

5-2014

# First Generation Americans' Perceptions on ASD: A comparison of generational worldviews on services

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## Recommended Citation

Tejada, Samantha, "First Generation Americans' Perceptions on ASD: A comparison of generational worldviews on services" (2014).  
*Rehabilitation, Human Resources and Communication Disorders Undergraduate Honors Theses*. 21.  
<http://scholarworks.uark.edu/rhrcuht/21>

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First Generation Americans' Perceptions on ASD:

A comparison of generational worldviews on services

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Honors Thesis

April 11, 2014

Abstract

The purpose of this study was to understand why parents of different ethnicity do or do not seek services or follow-up with recommendation for services for children with autism. Data was collected using an electronic questionnaire. The questionnaire asked demographic information about their family's cultural roots; the age of diagnoses and available services for a child with ASD; and worldviews on health and services for children with ASD, which was distributed via social media. A total of 26 individuals began the questionnaire but only thirteen complete it. A comparison was made between first generation American parents, those who come from families that have long been Americans, and mainstream Americans who have children on the autism spectrum. There is no clear ethnic difference on why parents do or do not seek services for children with autism. The emotional reactions to the diagnosis didn't vary from a mainstream immigrant, regardless of ethnicity: it was upsetting to all.

First Generation Americans' Perceptions on ASD: A comparison of  
generational worldviews on services

Autism is everywhere in the United States. It is depicted on television, in the movies and books, and blogged about on websites that connect to self-depictions on YouTube. These many sources report that now in the US one out of every 88 children are diagnosed as being on the autism spectrum (ASD). Websites (Asperger's Syndrome, Autism Society) as well as research reports (Wolters Kluwer Health) have conversed on the importance of early intervention to promote the best future for these children. From this, it would appear that many children have ASD and are getting services. However, this is not necessarily the situation at the community level in the US and certainly not in other countries around the world. For example, in areas of South Korea there are families of children with developmental disorders that will go to great lengths to avoid their child from being diagnosed with autism. They believe that having a child with autism is a "mark of shame" and a burden to the family. If these families are trying to avoid diagnosis they are most definitely not attempting to get services for their children.

Doctor Mayada Elsabbagh says "a global approach to understanding autism is not a choice, but a necessity" (as cited in Hughes, 2011). To truly help individuals of different ethnicities who are in need of services for autism, it is necessary to understand the role that worldviews have in their decisions about how to approach the problem. A global perspective is essential even in the US since immigrant families bring with them their worldviews on health, education and conditions such as ASD. They may come from countries that seldom talk about ASD and do not have many support services for families and children with this condition so they do not have a frame of reference for services. Their worldviews may be passed on to their

children during childhood so when first generation Americans (grown children) of these immigrants have children of their own, they may have similar or divergent perspectives about seeking services for ASD. Little is known about the ways that worldview change over generations of immigrants. What is known is that one out of 88 children of new, first generation Americans, and Americans who have lived here many generations are at risk for ASD. The worldviews of Americans who have lived here many generations versus those who are first generation Americans and their extended families might differ considerably and lead to diverse decisions about services for children. This study sought to investigate the impact of the worldviews and culture of first and long-standing American families on the recognition of and need for services when a child is identified as having ASD.

### **Review of the Literature**

This literature review will discuss Autism Spectrum Disorders (ASD), including the new DSM-V changes to the spectrum. Having a child with a developmental disorder also brings along parent concern. The review of literature will discuss some of those concerns that are normal for a mother or father, as well as ways to help them cope and learn how to help their child who has been diagnosed with ASD. In addition, the review will include how a speech language pathologist (SLP) can aid families who have children diagnosed with ASD, more specifically talking about the SLP's scope of practice pertaining to counseling. The prevalence of ASD globally and the reasons for different rates among different cultures will be included. Also covered is the impact of worldview on health and how it can affect the benefit of the child in relation to receiving the best services available.

## **Autism Spectrum Disorders**

Autism Spectrum Disorders (ASD) are “life-long neurodevelopmental disabilities with onset before 36 months characterized by impairments in reciprocal social interactions, impairments in verbal and non-verbal communication skills, and stereotyped behavior, interests, and activities (Autism Spectrum Disorders)”. ASD manifests within the first three years of life, characterized by abnormality of brain development and function. Although the causes are not known, there has been research shown that genetic factors and medical conditions can be some causal factors related to the diagnosis of ASD. (Autism Spectrum Disorders).

## **DSM-V released- Changes to autism**

The DSM-IV had ASD separated into three categories of diagnosis: autism, Asperger’s syndrome, and pervasive developmental disorder- not otherwise specified. The new DSM-V released in the summer of 2013 combined these disorders into one single spectrum, autism spectrum disorders. The reasoning for combining these disorders is due to the inconsistency of diagnosis between the categories.

There were several changes made to the DSM. The first main change is that childhood disintegrative disorder was eliminated for it was not being used as a diagnosis. A specific age in onset was added. Symptoms must be apparent as a child, even if they are not identified until later in life. Also, there were three diagnosis criteria and now there are only two, combining social and communication criteria into one, and the second criteria being restrictive repetitive behavior. The last major change is the inclusion of a number of specifications. A clinician will diagnose an individual with ASD, a single spectrum, but will have significant individual variability by including severity of symptoms, age of onset, type of onset, any intellectual and

verbal impairment, and what disorders are associated. Changes were made to help diagnosis of autism be more consistent amongst clinicians. (Swedo, n.d.).

### **Global Prevalence of ASD**

Diagnosis may be more reliable thanks to the changes in the DSM, but there is still a huge difference in prevalence rates across the globe. Studies have shown that prevalence rates vary from state to state and country to country. For example, in Cambridge, United Kingdom autism has a prevalence rate of 94/10,000 compared to Haifa, Israel which has a prevalence rate of 10/10,000 (Hughes, 2011). There are several factors that contribute to varied frequency of autism. First, it is important to keep in mind that individuals with the disorder who have not come in contact with services are undiagnosed and therefore not accounted for as cases in these prevalence studies. There are few studies that have been conducted that use a sampling technique that can guarantee reportage of close to the entire target population. (Hughes, 2011)

Additionally, some countries do not have the awareness and/or availability of services to make these diagnoses. Studies have also shown that some minorities may not have as much access to services. In trying to determine these differences in rates among immigrants and nonimmigrants a recent study was conducted in the Netherlands. The study found that minorities certainly were underrepresented cases in being referred to autism institutions, and it was also found that there was bias among “clinical judgment” that could help account for the underrepresented population. (Global prevalence of Autism and other pervasive developmental disorders)

Studies and surveys conducted by the CDC in the United States determined that rates were lower in areas that relied solely on health sources to make diagnoses compared to areas that

had access to educational records, etc. as well. These studies also found that white children have a higher prevalence of diagnosis than Hispanic and black children. It is highly unlikely that one group is affected by autism more frequently than the other. But as stated before, availability of services as well as socioeconomic status can account for some of the difference between racial groups. (Global prevalence of Autism and other pervasive developmental disorders)

It is clear that some countries have more awareness and services available to individuals with this neurodevelopmental disorder than others. There are groups and agencies who are trying to globally spread awareness and make more services available. But with that being said, it is up to the parents to seek these services for their child.

### **Parent Concern/ Involvement**

No matter what city or country, parents can express a lot of emotional stress when they first find out their child is diagnosed with ASD. When the life style of a mother and/or father go from taking care of a “typically developing child” to a child with ASD they are overcome with anxiety. Parents of these individuals need to cope and adjust to this new life their child and family will be living. However, it is not bad and they are not alone. Parents need to be informed about this disorder and need to be given resources to help them and their families in the best possible way. Ideally, parents should be involved in counseling and support groups to interact with families transitioning into the same lifestyle. In some countries parents simply don't have this information available to them and therefore they cannot have their child assessed, diagnosed, and enrolled in early intervention.

Studies have shown that family support is an important factor in having successful intervention and outcomes for a child with ASD or any learning disability (LD) for that matter.

A study was conducted on family support of children with ASD/LD versus family support of typically developing children. This study observed 33 parents of children diagnosed with AS and 43 parents of children diagnosed with a language disorder, compared to 45 parents of typically developing children. Results showed that families with typically developing children had the highest family support. (Heiman & Berger, 2008) “A child with special needs has significant effects on family functioning and on family relationships, and may create some changes in the family's routines. Parents of a child with special needs experience a larger number of care giving challenges such as more health problems, greater feelings of restriction, and higher levels of parental stress or depression, than parents of children without specific disabilities.” (Heiman & Berger, 2008, p.291) This shows how pertinent it is to receive support from family, and unfortunately those who need it the most (children with disabilities) receive the least amount of care.

### **Positive and Negative Cultural Views**

Family is so important to help the future of a child with a developmental disability, but it is clear that different cultures can have different opinions and views on intervention as well as treatment for children with disabilities. It is important to be respectful of all cultures, but it is also important to make sure every child, no matter their culture, has the opportunity to receive services/treatment that will only improve their life. Parents of a child diagnosed with a disorder on the spectrum are the ones who are responsible for getting their child assessed and into early intervention, and therefore are the ones who need to be educated and informed about this disorder. Not only does it become a hardship to diagnose due to lack of tools and services, but the views of the parents play a major role as well.

Samadi and McConkley (2011) conducted a study in Iran where 43 parents of children with ASD were interviewed. This study found that 12% of parents had no idea what the causes of ASD were or they simply didn't care about what the causes were. They found that in several nonwestern countries "the attribution of disability to sins or immoral deeds committed by the afflicted person's family or even ancestors leads to cultural shame and the blaming of family members and individuals with disabilities, thereby threatening the cohesiveness of the family unit" (Samadi & McConkley, 2011, p.4). There are numerous Americans that would be outraged at this idea but one reason parents would have this critical view on disabilities is due to limited access to information about ASD and other disabilities.

Other countries have taken great strides in developing awareness and services for individuals with ASD, such as the Netherlands. In 1998, the Netherlands developed The Growing Minds Program. "Growing Minds guidance programs focus primarily on helping children with Autism Spectrum Disorders to overcome limitations and impairments affecting their social independence, behavior and psychosocial functions (Autism Programs in Netherlands)". They assess each individual to determine their varying strengths and weaknesses and provide each child the most appropriate intervention to develop and improve their quality of life. There are plenty of countries like the Netherlands that provide accurate information and services to those in need.

Clearly the views of ASD immensely differ from culture to culture. In some countries it is a shame to the family to have a child on the spectrum compared to some countries where companies specifically seek employees with Autism. For the past decade, European countries including Denmark, England, Ireland, and Germany have been training workers with ASD and

sending them to tech companies. The United States is now beginning to follow this initiative. A recent statistic was released stating that by 2015 three percent of Computer Aid Inc., Delaware Valley's largest IT consulting company's employees will be individuals with ASD. Ernest Dianastasis, the company's managing director says, "This move is not about advocating for the rights of the disabled, it's about bringing highly skilled people, who have often been overlooked, into the corporate world" (Kendall, 2013, p.1). This shows that the benefit of the child could be at risk depending on what culture they are brought up in. Early intervention is essential to be able to give a child the most independent and prosperous life they could possibly have.

### **NOMS: Stages of intervention**

Early intervention can begin for a child from birth-three years of age. Symptoms of autism can be noticed as early as twelve months of age, and the disorder can be reliably diagnosed by eighteen months of age. Statistics show that between 25-50% of children receiving early intervention are mainstreamed into general education by Kindergarten. (Stephens)

In the 1990s ASHA developed the National Outcomes Measurement System (NOMS) to provide SLP's with a voluntary data collection service for the outcomes of their clinical services to children and adults. The first component of NOMS is Pre-Kindergarten. The child must be from ages three-five and cannot be enrolled in Kindergarten. Once admitted the child will begin intervention/treatment, and be re-evaluated each year. Once a child is discharged they may no longer need services and will then begin Kindergarten, or they can be admitted into the next component of NOMS which is Kindergarten-12. When admitted and/or discharged SLPs will enter information into the system stating the changes in the client's communication, which then goes into a large database. The final component of NOMS is adults. Once a child is discharged

and graduated from school, they become an adult and must be transitioned into the workforce. NOMS uses a Functional Communications Measure (FCM), a seven point scale, to describe the individuals' changes over time. The SLP's participating in this service then have access to all data collected. The data collected through NOMS has come to show the importance of services provided by SLPs. (Mullen & Schooling, 2010)

### **Counseling**

Counseling can be defined as “an interpersonal relationship that is intended to alleviate emotional stress arising from or contributing to the primary communicative disorder” (Roth & Worthington, 2011, p.360). Counseling is a very important part of the therapeutic treatment. It allows for clinicians to inform parents and clients on the disorder, helps clients share their emotions and fears, and also helps for the client to begin making behavioral changes. Roth and Worthington believe counseling develops through three phases: establishing the therapeutic relationship, implementing counseling intervention, and terminating the therapeutic relationship. The first stage of counseling involves providing adequate information to the client and family. However, it is also important to adjust what you share with them, since some families may only be able to handle a certain amount of information. For parents, it can be very overwhelming to hear all this information in an already fragile state. The second stage shifts from informative to a “problem-solving orientation”. The clinician needs to listen and observe the client to find what causes their bad behavior and how to control it. Finally, in the last stage the clinician will prepare the client to “become his or her own therapist”. It is the clinician's role to assist the client in developing responsibility for their behavior and decision but in this final stage, it will

now become the responsibility of the client to maintain the progress made through therapy and keep their behavioral changes. (Roth & Worthington, 2011)

### **Speech-Language Pathologists' Scope of Practice**

There are guidelines as to what speech language pathologists are and aren't allowed to do within their profession, also known as their scope of practice. ASHA's scope of practice for SLP's states that an SLP must provide services to individuals with a pragmatic or social communication disorder, which would include individuals with ASD. SLP's play a major role in screening, diagnosing, and improving social communication development for individuals with ASD. The SLP is also required to support the individual, the environment, and the communication partner to help the individual overcome obstacles and social isolation. (American Speech-Language-Hearing Association)

One really hard responsibility SLP's are faced with is telling a family that their child has been diagnosed with a life-long communicative impairment. The families will usually immediately feel a sense of loss. This comes from the loss of the idea of having a typical child, and a typical life. Clinician's should be aware of this and remember that families may show mixed emotions through therapy. Some common reactions parents have are grief, anger, depression, guilt, shame, anxiety, inadequacy, and isolation. (Roth & Worthington, 2011)

As discussed earlier, along with a child being diagnosed with ASD, comes parent concern. It is in the SLP's scope of practice to help the families with assessment and intervention. Family involvement and support is crucial for a client to receive the most proficient therapy. ASHA states "Speech-language pathologists should provide counseling, education and training, coordination of services, and advocacy for families" (American Speech-

Language-Hearing Association). It cannot be emphasized enough on how important it is for families to do all they can to help their child not just in therapy, but at home as well. Many parents just want to leave it to the “professionals” to help or fix their child, however when dealing with ASD that is not enough. Family interaction can begin in therapy, for example floortime. This is when the client is having play time on the floor, and the parents join in or bring any siblings to join and interact with the client while they are in therapy. This will help to build relationships involving affect and emotion. Ideally families will also practice activities they learn in therapy at home as well. But this is not all up to the family. The clinician should also help the family by giving them homework or assignments that they can be working on outside of therapy and/or at the home.

### **Worldview in health**

Ideally, all children would have the opportunity to be involved in early intervention and receive all the services available to them. But as we now know, all cultures do not have the same set of beliefs or assumptions. Worldview is defined as “philosophy of life that answers all of the most fundamental questions of human existence” (Tilburt, 2010, p.S178). It something that has been used in social science literature but has not been studied as much in the perception of human health, even though it is just as important. As hard as it may be to consider worldview, health professionals must be educated on this topic so they can effectively communicate with patients from populations all over the world who may not share the same worldview as the professional. “It is one thing for a health professional to know that a patient or family holds many unfamiliar beliefs, it is another thing to appreciate the mentality and the mindset that those beliefs create” (Tilburt, 2010, p.S179). This can also help to explain why health professionals

such as doctors have a higher ratio of patients that are of the same race as them. A patient would prefer to go to a doctor who has the same worldviews as them. This is why it becomes so critical to train new health professionals to be conscious of worldview to reduce discrepancy that occurs in the health profession so often today.

When a parent first finds out their child has a disability and is formally diagnosed with a developmental disorder, they go through many emotions. The majority of these families will not know any or not know an adequate amount of information on the disability of their child. It becomes the responsibility of the clinician or SLP to inform the families about the disorder and let them know about the loads of resources out there for them to utilize. It is important to understand that all families may have a different worldview than the professionals of the health care field. It then becomes the responsibility of the professionals in the medical field to appreciate the views of each family and help them to participate in understanding what is available and what the best services are that can be provided to their child.

A more refined yet little studied aspect of culture and worldviews on health, including disorders such as autism, is significant as well. Two generations of culture beliefs emerge when parents immigrate to the US. As identified in this literature review, each culture has a vast variety of beliefs. Long-standing Americans whose parents, grandparents, and so forth have all grown up in the US could have contrasting beliefs to first generation Americans, whose families and ancestors have all been raised in the US.

### **Summary and Questions of the Study**

As can be seen from this review of the literature, autism is a disorder that occurs in countries around the world yet the incidence of the disorder as well as the perceived need for

services vary greatly. This supports the idea that beyond just the identification of autism as a category of disorder, there are culturally linked worldviews that impact how autism and the need for services are understood. Because immigrants who come to the US bring their worldviews with them and pass these on to their children even as these children live as first generation Americans, perspective on autism and the importance of services may be acted on differently by these groups. Contrasting the perspective of long-standing American parents of ASD children with those of first generation American parents may provide different views that can help speech-language pathologists better understand the link between worldviews, acceptance of diagnosis, and value of services. The specific questions of the study are as follows:

1. Are there generational differences in acceptance ASD diagnoses?
2. Are there generational differences in acceptance and use of services?
3. Are there cultural differences in acceptance ASD diagnoses?
4. Are there cultural differences in acceptance and use of services?

## **Methodology**

### **Participants**

Fifty participants who are parents of children diagnosed with ASD were sought for this study. There was no control for age of the children, social-economic background or ethnicity.

### **Materials**

An electronic questionnaire was developed from the literature. This included a demographic section that provided information about family constellation and background; a section that described the child with ASD and that information sought about the diagnosis and use of follow-up services; and a final section on worldviews and cultural values.

## **Procedures**

The electronic questionnaire was made available through social media outlets. A link was used to bring possible participants to the study where it and implied consent were described prior to actual access to the questionnaire. Individuals who decide to participate clicked on the link and then if they wished to proceed, clicked on the questionnaire. The responses of individuals were not identifiable or traceable by the researcher. Results from the questionnaire were automatically uploaded into the electronic data base that is part of the electronic survey service.

## **Analysis**

The items from the questionnaire were paired with questions of the study for descriptive analysis.

## **Results**

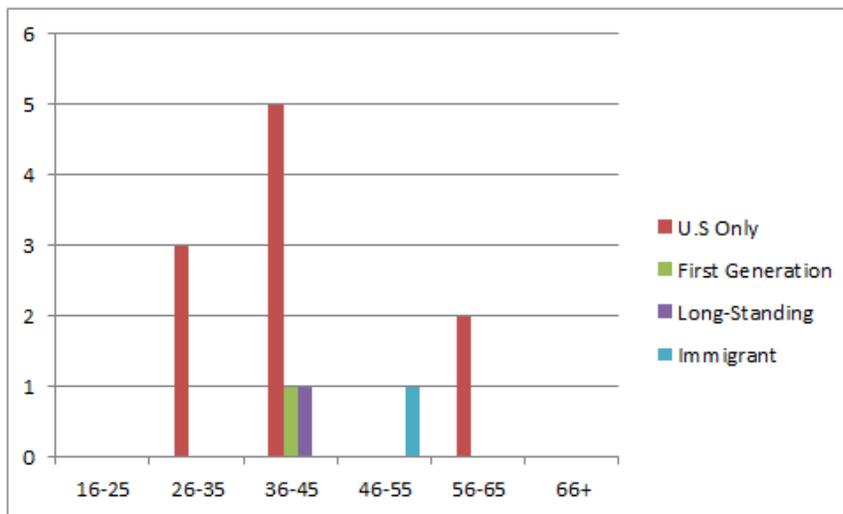
### **Demographics**

Items one through five of the questionnaire were used to describe the participants who took part in this study. A total of 26 individuals began the questionnaire but only 13 completed it. Table 1 illustrates the total number of participants who answered some items as well as those who answered all items by age ranges as well as generational standing. Ten participants were from the U.S. with no identified ethnicity. This group was not expected as participants but are included in the analysis to frame the responses of the other respondents and referred to as mainstream Americans. As illustrated in Table 1 participants of ethnic background included one participant was a first generation American from European decent, one participant was an immigrant from Sri Lanka, and one participant was a long-standing American from Mexican

decent. Three participants ages 26-35 were all from the U.S. There were seven participants ages 36-45, five were from the U.S. only, one was a first generation American, and one was a long-standing American. There was one participant at age 46-55 who was an immigrant, and two participants ages 56-65, both were from the U.S. only (see Table 1).

**Table 1**

*Age and Generation of Participants*

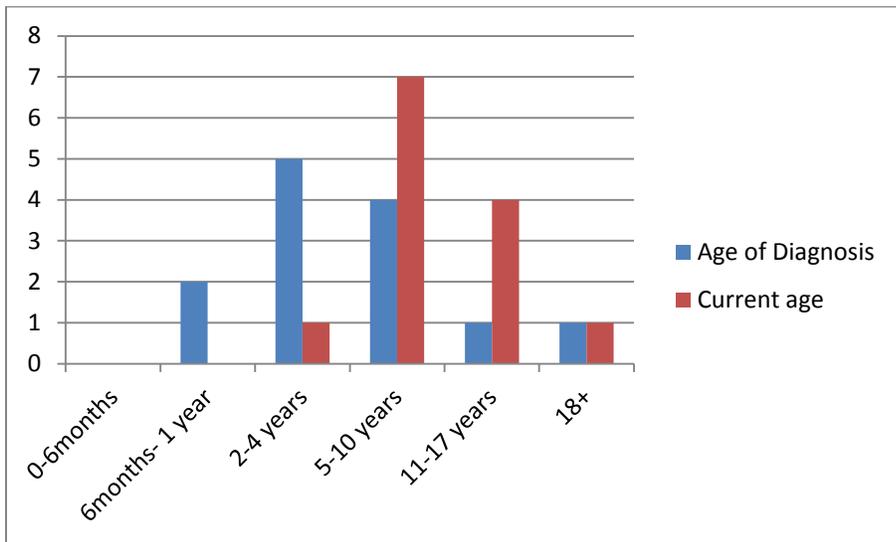


**Description of the Children reported with ASD**

Items six, seven, and eight of the questionnaire were used to describe the child diagnosed with ASD. The most common age of diagnosis was 2-4 years, with five participants. There were two participants whose child was diagnosed with autism at ages 6 months-1 year, four participants at 5-10 years, one participant at 11-17 years, and one participant at 18 years or older. No participants selected that their child was diagnosed before six months of age (see Table 2).

**Table 2**

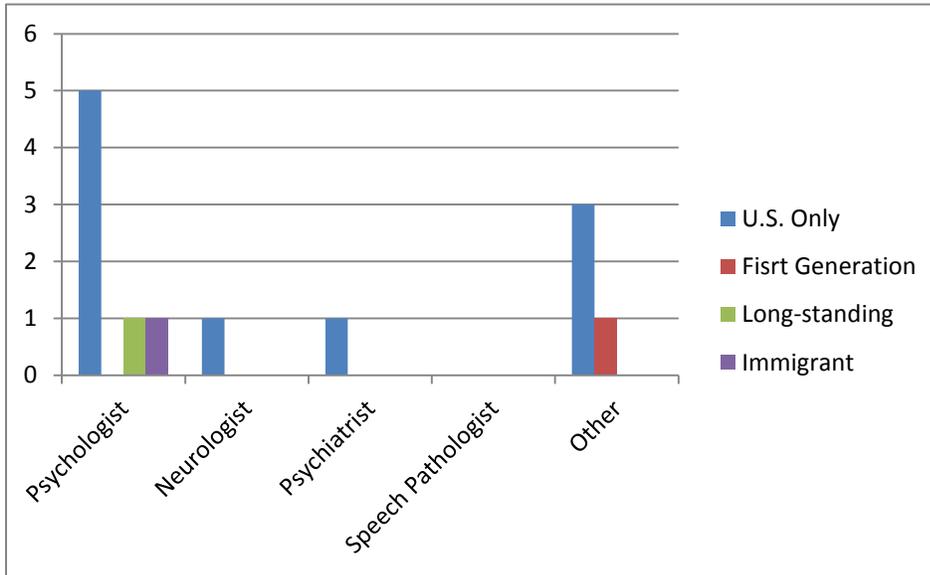
*Current Age and Age of Diagnosis*



The majority of participants (7) selected that a psychologist diagnosed their child with autism. One participant indicated that a neurologist made the diagnosis, one participant listed a psychiatrist, no one selected a speech pathologist, and four participants selected “other”. The participants are categorized by the professional who made the ASD diagnosis, as well as the participants’ generational standing in Table 3.

**Table 3**

*Professionals who made the Diagnosis*



**Question One**

The first question of this study asked if there were generational differences in the acceptance of ASD diagnoses. The demographics, description of diagnosed child, as well as item nine of the questionnaire were used to answer this question. Out of the thirteen participants, ten were mainstream Americans, one participant was a long-standing American from Mexican decent, one was a first generation American from European decent, and there was one immigrant from Sri Lanka. After hearing their child was diagnosed with ASD the immigrant from Sri Lanka felt “disappointed”, the first generation American felt “like I was experiencing the death of my child”, and the long-standing American felt “shocked, saddened, surprised, and fearful for his life”. There were varying responses among the remaining participants that were from the U.S. only. From the data collected there seemed to be little generational difference in the acceptance of ASD diagnosis.

Due to the lack of diversity and abundance of respondents from U.S. only this question was also analyzed by generations of ages. Results showed that the majority of the participants ages 26-55 years (11) felt sad, disappointed, surprised, overwhelmed, lost, angry etc. when they found out their child was diagnosed with ASD. However, the remaining two participants, ages 55-65 years both expressed that they felt “relieved” after the diagnosis. Out of these two participants one has a child age 5-10years who was diagnosed in the same age range (5-10), and the other participant has a child eighteen years or older, also diagnosed in the same age range (18+) (see Table 2). There is a wide-ranging age gap between the two children and the age of their diagnosis, yet both parents had a feeling of relief when the diagnosis was made. From these responses it can be reputed that there is a generational age difference in the acceptance of ASD diagnosis. The older generation (56-65) had a more positive response, while the remaining age groups (26-55) expressed a more negative reaction.

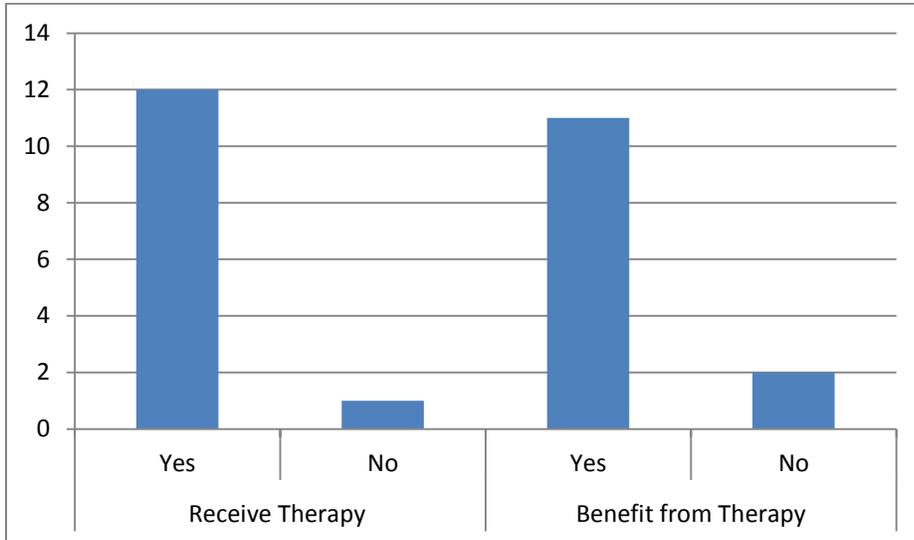
### **Question Two**

The second question of study asked if there were generational differences in the acceptance and use of services after a diagnosis was made. The demographics, description of diagnosed child, as well as items ten and eleven of the questionnaire were used to answer this question. Of the thirteen responses, twelve participants stated their child received therapy services. Only one participant, a mainstream American, did not use therapy or services (see Table 4). Out of the thirteen responses, twelve participants believed the therapy provided was beneficial to their child. Only one of the participants, a mainstream American, (excluding the participant that did not receive services) did not accept or find the therapy/services to be helpful to their child (see Table 4). From these results there was not a generational difference in

acceptance and use of therapy/services but again there was not an adequate amount of diversity in the sample to fully make this assumption.

**Table 4**

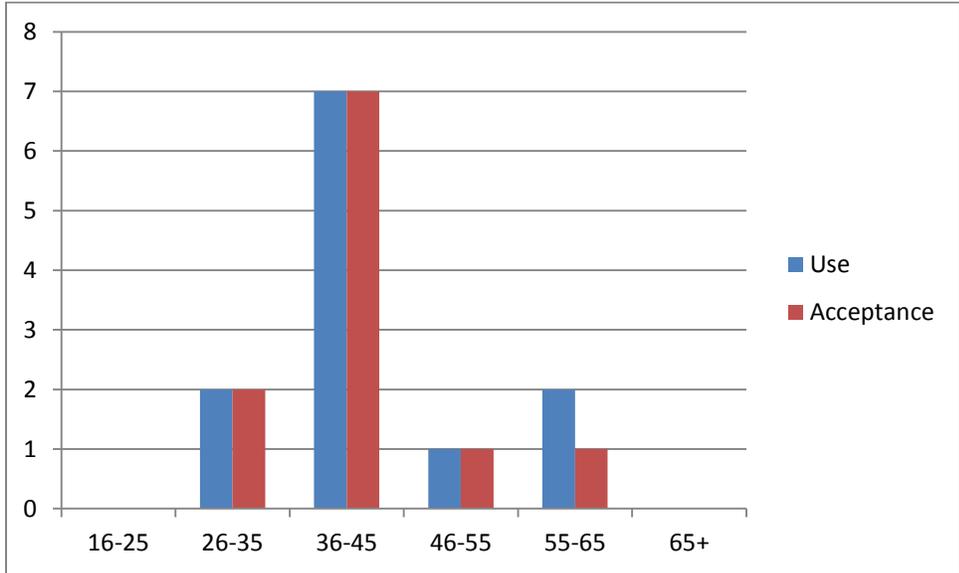
*Receive/Benefit from Therapy and Services*



Due to the lack of diversity, generational information was used to address the second part of the study question. Only one participant in the 26-35 age range responded that her 11-17 year old child has not or does not receive any therapy or services. Out of the twelve participants that stated their child did receive therapy and/or services, eleven believed the services were beneficial to the child. One participant in the 56-65 age range believed that her 18+ year old child did not benefit from any therapy that was received. This could have corresponded to the fact that the child was over the age of eighteen, but not enough data was collected to make that assumption. Results do not show a considerable difference between generations of ages in the use or acceptance of therapy/services. (see Table 5)

**Table 5**

*Relationship between Generational Age and Use/Acceptance of Diagnosis*



**Question Three**

The third question of study asked if cultural difference impacted the acceptance of ASD diagnoses. The demographics, description of diagnosed child, as well as item nine from the questionnaire were used to answer this question. As mentioned earlier, the first generation American, long-standing American, and immigrant all had negative reactions to their child being diagnosed with ASD, all of which varied little from the reactions of the mainstream Americans. Referring to Table 3, there was no significant cultural difference in who diagnosed the children with ASD. Both the immigrant and long-standing American went to or were referred to a psychologist, and the first generation American selected “other”. There was not enough data collected to determine if the difference in who made the diagnosis had an effect on the participants’ acceptance of the diagnosis. The first generation American had the most negative tone out of all responses. This could have been related to the participant’s culture or to what

professional diagnosed their child, however not enough data was collected to make this inference. It was also noted that the immigrant listed a negative one word response, the shortest out of all responses, where the long-standing American elaborated on their reaction. From these results there was not a significant difference in cultural acceptance of ASD; however there was found to be a difference in the degree of their emotional reactions.

#### **Question Four**

The last question of this study asked if there were cultural difference in acceptance and use of therapy/services after a diagnosis was made. The demographics, description of the diagnosed child, as well as items ten and eleven from the questionnaire were used to analyze this question. As stated in Table 4, only one participant did not have their child receive therapy or services. This participant was a mainstream American, she mentioned on the questionnaire that her daughter is Ethiopian and adopted. There was not enough information gathered to determine if the ethnicity/culture of the adopted child had any part in why she did not receive therapy/services. Only one participant, also a mainstream American did not believe therapy was beneficial to their child. The first generation American, long-standing American, and the immigrant put their child in therapy and they all felt it was valuable for their child. From these results it can be inferred that there were no cultural differences in the use and acceptance of therapy and/or services after a diagnosis is made.

#### **Discussion**

This study sought to understand if and if so, why parents of different ethnicity do or do not seek services or follow-up with recommendation for services for children with autism. As can be seen from the results of this study there is no clear ethnic difference on why parents do or

do not seek services for children with autism. Who participated in this study is probably the most striking aspect. A large number of respondents that were from the U.S. only and few respondents were of ethnicity. It cannot be determined from the data if people of ethnicity did not respond because of the way the questionnaire was delivered or if they are less willing to talk about their children to unknown individuals. In addition, over half the participants were middle-aged adults, ages 36-45, with few participants at the other ends of the age spectrum (see Table 1). Since younger individuals tend to use social media more and are more likely to be parents, it was anticipated that those below age 30 would contribute a good deal of information. Again, this pattern of response cannot be explained from the data collected. With regards to the diagnosis of autism, both the age that this occurred and the emotional reaction were striking. Specifically, there was a wide range of diagnosis age starting from six months to eighteen years or older (see Table 2). The emotional reactions to the diagnosis didn't vary from a mainstream American to an immigrant etc. However, results did show that the age of the adult made a difference in their emotional reaction to the diagnosis. This was most clearly seen in the split between the two participants ages 56-65 who had a more positive reaction as compared to the more negative responses from the remaining age groups 26-55.

From the literature, it was expected that the participants of ethnicity responses' would differ from the mainstream American responses (Global prevalence of Autism and other pervasive developmental disorders). One point that can be looked at is the comfort level of mainstream Americans versus those of ethnicity. People of ethnicity may not feel as comfortable talking about autism or their child with autism, and therefore are not as willing to participate in the questionnaire. Subsequently, there were very few respondents of ethnicity. The participants

of ethnicity that did respond were also not as open and willing to share their feelings as several of the mainstream Americans were. The literature explains that in many cultures, parents are ashamed if their child is diagnosed with autism or they simply don't want to accept the diagnosis (Samadi & McConkley, 2011). If this were the case it becomes more unlikely that these people would take part in a questionnaire discussing personal information about their child. After analyzing the mainstream Americans as a culture group, data implicated that they are the ones who do not seek services or do not feel the services provided are beneficial to their child. The differences on the perception of ASD and acceptance/use of services lie within the mainstream American population.

There are early intervention services available for parents and their children. The health professionals that provide a diagnosis should inform parents of early intervention services available to them (American Speech-Language-Hearing Association). It is presumed that the younger generations have been exposed to and are educated about autism and therefore more likely to seek services, when in fact there were no participants ages 16-25 and the one participant that did not seek services was age 26-35. Stephens (n.d.) conducted a study that exemplified how pertinent early intervention is to a child's academic success. Symptoms can be noticed as early as twelve months, and a child must be between ages three and five to be enrolled in the first component of early intervention. There was no diagnosis made at 0-6 months which agrees with the literature because that is too early for symptoms to be noticed. However, six of the thirteen children were not diagnosed early enough for beginning stages of early intervention. Four participants' children were ages 5-10 years, one was age 11-17 years, and one was eighteen or older (see Table 2).

From the literature (Heiman & Berger, 2008) it could have been predicted that all emotional reactions of the diagnosis would be negative, and even perhaps more negative for participants of certain ethnicity (Samadi & McConkley, 2011). Results showed that emotional reactions did not have much variation between ethnicities; however there was variation in reactions amongst the different age groups of participants. As noted in the results, the two participants ages 56-65 were both “relieved” to hear their child was diagnosed with autism. The issue of parental age of children diagnosed with autism is missing from the research literature. Certainly, these results while based on a limited sample do suggest that there may be relief in finally getting confirmation that something is different with one’s child.

### **Limitations of the Study**

The main limitations of this study were the limited number of participants and the lack of diversity of the sample. Only thirteen participants took the questionnaire, and out of those responses only three different cultures were touched on. There was also not enough variety in the ages of participants. There were not any participants in the youngest or oldest age group. Another limitation was the questionnaire itself. After reading some responses it was clear that some participants did not understand the content of the question or type of answer that followed from the questions. It cannot be determined if this lack of question clarity, the use of electronic media, or discomfort with the topic resulted in the high rate of partial responses to the questionnaire, incomplete. Lastly, some items turned out to not be very precise, for example an age group was selected instead of the exact age, which limited the way the questions could be answered.

### **Future Directions**

This study can be viewed as a first step into an important issue. As such, it gives direction to future research. To provide for better study data future research should be collected face to face. This will eliminate misunderstanding of the questions asked and give opportunity for follow up questions to receive more thorough answers. Interviewing will also allow the results to be more personable. Participants will be sought out based on the required demographics and their willingness to share their views on ASD, creating more diversity of the sample. The questions asked will be less generic and vary from person to person as to better understand their individual views. An interview guide will be used instead of a questionnaire to allow for secondary questions, leading to more descriptive and subjective results.

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## **Appendix A**

### ASD informational survey

I am a student at the University of Arkansas researching the perspective of long-standing American parents and first generation American parents, both whom have children with ASD, on the acceptance of diagnosis and value of services. I hope to better understand the effect of culture on worldviews pertaining to autism.

1. What is your age?
2. Where were you born?
3. Are you the first family member to be born/raised in the United States?
  - A. Yes
  - B. No
4. Where were your parents born?
5. Where were your grandparents born?
6. How old is your child diagnosed with ASD?
7. How old was your child when diagnosed with ASD?
8. Who diagnosed your child with ASD?
9. Explain any reactions or emotions felt when your child was diagnosed with ASD.
10. Did your child receive any therapy/services? If so, what type and for how long?
11. Do you feel like the services provided were beneficial to your child?
  - A. Yes
  - B. No

November 22, 2013

MEMORANDUM

TO: Samantha Tejada  
Fran Hagstrom

FROM: Ro Windwalker  
IRB Coordinator

RE: New Protocol Approval

IRB Protocol #: 13-11-279

Protocol Title: *First Generation Americans' Perceptions on ASD: A Comparison of Generational Worldviews on Services*

Review Type:  EXEMPT  EXPEDITED  FULL IRB

Approved Project Period: Start Date: 11/22/2013 Expiration Date: 11/21/2014

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Your protocol has been approved by the IRB. Protocols are approved for a maximum period of one year. If you wish to continue the project past the approved project period (see above), you must submit a request, using the form *Continuing Review for IRB Approved Projects*, prior to the expiration date. This form is available from the IRB Coordinator or on the Research Compliance website (<http://vpred.uark.edu/210.php>). As a courtesy, you will be sent a reminder two months in advance of that date. However, failure to receive a reminder does not negate your obligation to make the request in sufficient time for review and approval. Federal regulations prohibit retroactive approval of continuation. Failure to receive approval to continue the project prior to the expiration date will result in Termination of the protocol approval. The IRB Coordinator can give you guidance on submission times.

**This protocol has been approved for 50 participants.** If you wish to make *any* modifications in the approved protocol, including enrolling more than this number, you must seek approval *prior to* implementing those changes. All modifications should be requested in writing (email is acceptable) and must provide sufficient detail to assess the impact of the change.

If you have questions or need any assistance from the IRB, please contact me at 210 Administration Building, 5-2208, or [irb@uark.edu](mailto:irb@uark.edu).