Monolingual and Bilingual Development and Autism Spectrum Disorder

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Bilingual and Monolingual Language Development and Autism Spectrum Disorder

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ABSTRACT

The number of individuals with autism spectrum disorder (ASD) from bilingual families continues to increase. With 1 in 88 children receiving a diagnosis of being on the autism spectrum, it is important to expand upon current research. This present research study surveyed caregivers regarding their perceptions and experiences of raising a child on the autism spectrum in a bilingual language environment. Information on how families are counseled regarding bilingualism and language development in ASD is limited. Caregivers often find themselves receiving conflicting advice from professionals about whether or not to incorporate bilingualism into the life of their child with ASD; they expressed a need for more information and support. Four common themes resonating through parent responses in this study included feelings of (1) confusion and (2) hesitation, and experiences with (3) inconsistent advice or (4) their child with ASD not having the language capabilities to speak an additional language. A survey was sent to approximately 125 Autism Society of America chapters through email, as well as a few other organizations related to autism and bilingualism. The concern of parents reinforces the pertinent need for continued research for children with ASD who are in bilingual (and multilingual) language environments.
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INTRODUCTION

Autism Spectrum Disorder:

Autism spectrum disorders (ASD), also known as pervasive developmental disorders, are complex development disabilities involving a range, or spectrum, of severity with impairments in social interaction, communication, and behavior. Some parents of children with ASD say they feel they start to see developmental problems around the child’s first birthday, but diagnosis is not commonly made at that time (CDC, 2012). As of the year 2012, children can be diagnosed before the age of 3, but are often not diagnosed until around age 4 (ADDM). There are five different disorders that fall into the autism spectrum in the current DSM-IV-R (American Psychiatric Association, 2000). In the upcoming revision to this document, DSM-5, the categories are simplified to the term autism spectrum disorder (ASD). This term will be used once it is published, expected later in 2013. In this document the term ASD will be used to conform to this new usage. Other terms were included in the survey, as those might have been familiar to the parents or used in their children’s diagnoses.

Autism involves severe impairments in social and language functioning and repetitive behaviors. Autism is five times more common in boys than in girls (CDC, 2012). There are several common characteristics of individuals with ASD. A child with autism may have difficulty relating to others and starting or in engaging conversations. He or she prefer solitude and like to stick to routines. Often when there is a disturbance to a routine or if there are additional unknown outside factors, he or she may react with repetitive movements such as hand flapping or rocking back and forth. Language delays are often present; sometimes individuals with autism are even nonverbal. With autism, senses may be atypically heightened or dulled, making it even more difficult to relate to their surroundings and other people (Mayo Clinic Staff,
Children with autism may also suffer from seizures and have intellectual disabilities (Autism Spectrum Disorders, 2012). Other disorders that can be associated with autism include Fragile X syndrome, Tuberous Sclerosis and intellectual disabilities (Autism, 2012).

At this time the cause of autism is unknown. It is speculated that the cause has both genetic and environmental roots as studies have revealed effects from both (Autism Fact Sheet, 2009). A variety of treatments have been tried but at this time there is no particular treatment that guarantees success, although some have proven beneficial in individual cases. Some treatments include diet adjustment (removing gluten and casein from the diet), Applied Behavioral Analysis (ABA), occupational therapy, physical therapy, speech-language therapy, Treatment and Education of Autistic and Related Communication Handicapped Children (TEACCH), and various medications to address symptoms of aggression, mood stability and irritability (e.g. risperidone and methylphenidate) (Autism, 2012).

Asperger syndrome is considered a mild form of autism, sometimes also referred to as a high-functioning autism. Asperger syndrome is often diagnosed when a child is older, around the age of 6 (CDC, 2012). A person with Asperger syndrome often has normal intelligence and language development but greater difficulty with social communication. There are several reasons why engaging in social interactions with others can be difficult (Autism Spectrum Disorders, 2012). For example, an individual with Asperger syndrome may resist changes in routine, have difficulty maintaining a conversation, have trouble picking up social cues, struggle to empathize with others, have unusual facial expressions or use an oddly formal or flat tone of voice. They may also only show high interest in one topic which would impact most of their conversations (such as zoo animals or cartoons) (Asperger Syndrome- Symptoms, 2010). As
previously noted, this disorder classification will be merged with the general term autism
spectrum disorders sometime in 2013.

The American Speech and Hearing Association (2006) states that, “the core features of
ASD include impairments in social communication . . .” which further highlights the importance
communication serves as a large role in the outcome of someone’s quality of life. Through
communication we express our wants, desires and basic needs. Notredaeme (2010) found that,
when studying individuals with pervasive developmental disorders, the most prominent concern
of parents which causes them to seek professional assistance is communication impairments,
followed by social interaction behaviors. The prominent role of communication in a person’s life
reinforces the critical need to address deficits and research outside influential factors.

Individuals with autism and PDD-NOS show signs of language regression or delay before
the age of three. The term “language regression” means that amidst typical development gradual
signs of skill deterioration begin to occur. Individuals with Asperger syndrome often show signs
of language delay after the age of three (if present). The official Autism Speaks website (2005)
offers a list of signs for parents to be aware of in the early years of their child’s development.
Their list states the following:

- No big smiles or other warm expressions (6 months or later)
- No interactive sharing of sounds, smiles, or other facial expressions (9
  months or later)
- No babbling (by 12 months)
- No interactive gestures, such as pointing, showing, reaching, or waving (by 12
  months)
- No words (by 16 months)
- No two-word meaningful phrases, without imitation (by 24 months)
- Any loss of speech or babbling or social skills at any age

Boucher (2003) presents other issues individuals with ASD may face concerning language development, including:

- Nonverbal communication skills (facial expressions, gestures, vocal prosody)
- Repetition (e.g. echolalia)
- Egocentric interactions (single-sided interest in communicative interactions)
- Expressive and/or receptive language difficulties
  - Individuals with autism show greater severity in receptive rather than expressive language abilities (comparison study between individuals with autism and individuals with developmental delays) (Weismer, Susan Ellis, Lord, Catherine & Esler, Amy, 2010)
- Oral or manual dyspraxia (neurological disorder of motor coordination)
- Trouble with word play (metaphors, irony, etc)
- Narrow, context bound mindset (struggle with the abstract)

The above factors may not be found in all individuals with ASD, and some individuals may display only a few difficulties while others exhibit several.

*Introduction to ASD and Bilingual Development:*

A less researched concern for language development for individuals with ASD is how the context of language development is affected by a bilingual or multilingual environment.

According to data in the US Census Bureau’s 2012 Statistical Abstract on population (2009) the number of people speaking a language other than English in their homes was recorded at 85,677,565 people. The United States is known as a country with rich...
Census Bureau’s national population projections, the United States is reported to be growing in racial diversity. Currently 20.6% of the United States population speaks a language other than English in their homes; 12.8% of them speak Spanish. Spanish is the most prevalent non-English language group in the US (Linton, 2004). Individuals with Hispanic origin are projected to increase while the non-Hispanic White population growth is expected to decrease. The Black, Pacific Islander, and Asian populations are all expected to grow exponentially, but the Hispanic origin population will be seeing the greatest growth overall. By 2015, the Hispanic origin group is expected to double their population from 1990, and from 2010-2030, Hispanics will have contributed to 45 percent of the nation’s population growth (US Census Bureau: Population Division, 2010).

With the projected growth in the multilingual population, the conclusion can be drawn that there will continue to be an increase of bilingual or multilingual family language environments. With a similar continuous increase being seen in prevalence of autism spectrum disorders, it is important to look at the potential implications of raising an individual with autism in a bilingual environment to assist both professionals and caregivers in providing evidence-based best practice.

When considering the perceived dominance of the English language in the United States, and globally, Merchant and Osterling (2009) suggest that English is no longer the sole language of business. The multilingual and multicultural identity of immigrants and citizens alike is becoming not only something to be embraced, but something sought after in our increasingly diverse nation and interconnected world. In the following section a brief historical outlook on bilingualism in the United States is discussed, followed by a more in depth look at bilingualism itself and current research concerning bilingualism and developmental delays and disorders.
History of United States Policy on Bilingualism:

Less than one hundred and fifty years ago, during the time periods of the Civil War, World War 1 and World War 2, bilingualism was viewed as a threat to national unity (Multilingual Mania, 2010a). During the times of increased immigration, especially around the World Wars, English was encouraged over minority languages. English was encouraged because (1) some immigrants were coming from racially distinct areas that were viewed as less, or lower, than Americans, (2) during the First World War the large German minority was not trusted and speaking German was considered disloyal, and (3) the economy during this time period provided few opportunities encouraging bilingualism (Garcia, 1984).

In 1839 Ohio was the first state to provide bilingual programs to help integrate non-native English speakers in public schools, though coming into the 1900’s there continued to be tension amongst the population concerning bilingualism (Multilingual Mania, 2010a). A summary of the history and attitudes of bilingualism and civil rights is available at Multilingual Mania: Cultivating a Multilingual World, a website that offers research, resources and information on multilingualism, bilingualism and multiculturalism. The summary discusses the hardships experienced by Native Americans as they were assimilated into the American lifestyle, their
children forced to learn and use English over their native language. Immigrants were required to learn English before becoming citizens after the passage of the Nationality Act in 1906. Just eleven years later, after the passage of the Burnett law, immigrants were also required to take a literacy test making the naturalization process even more difficult and culturally biased.

Garcia distinguished two different kinds of bilingualism that describe more specifically the outlook of bilingualism at this time. Natural bilingualism (second language learned naturally and incorporated into society) continued to be discouraged, though learned bilingualism (second language learning for individual enrichment, often in schools) was often encouraged (Garcia, 1984). Explanation for these feelings from US citizens rests in the effect the two have on the public. Natural bilingualism involves the opportunity of both languages (mother tongue and English) being used by the individual for personal as well as public matters. Natural bilingualism was typically countered with more anxiety and judgment from the general public. Learned bilingualism, being a private matter, was much less upsetting to the public and actually was even favored, seen as an opportunity to take part in international concerns (Garcia, 1984).

Another way of viewing this is through the terms bilingualism and bilinguality. Padilla (1998) suggests that the general American belief sees bilinguality, which is a characteristic of an individual, and holds this in higher esteem in terms of education as opposed to bilingualism which Padilla defines as a societal phenomenon viewed as a liability for the collective group or society. By liability, he is referring to the feeling of disloyalty and threat to the nation’s unity. Garcia (1984) stated that even with programs in place in schools to help foster bilingualism amongst students, success in learning another language will always be a struggle with the common attitude equating bilingualism with foreignness and disloyalty. In fact, bilingual language-minority students were once blamed for their academic failure in schools in their
assimilation into American society. Teachers and school administrators did not take appropriate measures to ensure academic success for those students, believing them to be the ones to blame rather than taking the initiative themselves to help those students find ways to learn (Ovando, 2003).

In response to the Soviet Union’s launch of Sputnik, the 1958 National Defense Education Act was created to encourage education in math, science, and foreign-languages (Ovando, 2003). This Act was a positive step towards encouraging bilingualism in the United States. However, it was somewhat inefficient because the focus remained on monolingual English students rather than fostering the gifts of natural bilinguals and the skills they had to offer (Ovando, 2003).

The Civil Rights Act passed in 1964 which helped recognize bilingualism as a civil right of the people, and four years Congress passed the Bilingual Education Act in 1968 which helped encourage and fund language instruction programs in schools (Multilingual Mania, 2010b). An unintended consequence of the Bilingual Education Act resulted in a negative perspective of bilingualism as many of the programs highlighted assistance to educationally disadvantaged and poor individuals (Contreras and Valverde, 1994). A Supreme Court decision in Lau v Nichols 1974 made it a requirement for schools to provide equal-opportunity educational programs. These programs helped foreign-language students become proficient in English. To make the educational programs possible, Congress passed the Equal Education Opportunities Act in 1974 to mandate federally-funded schools to take appropriate measures to make the programs possible (Multilingual Mania, 2010b). Following Lau v Nichols, the 1975 Lau Remedies from the Office of Civil Rights established requirements for identifying language-minority students, determining their English-language proficiency, moving English language learners (ELLs) into mainstream
classrooms in a timely fashion and establishing professional standards for bilingual education teachers (Ovando, 2003).

In 1981 the Castaneda v Pickard court case reinforced the ruling in Lau v Nichols, requiring assessment of programs for language-minority students (Ovando, 2003). Also in 1981, Congress considered for the first time declaring English as the official language of the United States (Linton, 2006). Since that time two activist groups were founded to address this issue. One group called U.S. English supports the idea of establishing English as the official language. This group is most often referred to as “English Only.” The other group is referred to as English Plus and they support all immigrants having the right to use and learn English in addition to any other language they may choose. Not only does English Plus advocate this concept for immigrants, for all Americans (Lipton, 2006). The English Plus movement involved the encouragement of English fluency along with the development of native-language skills.

Similar to thoughts during the time period of the Civil war, multiculturalism again began to be seen as a threat to national unity. In 1988, an amendment to the Bilingual Education Act relaxed restrictions on English immersion and emphasized transitions into English classrooms and in 1994 the Bilingual Education Act, upon being reauthorized, promoted the benefits of bilingualism (Multilingual Mania, 2010c). In 1998 Proposition 227 was passed in California which required English learners to learn English through structured programs, mainstreaming them into English-language classrooms (American Institutes for Research and WestEd, 2006). This proposition was intended for more of an “English only” approach rather than embracing the opportunity to learn or retain other languages as well.

The latest in bilingualism and US policy came from the No Child Left Behind Act (NCLB) of 2001 which eliminated the Bilingual Education Act, discouraging instruction in
bilingualism and encouraging English acquisition (Multilingual Mania: Cultivating a Multilingual World, 2010). The Executive Director of the National Association for Bilingual Education (NABE), explains that NCLB falls short in providing the resources and accountability necessary to effectively education English Language Learners (ELLs- students who are learning English as a second language)(Crawford, 2004). The director adds that there are several factors that affect accountability, such as assessments that fail to provide appropriate benchmarks which affects data assessment (Crawford, 2004). He also relays that the demographic profile of the students affects school performance as areas with higher immigration or poverty are likely to struggle more than societies with affluent demographics (Crawford, 2004).

Crawford provides an example of another program that he feels show promise, the Castaneda standard. The Castaneda standard provides a proven set of tools to assess whether or not obligations are being met for English proficiency in ELL students (Crawford, 2004). Due to lack of resources this program has faced limitations in implementation, however Crawford feels the framework could still be successfully used (Crawford, 2004).

*Introducing another language (typical development):*

Bilingual, or multilingual, language development has been studied extensively. Many studies have investigated dual language acquisition, the effects of bilingualism on cognitive abilities, code-mixing, and general effects seen in a person’s language development when they are introduced to two (or more) language systems as opposed to one. When learning multiple languages, the languages can be acquired in from a choice of three basic ways. Languages can either be acquired simultaneously, sequentially or a person can learn a second first language.

For simultaneous language learners there are two proposed language system hypotheses that discuss the process of language acquisition for infants when learning two different languages
at the same time. The two hypotheses are the Unitary Language System Hypothesis and Dual Language System Hypothesis. The Unitary Language System Hypothesis proposes that bilingual children have a single language system that combines the grammar and words heard in the dual language input. Over time children begin to differentiate the vocabularies of the two languages and around age three the grammatical rules of the two languages begin to separate as well (Volterra and Taeschner, 1978- as cited in Paradis, Johanne, Crago, Martha, Genesee, Fred & Rice, Mabel, 2011). The Dual Language System Hypothesis assumes that two separate linguistic systems exist in children’s minds from the beginning when exposed to more than one language (Paradis et al., 2011). Genesee (1989) claims that children can even use their language in contextually sensitive ways, such as switching language usage according to who is being spoken to, what they are speaking about, or what the individual may be trying to emphasize. For example, if a child learns both English and Spanish from birth, they may speak Spanish the majority of the time because it is the main language in the home. However, if the child goes to preschool and all the other children speak English, the child is able (having learned English in addition to Spanish) to pick up on the language change and speak English more often than Spanish to the other children.

In a literature review about past studies on bilingual language acquisition, Lihong Du (2010) compared nine studies geared specifically towards the topic of bilingual language acquisition. Of the nine studies, two were in support of a single, unitary language system from the start of acquisition while seven were in support of the theory of two separate language systems from the start of acquisition. The two studies that supported a single, unitary language system were carried out by Volterra and Taeschner (1978) and Redlinger and Park (1980). The seven studies supporting a separate, dual, language system acquisition were Quay (1995), Meisel

If an individual learns sequentially they learn one language first, and the second language (or additional languages) at a later time. A sequential language learner is someone who acquires their second language during almost any age or life stage (Kohnert, 2008). The concepts having a majority and a minority language are frequently discussed in the second language acquisition literature. A person’s majority language is the one used by the society the person is in. The media, authority and political bodies would all use the majority language in the community. The minority language has relatively low economic, political, or social power in the society in which the person lives (Paradis et al., 2011) and may only be spoken in the child’s home or school environment. There are also majority and minority ethnolinguistic communities. A majority ethnolinguistic community is when the community is generally based around and supportive of the dominant language of the area, the language of the majority. The minority ethnolinguistic community is a community of people, considered to be a minority in the nation they reside, who speak their native language (Paradis et al., 2011).

A third acquisition method, other than simultaneous and sequential bilingualism, is language learners who learn a second first language. These cases are most often seen in international adoptions, where the child may be exposed to their native language, but upon being adopted the native language is completely removed and the majority language of the child’s new home environment becomes their first language, second to the original native language that they were exposed to. This area of bilingualism is less common and has not been studied as extensively as the other types.
Learning two languages at the same time often results in one language affecting the other during acquisition, such as in code switching or code mixing. Most studies of infant bilingual development have found that children mix elements of their two languages during acquisition (Genesee, 1989). Code switching is when words, phrases or sentences are mixed within the same speech event and across sentences, when a person alternates between two languages (Kachru, 2003). Code-mixing occurs when components (phonological, lexical, morphosyntactic) of two languages are used in the same utterance (sentence) or stretch of a conversation (Genesee, 2006).

Paradis et al. discuss at length code-mixing, especially in the contexts of both children and adults. With adults, code-mixing is an informal style of conversation that mostly maintains grammatical structure and rules. Child code-mixing on the other hand is viewed differently. Professionals and parents are often concerned that code-mixing indicates the child is experiencing confusion with the dual language input (Paradis et al., 2011; Lowery, 2011). However, studies show that code-mixing is not an indicator of confusion with dual input the child receives (Brice, 1999; Lowery, 2011; Paradis et al., 2011). Code mixing has even been found to be a patterned occurrence in grammar and certain language elements (Sridhar et al., 1980).

Bilingual bootstrapping is a term used referring to the use of language to help “boost the other language. In other words, with bilingual bootstrapping the nondominant language can be advanced, or “boosted,” by the more dominant language (Gawlitzek- Maiwald and Tracy, 1996). As an example, a child may be conversing with someone in French but they do not know the French word for “swimming” so they use the English term that they do know. Bilingual bootstrapping helps increase expression of abilities in the other, less dominant, language. This could help explain why children raised bilingually are not substantially behind monolinguals in
reaching developmental milestones because what an individual knows of the languages is used to help compensate and further the other. Currently there is relatively little research exploring bilingual bootstrapping to know the linguistic and cognitive abilities and effects involved (Paradis et al., 2011).

Several studies support that there are cognitive benefits linked with bilingual language acquisition. Looking back through history, bilingualism used to be associated with intellectual impairments, the perspective being that additional languages delayed development. Peal and Lambert (1962) were the first to change this mindset and kick start further research concerning bilingualism and cognitive benefits. Since 1962, some benefits researchers have discovered include:

- Being able to learn new words easily
- Playing rhyming games with words like "cat" and "hat"
- Breaking down words by sounds, such as C-A-T for cat
- Being able to use information in new ways
- Putting words into categories
- Coming up with solutions to problems
- Good listening skills
- Connecting with others (ASHA, 1997-2012).

Evidence has been found supporting enhanced executive control as a benefit of bilingualism (Luo, Luk, & Bialystok, 2010; Bialystok, Craik & Luk, 2008; Bialystok and Barac, 2012). The executive control system is important for language processing, especially when a bilingual individual may be using language switching (Bialystok, 2011). Executive control is associated with the areas of the brain involved with effortful attention or selective attention and
the ability to decipher misleading information from necessary information. Bialystok and Barac (2012) studied the areas of executive control and metalinguistic awareness in children attending immersion programs. Metalinguistic awareness is the ability to construct mental representations and consciously reflect on the properties of language (Van Kleeck, 1982, - as cited in Kamhi, 1985; Bialystok, 2001). The two areas were studied by comparing level of proficiency in language (ability level) with performance on metalinguistic tasks, and length of time in the immersion program (environment) to performance on executive control tasks (Bialystok & Barac, 2012). In both areas bilinguals were at a greater advantage than their monolingual peers. Hakuta et al. (1987) defined cognitive bilingualism as an individual’s possession of two language systems, with particular attention to the variables (1) level of mastery and (2) the specific cognitive functions used. The executive function system helps in controlling attention and inhibiting distraction. People who have been bilingual throughout their lives show signs of delayed cognitive decline as they age (Bialystok, 2010).

Language development milestones for bilingual children are very similar to the language milestones for monolingual children, even though one involves learning an additional language’s grammar, vocabulary, etc. According to Genesee (2008), development may be delayed by a few months for bilingual infants in comparison to monolingual infants, but the delays are not permanent or impairing to the child in their language acquisition (simultaneous and sequential). He also states that bilingual infants babble, speak their first words, and speak multi-word sentences at similar developmental milestones as their monolingual peers (2008). In fact, a study by Sundara, Polk and Molnar (2008, pg. 240) states, “Even when faced with contrasting phones having overlapping cue distributions, bilingual infants keep pace with their monolingual peers:
they develop detailed phonetic representations that accurately reflect their bilingual phonetic world.”

*Introducing another language (ASD):*

Language regression and delay seen in individuals with autism spectrum disorder supports the concerns of many parents and professionals of introducing a child with ASD to another language to an individual with autism spectrum disorder. Parents and professionals are afraid that by adding another language system with additional vocabulary, a different grammatical structure, variation in phonology, etc., the development of the child’s language may be further delayed. Parents also worry about causing their child additional confusion when they already struggle in language development. With uncertainty and lack of evidence-based research, professionals often encourage caregivers to only use one language with the child, even if the rest of the family is bilingual.

Dopke (2006) reflected upon potential difficulties ASD could cause a child in a dual language environment and stressed the importance of considering the child’s sensory abilities and his or her ability to generalize. Dopke discussed how a child’s sensory perception is usually atypically heightened in some areas and perhaps dulled in others with ASD. A person’s senses allow them the ability to learn about the world through how they feel, and what they see, smell, hear, and taste. If a person’s senses are atypical, they will perceive the world around them differently than the typical person would, resulting in a difference and potential insufficiency of cognitive development.

The second idea, generalization, is the ability to learn something in one context and apply it to another (from explicit learning to general application). Individuals with autism struggle to take what they learn explicitly in one context and then apply it to another. For example, a child
may learn how to eat properly and behave at the dinner table at home, but if they went to a friend’s house those same mannerisms may not carry over and they would need to be explicitly shown again what is appropriate. The ability to generalize is important in language development for the purpose of applying language use in different contexts and using different structures. As a result, it is generally assumed that adding an additional language would just add to the confusion the individual with ASD experiences and should try to be avoided.

Despite the widespread presumption that a bilingual environment would cause confusion, looking at current and past research in this area, though sparse, the studies show no evidence of additional confusion or delay with added language input. Multiple studies that have been carried out look at bilingual language development within the context of a variety of developmental and language disorders (developmental delays, specific language impairment, Down syndrome). There have only been a few studies that have specifically researched bilingualism and autism. Current studies regarding bilingual language development and individuals with ASD have shown no evidence that adding additional language causes further language delay (Hambly and Fombonne, 2011). That being said, it is important to keep in mind that research is still very much needed in this area. Also, all individual cases are different. What may work well for one individual based on their circumstances, may in fact be less beneficial to a person in a different situation.

Bird, EK, Lamond E, & Holden J (2011) conducted a survey involving 49 parents (or guardians) of children with autism who lived in a bilingual home environment. From the survey many caregivers indicated they were advised by professionals to expose their child to only one language, even if multiple were spoken in the home. Of the 37 bilingual families surveyed who ended up encouraging bilingualism, 11 received negative feedback and 5 received negative and
positive feedback for fostering a bilingual language environment. From the 12 bilingual families who decided to raise their child as monolingual, 5 were discouraged from introducing their child to two languages. Some parents followed the advice they received from professionals but others found it more important to encourage bilingual development and continued fostering bilingualism in their homes.

Hambly and Fombonne (2011) looked at different exposure groups of individuals who have ASD and their later dominant language outcomes. Individuals with ASD between the ages of 36-78 months who were being raised in a bilingual language environment were placed in two exposure groups. The exposure groups were based on the children’s history of age of second language acquisition, meaning the exposure groups were based on language exposure from the time the children were younger (twelve months and earlier) rather than their current exposure. This specific division was created in hopes of separating the families whose initial intent was to raise their child bilingual or monolingual regardless of delay (the twelve month age divide removes the interference of seeing potential delay as delays are usually not evident at twelve months).

The children were either considered simultaneous bilinguals (before the age of twelve months for this study) or sequential bilinguals (after the age of twelve months). Both groups were studied on individual characteristics, a Language Environment Interview, identifying major language exposure changes, socioeconomic status levels, early language milestones, a week-long language diary, Social Responsiveness scale measures, a family background questionnaire, a list of services, and the MacArthur Communicative Development Inventory: Words and Sentences. The authors found that children with ASD immersed in a bilingual environment from birth or
early childhood do not experience additional delays in comparison to children with ASD receiving monolingual language exposure.

Kremer-Sadlik (2005) claims that it is best to offer a child with autism the opportunity to learn both their family’s mother tongue and English (or the majority language). Exposure to both rather than just the majority language (in this case, English) benefits the child with ASD’s language development and abilities as well as their communicative interactions with their family. Kremer-Sadlik bases this claim on a few case studies she observed in different contexts. For example, one study involved two bilingual children. The parents of both children were professionally advised to discourage bilingualism and raise their child in a monolingual language environment. Of those parents, one set decided to raise their child monolingually based on the professional recommendation while the other set continued to raise their child bilingually, despite professional recommendation not to do so. In the two case studies it was observed that the child who was raised as monolingual experienced separation and isolation from their family members, as the family members continued to speak bilingually. The other child experienced more inclusion and understanding amongst the family members through the common bilingual language experience.

Seung, Siddiqi, Elder, and Aan (2006) also conducted a case study about an individual with autism raised in a bilingual language environment, and how the child responded to intervention services received. The individual in the studied was diagnosed with language delay at the age of 3, and at 3 and 6 months was diagnosed with autism. This longitudinal study followed the child for 24 months and intervention was provided during that time. The child’s intervention was given for the first twelve months in his primary language, Korean. The next six months was a mix of Korean and English while the last six months was only English. This study
positively supports providing intervention services in the child’s primary language with gradual transition to the second, or majority, language.

Other studies regarding bilingualism and language delays or intellectual disabilities (developmental delays, specific language impairment, Down syndrome) have evidence supporting the inclusion of bilingualism in the individual’s language environment. For example, there are many studies on bilingualism and specific language impairment looking at the potential effects language impairment may have on language development in a dual language environment. Studies to date show that a child with specific language impairment raised in a dual language environment will not experience adverse effects or additional delays in their language learning abilities that would differentiate them from monolinguals with specific language impairment (Paradis, Crago, Genesse, and Rice, 2003; Gutierrez-Clellen, Simon-Cereijido, and Wagner, 2008; Spoelman & Bol, 2012), and some even theorize bilingualism to be beneficial to the individual with SLI (Roeper, 2011).

Some studies show contrasting results. Verhoeven, Steenge, Van Balkom and Van Weerdenburg (2010; 2011) found that children with SLI raised in a bilingual language environment are additionally disadvantaged (in areas of grammar and verbal morphology) as compared to their monolingual peers with SLI and typically developing bilingual and monolingual peers. Paradis (2007), however, found that children with SLI raised bilingually did not lag behind their peers in grammatical rates and patterns. Though there are some inconsistencies amongst these studies, to date most evidence supports the claim that dual input does not impede language development for individuals with SLI.

Studies regarding bilingualism and Down syndrome (DS) have also found the incorporation of bilingualism to not cause further language delay or detriment to the child’s
language development (Bird, Lamond and Holden 2005). Kay-Raining Bird et al. (2005) implemented a study to observe the ability of individuals with DS in acquiring a second language. Fifty-one participants were divided into four groups. The four groups were monolingual and bilingual typically developing children and monolingual and bilingual children with DS. All of the children were in the early stages of language development. Measures taken were of cognition and English language ability. A separate language sample and questionnaire were also completed by the bilingual groups. Of the 51 participants, 19 were bilingual and 8 were bilingual with Down syndrome. The results of the study indicate that individuals with autism have the ability to acquire two languages, though some are more capable of acquiring two languages than others and further research needs to be done to determine the success factors involved in dual acquisition. The final note from Kay-Raining Bird et al. (2005) advises families to pay careful attention to the needs of the individual and of the family when making a decision on monolingual versus bilingual language development.

Feltmate and Kay-Raining Bird (2008) also studied bilingualism and Down syndrome. The study analyzed semantic and morphosyntactic ability and their results encourage dual language acquisition and for an individual with DS. One of the important factors they noted regarding successful acquisition is the frequency of exposure to each language. A short article by Wilken (2003) describes a variety of language acquisition situations for individuals with DS in Germany. From the examples, Wilken draws the conclusion that the ability to acquire a second language rests largely in the individual child’s abilities.

Besides studies on autism, Down syndrome and specific language impairment, there have been reviews and studies over general developmental disorders and delays as well. In Toppelberg, Snow and Tager-Flusberg (1999), the reasons for additional difficulty in dual
language acquisition are discussed such as pragmatic difficulties due to lack of confidence or impairment as well as the individual’s specific language deficits or difficulties. Another concern in the United States specifically is the dearth of sufficient input in either the first or second acquired language to foster their development.

When considering whether or not to expose an individual with autism to multiple languages it is important to not only consider cognitive and language affects but also the social implications the decision can have on the child amongst their family, peers and community. If a child is raised in a bilingual environment amidst family and a community of people who are also bilingual, otherwise known as an additive bilingual environment, the child will receive the support and input necessary to effectively acquire both languages (Paradis et al., 2011). They will also feel included in their community through the common ethnic background and culture, which can assist in their social development. In another situation, an individual with autism may be raised in a bilingual language environment but discouraged from learning the native language in favor of them learning the majority language. However, if the child is still raised in a bilingual family and community of people, they may experience isolation and struggle to identify themselves with others, further hindering social development and close relationships with family and peers.

The above studies discuss situations that assume a strong support system in the native language, but what if the individual with autism is raised in a subtractive bilingual environment (Paradis et al., 2011) where the native language does not have a strong support system in the community and amongst peers? In that situation, encouraging the native language would be beneficial for strengthening family relationships, but the child will need additional exposure either from school, community programs, or the home to learn the language effectively. In a
subtractive bilingual environment it may prove more beneficial to discourage bilingualism if the child will not be receiving the proper quality and amount of input to fully develop the additional language system. More research is needed in this particular area of study.

All of these factors are important to consider because depending on the amount of language input, the surrounding language environment, and the resources available to the individual with autism and their family, the decision of whether or not to be bilingual can vary. The intangible costs of choosing monolingualism should be considered such as the poorer interactions with family and community, loss of educational opportunities, a shift in ethnic identity, and limited access to the ethnic community (Paradis et al., 2011). Looking closely at the situation of each individual is crucial for pursuing the best option for that child.

The purpose of this study was to investigate autism and bilingualism and to examine the perspectives of caregivers on whether or not to encourage bilingualism for their child who has ASD. This study also addresses whether there are any developmental differences between children with autism and bilingual families compared to monolingual families. The survey results were collected from controlled families, but due to a smaller sample size the main focus of this study will be focused on the perspectives of caregivers and their personal experiences.

**METHOD**

*Survey Development:*

The survey was created encompassing questions related to general demographics, family background, language background, diagnostic information for the child with ASD, language background of child, language exposure, and a qualitative portion asking for parent’s opinions and experiences concerning raising a child with autism in a bilingual/multilingual language environment.
There were a total of 51 questions: 39 multiple choice, 6 short answer and 7 extended response. Monolingual caregivers completing the survey were redirected to the end of the survey after question 21 if they responded that their child did not speak/understand multiple languages. If the caregiver indicated that their child did speak or understand multiple languages, they continued with the rest of the survey and completed the extended response.

The demographics section of the survey includes family background and child background questions. For family background 4 multiple choice questions concerning family size, family members residing in the household, roles and ages of family members and education level. For the background information on the child with ASD there are 12 multiple choice questions regarding the child’s age, diagnosis, level of functioning, speech and language abilities, living situation, education inclusion and supports and services provided.

The next section inquires about language history. There are 27 questions in this section that ask for an indication of level of proficiency for each language spoken, family members’ fluency in other languages, how well the child with ASD understands and/or speaks the other languages, child’s fluency in other languages, professional advisement on bilingualism pre and post diagnosis, amount of media exposure to native language and English, the language parents use to address the child, and which language the child prefers.

The final section of the survey consists of 7 qualitative questions seeking the caregiver’s opinions and experiences with raising a child on the autism spectrum in a bilingual language environment. The survey was approved by the Human Subjects Research Board on 02/20/2012 and the survey was sent out to Autism Society of America chapters within the United States (available from the Autism Society of America official website). The Autism Society chapters were invited to assist with the study by forwarding a prewritten email and survey link to their
members, inviting them to participate in the study. The email invitation was also sent to several other American associations whose focus related to the topics of bilingualism or autism.

Participants:

A link to the survey was sent out to Autism Society chapters across America found on the Autism Society of America website. Chapters were contacted through email, with the survey link and general survey information included. All participants were at least 18 years of age, and were caregivers of individuals with autism spectrum disorders.

Results

Quantitative Data:

The survey had a total of 32 participants, 10 participants with a bilingual language background. Of the 32 participants 31 claimed to be the primary caregivers of their child with autism. The ages of the children with autism spectrum disorder range from 2 to 22, with a median of 10 and a mean of 10.839. One participant did not include the child’s age. There were 23 male children with ASD as subjects of the survey, and 9 female children.

The children from the survey were diagnosed, on average, at the age range of 1-2. There were 14 children were diagnosed from 1-2, 9 were diagnosed from 3-4, 5 were diagnosed from 5-6, and 1 was diagnosed in each of the ranges of 7-8, 9-10, and older. One participant did not respond. When asked who diagnosed their child, there were multiple responses from several of the caregivers. Overall, there were 14 references to Developmental Pediatricians, 9 references to a neurologist or neuropsychiatrist, 6 references to both psychiatrists and psychologists, 3 references to the family physician and 1 reference for an early intervention team, DSM IV testers, the school, school psychologist, psychology team, a study at National Children’s Medical Center, a multidisciplinary team and a speech pathologist. The diagnoses of the children in the
survey include 5 with PDD-NOS, 10 with autism spectrum disorder, 16 with autism (one also blind, and one with oppositional defiant disorder), and 1 with Asperger syndrome. One person received 2 diagnoses (PDD-NOS and autism; both were included in the above count which brings the total number of diagnoses to 33).

When asked about past and current services received, the participants selected from a list including occupational therapy, physical therapy, speech therapy, special education classroom, one-on-one aide, intensive behavioral intervention, job coach, educational accommodations, and other. Twenty-nine (93.5%) of the participants access occupational therapy, 19 (61.3%) access physical therapy, 30 (96.8%) utilize speech therapy, 25 (80.6%) are in a special education classroom, 21 (67.7%) require a one-on-one aide, 14 (45.2%) are in intensive behavioral intervention, 4 (12.9%) have a job coach, and 14 (45.2%) require educational accommodations. The other services caregivers commented on using included home visits from the Help Me Grow program and the Family Child Learning Center, Adapted Physical Education, Applied Behavioral Analysis, personal care, music therapy, aide in classroom shared with several students, vision services and orientation and mobility.

In the survey, question 21 asked the caregivers if anyone in the household fluently spoke another language. Based upon answers to that question, survey participants were either directed to follow questions regarding language history (if answered yes) or to the end of the survey (if answered no). There were 10 participants who responded “yes,” that they or someone in their household could fluently speak another language, and 22 responded “no”. One respondent, who answered “no,” ended up completing the additional questions as well. However, since there response to question 21 was no, their responses for the remainder of the survey were disregarded.
All children began learning language from birth. The following questions asked about the child’s exposure to and fluency in different languages. First, a question asked if the child spoke or understood other languages (6 responded yes, 4 responded no). Caregivers reported to speak English, French, German, Spanish, Nepali, Swedish, Russian, Italian, Japanese, Chinese-Cantonese, Chinese-Mandarin, and sign. When asked which languages the child is able to understand or speak, 6 speak English only, 3 speak the native language and English, and one speaks English and their native languages plus an additional language or languages. The additional languages spoken or understood by the children include Chinese-Cantonese, Swedish, Nepali, Japanese, Russian, and Spanish. It is important to note that the child reported to speak English and their native language plus additional language or languages was also reported to be mostly nonverbal with a limited understanding of their native language and English. When asked about fluency in speaking English, 2 children were reported to understand and speak fluently, 3 understand well but do not speak fluently, 4 understand fairly well but only speak a little, and one understands a little but does not speak.

Sixteen of the remaining questions addressed language exposure, three questions regarding professional advice the caregivers were given and two questions inquired about the child’s preferred language in different contexts. The responses from the caregivers are included with the survey results in Appendix A. The majority of the bilingual children (7 out of 10 responses) indicated greater exposure to English in the school and home environment than other languages. The parents’ language use was a little more diverse with 50% of the parents using both the native language and English with their child, 20% using the one parent one language method with the child (one parent would only speak to the child in English while the other would only speak to the child in the native language), and 30% of the parents spoke to their child in just
English. The majority of children preferred to use English in social situations and in most general contexts.

Caregivers were asked to share their decisions in deciding whether or not to raise their child bilingually before and after learning of their child’s diagnosis. Before learning their child had ASD, 60% of caregivers spoke both languages to their child, 30% of caregivers spoke the native language and 10% of caregivers spoke just English. After learning of their child’s diagnosis, 60% of caregivers still reported to speak both languages to their child, 0% spoke just the native language, 30% decided to speak just English and one participant relayed receiving conflicting advice from professionals, being told from different people to speak just English, to pursue bilingualism, and to speak just Japanese (participant’s native language).

Table 1 is a compilation of responses from both monolingual and bilingual families. The table shows the responder’s numbers, then points are distributed to each based off of their responses to each of four chosen questions. The questions chosen include:

1) What is your child’s overall functioning, relative to age peers, in your opinion (consider all contexts- home, school, play, community, vocational as relevant)?

2) Please check the response that most clearly describes your child’s speech ability.

3) Please check the response that most closely describes your child’s language ability.

4) Please indicate which level of inclusion your child experiences.

Answers to these multiple choice questions were given a point value, on a scale of either 1-5, 1-6, or 1-10 (depending on how many multiple choice options were available). The greatest number of points was granted to the answer believed to indicate highest level of functioning (or closest to typical development), and the lowest point value was given to the answer indicating lowest level of functioning (or furthest from typical development) for each response.
The questions were chosen from the survey that appeared to offer the greatest information for determining a general idea of each subjects’ level of functioning. The point values for each started with the highest points going to the first available response and ending with the last available response (responses already previously ordered from greatest similarities in typical development to least). For example, below is question 1 from the chart with the question, the responses (in order) and a point value assigned to each response:

What is your child’s overall functioning, relative to age peers, in your opinion (consider all contexts- home, school, play, community, vocational as relevant)? N=32

1) Close to normal for age in almost all areas. Differences from typical are subtle. – 5 points
2) Able to do most things that age peers do, with minimal supports. Some challenges. – 4 points
3) Able to do some things age peers do, with support. Several challenges. – 3 points
4) Difficulty participation in activities that other age peers can do. May be able to participate in same with moderate-intensive supports. – 2 points
5) Difficulty in all areas; intensive supports needed at all times. - 1 point

The points for each participant’s responses to the four questions were added together for a total amount. The total then represents a comparison number to the other subjects, observing the range of abilities across the total sample population. All of the total scores were then added and averaged for two separate categories: ASD in bilingual environment and ASD in monolingual environment. For this survey the averages were calculated to see if there would be a difference in level of functioning between the two groups, to see if being bilingual as opposed to monolingual had an impact on level of functioning. The average level of functioning for bilinguals with ASD
was found to be 15.9. The average for monolinguals was found to be 15.818. The average standard deviations were also found, for bilinguals at 5.3427 and monolinguals at 5.770.

Table 1. Level of Function in Bilingual and Monolingual Environments.

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<td>Average/SD: 15.9/5.3427</td>
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R= Responder
Q1= What is your child’s overall functioning, relative to age peers, in your opinion (consider all contexts-home, school, play, community, vocational as relevant)?
Q2= Please check the response that most clearly describes your child’s speech ability.
Q3= Please check the response that most loosely describes your child’s language ability.
Q4= Please indicate which level of educational inclusion your child experiences.

Four Questions Addressed in Table 1:

What is your child’s overall functioning, relative to age peers, in your opinion (consider all contexts-home, school, play, community, vocational as relevant)? N=32

1) Close to normal for age in almost all areas. Differences from typical are subtle= 5 points
2) Able to do most things that age peers do, with minimal supports. Some challenges = 4 points
3) Able to do some things age peers do, with support. Several challenges = 3 points
4) Difficulty participation in activities that other age peers can do. May be able to participate in same with moderate-intensive supports = 2 points
5) Difficulty in all areas; intensive supports needed at all times = 1 point

Please check the response that most clearly describes your child’s speech ability. (N=32)

1) Communicates using clear, easy to understand speech = 5 points
2) Communicates using speech, but with some speech errors= 4 points
3) Communicates using some speech, not always intelligible= 3 points
4) Limited vocal communication, very hard to understand = 2 points
5) Communicates primarily by using means other than speech= 1 point

Please check the response that most loosely describes your child’s language ability. (N=32)

1) Uses complete grammatically correct sentences = 6 points
2) Use mostly correct sentences, some errors but typical for age = 5 points
3) Speaks in sentences, with errors in word choice or grammar, not typical for age= 4 points
4) Limited ability to speak in sentences, uses short phrases= 3 points
5) Uses single words only = 2 points

6) Does not speak = 1 point

Please indicate which level of educational inclusion your child experiences. (N=32)

1) Fully included, no aide = 10 points

2) Fully included with one-on-one aide = 9 points

3) Included for most subjects but attends resource classroom part-time = 8 points

4) Included for one or two activities but spends most days in special education classroom = 7 points

5) Experiences reverse inclusion (typical classmates come to his or her classroom) = 6 points

6) In separate support classroom, in the school building, not included with typical peers = 5 points

7) Attends specialized program for students with disabilities in separate building = 4 points

8) Home schooled = 3 points

9) In college = 2 points

10) Not in school at this time = 1 point

Qualitative data:

The parents with children you have ASD and also are bilingual responded to the extended response questions (N=10). The questions in the survey were:

- What is your belief about the effects of hearing more than one language in the home on the development of a typical child (one who does not have a disability)?

- What is your belief about the effects of hearing more than one language in the home on the development of a child with ASD?

What were you encouraged to do concerning speaking more than one
language in your family when you learned of the diagnosis of your child?

What did you decide to do as result?

- If your decision was to avoid speaking English to your child or around your child, what in your opinion have been the effects of that decision for your child and your family?

- If your decision was to continue speaking more than one language to your child, what in your opinion have been the effects of that decision for your child and your family?

- Do you know other families who have been in similar situations? What did they choose?

- Please share any additional thoughts you may have.

The four common themes (with example responses from survey participants) include:

- **Confusion**
  
  “I am confused, I hate to make things more difficult for him. But would really like him to speak both.”

- **Hesitation**
  
  “May cause confusion and hold to wait until he can master the English language first.”

- **Inconsistency**
  
  “At first I got all conflicting advice. Pediatrician suggest English, SLP suggest both, and some even suggests Japanese only, as parents are not capable of fully communicating to the child in their non-native language.”
Inability of child with ASD

- “Our children with ASD have found it incredibly difficult to learn another language, in addition to English. They both adhere to “rules” which will not allow for something to have more than one name. This makes the label of another language very difficult for them to accept.”

Additional examples of parent responses can be viewed with the survey results in Appendix A. The examples listed above display a global characterization for the ten respondents of negative feelings during the decision making process concerning whether or not to raise a child with ASD in a bilingual language environment. Though some of the parents ignored the advice they were given, and others followed exactly what was suggested by the professional they consulted, the caregivers’ decisions and chosen path were pursued with limited confidence because of the uncertainty and conflicting advice amidst those they (the caregivers) trusted to be experts (the professionals).

Discussion

The purpose of this study was to investigate autism and bilingualism and to examine the perspectives of caregivers on whether or not to encourage bilingualism for their child who has ASD. This study was also intended to compare the level of functioning between participants exposed to a bilingual environment as opposed to a monolingual environment, but due to this survey’s small sample size, focus for this study remained on the caregiver’s perspectives and experiences.

These findings demonstrate several aspects of the decision making process when contemplating language environment. For bilingual families with children who have ASD, the responses given indicate that caregivers take into consideration their child’s ability to learn
multiple languages, the effect it will have on family relations, and the level of importance they have on sharing their native culture with their child.

From the review of literature summarized earlier in this paper, there is evidence from past studies that address the above concerns. For example, Hambly and Fombonne (2011) found that adding an additional language does not cause further language delay in individuals with autism. This addresses caregiver concerns about additional languages causing confusion or further delay in the child’s language development. Kremer-Sadlik (2005) found incorporation of family’s native language and English (majority language) to benefit the child’s general language development and interactions with family. It is important for children to be included in their family environment and interactions because children acquire much of their language development from interactions in the home. In relation to home interactions, Paradis et al. (2011) insist on the importance of the child being involved with the community and environment around them to assist in their social development. If the child’s home life or community is related to a minority ethnic background, it is important that the child can be included in that environment as well as the environment of the majority. Providing the child an opportunity to grow within their family’s ethnic background and cultural customs allows the child to interact and build stronger social relations. An aspect of this development may include incorporating an additional language for the child to interact in accordance with their surroundings, when different from the family’s ethnic background.

The findings from this study offer insight to professionals, educators and parents on the thoughts, feelings and experiences of bilingual families and some of the conflicts they face in trying to decided what is best for their child. The four common themes found in the qualitative portion of the survey are feelings and thoughts of confusion, hesitancy, inconsistency, and
acknowledgement that some individuals are simply unable to acquire two, let alone one, language.

This study is helpful in that it identifies a need for further research and precautionary measures when addressing caregivers’ concerns on raising a child with autism. The responses shared in this survey expressed many conflicted thoughts regarding whether or not bilingualism would be detrimental to the child’s language development. It is important for professionals and educators to assume the role of expert and seek out current research and evidence on the topic, even if research is limited. The research that exists is still capable of informing professionals to offer similar advice to parents and caregivers seek the best options for their child and family.

The American Speech-Language- Hearing Association’s Code of Ethics (2010) requires in Principle 2 that speech language pathologists have a “responsibility to achieve and maintain the highest level of professional competence and performance.” To maintain the highest level of professional competence a professional must be responsible for staying up to date on latest research and evidence-based practices. In part C of the same section, it reinforces this idea by stating, “Individuals shall engage in lifelong learning to maintain and enhance professional competence and performance.” These ethical principles are specified for SLPs but generalize to other professional fields as well. Not only is it important to continue to research and stay updated on most recent research for the clients, it is ethical practice to do so and compliance is required of professionals in all fields.

This study is helpful for recognizing current feeling and experiences of caregivers with children being raised in a bilingual environment. Awareness of the caregivers’ perspectives offers guidance to professionals in finding better ways to serve this population of clients, and what the caregivers need in order to move forward with confidence in the decision they make to
most benefit their child. This study’s small sample size resulted in inadequate information for in-depth analysis and only informs regarding a small number of the population. This study is also biased towards individuals who are involved with an Autism Society of America chapter in their area, have access to a computer and are literate in English. Considering this survey sought out bilingual individuals, this survey was not accommodating to caregivers who cannot read English, or who are recent immigrants or are in low SES circumstances and may not have access to necessary resources. To address these needs, future survey studies could be sent through mail and email, as well as shared at some social service facilities if the opportunity exists to do so. It would be appropriate to have the survey translated to multiple languages to address the needs of those who may not speak, read or write in English.

Conclusion:

In summary, past studies indicate that bilingualism is not detrimental or that it will cause further language delays for children who have autism spectrum disorders. However, past research includes fairly small sample sizes and only a select few of the studies have been completed in the United States. This survey shows caregivers to be confused and often presented with conflicting advice. Current research indicates we can encourage parents to expose their child with ASD to a bilingual environment if that is what their natural home environment includes and sufficient input is available. Professionals and educators should, at the minimum, pursue being on a common ground by staying up to date on current research, as well as pursuing additional research opportunities. When offering advice to parents and caregivers, basing the advice on current available research is ethical practice and will hopefully reduce the caregivers’ feelings of confusion, hesitancy, and inconsistency that many experience today.
References:


http://www.autismspeaks.org/what-autism

fromhttp://www.webmd.com/brain/autism/autism-spectrum-disorders


APPENDIX A

Family Background

2. How many family members are in your household? (N=32)

1) 2-12.5% (4)
2) 3-15.6% (5)
3) 4-43.8% (14)
4) 5-12.5% (4)
5) More-15.6% (5)

3. Are you now, or were you formerly, a primary caregiver of a family member with ASD? (N = 32)

Yes = 93.8% (30)
No= 6.3% (2)

4. Please list the role and age of each family member below (start with yourself; ex. Mother, 32, Brother 7) (N = 32)

Number =
Mother- 31
Father- 26
Daughter- 28
Son- 33
Grandmother- 3
Grandfather- 1

Mean =
Mother: 43.81
Father: 47.15
Daughter: 11.18
Son: 11.45
Grandmother: 72.67
Grandfather: 92

Range =
Mother: 32-56
Father: 33-65
Daughter: 3-22
Son: 2-25
Grandmother: 70-78
Grandfather: 92

SD =
Mother: 7.37
Father: 8.098
Daughter: 5.62
Son: 6.64
Grandmother: 4.62
Grandfather: -

5. What is your education level? (N= 32)
   1) 0-12 years, no high school diploma = 0 (0)
   2) High school diploma = 9.4% (3)
   3) Some college = 25% (8)
   4) Associate’s degree = 6.3% (2)
   5) Bachelor’s degree = 21.9% (7)
   6) Master’s degree = 18.8% (6)
   7) Doctorate or professional degree = 18.8% (6)

Child with ASD Background Information

6. Age of your child (with ASD): (N = 30)
   Mean = 10.57
   SD = 5.73
   Range = 2-22

7. Gender: (N = 32)
   Male- 71.9% (23)
   Female- 28.1% (9)

8. Age when your child was diagnosed with ASD. (N = 31)
   1) 1-2: 45.2% (14)
   2) 3-4: 29.0% (9)
   3) 5-6: 16.1% (5)
   4) 7-8: 3.2% (1)
   5) 9-10: 3.2% (1)
   6) Older: 3.2% (1)

9. Please provide information about who diagnosed your child: (N= 28)
   Family physician: 10.7% (3)
   Neurologist/ neuropsychiatrist: 32.1% (9)
   Psychiatrist: 21.4% (6)
   Developmental Pediatrician: 50.0% (14)
   Psychologist: 25.0% (7)
   Speech Language Pathologist: 3.6% (1)

   Other:
   - Multidisciplinary team,
   - School
   - Study at National Children’s Medical. Center
   - School psychologist and DSM IV testers
   - Team diagnostic
   - Early Intervention Florida

10. What is your child’s current diagnosis? (N = 32)
Autism: 46.9% (15)  
ASD: 34.4% (11)  
PDD-NOS: 15.6% (5)  
Asperger syndrome: 3.1% (1)

11. What is your child’s overall functioning, relative to age peers, in your opinion (consider all contexts—home, school, play, community, vocational as relevant)? (N= 32)

1) Close to normal for age in almost all areas. Differences from typical are subtle. 12.5% (4)
2) Able to do most things that age peers do, with minimal supports. Some challenges.21.9% (7)
3) Able to do some things age peers do, with support. Several challenges.28.1% (9)
4) Difficulty participating in activities that other age peers can do. May be able to participate in some with moderate-intensive supports. 3.1% (1)
5) Difficulty in all areas; intensive supports needed at all times.34.4% (11)

12. Please list and briefly describe any special talents your child has: (N= 23)

1) Sports, music
2) Remembers events from earlier years that she points out to me
3) Spatial memory
4) Very musical, and great athletic skills
5) Solitary sports
6) Counts numbers to 20. Knows ABCs and show tunes
7) Film maker
8) None, but sweet and adorable
9) Computers
10) Computer, numbers, music
11) Math, puzzles
12) Strong interest in animals- can see things in great detail
13) Sense of humor, smart, strong memory in different areas (past events, numerical info, etc.), loving and enjoys- though not able to form in typical manner- relationships, energetic and full of life, engaging child
14) Strong academic skills
15) Builds and programs computers
16) Excellent rote memory, highly technologically inclined
17) Reading, at 3 learned whole alphabet in 2 months. Could point to letters though couldn’t speak.
Reads at 2nd grade level in kindergarten, very good memory and very good with animals
18) Art, he draws and paints
19) Writing poetry
20) Very musical.
21) Likes to play the piano and sing, memorizes songs and books pretty quickly
22) Great at puzzles, math, spelling words, memorizes scenes
23) Mathematics, visual. memory, excellent sense of direction

13. Please check the response that most clearly describes your child’s speech ability: (N = 32)

1) Communicates using clear, easy to understand speech 21.9% (7)
2) Communicates using speech, but with some speech errors 28.1% (9)
3) Communicates using some speech, not always intelligible 21.9% (7)
4) Limited vocal communication, very hard to understand 15.6% (5)
5) Communicates primarily by using means other than speech 12.5% (4)

If communicates by using means other than speech, please list:
- Single words (mands) pointing bringing person to object/ location PECS Proxtal.ker Proloquo2go
- Uses iPad as AAC, with Proloquo2go app
- PECS, some sign language
- He has no language for emotions, he cannot answer yes no questions without great difficulty
- Proloquo2go on iPad, sign language

14. Please check the response that most closely describes your child’s language ability: (N= 32)
   1) Uses complete grammatically correct sentences 18.8% (6)
   2) Use mostly correct sentences, some errors but typical for age 9.4% (3)
   3) Speaks in sentences, with errors in word choice or grammar, not typical for age 21.9% (7)
   4) Limited ability to speak in sentences, uses short phrases 12.5% (4)
   5) Uses single words only 25% (8)
   6) Does not speak 12.5% (4)

15. What is your child’s current living situation? (N= 32)
   1) Lives with family 96.9% (31)
   2) Attends residential k-12 school 3.1% (1)
   3) College student living in dorm
   4) Supported living situation in community (staff on site 24 hours)
   5) Supported living situation in community (support staff visits occasionally)
   6) Lives independently in community without supports

16. What is your child’s education level? (N= 29)
   1) Nursery/Preschool 13.8% (4)
   2) Kindergarten 17.2% (5)
   3) Elementary 24.1% (7)
   4) Middle School 20.7% (6)
   5) High School 20.7% (6)
   6) Some College 3.4% (1)
   7) College Graduate 0
   8) Other: 4

17. Please indicate which level of educational inclusion your child experiences: (N= 32)
   1) Fully included, no aide 18.8% (6)
   2) Fully included with one-on-one aide 9.4% (3)
   3) Included for most subjects but attends resource classroom part time 12.5% (4)
   4) Included for one or two activities but spends most of day in specialized classroom 12.5% (4)
   5) Experiences reverse inclusion (typical classmates come to his or her classroom) 3.1% (1)
   6) In separate support classroom, in school building, not included with typical peers 18.8% (6)
   7) Attends specialized program for students with disabilities in separate building 18.8% (6)
   8) Home schooled 3.1% (1)
   9) In college 0% (0)
10) Not in school at this time 12.5% (4)

18. What supports and services has your child experienced (past or present)? (N= 31)
   1) OT 93.5% (29)
   2) PT 61.3% (19)
   3) Speech 96.8% (30)
   4) Special Education classroom 80.6% (25)
   5) One-on-one aide 67.7% (21)
   6) Intensive behavioral intervention 45.2% (14)
   7) Job Coach 12.9% (4)
   8) Educational Accommodations 45.2% (14)
   9) Other: (6)
Language History

19. Please indicate your level of proficiency for each language, using a 1-5 scale (1 being the least proficient with little fluency or understanding, 3 being some fluency and understanding, and 5 being completely fluent and understanding). (N = 31)
   1) Language 1 (n=31)
      1 = 0 (0)
      2 = 6.5% (2)
      3 = 3.2% (1)
      4 = 12.9% (4)
      5 = 77.4% (24)
   2) Language 2 (n=14)
      1 = 21.4% (3)
      2 = 35.7% (5)
      3 = 14.3% (2)
      4 = 21.4% (3)
      5 = 7.1% (1)
   3) Language 3 (n=4)
      1 = 75.0% (3)
      2 = 0 (0)
      3 = 25% (1)
      4 = 0 (0)
      5 = 0 (0)
   4) Language 4 (n=2)
      1 = 100% (2)
      2 = 0% (0)
      3 = 0% (0)
      4 = 0% (0)
      5 = 0% (0)

20. Please list your native language (L1) followed by any other languages you may also speak:

Native languages (n=30): Spanish (2); Japanese (2); Cantonese Chinese (1); English (25)
Other (n=19):
   - English (5)
   - French (4)
   - Spanish (4)
   - Russian (1)
   - Swedish (1)
   - Italian (1)
   - Sign (1)
   - Nepali (1)
   - Mandarin Chinese (1)
   - German (1)

21. Do you or anyone in your household fluently speak another language? (N= 33)

   Yes 30.3% (10)
   No 69.7% (23)

22. Does your child speak/understand multiple languages? (N= 11)
Yes 60% (6)
No 40% (4)

23. Which language(s) has your child who has autism learned? (N= 11)
   1) Native language only 0(0)
   2) English only 60% (6)
   3) Native language and English 30% (3)
   4) Both languages plus an additional language or languages 10% (1)

24. List of other language(s) your child understands and/or speaks: (N= 7)
   - Spanish (1)
   - Japanese (2)
   - Russian (1)
   - Nepali (1)
   - English (2)
   - Chinese-Cantonese (1)
   - Swedish (1)

25. Around what age did your child with ASD begin to learn English (if spoken)? (N= 10)
   1) From birth 100% (10)
   2) 1-2: 0(0)
   3) 3-4: 0(0)
   4) 5-6: 0(0)
   5) 7-8: 0(0)
   6) Not applicable: 0(0)
   7) Other:
      o “Practically nonverbal with limited understanding of both Japanese and English”

26. How fluent is your child in English (if child speaks more than two languages, refer to most fluent second language)? (N= 11)
   1) Understands and speaks fluently 20% (2)
   2) Understands well but does not speak fluently 30% (3)
   3) Understands fairly well but speaks only a little 30% (3)
   4) Understands a little but does not speak 20% (2)

27. After you learned that your child was diagnosed with ASD, were you ever professionally advised to: (N= 11)
   1) Discourage bilingualism with your child 60% (6)
   2) Encourage bilingualism with your child
   3) Neither encouraged nor discouraged 40% (4)
   4) Other: (1)
      o My husband - who is native Nepali speaker - had significant reservations about teaching our son Nepali - felt that this would further confound our sons process of learning to speak. I encouraged my husband to engage bilingually with our son and did not have similar concerns. I do not speak much Nepali so my husband was the only resource to teach our son the second lang. now that our son is older, my husband is not as concerned and has begun to speak more Nepali with our son...

28. How often does the family speak in the native language in the home around the child who has autism? (N= 11)
   1) 0-20% [30% (3)]
   2) 30-50% [40% (4)]
   3) 60-80% [20% (2)]
   4) 90-100% [10% (1)]

29. How often does the family speak English in the home around the child who has autism? (N= 11)
<table>
<thead>
<tr>
<th>Question</th>
<th>Response Options</th>
</tr>
</thead>
</table>
| 30. How often is a language other than the native and second language spoken in the home to the child who has autism? (N= 10) | 1) 0-20% [80% (8)]  
2) 30-50% [20% (2)]  
3) 60-80% [0 (0)]  
4) 90-100% [0 (0)] |
| 31. How often do siblings speak your native language? (N= 10)            | 1) Rarely 0 (0)  
2) Occasionally 20% (2)  
3) Frequently 30% (3)  
4) Never 10% (1)  
5) Not applicable 40% (4) |
| 32. How often do the siblings speak English? (N= 10)                    | 1) Rarely 0 (0)  
2) Occasionally 0 (0)  
3) Frequently 70% (7)  
4) Never 0 (0)  
5) Not applicable 30% (3) |
| 33. If you are originally from another country, do you and your child ever travel back to your native country? (N= 10) | 1) Rarely 10% (1)  
2) Occasionally 20% (2)  
3) Frequently 20% (2)  
4) Never 20% (2)  
5) Not applicable 30% (3) |
| 34. Which language is most often spoken to your child at school? (N= 10) | 1) Native language 0(0)  
2) English 100% (10)  
3) Third language 0(0)  
4) Spoken Equally 0(0)  
5) Other 0(0) |
| 35. Which language is most often spoken to your child at home? (N= 10)   | 1) Native language 10% (1)  
2) English 70% (7)  
3) Third language 0 (0)  
4) Spoken Equally 20% (2)  
5) Other 0(0) |
| 36. Which language do both parents use to address your child who has autism? (N= 10) | 1) One parent speaks native, other parent speaks English 20% (2)  
2) Both speak native language only 0 (0)  
3) Both speak English only 30% (3)  
4) Both speak native and English to child 50% (5) |
| 37. Do other family members live in the home? (N= 10)                    | Yes 30% (3)  
No 70% (7) |
| If yes, which language(s) do they speak?                                | Spanish and English  
- Father- Russian, Sister- Very little Russian  
- Spanish |
| 38. What was your approach, as a parent, to speaking more than one language to your child before you knew that your child had ASD? (N= 10) | 1) Encouraged native language 30% (3) |
2) Encouraged English 10% (1)
3) Encouraged both 60% (6)
4) Was not concerned with which language to speak

39. What was your approach, as a parent, to speaking more than one language to your child after you knew that your child had ASD? (N= 8)
   1) Encouraged native language 0 (0)
   2) Encouraged English 50% (4)
   3) Encouraged both 50% (5)
   4) Was not concerned with which language to speak

   Other (3):
   1. “Given conflicted advice, some suggests English only, other suggests bilingualism, and yet some suggest speaking Japanese only.”
   2. “But, as mentioned earlier- once my husband learned our son had ASD, he stopped speaking both languages to our son or a number of years”
   3. “we were hesitant but kept speaking two”

40. How many years of formal school instruction has your child received in learning the second language, if any? (N= 9)
   1) None 77.8% (7)
   2) 1-2 years 22.2% (2)
   3) 3-4 years 0(0)
   4) 5-6 years 0(0)
   5) 7-8 years 0(0)
   6) More than 8 years 0(0)

41. How did your child learn the second language (check all that apply)? (N= 8)
   1) Parents 100% (8)
   2) School 12.5% (1)
   3) Extended family 37.5% (3)

42. What is the child’s preferred language? (N= 10)
   1) Native 0 (0)
   2) English 70(7)
   3) Uses both equally 30 (3)

43. Which language is used by the child when socializing? (N= 9)
   1) Native language 0(0)
   2) English 77.8% (7)
   3) Both interchangeably 11.1% (1)
   4) Neither 11.1% (1)

44. How many hours per day is your child engaged with media such as the web, television, video games, etc. in their native language? (N= 10)
   1) None 60% (6)
   2) 1-2 hrs 30% (3)
   3) 3-4 hrs 0(0)
   4) 5-6 hrs 10% (1)
   5) More 0 (0)

45. How many hours per day is your child engaged with media such as the web, television, video games, etc. in English? (N= 10)
   1) None 10% (1)
   2) 1-2 hrs 50% (5)
   3) 3-4 hrs 20% (2)
   4) 5-6 hrs 20% (2)
   5) More 0 (0)

In your own words:

46. What is your belief about the effects of hearing more than one language in the home on the development of a typical child (one who does not have a disability)? (N= 10)
   1) it broadens the cognitive ability in a child.
2) It is a benefit for the child to speak and understand as many languages as possible.
3) Immersion in more than one language at a young age helps children to grow with the ability to more readily learn another language.
4) Believe it does not cause any problems
5) Children absorb language naturally at a young age. My concern was that she would mix up the languages, so I wanted her to be firmly in English.
6) Positive. I regret that I once tried focusing on English per advice by a developmental pediatrician. She now primarily speaks English.
7) benefits development
8) It is great. Language may be delayed initially but they pick up
9) Better for child
10) may initially cause confusion, but good for the child to understand the language and get used to it

47. What is your belief about the effects of hearing more than one language in the home on the development of a child with autism spectrum disorder? (N= 10)
   1) it could help their thinking and verbal communications with their reasoning development.
   2) I think that being bilingual ENHANCES her comprehension of life skills and events because if she cannot get a concept in one language she does get it in the other.
   3) Our children with ASD have found it incredibly difficult to learn another language, in addition to English. They both adhere to "rules" which will not allow for something to have more than one name. This makes the label of another language very difficult for them to accept.
   4) No bad effects
   5) I think every child on the spectrum is different and if it isn't a problem for a child, then I don't see a problem. I know that my daughter resists learning another language, but I know she understands some spoken Russian.
   6) I don't think there are much of difference. It is understanding, not language per se.
   7) benefits development
   8) I am confused. I hate to make things more difficult for him. But would really like him to speak both
   9) Now I believe it is better for him
   10) may cause confusion and hold to wait until he can master the English language first.

48. What were you encouraged to do concerning speaking more than one language in your family when you learned of the diagnosis of your child? What did you decide to do as a result? (N= 10)
   1) I was told by the doctor who diagnosed my child and by the IEP case worker not to confuse my child with another language other than English because in the school, the teachers will only speak in English. Therefore, I just wanted to do whatever I was told to help my child and I did not speak nor introduced Spanish to her as a toddler/child. However, with family members I do speak in Spanish in front of her, but she seems to tune it out.
   2) In Japan, we were told to use only Japanese. In the US, we were told to use both. We ignored the advice from the Japanese doctor right from the start. We use both interchangeably although we are fading out speaking Japanese with her but not by any plan but because my wife is becoming more comfortable using English. However, when they went to Japan, after being away for a year, my daughter had no problem using and understanding only Japanese. When she came back, she had no problem going back to school using English only. Her comprehension of both languages exceeds her production.
   3) As both were late in speaking, we were encouraged to speak to them only in English. We continue to speak in both French and English, however both children with ASD have adhered strongly to English.
   4) Only English, only English spoken
   5) Nothing. It never came up, so we did nothing different.
   6) At first I got all conflicting advice. Pediatrician suggest English, SLP suggest both, and some even suggests Japanese only, as parents are not capable of fully communicating to the child in their non-native language.
7) Clinicians said it would be fine to teach multiple languages. Professional feedback had no impact on my husband's perspective nor my own.
8) Some therapists did not encourage or discourage. Family members discouraged.
9) Encouraged to speak English only with him. We did as told. This was about 4 years ago.
10) No one encourage to teach my son with autism to speak native language except the extended family.

49. If your decision was to avoid speaking English to your child or around your child, what in your opinion have been the effects of that decision for your child and your family? (N= 6)
   1) n/a
   2) N/A
   3) n/a
   4) Not applicable
   5) It has decreased my son's ability to speak two languages - decreased his ability to communicate with his paternal family members - I feel that interacting in two languages might have had a positive impact on neurological development, so in this way it may have been a missed opportunity.
   6) Avoid speaking English is only temporary, we are planning to put him in Chinese school next year because my son's language ability is showing great improvement.

50. If your decision was to continue speaking more than one language to your child and around your child, what in your opinion have been the effects of that decision for your child and your family? (N= 7)
   1) n/a
   2) N/A
   3) Our other children have learned both languages but the two with ASD have not.
   4) No difference.
   5) I don't understand this question.
   6) We are happy that he speaks some Swedish. We just hope it does not interfere with his development.
   7) It affects the other sibling who we want her to learn more Chinese.

51. Do you know other families who have been in similar situations? What did they choose to do? (N= 10)
   1) No.
   2) They chose monolingualism, but after hearing about our experience they integrated both languages.
   3) n/a
   4) No
   5) Not applicable.
   6) I don't know. I know one family spoke Japanese exclusively, but their plan was to go back to Japan. Other families, whose native language is not Japanese, speak in English when we are together and even with the child.
   7) Yes - we have at least three family/friends whose children have ASD and they are in bilingual households. I believe that all three have chosen to teach their children two languages.
   8) No
   9) No
   10) They choose the most used language in the country.

52. Please share any additional thoughts you may have: (N= 7)
   1) I should have spoken Spanish and English to my child from the start of her symptoms and then diagnosis because I will never know if she could have handled it or could have helped her in her thinking ability as a challenge for her mind and the connection with her speech.
   2) Some concepts are learned more easily in only one language, some can be learned in both. But you will not know which one unless both languages are "equally" used.
   3) I think my husband may also be on the spectrum and he eats up languages. My daughter with ASD resists, but I know her passive vocabulary in Russian is decent. She listens to Russian and replies in English. Her responses show that she understands what is being said, when she
responds. If she does not understand, she does not respond. She tries once in a great while to speak a few words. But I am sure that some children on the spectrum could be natural foreign language learners, but it's in a different way than a neurotypical person. My husband treats languages like candy, but doesn't care to understand the linguistics and doesn't use his skills appropriately sometimes. I majored in Russian in college and I'm much better at linguistics than usage, so I know the difference. It's hard to put into words what I observe and sense. My youngest daughter is much more receptive and open to learning to speak Russian. She doesn't resist like my daughter with ASD does.

4) I deeply regret that my choice to speak English only for a while negatively impacted the sibling's ability to speak. I do not think my ASD son's verbal capacity would change. He's practically bilingual, though his vocabulary is extremely limited. He speaks whatever he picks up.

5) Clinicians need to be provided with additional info about the impacts of bilingual language development in kids with ASD - and, presuming that speaking two languages has benefits and/or is not a detriment to ASD kids - clinicians need to be encouraged to counsel families to go ahead and speak both languages with their kids. ASD individuals have restricted skills and opportunities due to their disability and I think that learning a second language can only expand their skill set and opportunities to connect with family, community and opportunities in the community. - Also - was this survey offered in multiple languages??? Please consider in the future doing so when soliciting feedback from non English speaking individuals.

6) Now I don't think it really matters either way he is intelligent enough to figure it out both languages. He just can't seem to communicate.

7) Parents don't want to add additional pressure to the child with autism by demanding two languages.
APPENDIX B

DATE: February 22, 2012

TO: Tayler Finsel
FROM: Bowling Green State University Human Subjects Review Board

PROJECT TITLE: [298866-1] Monolingual and Bilingual Development in Autism Spectrum Disorder
SUBMISSION TYPE: New Project

ACTION: APPROVED
APPROVAL DATE: February 20, 2012
EXPIRATION DATE: February 19, 2013
REVIEW TYPE: Expedited Review

Thank you for your submission of New Project material(s) for this project. The Bowling Green State University Human Subjects Review Board has APPROVED your submission. This approval is based on an appropriate risk/benefit ratio and a project design wherein the risks have been minimized. All research must be conducted in accordance with this approved submission.

The final approved version of the consent document(s) is available as a published Board Document in the Review Details page. You must use the approved version of the consent document when obtaining consent from participants. Informed consent must continue throughout the project via a dialogue between the researcher and research participant. Federal regulations require that each participant receives a copy of the consent document.

Please add the text equivalent to the HSRB IRBNet approval/expiration date stamp to the "footer" area of the electronic consent form.

Please note that you are responsible to conduct the study as approved by the HSRB. If you seek to make any changes in your project activities or procedures, those modifications must be approved by this committee prior to initiation. Please use the modification request form for this procedure.

You have been approved to enroll 2,000 participants. If you wish to enroll additional participants you must seek approval from the HSRB.

All UNANTICIPATED PROBLEMS involving risks to subjects or others and SERIOUS and UNEXPECTED adverse events must be reported promptly to this office. All NON-COMPLIANCE issues or COMPLAINTS regarding this project must also be reported promptly to this office.

This approval expires on February 19, 2013. You will receive a continuing review notice before your project expires. If you wish to continue your work after the expiration date, your documentation for continuing review must be received with sufficient time for review and continued
approval. before the expiration date.

Good luck with your work. If you have any questions, please contact the Office of Research Compliance at 419-372-7716 or hsrb@bgsu.edu. Please include your project title and reference number in all correspondence regarding this project.

This letter has been electronically signed in accordance with all applicable regulations, and a copy is retained within Bowling Green State University Human Subjects Review Board's records.