing list, parents of children enrolled in the Chicago Public Schools’ Autism program, and parents of children with autism who attended a therapeutic day school. The respondents answered three open ended questions that addressed the effect that their child’s diagnosis has on the family and themselves personally. One question asked for the parents to describe their autistic child in three to four sentences. The findings from this study indicate that families who have children who have autism value “sticking together” and “being connected” and approximately 62% of the families said they are now closer after learning of their child’s diagnosis. Two major qualities that were identified for staying connected included being flexible and communicating with one another (Bayat, 2007).

Several themes of strength and resilience emerged from this study. The respondents in the survey found that when they could make meaning out of the adversity they faced, they felt better equipped to cope with diagnosis and could more readily accept the condition and find strength and meaning in the change. The respondents also indicate

several strengths they learned through understanding their child's disability. Some parents felt that they were now more compassionate, sensitive, and caring after accepting their child's diagnosis and felt that they were more mindful of individual differences. Additionally, the parents in this study also found strength through having a spiritual belief system. Nearly half of the respondents made some reference to God, which shows that the role of spirituality helps these families understand, cope, and accept the challenges they face. These results indicate that attributes of resilience can be found among these families, and these families possess thoughtfulness for how to work with these children and with other children who have disabilities (Bayat, 2007).

Children from diverse backgrounds have unique attributes of resilience that help them cope and heal from hardships and stress. In another study, Ungar (2008) found that there are several factors that contribute to personal resilience that also reflect a person's cultural influences. This study investigated several aspects of resilience by identifying the multidimensional constructs of resilience and strength within a community and culture by using a mixed method design for a sample of 1500 youth, ages 12-19, from five different continents. These children were recruited to participate through several sites across the globe that served children with autism, and relied on personal partnerships and the facilitation of community organizations and groups.

This study found that children from all over the country have cultural explanations for their understanding of the world and how they manage to navigate through troublesome times. Several participants indicated that a strong sense of attachment or closeness to their parents and family helps them get through hard times and that a positive relationship with family is crucial to the development of how they view the

world (Ungar, 2008). Many of the youth involved in this study also indicated a desire to hold onto cultural ties, despite feeling ostracized from their peers. One participant, who newly immigrated to a host country, explained that she continues to wear Muslim attire and eats Muslim food, even though these actions separate her from her peer group. For this participant, a close bond with her culture and ethnicity is a protective factor that makes her feel stronger in her faith and closer to her family and homeland (Ungar, 2008).

The respondents in this study also indicate a desire to have health services available that are culturally and contextually appropriate, so they can access needed services that have a positive influence on their mental and physical health. This study also provides implications for future research, and recommends that professionals need to identify specific interventions that could help improve health outcomes for children by addressing the resilience within these groups and finding how these attributes of resilience can have an impact on the population being served. (Ungar, 2008).

### **Social Work and Childhood Autism**

Social workers should be interested in and concerned with the issues affecting children who have autism and their families, as this condition requires an intense amount of services and support that may be difficult to manage and understand. One study, by Preece and Jordan (2006), examined social workers' understanding of autism and how this impacts the assessed needs of the family and child, along with the types of interventions and services that are then provided. This research was completed in response to parental feedback indicating that social workers seem to struggle with understanding autism and they appear to lack the skills to work with this client population. Before this study, no other research had been completed regarding social



workers' understanding or knowledge of autism spectrum disorders. A total of 27 social workers who work first hand with children with disabilities completed a survey to determine their understanding of the causes and the diagnosis of autism, as well as their awareness of the treatments available for autism.

This study found that several of the social work respondents were unaware of the primary causes for autism, as some believed that autism was caused by “maternal coldness or social causes” and over a fifth believed that the measles, mumps, and rubella (MMR) vaccine caused autism. While society no longer holds the view that maternal coldness causes autism, there continues to be debate regarding the causal link between the MMR vaccine and autism. Over half of the respondents also did not know when a child starts to display signs of autism, and this half felt that autism became “fully present after the age of three” which is inaccurate and conflicts with the diagnostic criteria for autism that states the criteria for an autism diagnosis to be present primarily prior to the age of three (Preece & Jordan, 2006).

The respondents involved in this research also had inaccurate understandings of the approaches that are used with children with autism. The majority of the social workers involved in the study felt that a specialist would not be helpful for working with a child who has autism develop social and emotional understanding however, this is often a preferred focus of many interventions utilized by specialists. These results of this study indicate the need for further training and education for social workers who are involved in the care of children who have autism, as this limited understanding of the causes and treatment methods creates barriers for care among social workers who work with these children and their families. This study will help determine the interventions and treatment

modalities that several different professionals utilize, in order to determine the effectiveness of these treatments.

## Conceptual Framework

After reviewing the research that is available regarding autism treatments and interventions within multicultural populations, a framework for understanding the key issues emerged. The ecological perspective was developed by the psychologist Urie Brofenbrenner in 1979, and is an integrative framework for understanding multiple levels of systems to understand the “bigger picture” (Oetzel, Ting-Toomey, & Rinderle, 2006). This perspective requires us to identify the cultural and societal contexts, along with the historical and economic influences on a person’s life and understanding of self.

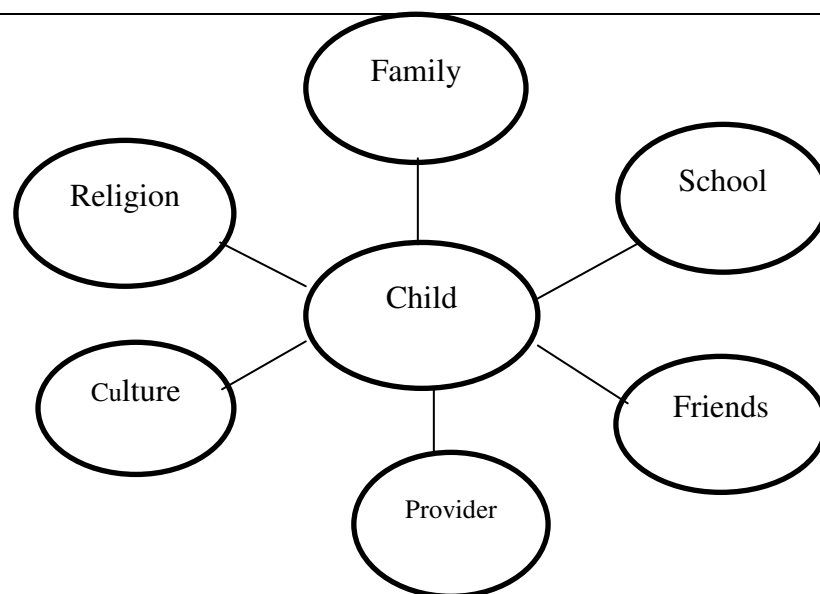
The ecological model is made up of several “systems” that help influence child development. These systems include: micro-system, meso-system, exo-system, macro-system, and chrono-system (Onchwari, Onchwari & Keengwe, 2008). For children who have autism, *micro-systems* are often reflected by those who are immediately involved with the child. This could be the child’s family, teachers, friends, religious group or anyone else that the child is close to. *Meso-system* applies to the interrelationships between the microsystems. An example of this would be if a child comes from a multicultural family. At home, the child would be expected to speak the native language and adhere to traditional cultural expectations. At school, however, the child may be expected to speak English and adhere to a whole new set of cultural expectations. *Exo-system* refers to the influential factors in a child’s life. This could be represented by children who are being raised in a single parent home, or whose parents work during the day. *Macro-systems* are also a focus of the ecological model, and can be described as the larger social functions that impact the other systems. Examples of this could include policies that pertain to children with a disability and children from a multicultural or

immigrant background. *Chrono-system* refers to the changes that happen across time and affect the other systems (Onchwari, Onchwari & Keengwe, 2008). Examples of this could be either external or internal, such as a divorce or death in the family or the developmental and physiological changes that occur during the aging process of a child who has autism, respectively.

An important concept in the ecological perspective is the principle of “goodness-of-fit,” which suggests that supportive and safe environments help a person advance in life and develop appropriately. In contrast, hostile environments can have the opposite affect and can deter a person from developing to their full potential (Ohmer, 2010). When a child with autism has access to appropriate treatments that help them in the process of recovery, the principle of “goodness-of-fit” would support the notion that the child is more likely to make substantial progress.

An eco-map (figure 1) is a simple way to portray the concepts of an ecological perspective, and provides a representation of the various systems at play in a child’s life.

*Figure 1. Eco-map of a child who has autism.*



### **Professional Lens**

During my employment as an undergraduate level social worker, I have worked in settings that provide services to adults, and I have not worked in a setting that primarily serves children. My interest in this project developed from an interest of multicultural interventions in the context of treatments interventions for children who have autism. I have worked with many Somali and Hmong adults and I have an interest in understanding the needs of these and other immigrant or multicultural populations. I chose to research autism in the context of multicultural studies because I was curious about the impact that one's cultural identity has on the diagnosis and treatment of autism.

### **Personal Lens**

I am a step-mother to an amazing eight year old child. He does not have an autism diagnosis, but I can understand autism in the context of child development by comparing this development to my own step-son. I first began having an interest in multicultural populations when I started working with these populations and recognizing the needs of many immigrants and refugees. I also took a clinical practice with immigrants and refugees class last year, which heightened my understanding and awareness of the needs of this population and how autism may affect the different multicultural communities who are represented in Minnesota.

## **Methodology**

### **Research Design**

Children with autism often work with a variety of professionals across several disciplines, and this same diversity among professionals was reflected in the research (Jensen & Spannagel, 2011). In order to obtain data regarding helpful interventions for working with multicultural children who have autism, five professionals who currently work with children who have autism were interviewed. All of these professionals have experience working with children from multicultural backgrounds. Participants were chosen for the interview if they were currently working with children who had an autism spectrum disorder in either a school setting or a treatment program. The research focused on professionals in both settings to reflect the diversity of interventions and treatment methods that are used when working with children who have autism. Another inclusion criterion for this study was the selection of professionals, identified as social workers, psychologists, or mental health professionals who are licensed to practice, as according to their individual professional guidelines.

The participants were recruited through “snowball sampling” which is a nonprobability sampling strategy that allows the researcher to first identify providers who meet the inclusion criteria of currently working with children who have autism, are licensed to practice, and are involved as either a social worker, psychologist, or mental health professional (Berg, 2009). These initial providers also signed agency consent forms, stating that they understood that the researcher was employing snowball sampling techniques, which would allow the researcher to recruit participants through referrals from the initially specified providers. These subjects were then asked for referrals of

other people who work with children who have autism in either the same agency or in another agency that serves children who have autism. Snowball sampling alone did not recruit the desired number of participants, so the researcher also made flyers and distributed these to potential participants and asked them to call or email the researcher to participate in the interview (Appendix A).

### **Protection of Human Subjects**

In order for the research proposal to reach approval, the researcher submitted an application to the University of St. Thomas Institutional Review Board (IRB). The research was considered an expedited review which means that the risk was minimal, as the study did not include intentional deception, did not employ sensitive populations or topics, and included appropriate consent procedures. Before the interview began, the respondents were provided with a consent form that was approved by the University of St. Thomas Institutional Review Board (IRB) in order to ensure respondent protection. The consent form explained the purpose of this study and how the participant was chosen for an interview. The consent form also described the procedures that were used, and explained that there were limited risks and no known benefits. Lastly, the consent form described aspects of confidentiality, such as keeping the identity of the children anonymous, and explained the voluntary nature of participating in the study. In order to maintain confidentiality and anonymity of any of the children or families that the respondents worked with, client cases were only discussed if the person or family remained nameless, and no client demographic information was revealed in the interview process. A list of questions were provided to the respondent prior to the interview (Appendix B). In addition to the consent forms, the respondents were also provided with

a verbal explanation of the consent form and the nature of this study, and were provided with an opportunity to ask any questions regarding the study. At the end of the study, the researcher provided a list of resources in the autism community along with a list of agencies who provide emotional support (Appendix C). This list was provided to ensure that the participants had support after the meeting, in case they suffered any emotional distress by answering questions related to their work with children.

### **Data Collection**

Semi-structured questionnaires were used as the primary instrument for this qualitative study. The participants were asked to participate in an interview, which lasted approximately 30-45 minutes, at the location of his or her choice. The locations were held in a place that ensured client confidentiality, such as an office or a private meeting space. Interviews were audio recorded on a tape recorder owned by the researcher for transcription purposes.

The interviews consisted of 11 open ended questions that were developed by the researcher, reviewed by committee members, and approved by the IRB. These questions were developed after completing a review of the literature, which helped the researcher understand the issues surrounding multicultural children who have autism and the treatments they are provided. The interview questions were non-threatening and addressed service utilization, treatment options, and multicultural interventions that are provided within this community. In order to reduce risk, the researcher provided a list of available agencies who provide emotional support, and encouraged the participant to tell the researcher if they were uncomfortable answering any questions or if they needed to



stop the interview. Care was taken to reduce any concerns regarding confidentiality, and the researcher personally handled all material that was generated from the interview.

After the interviews were completed, the researcher personally transcribed the data. The transcribed interviews are stored on a password protected computer and will be deleted from the computer by June 1, 2012. The audiotapes of the interviews are stored in a locked file drawer in the researcher's home office, and will also be destroyed by June 1, 2012.

### **Data Analysis**

The data was analyzed using grounded theory methods, which is a method of coding the collected data through identifying similar concepts and themes and “allows researchers to link or ground these categories to the data from which they derive” (Berg, 2009, p. 347). The interviews were carefully transcribed and examined to find codes and themes. Once the researcher was unable to identify any new codes, the collected data and identified codes were re-read for any missed latent content. The researcher then grouped similar topics that related to each other into broader categories and listed any themes that helped answer the original research question. Each theme consisted of at least three direct quotes from the interviewee, which helped strengthen the concepts found in the data and increased the trustworthiness of the results.

### **Strengths and Limitations**

The strengths of this qualitative study were the diverse nature of respondents from a variety of professional backgrounds. The respondents ranged from social workers (one participant), psychologists (two participants) and mental health practitioners (two participants). The diversity reflected in this research helped support knowledge of how

interventions are applied by a variety of disciplines, and provided rich data to understand the key concepts regarding treatment interventions that are used with multicultural children who have autism

Limitations that derived from this study include the constraints of conducting only five interviews, which is not large enough to be considered a representative sample. Future studies should incorporate the use of more professionals in order to accurately reflect the viewpoints of the larger professional population who work with children who have autism. It was difficult to recruit more participants for this study using snowball sampling techniques because the research was conducted in a short time span, which was not enough time to generate referrals for participation. The use of snowball sampling techniques also created limitations with the sample, as several participants were referred because they worked at the same agency as another participant. The use of multiple participants from a smaller pool of agencies likely contributed to less variety among the results.

## **Findings**

The intent of this research paper was to gain an understanding of the treatments that are useful and effective when working with multicultural children who have autism and their families. The study attempted to gain insight into the therapeutic modalities utilized, the barriers associated with these modalities, and the techniques or recommendations that the participants suggest.

The participants in the study came from varying professional backgrounds. Two participants were psychologists, one was a counselor, one was a mental health practitioner, and one participant was a clinical social worker. Four of the five participants used treatments developed under the model of Applied Behavioral Analysis (ABA) and one modeled their practice after Relationship Development Intervention (RDI). Four of the participants were female and one was a male. Four of the five participants have experience working with a wide range of multicultural families, but generally the most experience was with children from Somalia. The fifth participant reflected on their experiences working with a family from China. The participants had a range of knowledge regarding multicultural children who have autism, with a range of perspectives concerning the barriers to care and treatment techniques that are the most helpful for this specific population. The following table (Table 1) demonstrates the characteristics of the participants.

Table 1

*Characteristics of Participants*

	<i>n</i> (%)
Gender	
Male	1 (20%)
Female	4 (80%)
Profession	
Social worker	1 (20%)
Counselor	1 (20%)
Psychologist	2 (40%)
Mental Health Practitioner	1 (20%)
Therapy Model	
ABA	4 (80%)
RDI	1 (20%)

*Note.* This table reflects the characteristics of the participants involved in the study.

The researcher transcribed the data from the interviews and read through the transcripts, finding five major themes. The researcher then reread the data, looking for any missed latent content. The five themes that emerged from the data are: Language, meaning of play, family education, gender roles, and stigma. *Language* refers to the participants' statements regarding the role of English being the primary language used in the home, and the benefits and disadvantages of this practice. *Meaning of play* includes the participants understanding of how other cultures interpret play and why they may seem less engaged and interested with how their child is functioning in this context. *Family education* is another theme, which refers to the statements made regarding the role of the family and how to engage family members in the services by educating them about the skills and techniques used with the child so the family can continue these skills in the home. *Gender roles* are another theme, which refers to participants' statements

about the role of gender in multicultural families, particularly in families that have a patriarchal family system. Finally, *stigma* refers to the negative connotation that some cultures have regarding an autism diagnosis. Participants offered viewpoints regarding the impact that this stigma has on a family's ability to adapt to the needs of their child and accept help from professionals. The following table (Table 2) outlines the major themes found, the words that were used to illuminate these themes, and the responses.

Table 2

*Thematic Categories and Word Table*

Theme	Key terms	Responses
Language	Language or English	-English should be the main language. -The native language should be predominant. -Language should not be the focus of interventions.
Importance of play	Play, toys, games	-Lack of toys. -Lack of parental engagement in play activities. -Cultural view on play as a developmental task.
Family education	Family education, skill building, skill training, teaching, understand, skills	-Engagement and education leads to better follow through. -Teaching developmental skills leads to -shared meaning and understanding. -Supporting families and teaching skills.
Gender roles	Gender, patriarchal, sex, father, mother, female, male	-Father dictating therapist's role in own home. -Male therapist's gender a disappointment. -Patriarchal family and treatment goals.
Stigma	Stigma, connotation, negativity, labels, mental health	-Normal vs. crazy. -Autism as a mental illness. -Severity of stigma in the community.

*Note.* This table reflects the themes, key terms, and responses to the survey questions.

## Language

Language was a common theme that addressed by every respondent. However, the interventions that were recommended for confronting language barriers and helping a child overcome this in treatment were varied. Two participants described the importance of having consistency with the language used in the homes of multicultural children who have autism, stating:

*We are teaching the child English and we are stressing that English be taught and spoken in the house because if they are not getting English at any other time except therapy you are not going to see the language improve.*

*I have heard of some families who do not use English in the home and they have been discharged or threatened to discharge from the program because they have not put these things into place, which we recommend.*

Both participants indicate that families need to use English in the home in order to progress in therapy and remain in the recommended treatment, and feel that this is a foundational aspect of autism that needs to be addressed in order for the child to develop language skills.

Two other participants described the limitations of recommending that English be the predominant language used in the home:

*Kids start treatment in settings where English is predominant. Even when interpretation and dual language can be provided, it often is not. And guess what happens? They start to develop language and it is in English and they develop a preference for that and at a certain point they lose all of their native speaking or understanding. And after a point, they cannot communicate effectively with their parents and it is a tragedy.*

*I think it is important to keep their language as the primary language and have English the second language but the reality is they are being taught these skills by people who speak English, so they are losing a lot of their own native language skills in the process.*

These participants focused on the issues that an English-only doctrine presents, particularly as this relates to the child's ability to communicate with parents and have advancements with understanding their native language.

Another participant felt that the emphasis on language was unnecessary, and generally felt that the focus of interventions should not be solely on language:

*A lot of times, language is not the behavior that we are targeting. You often times will see a child who talks way too much and is reliant on one mode of communication. Language is not the problem, the problem is about [the therapist] changing your philosophy, what do you assess, what are you trying to fix.*

In comparing these statements regarding language, there is a major difference across all participants regarding the role of language in treatment. Some participants try to enforce rules around language and feel that parents should comply with using only English in the home if they expect to see results with their child. Other respondents spoke to the tragedy that an English-only doctrine presents, as the child then faces challenges with understanding their native language and communicating with family. The final respondent felt that language should not be the focus of interventions, suggesting that therapists need to change their philosophy regarding language and feels that language is not a primary concern in treatment. The contrast in these responses indicates that professionals, when using a variety of intervention and therapeutic methods, have no standard opinion regarding the use of language and how different languages should be considered in the context of autism.

### **Importance of Play**

Several participants in this study also indicated that the meaning of play is understood differently across cultures. In American culture, it is considered a normal part of child development to engage in play, and it is considered normal for the parents to play

with their children. In other cultures, play is not recognized as an important part of child development and the parents do not engage in play-time activities with their children.

Participants in this study often use play as a gauge for how the child is interacting on a social level, and play is a core component to many behavioral interventions that therapists use with children. The lack of toys and the difficulty with understanding the importance of play among multicultural groups is described as follows:

*A lot of immigrant parents cannot talk to you about play because they do not know anything about it. They do not have on their radar how their child is interacting with toys and other people because that has never been their job. They do not see this as part of their parental set, or how a child's play skill will help the child talk or learn other tasks.*

*I have gone in the houses and they literally have no toys. You talk to the families and they are like we had nothing; there is a tire, there is a stick, that is how we played in Somalia. So they get here and the houses have a lot of people in them, and they don't put a lot of toys in there.*

*They are a very oral community so they want to focus solely on language most of the time and they don't want to focus on social interaction or play and they don't often have toys in the Somali culture, they often times make their own toys so it just isn't very important to them.*

As shown in these statements, the importance of play has significant cultural implications. Several of the participants commented on the lack of toys in homes of Somali children and commented that parents from different countries may not understand the role of play or how to incorporate play into their parental skill set.

### **Family Education**

Another important finding from this research indicates that involving multicultural families through education about autism is an effective way to engage the family and help reach shared meaning and agreement on goals that the child should be



working towards. Four of the five respondents indicated the importance of educating the family, stating:

*Once they are engaged and see some changes, once they are taught the skills and can practice these at home, then they are much more likely to want to continue learning how this all works.*

*A bulk of what we do in the skills training services as practitioners is teach the developmental skills. They coach the parents on a lot of this and this is the entry point for a lot of our families. It helps to make the transition from evaluation of the child to understanding what the child needs.*

*Parents may not be the most educated, they don't have special education degrees, they didn't chose to work in this kind of work, but they sure got straddled with having a kid that needs a lot more work than a normal kid, so it is supporting them and helping them with the skills.*

*If you don't help them understand "when it looks like this, here is what is happening" if you don't start at that basic level, they are not going to engage in services.*

These four respondents indicated that in order to engage a family in services, education regarding the evaluation and treatment process needs to be provided first. Then, as the therapist and the family develop a rapport, it is important to help them understand what progress will look like and what skills the parents can practice when they are with their child. These respondents also indicate that if the family is not engaged in the process in the beginning and taught the basic skills, the family will not have an alliance with the therapist.

### **Gender Roles**

Three of the five respondents also discussed the gender roles in multicultural families, particularly when working with African families. These respondents indicate that the patriarchal roles in Somali families and the implications of having either a male or female therapist can affect the therapeutic relationship stating:

*...one of the therapists had a sick child at home and she asked if she could schedule the shift for later in the day. And she said this to a Somali family. And the father in the home said no, you need to be home with your child. And the therapist said, well my husband will be home later, but the Somali man said no, you need to be home that is your job.*

*In general, my sex is disappointing in this line of work as far as fathers go. A lot of the Somali community it is quite a bit more patriarchal and the dads dictate quite a bit more. I have one family that didn't want me to work with the kid, who was a girl, because I am a guy.*

*Some of these families, the fathers make all the rules. They do not like a female therapist coming into the home, teaching the father and mother how to play or interact with his child. There is some resistance, it seems, when doing in home work and trying to get some of these fathers on board with the treatment plan.*

These respondents all remarked on this dynamic towards the end of the interview, when asked if there were any other experiences or observations they wanted to add. It was a surprise to discover this dynamic, as previous research did not discuss how gender roles can present additional challenges to consider when working with multicultural children with autism. It is also interesting to note that two females and one male respondent commented on this theme, indicating that either gender can be affected by this dynamic in multicultural families.

## **Stigma**

As the literature review suggests, stigma is a major theme when working with children from multicultural backgrounds. Three of the five respondents felt that the role of stigma when labeling a child with an autism diagnosis had a major impact on family engagement in therapy, stating:

*If you go back to Somalia and other countries too they do not like labels, there is a societal views of either normal or crazy. You don't want that kind of label or stigma as far as your family goes, so if your kid goes there you need to hide them in the house and pretend the kid isn't there.*

*I would say that in the Somali culture, typically any child diagnosis, mental health or mental illness, they hear autism and they think it is the same thing.*

*One thing which is true across all cultures is that there is a stigma about a child having a disability...But in some communities I do not know that we can appreciate the stigma. In some communities, you cannot take the risk that someone will see that this is your child because once this is known you could risk being stigmatized by the community.*

These respondents all described stigma in the context of multicultural families, indicating that the stigma plays a major role in the family's ability to accept that their child has an autism diagnosis. These statements reflect the risk that families from multicultural families, particularly Somali families, encounter when having a child with autism. The third respondent indicated that the stigma in these communities cannot be appreciated by some therapists, because while the concept of stigma is understood in American culture, it is difficult to truly understand the impact that stigma has on other cultures because the response from the community is more severe and long-lasting.

### **Summary**

In summary, language, play, family education, gender roles, and stigma are all important themes which inform the therapeutic interventions used when working with multicultural children who have autism and their families. The participants of this study spoke to the many barriers associated when working with multicultural children who have autism, but did not always indicate how they navigate through these barriers. These findings helped establish potential concepts that could be anticipated in future work with multicultural children who have autism, and provided a unique vantage point for understanding the key issues that impact working with multicultural populations.

## **Discussion**

The research examined the interventions that are helpful when working with multicultural children who have autism by interviewing a small sample of providers who work with this client population. The findings indicate that there are some common obstacles and barriers to treatment with children who have autism. The purpose of this section will be to examine similarities and differences between recent studies and this current research, and the themes will be related back to the literature and examined to help understand the key issues around treatments and interventions that are helpful when working with multicultural children who have autism.

### **Language**

There were several similarities between previous research and this current study regarding language and how this impacts treatment when working with multicultural children who have autism. Kim & Keefe (2010) described several barriers for multicultural populations, stating that the lack of providers who speak a second language and who understand different cultures has a strong impact on a family's desire to seek services and follow through with treatment recommendations for their child who has autism. Zhang and Bennet (2003) also discussed the role of language, and indicated that parents are more likely to participate in services if they can support the child at home using learned interventions. The parents are more likely to develop competency with understanding the interventions if these are being taught to both the parents and the child in their native language.

This barrier was also represented in the current study, when participants discussed themes related to language among multicultural families. Participants in the current study

had contrasting viewpoints regarding language. Some felt that, when working with children from multicultural families, English should be the primary language used in the home because consistency is needed when working with children who have autism. These participants felt that if English is primarily used in the home, then the child will progress in therapy and will have noticeable improvements with language and communication skills. These professionals fear that if a child only hears and uses English when they are with a therapist, then the child will not develop effective language skills.

This opinion differs from two other participants, who indicate a preference for helping the child develop language skills in their native language. These participants felt that if English is the language preferred by the therapist, the child may develop the ability to only communicate in English. When this happens, the child may struggle with communicating effectively with their parents, which creates another set of barriers for the family. These participants generally felt that more should be done to incorporate the client's native language into therapy by using dual language interpreters. This could help ensure that the child is learning the skills he or she needs to communicate in the home and in the community. One participant indicated that the loss of native language is a tragedy, and should be evaluated further.

The findings from this research present some controversies regarding the use of language. The results indicate that professionals struggle with balancing the expectations of language skill development when working with multicultural families from a non-English household. These professionals voiced the complications they face when trying to help a child develop meaningful, verbal communication. Several participants acknowledged this barrier, indicating that when English is the primary language used in

therapy, children are inevitably going to lose some of their native speaking skills. These participants struggled with finding solutions to this problem, as they have to balance the child's potential for progress with the parents' willingness to participate and engage in the process, when these parents then loss communication with their child.

### **Family Education and Lack of Toys**

Previous research, along with this current research, had several similarities regarding family education and the lack of toys within some cultures. Kim & Keefe (2010) describe how multicultural families struggle with a lack of knowledge about available treatments and how these interventions can help children. This dynamic creates service barriers because families are less likely to encourage their children to participate in a treatment program for autism if they do not understand the treatment or how the interventions help their child. Families are less involved with therapeutic interventions with their child if they do not understand the developmental milestones and the need for certain treatments to determine the level of achievement towards these milestones.

This insight was also shared among participants in the current study, when discussing themes related to family education and lack of toys. Several participants commented on how to engage a family with services, indicating that when they fully educate a family about their child's disorder and how symptoms manifest, the family is more engaged in the treatment process. Participants in this study suggest that when they take the time to explain the importance of certain interventions, such as the importance of play in the context of treatment, then the family is generally more engaged in the process and can see results more clearly. This collaboration between providers and families can

also create a sense of shared meaning and trust, which could lead to a more positive outcome and better results when working with the child.

Several of the participants commented on the lack of toys in homes of Somali children and indicated that parents from different countries may not understand the role of play or how to incorporate play into their parental skill set. In Somali culture, children are provided with few toys and the parents are not expected to supervise or interact with a child when they are engaging in play activities. This dynamic is outside of the parental role in Somali culture and is not considered a normal aspect of child development. This helps to explain why the concept of play, when encouraged by behavioral therapists, is not where some multicultural families want to focus their efforts. If providers focus more effort on educating the family about the role of play and how to incorporate play into their culture, they may see better results and more engagement from the child and their family.

### **Stigma**

Stigma was a major theme that was found in both previous research and this current study. Cook et al. (1997) indicates that when a multicultural family has a child with autism, they have an increased risk of stigma from the community. These families may struggle with leaving the home with their child or bringing their child in public places. This stigma can create barriers to care, as the family may be too ashamed and afraid of accepting services because this could make the child more exposed to the community.

Several participants commented on the role of stigma with the families that they work with. These participants indicate that the stigma associated with autism or anything

perceived to be a mental disorder is so severe in some communities that it cannot be truly comprehended by someone who is from a culture where stigma is not as big of a concern. Participants felt that this dynamic creates significant disruptions in services, because families may be afraid to participate in services, even if these services could benefit their child. The stigma in these communities presents a challenge for social workers and other professionals who work with multicultural children who have autism. If the larger community has a better understanding about the causes of autism, there may be fewer stigmas attached to an autism diagnosis. Until then, providers should recognize the stigma within these communities and should try to focus treatment and discussions on the symptoms being expressed instead of such a focus on a diagnosis or label.

### **Strengths and Limitations**

This qualitative research examined the interventions that are helpful when working with multicultural children who have autism and their families by identifying current barriers to treatment and cultural implications of current treatments. There were several strengths associated with this study and the knowledge that was gained from this experience. One strength of the study is that it relied on interviews with professionals, or qualitative data, to influence the findings. Using a qualitative method is a strength of this research because the participants could ask clarifying questions and could emphasize certain aspects of their experiences that they felt were the most important. The data was formed from participant's words and stories, which gave a stronger voice to the issues that affect children who have autism. Another strength of this research is that a diverse group of participants were recruited, which accurately reflected the diversity among professionals that work with children who have autism. This diversity helped the



researcher understand the treatment models and interventions from a variety of approaches, which enhanced the quality of the data provided.

There were also limitations of this study. The sample size was small in relation to the amount of professionals who provide services to children with autism. This study cannot be considered a representative sample for that reason. Another limitation of this study was the recruitment method. Participants were recruited through snowball sampling techniques, which resulted in the recruitment of several participants who worked for the same company. Although these participants worked together, they all had different professional backgrounds and had different experiences. However, some of the perspectives could have been reflective of the agency. Another limitation of this research is the questions themselves. After the research was completed, the researcher realized that no question directly addressed the focus for this study. Participants were asked about their experiences, and most reflected on the interventions they use with all children, instead of focusing on interventions when working with multicultural children who have autism. This oversight created some confusion with how people interpreted the questions.

### **Implications for Practice**

This study has implications for social work and other professionals involved with children who have autism. Language was a consistent theme within the previous research as well as this current study. Participants expressed concerns regarding how to work with children who come from families where English is not the spoken language and were concerned about the impact that language has on communicative functioning. Providers should continually assess and determine the language implications within the family and how this shapes the family's view of progress. Providers should discuss and think about

their interventions, and should consider the use of dual-language providers when working with a multi-lingual family.

Providers should also be aware of the need for rapport and collaboration within multicultural families. This could start with the providers educating the families about autism in general, how this progresses, and which treatments are recommended and the rationale behind these treatments. Providers should consider the cultural implications and barriers when working with families where toys, for example, are not considered an important aspect of child development. Providers have a responsibility to the families to educate them about child development, while also collaborating with the families to determine how to engage the family and find things within the culture that are meaningful and significant.

Stigma was a theme within the research, indicating that some populations who need services are unable to reach out for help because they fear the stigma in their communities. This stigma is so intense that some populations will not take their child who has autism to public places, for fear of exposure. It is important for providers to understand their own cultural values so that they can tune into the needs of multicultural families who have a child with autism. It is already difficult to imagine the stigma that is so prevalent in other cultures, but practitioners need to have a keen awareness of this stigma and should work on advocating for this population and influencing policy regarding the needs of this population. With more education and outreach to the community, underserved populations could get needed access to services.

## **Implications for Research**

In general, interventions for multicultural children who have autism is understudied, so any increase in the body of research for this population would benefit both the providers and the people utilizing services. It would be helpful to focus more research on language development, as there was disagreement among the participants in this study regarding the use of English during treatment and in the home. Previous research suggests that it is important to use a client's native language and to involve interpreters for the child and the family on a consistent basis. However, some participants indicated that by using one language with a therapist and one language in the home, the child will likely struggle with developing language at all. Future research should study this dynamic and assess whether it is more helpful for a child to have therapy provided in a dual language setting versus a setting where English is the primary language used. Professionals could also then gain an understanding of how to work with children who may use a different language in the home.

It would also be helpful for future research to address the subjective experience of a multicultural family who has a child with autism. This vantage point could help provide a more clear understanding of the issues that affect these populations, and how a provider could try to engage with the family and refer them to appropriate services. The lack of family education was a theme within this research, which indicates the need for more research around multicultural families and how they interpret disorders and effective treatments.

Another implication for future research could be a replication of this current study on a larger scale. The participants all had experiences working with multicultural children

with autism and had unique perspectives for how to engage with this population. If this study was replicated on a larger scale, there would be a more representation of professionals who could voice their thoughts and experiences regarding this client population. It would also be interesting to determine how providers from different states or regions reacted to questions related to this research.

Future research could also concentrate on gender roles and how gender impacts treatment for children who have autism. Gender roles were not a subject identified in previous research, but were a major finding from this study. Social workers and other professionals need to understand how gender, particularly in patriarchal families, effects treatment so that we can be culturally sensitive and appropriate when working with multicultural families. Future research could examine the gender roles and the impact that gender has when working with multicultural families, and how gender can either help or potentially hinder progress towards goals.

There also needs to be more research about the causes of autism. Current research has not yet indicated the causes, which makes it a difficult concept for people to understand. If social workers are involved with education, outreach, and treatment then they need to have more concrete answers regarding the causes. In order to treat autism, social workers and other professionals would benefit from understanding how to prevent autism.

## **Summary**

In conclusion, autism has the potential to affect everybody. With such high prevalence rates, it is likely that every person will know a child with an autism spectrum disorder. With an increase in diagnoses creates an increase in the need for research to

inform clinical interventions when working with this population. It is important for future researchers, providers, and families alike to consider the issues discussed in this research study so that future research and implications can reflect the needs of all children who have autism.

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## Appendix A

# Professionals that work with children who have autism needed!

Would you like to participate in research that will help identify different interventions that are helpful when working with children who have autism?

Do you currently work with children who have autism, and are you involved as a social worker, psychologist, speech or occupational therapist, psychiatrist, or mental health professional?

If your answer is yes, please contact me!

My name is Stephanie Kitzhaber and I am a student at the University of St. Thomas/St. Catherine's University. I am currently working on completing my Master's Degree in Clinical Social Work and I am interested in interviewing people who currently work with children who have autism. This research will also seek to identify which interventions or treatments are helpful when working with multicultural children.

The interview would last approximately 45-60 minutes, and will be held in a private location. Interviews will also be audio-taped for transcription purposes. Your participation in this study is completely voluntary and anonymous.

I would love to share more information about this project with you. Please call me at \_\_\_\_\_ or email me at [kitz1173@stthomas.edu](mailto:kitz1173@stthomas.edu) for additional information

If you have any questions about your rights as a subject/participant in this research, or if you feel you have been placed at risk, you can contact the Chair of the Human Subjects Institutional Review Board, through St. Catherine University at (651) 690-7739.

## Appendix B

### Interview Questions

1. Could you describe the setting that you work with children who have autism, and what your role is in this setting?
2. What is your experience working with children who have autism and their families?
3. What is your education background? Why did you choose to work with this client population?
4. Which interventions or treatment modalities do you use when working with children who have autism and their families?
5. What has led you to choose the treatment models that you use over other treatment models or interventions that are used when working with children who have autism?
6. What are the advantages and disadvantages of this particular treatment or intervention?
7. What types of ethnic groups do you work with in your profession?
8. Have you noticed any cultural implications or barriers when using the above mentioned treatments with children from multicultural backgrounds?
9. Are there any observations or experiences that you would like to add, as it relates to this client population?
10. Are there any resources that you could recommend for furthering my understanding of children who have autism?
11. Do you know anyone else that may be interested in participating in this interview?

## Appendix C

### **Autism resources and support:**

<http://www.ausm.org/> Autism society of Minnesota (651) 647-1083: The Autism Society of Minnesota (AuSM) is an organization of families, educators, care givers, and professionals committed to supporting individuals with autism spectrum disorders (ASD). The Autism Society of Minnesota exists to enhance the lives of individuals with autism spectrum disorders. AuSM seeks to realize its mission through education support, collaboration, and advocacy.

[www.arcgreatertwincities](http://www.arcgreatertwincities.org) Arc Greater Twin Cities (952) 920-0855: Non-profit, volunteer driven organization. Provides advocacy and support services for people who have developmental disabilities and their families.

[www.AnokaCounty.us/autismguide](http://www.AnokaCounty.us/autismguide): This provides a link to the Autism Resource Guide. The purpose of the Autism Resource Guide is to help families who have a child with an Autism Spectrum Disorder (ASD) understand and access needed services within a very confusing and complex system. It is an effort to identify and organize the most useful information about autism resources/services available primarily to families in Anoka and northern Hennepin County. This Autism Resource Guide was developed by a collaborative work group that included parents, advocates, and professionals from Education as well as County Social Services and Public Health.

[www.autismawarenessonline.com](http://www.autismawarenessonline.com): Another online resource that provides information about local resources. There is also an autism message board, and links for articles or books about autism.

### **Emotional Support:**

If you suffered emotional distress from discussing your practice with children who have autism, please call any of the following counseling centers:

Boone Counseling Services 314 Clifton Ave Minneapolis, MN 55403 612-454-9799

Transitions Counseling Services 1500 Golden Valley Rd Minneapolis Mn 55411 612-296-1514

Hennepin County Mental Health Center 1801 Nicollet Ave Minneapolis, MN 55403 612-347-5770

Associated Clinic of Psychology 3110 W Lake St. Minneapolis MN 55416 612-925-6033

Nystroms and Associates 1900 Silver Lake Road Suite 110 New Brighton, MN 55112 651-628-9566