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Beyond Therapeutic Techniques: Successfully Serving Hmong Families Living with an Autism
Spectrum Disorder

BY

Der Ariel Xiong Her, B.A.

MSW Clinical Research Paper

Presented to the Faculty of the
School of Social Work
St. Catherine University and the University of St. Thomas
St. Paul, Minnesota

Master of Social Work

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Abstract

Autism, also known as Autism Spectrum Disorder (ASD) has not only been puzzling for parents but for professionals as well. Although ASD affects all races, economic and social classes, and genders, many research studies have shown that ASD is not represented fairly among all races, ethnicities and socioeconomic groups. Multiple research studies have shown the importance of early intervention for children diagnosed with ASD. Research has also found that minority children with ASD are diagnosed at a later age. Very little research has been done among Southeast Asian communities, especially Hmong communities.

We assume that many mental health professionals treating children with ASD are probably using similar techniques. However, what this research paper would like to explore further is looking closer at what professionals are doing beyond the therapeutic techniques that keep Hmong families in therapy. As a developmental disability case manager, it has been my experience that the majority of Hmong families do not seek outside resources such as therapy, for their children with ASD. However, for the few who are using different therapeutic services, what is it that those providers are doing that is drawing Hmong families to their clinics? What additional therapeutic techniques are mental health professionals using when working with Hmong children with ASD that motivates them to come back?

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“The Lord is my strength and my shield; my heart trusts in him, and he helps me. My heart leaps for joy, and with my song I praise him.” (Psalm 28:7 New International Version)

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“Close friends are truly life’s treasures. Sometimes they know us better than we know ourselves.

With gentle honesty, they are there to guide and support us, to share our laughter and our tears.

Their presence reminds us that we are never really alone.” (vanGogh, V. (2015). Vincent van

Gogh quotes. Retrieved from the Goodreads website:

http://www.goodreads.com/author/quotes/34583.Vincent_van_Gogh)

Introduction and Purpose Statement

What Autism Is

Autism, also known as Autism Spectrum Disorder (ASDs), is a developmental disorder that impairs an individual's social interactions and communication development (American Psychiatric Association 2000. Diagnostic And Statistical manual of Mental Disorders Fourth Edition Text Revision; Shyu, Tsai, J., Tsai, W., 2010; Stadnick, Drahota, & Brookman-Franzee, 2013; Thomas, Ellis, McLaurin, Daniels, and Morrissey, 2007). Individuals who are diagnosed with ASD not only share similar characteristics, such as social and communicative difficulties, but may also display certain behavior patterns (American Psychiatric Association 2013; Stadnick, Drahota & Brookman-Fraze, 2013; Thomas, Ellis, McLaurin, Daniels, and Morrissey, 2007). The symptom of ASD and how it impacts the individual differs from one person to the next and also varies, depending on the individual's age and developmental level (American Psychiatric Association 2000). According to the DSM-5 (2013), individuals who are diagnosed with ASD, their social interactions with peers may manifest itself different at various ages. One common behavior individuals with ASD exhibits, is the lack of awareness of others and not being able to identify or notice if and when someone is in distress (American Psychiatric Association, 2013). Similarly to social interaction, communication development also differs from one individual to the next (American Psychiatric Association, 2013). For instance, this researcher has experienced in her line of work, working with an ASD child who is not able to communicate using verbal speech, however is able to sing.

Within the last couple of years, ASD has become a well-known term. Nonetheless, ASD continues to be puzzling for parents as well as for professionals. Researchers continues to look at the causes of ASD, how to live with it, and which nutritional diet makes it worse or better.

Within the last century, there really has been no topic within ASD that has not been challenged and/or explored (Dyches, Wilder, Sudweeks, Obiakor, & Algozzine, 2004).

ASD was once thought to be a pretty low-prevalence disorder. However, it is now considered one of the most widespread forms of intellectual developmental disability in our society among individuals with developmental disabilities (Boyd, Odom, Humphreys & Sam, 2010; Newschaffer et al., 2007; Shyu, Tsai, Tsai, 2010). In fact, according to Zahner and Pauls (1987), within the last two decades, ASD has increased pretty significantly. Multiple studies have shown the dramatic increase in ASD. In the 1960s to 1980s the ratio of those diagnosed with ASD was 1 in every 14,000 individuals. In 2005 that diagnosis increased to 35 – 60 in every 10,000 individuals (Boyd, Odom, Humphreys and Sam, 2010; Fombonne, 2005; Zahner and Pauls, 1987). Although no research has shown a reason for the dramatic increase in the ASD diagnosis within the last decade, it is believed that a contributing factor is the clinicians' increased ability to diagnosed children at a younger age (Boyd, Odom, Humphreys and Sam, 2010; Lord et al., 2006; Stone et al., 1999).

ASD affects all races, socioeconomic groups, and genders. However, a study done by Rice (2007) shows that among the children who are diagnosed with ASD, boys were 3 to 4 times more likely than girls to be diagnosed with ASD (Boyd, Odom, Humphreys and Sam, 2010). With the age of diagnosis as early as 2 to 3 years of age, ASD is also now being considered one of the most common psychiatric disorders among children (Boyd, Odom, Humphreys and Sam, 2010; Shyu, Tsai, J., Tsai, W., 2010). There has been an increase in federal funding to help identify early ASD signs among infants (Boyd, Odom, Humphreys and Sam, 2010) instead of waiting until later in age.

Being able to identify signs of ASD in infants rather than waiting until ages 2 to 3 is important for earlier intervention (Boyd, Odom, Humphreys and Sam, 2010). Multiple studies have shown that the sooner the child can partake in early intervention, the better the long-term results (National Research Council, 2001; Boyd, Odom, Humphreys & Sam, 2010). Due to multiple developmental challenges among children with ASD, early interventions can assist children with their communication, cognitive and social skills and also can address some of the behavioral issues such as tantrums and self-injury (Powell et al., 2000).

Autism is Not Represented Fairly Among all Races

Multiple studies have shown that ASD is not represented fairly among all races, ethnicities and socioeconomic groups (Boyd, Odom, Humphreys, and Same, 2010; Mendal, Listerud, Levy, & Pino-Martin, 2002; Mendal, Novak, & Zubritsky, 2005; Mandel et al., 2009). For this reason, children from different races/ethnicities as well as lower socioeconomic groups are often not diagnosed with ASD until they are much older in age (Boyd, Odom, Humphreys & Sam, 2010) and are not receiving therapy or early interventions in comparison to white children of higher socioeconomic groups (Mandel, Listerus, levy, & Pinto-Martin, 2002; Levy et al., 2003; Landa, Tek, 2012; Thomas, Ellis, EcLaurin, Daniels, & Morrissey, 2007).

Research has also shown that when minority children are diagnosed, they are often times diagnosed with something other than ASD (Landa & Tek, 2012). It is estimated that in the United States approximately 6 million children from culturally and linguistically diverse backgrounds are diagnosed with some form of communication disorder (Battle, 2002). For instance, in two separate studies done by Landa and Tek (2012), and Mandell et al., (2009), both found that African American children are often misdiagnosed with ADHD rather than ASD.

There have been multiple studies concluding that minority children of lower socioeconomic status diagnosed with ASD are not fairly represented in research and early interventions (Hilton et al., 2010; Pierce et al., 2014; Tek and Landa, 2012). There continues to be a gap in research to better understand children with autism from diverse backgrounds (Zhang & Bennet, 2003; Zionts & Zionts, 2003; Jagatheesan, Miller & Fowler, 2010). Even when gathering information for this literature review, there were limited studies found regarding ASD and how it affects Southeast Asians children, particularly Hmong children.

We know the importance of early intervention for children diagnosed with ASD. We also know that according to research, minority children are diagnosed at a later age and that very little research has been done among Southeast Asian communities, especially the Hmong community. We also know that according to what has been found in this literature review, minority children with ASD are not receiving the same kind of early intervention or therapy as Caucasian children are. Therefore, it is essential to this research to examine the different techniques and/or ways mental health professionals are serving Hmong children who are living with an ASD.

The Purpose of This Research

Research has shown that it is crucial that parents get their child diagnosed early and seek training for themselves so that they (as parents) can better understand ASD, and educate themselves to appropriately assist their child in their rehabilitation (Howling, 1998; Shyu, Tsai & Tsai, 2010). However, what we would like to explore further in this study is: How many Hmong children are really utilizing early intervention and/or therapy? How much do Hmong parents really understand about mental illness and in particular ASD? Are Hmong parents

receiving training or education so that they can assist their child with his/her rehabilitation? Do Hmong parents even understand the techniques enough to replicate them at home with their child? More importantly, as mental health professionals, how do we bridge this gap?

We assume that many mental health professionals are possibly using the same techniques. However, what this research paper would like to explore further is to take a closer look at what mental health professionals are doing beyond the therapeutic techniques that keep Hmong families coming back for therapy. As a developmental disability case manager, it has been my experience that the majority of Hmong families do not seek outside resources such as therapy, for their children with ASD. However, for the few that are using it, it is important to explore what is it that those providers are doing that is drawing Hmong families to their clinics? In addition, what is it that is bringing Hmong families back to their clinics/organizations over and over again? What other therapeutic techniques are mental health professionals using when working with Hmong children with ASD that motivates them to come back?

Literature Review and Research Question

History of Hmong People

In the Western culture, disability is normally explained by using medical terms (Gilligan, 2013). However, in many other cultures, disabilities can either be seen as gifts or punishments from God or a higher power (Gilligan, 2013). Therefore, before diving into the logistics of this research question regarding Hmong families and the gap in therapeutic services, it is essential to have a better understanding of Hmong culture, traditions, and beliefs in regards to how Hmong parents perceive children with disabilities, especially children with ASD. By having a clearer understanding of this, it hopefully will help professionals enhance their understanding of Hmong

culture as well as make them aware of why it may be hard for Hmong parents to seek therapy for their child.

Hmong people originated from Siberia and Central Asia, where they lived among the Chinese people for many centuries, mostly as slaves (Livo & Cha, 1991). Shortly after the consolidation of the Manchu Empire in 1775, many Hmong people were targeted and killed. In result of this, it forced the survivors out onto the mountainsides of Burma (now Myanmar), Laos, Thailand and part of Vietnam (Livo & Cha, 1991; Tatman, 2004) to find refuge. There on the mountainside, Hmong families farmed and raised animals as a way of life. During the Vietnam War, many Hmong individuals known as the CIA's secret army, were recruited by the United States to help fight against the Viet Cong. (Livo & Cha, 1991). These Hmong individuals were trained to be fighters and an intelligence-gathering force (Livo & Cha, 1991, p. 2). Their role was to sabotage equipment that was being moved along the Ho Chi Minh trail and to help rescue American pilots who went down over Laos (Livo & Cha, 1991).

When the war ended and American troops withdrew from Vietnam and Laos, the Hmong became the targets of genocide by Pathet Lao (Livo & Cha, 1991, p. 2). Many Hmong families found themselves having to leave their homes and crossed the Mekong River into Thailand in hope to find refuge (Livo & Cha, 1991). In 1976, Hmong individuals started arriving in the United State from the Thai refugee camps (Livo & Cha, 1991). According to the 2010 Census, Minnesota is second only to California (91,224) in its high Hmong population: 66,181. In Minnesota, Saint Paul (29,662) and Minneapolis (7,512) hold the highest populations of Hmong.

History of Hmong Culture and Spiritual Beliefs

The Hmong people traditionally are animistic in their spiritual practice. Hmong People traditionally have a strong belief that disease, death and misfortune are caused by spirits (Livo & Cha, 1991; Tatman, 2004). *“They believe that ponds, streams, rivers, hills, valleys, trees, rocks, and even wind currents all have individual spirits. Ancestors are particularly revered and are worshipped as though they possess god-like qualities”* (Livo & Cha, 1991, p. 3). It is believed that the dead spirits of your ancestors, nature, spirits, evil spirits that are lingering and need a place to rest, and/or spirits who has always resided in the home, are responsible for your health, your family members’ health, death of family members or your misfortune (Tatman, 2004). It is believed that if someone is sick, it is because their soul has been led away by a certain spirit (Livo & Cha, 1991) or that a spirit has been disturbed or angered, therefore a certain ritual will need to be performed (Tatman, 2004).

Shamans, which are seen as *medical doctors, psychologists, holy men, spiritual healers, and advisors* (Livo & Cha, 1991, p. 3) are called upon to perform these rituals. It is believed that if the soul does not return to the body, the individual will die (Livo & Cha, 1991). Because of these cultural beliefs it has been hard for Hmong families to understand the complexity of their child’s disability, especially if the child has Autism Spectrum Disorder (ASD) and there are no physical signs of the disability (as compared to a child with Down Syndrome who often times will show physical signs). The book *The Spirit Catches You And You Fall Down* is used in much research to help medical providers as well as other professionals better understand Hmong people and their beliefs in animism. *“Hmong patients with chronic illnesses...may not always have the framework for understanding their illnesses within their cultural repertoires”* (Helsel, Mochel, & Bauer, 2005, p. 153). Therefore, it is very important to note that when a disability is

seen as something the individual did (in his or her past life), there is a higher chance that the families of this individual will either turn down or not seek outside resources to help this individual (Gilligan, 2013).

How Hmong and Other Ethnic Minorities View or Understand Children with Disabilities

Due to the lack of research found for this literature review with regards to the Hmong community and their understanding of children with disabilities. Studies on other ethnic minorities will be used to show and compare some of the similarity in beliefs that holds true for the Hmong community as well.

Hmong people, similar to other Southeast Asian individuals, have always looked for supernatural explanations for their child's disorder. Even in non-Southeast Asian families, parents of children with a disability lean on their religious beliefs (whatever their religion may be) to help them make better sense of their child's disability as well as put it within a meaningful context. (Jagatheesan, Miller, and Fowler, 2010).

In a study done by Skinner, Baily, Correa & Rodriguez (1999), they found that of the 250 Latino mothers who have children with some form of developmental disability, 55% of them strongly felt that the disability was a sign from God (Jagatheesan, Miller, & Fowler, 2010). Some associated this sign as a curse or a punishment for their sins, however some saw it as a blessing and felt that caring for this individual would help make them more compassionate (Jagatheesan, Miller, and Fowler, 2010). On the other hand, Skinner, Baily, Correa and Rodriguez (1999), found that younger Latino mothers in the United States who are more westernized believed that the older Latino generations are simply ignorant, and saw their children's disabilities more as a blessing, not a result of their sins (Skinner, Baily, Correa, & Rodriguez, 1999). Many of the older generational Hmong parents, similar to the Latino mothers,

also believe that their child's disability is a curse or punishment for something they did or said in their earlier life.

In another research study by Shaked (2005), among 30 ultra-Orthodox Jewish Israeli families of children with autism (Jagatheesan, Miller, and Folwer 2010, p. 98) 20 of the families saw their child as having spiritual gifts and as carrying out "*an important religious mission, a view that is based on the Jewish variant of the doctrine of reincarnation*" (Jagatheesan, Miller, and Fowler, 2010, p. 98). Jagatheesan, Miller, and Fowler (2010) conducted their own study among Muslim families from South Asia and found that according to Hindu beliefs regarding reincarnation and karma, these parents believed that children born with a disability are a gift from god. It is believed that this child was born with this gift (which is the disability) because their family (whom the child with disability is born into) or their parents still have a lesson to be learned, which they did not learn in their past life (Jagatheesan, Miller, and Fowler, 2010).

Therefore this child's gift is to help them learn their lesson (Jagatheesan, Miller, and Fowler, 2010). In the same way, Hmong families often time will perform rituals to see if their child with ASD or other disabilities possess the gift to be a "shaman." This is especially true if their child is on the higher end of the ASD spectrum where many of their functional skills are not as compromised.

In a study done by Shyu, Tsai & Tsai (2010), many Taiwanese parents (like Hmong parents) will often seek fortune-tellers to help explain the reason for their child's disability, especially if it is associated with the child not being able to speak. One parent who was interviewed in Shyu, Tsai & Tsai (2010) said,

“The fortune-teller told us that in his prior life he (the child) was a very lazy and wealthy man. When he wanted to eat, he did not need to ask for it –he just opened his mouth. That’s why he does not want to talk now.”

(Shyu, Tsai & Tsai, 2010, p. 1327).

In another study by Baker, Miller, Dang, Yaangh & Cansen (2010), some of the participants stated that their child’s disability might be a result of either their (the parents) or their ancestor’s *“mistakes, omissions (such as improper burial location), or a “spiritual curse”* (p. 148). Southeast Asian parents, including Hmong parents’, spiritual beliefs and perceptions of their child’s disability can also impact how they pursue treatment or resolution for their child (Wilcox et al., 2007, Shyu, Tsai, Tsai, 2010). *“The way in which people adapt to and seek treatment for an illness is influenced by how they perceive and explain that illness.”* (Shyu, Tsai, Tsai, 2010, p. 1323).

The Benefits of Therapy and Early Interventions are helpful

There is no playing around when it comes to therapy and intervention for individuals with ASD. According to the literature review, parents often commented on the amount of work therapy involves. Although therapy may be helpful, the countless hours of therapy and all the different kinds of therapy and interventions their child has to attend each week are found to be stressful, draining, exhausting and overwhelming. Research has shown that treatments for ASD are lifelong, however early intervention, as early as 35 – 41 months old, is shown to be more effective (Howling, 1998; Shyu, Tsai, & Tsai, 2010). It is often advocated that preschool children diagnosed with ASD received early, intensive, or a “high dosage” of family intervention (Webster, A., Feiler, Webster, V., and Lovell, 2004) as soon as possible.

The wonderful thing about therapy and intervention for children with ASD is that there are such a wide range of different options such as; swim therapy, music therapy, speech therapy, and behavioral therapy, as well as all the different theoretical perspective that are used among each mental health provider (Webster, A., Feiler, Webster, V., and Lovell, 2004). Although there has been a lot more research done regarding the effectiveness of behavioral therapy used among children with ASD, expressive therapies are also known to be very effective in helping with enhancing a child's functioning skills (Anjum and Ajmal, 2012). Expressive therapy or play therapy helps the child with not only their thought process but also enhances their communication skills and social interactions with others (Bromfield, 1989, Sidoli & Villefranche-sur-mer, 2000, Kozima, Nakagawa, & Yasuda, 2005, Anjum & Ajmal, 2012).

In a research conducted by Anjum and Ajmal (2012), using the humanistic intervention approach by integrating different alternative therapies together such as play therapy, speech therapy, art and music therapy, has been shown to improve the child's basic learning skills and also shown to be much more effective. Other research has supported the idea that when there are intensive therapeutic plans put in place, the child with ASD has a higher success rate (Lovaas, 1987; Conner, 1998; Higbee, 2007, Anjum & Ajmal, 2012). In another study conducted by Fein (2009), it was found that in children diagnosed with ASD who received intensive behavioral therapy, ten percent of them also overcame their Autism by the age of nine.

The Challenge with Therapy and Ethnic Minority Parents

Yoder and Canham (2009) found that, according to Hastings' research, there are four coping styles parents often used when trying to understand their child's ASD: "active avoidance coping, problem-focused coping, positive coping, and religious/denial coping" (Yodar & Canham, 2009, p. 223). In the *Active Avoidance* phase, parents normally had concerns regarding

their child's behavior however, due to either lack of knowledge about ASD and/or lack of support from friends and family, parents took no action to seek help (Yodar & Canham, 2009).

In the *Positive coping* phase, parents know something is wrong and are anxious and determined to get an answer, as parents recognized the need to have a better grasp of the situation (Yodar & Canham, 2009). In the *Religious coping* phase, it is believed that the parent still needs to pay a debt from their previous life, therefore, this child with ASD has been given to them as a way to help them pay back that debt so that they can enter into their next life debt free (Yodar & Canham, 2009).

Many of the research used in this literature review emphasizes the importance of early intervention and therapy. Studies have shown that treatments for Autism Spectrum Disorder (ASD) are lifelong, however, the earlier the intervention the more effective the treatment is (Howling, 1998; Shyu, Tsai, & Tsai, 2010). Research has also shown the importance of the role parents' play when it comes to early intervention. As mentioned earlier, it is crucial that parents get their child diagnosed early and to also seek training for themselves so that they (as parents) can better understand and educate themselves to assist their child in rehabilitation (Howling, 1998; Shyu, Tsai & Tsai, 2010).

A study by Thomas, Ellis, McLaurin, Daniels, and Morrissey (2007) shows that ethnic minority parents have a lower rate of seeking out psychologists or pediatricians who specialize in children with developmental disabilities. Research regarding Hmong children with ASD and the use of therapy was very limited for this literature review. The most comparable research in regard to Hmong cultural norms, is probably best presented by Shyu, Tsai and Tsai (2010) who conducted a study among Taiwanese parents to better understand why Taiwanese parents sought professional help for their child with ASD.

Shyu, Tsai and Tsai (2010) found that the number one reason Taiwanese parents reached out to professionals was due to their child's delay in speech development. Some of the other reasons Taiwanese parents sought professional help included "poor social interaction, lack of eye contact, and lack of response to environment, as well as self-centered, obsessive, and fixed behavior" (Shyu, Tsai, & Tsai, 2010, p. 1325). Like many parents across all the racial and socioeconomic spectrum, Taiwanese parents really struggled in accepting their child's ASD diagnosis, as they tried to comprehend what ASD means and how it affects their child (Shyu, Tsai, & Tsai, 2010). Some Taiwanese parent even changed their child's name in hope that it would also change their child's fate (Shyu, Tsai, & Tsai, 2010). This action represents beliefs very similar to Hmong cultural beliefs.

Balancing Both Cultures

As mentioned earlier, because of different cultural beliefs and practices, many parents seek out supernatural explanations for their child's ASD instead of taking their child to therapy or putting early interventions in place. According to Shyu, Tsai, and Tsai's (2010), instead of using the western biomedical model, Taiwanese parents also chose to use alternative modalities such as acupuncture, "*vitamin supplements, sensory integration, treatments for food allergies or detoxication therapy*" (p. 1328). However, there were parents who tried both western biomedical models as well as other treatments, as mentioned earlier. The Shyu, Tsai and Tsai (2010) study was similar to another study done by Wong (2009), which found that for parents who used both western medicine and alternative medicine, many did not want their western doctors to know that they were using alternative medicine on the side. Shyu, Tsai and Tsai's (2010) found that in their first couple of interviews Taiwanese parents were pretty secretive

about the use of alternative medicine. It wasn't until trust was established between the interviewer and the parents (in the second interview) that parents were more open to sharing their use of alternative medicine (Shyu, Tsai & Tsai, 2010).

Not Culturally Sensitive Enough

Taiwanese parents who did seek outside resources, such as speech and occupational therapy, mentioned how exhausted they were due to having to attend all the different treatments, and the cost associated with all the treatments (Shyu, Tsai & Tsai, 2010). Shyu, Tsai and Tsai's (2010) found that parents chose their child's therapy treatments based on some of the following: "attribution of causes, effect of the selected treatment strategy, the child's preference/resistance to treatment strategy, and the fit of the child/parents with the therapist" (Shyu, Tsai & Tsai, 2010, p. 1328). Other research has found that parents feel like they are not given accurate information regarding the services their child is receiving, and oftentimes feel confused about the purpose of the treatment (Baker, Miller, Dang, Yaangh, & Lansen, 2010). In another study done by Webster, A., Feiler, Webster, V., and Lovell (2004), they found that parents often time had difficulty relating to the tutors, "*whose approach was inflexible or out of step with their knowledge of the child's skills*" (p. 41). This lack of information parents are receiving from their providers has created barriers for families of children with ASD (Baker, Miller, Dang, Yaangh, & Lansen, 2010).

Language Barriers

We know that oftentimes language can be a barrier in the effectiveness of services. It is important to not that concepts from one language is hard to interpret into another language to

another given that the content are not always translatable. To add to the complexity of language, there are medical terminologies that do not exist in many languages, including Hmong. When trying to define or interpret ASD, oftentimes one is describing the symptoms more so than the terminology, which can complicate things even more, especially when ASD manifests differently among each individual.

As a Developmental Disability Social Worker for Ramsey County, it is often my experience that many organizations do not have culturally linguistic staff members nor do they provide interpreters during therapy. Therefore, many parents feel left out and oftentimes leave sessions not knowing what they need to do at home or what was done during the therapy sessions. In the Shyu, Tsai and Tsai (2010) study, one parent said, *“I can understand that the teacher (therapist) does not want parents to be present to interfere with the training. I think at least he (the therapist) needs to talk to me about my son.”* (p. 1329). According to Lasky and Karge (2011), immigrant parents are oftentimes judged as failing their children, all because immigrant parents have limited English or do not share the same values that are found in Western culture.

Language continues to be a barrier in the effectiveness of services between mental health professionals and non-English speaking parents. This may be more true in Hmong families where there are still lives in multiple generations living under one roof and parents may speak English but grandparents may not. It is important to explore what mental health professionals are doing when working with the whole family where not all members are English speakers.

Research Question and Conclusion

As mentioned earlier, this research is looking at what each agency is doing to retain their Hmong clientele. Looking beyond the therapeutic techniques and interventions that mental health professionals are already using when working with Hmong children with ASD, what are some providers doing differently that successfully help them retain their Hmong clients and keep Hmong families coming back?

Conceptual Framework

Problem Statement

As previously mentioned, in the United States alone approximately 6 million children from culturally and linguistically diverse backgrounds are diagnosed with some form of communication disorder (Battle, 2002). Multiple research studies have also concluded that minority children of lower socioeconomic status diagnosed with Autism Spectrum Disorder (ASD) are not fairly represented in research as well as in interventions (Hilton et al., 2010; Pierce et al., 2014; Tek and Landa, 2012). Based on the articles that have been found in this subject matter, it is likely that minority children with ASD are not receiving the same kind of early intervention or therapy as Caucasian children. Therefore, it is hard to estimate just exactly how many Hmong children with ASD are actually using therapy or have ever used therapy in their lifetime.

As mentioned earlier, studies show there is a gap in research to better understand children with ASD from diverse backgrounds (Zhang & Bennet, 2003; Zionts & Zionts, 2003; Jagatheesan, Miller & Fowler, 2010). Given the information found for this literature review and knowing that according to the 2010 Census, Minnesota has the second highest Hmong population. It is also important to have a good sense of the number of Hmong children with ASD who are actually in therapy. If this number is small, it is important to understand why. Is it because Hmong parents are not seeking therapy or is it because Hmong children are not being diagnosed at an earlier age, as suggested by research.

This research will hopefully provide more clarity to both current and future mental health professionals on services for Hmong ASD children, whether these services are effective, and if these services are not effective how we can change the system and/or culture to motivate and retain our Hmong clientele. It is important to explore and ask mental health professionals about

the different techniques and interventions that each of them are using, and if those techniques and interventions are found to be useful when working with the Hmong parents and their child.

Cultural Competency Theory and System Theory

We can see pretty clearly how both the cultural competency theory and system theory plays a huge factor in this issue. Parents play an important role in ensuring their child correctly gets diagnosed, seek training for themselves so that they (as parents) can better understand and assist their child in their rehabilitation (Howling, 1998; Shyu, Tsai & Tsai, 2010) and make sure certain appropriate services are put in place to assist their child with ASD. Of the Hmong parents who actually are bringing their children to therapy, it is hard to know exactly how many Hmong parents find therapy to be useful or not. It is hard to know just how much education Hmong parents are receiving or have received regarding ASD, or if they really understand the extent of their child's ASD. Also, if their child is receiving some form of therapy, do Hmong parents understand the techniques enough to replicate them at home with their child?

As mentioned earlier, language, for years has been a huge barrier in the effectiveness of services between mental health professionals and non-English speaking parents or, in some of the cases this researcher have witness, non-English speaking grandparents. Many Hmong family still lives in multi-generational household. This often leaves grandparents as the main caregiver for their grandchildren with ASD since parents are mostly out of the home working full time jobs. As a caseworker, I see English speaking Hmong parents take their children to therapy. However it is not so much the parent but the non-English speaking grandparents who struggles to communicate with their ASD grandchildren who are caring for them. I often witness grandparents not being able to effective use the communicative devices and/or carry out the skills and techniques learned at the therapy session with their grandchildren with ASD. This is

where language becomes a barrier in services between providers and non-English speaking care takers of children with ASD.

The issue is not the device itself and/or the skills and therapeutic techniques that were taught during the therapy sessions. The problem is that communication devices, communicate in English. Most therapists speak in English, therefore the skills and techniques used in therapy are relayed in English. Speech therapy, which according to Shyu, Tsai and Tsai (2010) is the number one reason why Taiwanese parents seek professional help for their child's delay in speech development, is taught in English. Therefore, language becomes a bigger barrier when grandparents, who are the main caregiver, speak only in Hmong. As a caseworker, often time, I see situations where you now have a child who uses a device to communicate in English to a grandparent who speaks only Hmong. Grandparents who do not understand the purpose of the device or understand that this device is the child's way of communicating will instead see this device as a toy and will often either take it away or ignore what the child is trying to communicate. When children go back to therapy and it looks as though the child has not been using their communicative device, the therapist will then question Hmong parents as to whether they are really following through with what was suggested.

Immigrant parents are often judged as failing their children, all because immigrant parents have limited English or do not share the same values that are found in Western culture (Lasky and Karge, 2011). This can be argued from either a cultural competency theory or a system theory. Regardless of what theory this is looked from, the barrier between mental health providers and Hmong parents is clear.

Methods

Research Design

St. Catherine University and University of St. Thomas in the Master of Social Work Program, graduate students are required to either conduct a qualitative or quantitative research study. It involves creating and conducting a research, analyzing the data, and completing a final written report for publication (St. Catherine University and the University of St. Thomas MSW Program Syllabus, 2014 – 2015). For the purpose of this assignment, this researcher conducted a qualitative research project or study by interviewing three mental health professionals. These professionals are currently working in organizations that provided some form of therapy for Hmong children with ASD. This qualitative research study consisted of the following steps:

1. Chose a topic pertaining to the area of social work professionals.
2. Two outside committee members were picked by the researcher to review the final Clinical Research Project Report, give feedback and provide consultation. As well as to attend the final presentation of the researcher's clinical research study.
3. A topic was picked and approved by the chair.
4. Once topic was approved by chair: the researcher gathered articles, completed a literature review and proposal of the research, submitted proposal to the St. Catherine University Institutional Review Board (IRB) to review and approve.
5. Once proposal was approved by the IRB, researcher then emailed out a snowball sampling questions to mental health professionals asking a "yes" or "no" question to whether they are currently serving Hmong children with ASD or not.

6. If providers answered, “yes” to the snowballing questionnaire, they were then contacted by phone for a face-to-face interview. Providers were told that the face-to-face interviews would run about 60 minutes.
7. All face-to-face interviews were audio recorded. Researchers then transcribed each audio recording, coded, analyzed the data, and completed the findings and implications for this publication.

Process and Subjects

A snowball sampling technique was used to help identify mental health professionals who are currently providing early intervention and some form of therapy for Hmong children with ASD within the Minnesota Twin City Metropolitan area. This included the surrounding suburbs of the Twin Cities. A list of providers was obtained through <https://www.autismspeaks.org>, and publicly available email addresses were gathered through different counties Human Services Departments and the Autism Society website <http://www.ausm.org/resource-directory.html>. One screening question was sent out to seventy-eight providers as a way to identify inclusion in the study: Are you currently providing therapy to Hmong children with ASD? Of the seventy-eight emails that went out, five came back. Only one responded, “Yes” to the screening question and four responded “no”.

Due to the low responses from the emails, a follow-up phone call was made to each provider. The phone calls resulted in four “Yes” responses, eight responded that they were not currently serving any Hmong children with ASD at the moment but have in the past, and 12 said they were not sure but would pass the information on to the therapists. The rest of the phone calls were deemed irrelevant due to the researcher having to leave a message and never receiving

a call back. Of the four providers that answered “yes” only three agreed to a face-to-face interview.

Although the proposal aimed to interview 6 – 8 mental health professionals, only three interviews were completed. The proposal also suggested that the researcher would try to interview two male therapists and four female therapists. However, all interviewees used in this research identified themselves as females and the researcher was not able to contact and interview any male therapists for this study.

Protection of Human Subjects

This study was submitted to the St. Catherine University Institutional Review Board for approval. A consent form (*see Appendix A*) was revised from a template created by St. Catherine University to fit this research study. The Chair and committee members reviewed and approved the consent form. At the time of the face-to-face interview, interviewees were given the consent form to review, sign and give back to researcher. A copy was given to interviewee upon request.

To ensure the confidentiality of all participants participating in this qualitative research study, all consent forms and audio recording were kept in a protected password only electronic folder at which only the researcher had access to.

Settings

All interviews were done face-to-face and held in a private room at the office of where each interviewee worked. The interviews were conducted in a private room to assure no interruptions and confidentiality. Being in a private room also helped eliminate background noises during the recording.

Data Collection instruments and process

Once the interviewees had been identified and had agreed to participate in a 60-75 minute in person interview, a day, time, and location, at the preference of the interviewee, was scheduled. Prior to initiating questions, interviewees read and signed the informed consent letter. A copy of the consent was given to the interviewee upon request. Each interview was audio recorded. Once the interview was completed, each of the audio-recorded interviews were transcribed, analyzed and then coded by the researcher.

Interviews consisted of five open-ended questions (see *Appendix B*), which explored the nature of therapeutic techniques used with Hmong children with ASD. Interviews explored both successful and unsuccessful modalities. Researcher used a semi-structured approach to interview, which allowed the researcher to collect information about therapeutic techniques while probing for additional information on related topics.

Data Analysis Plan

All the data were analyzed using a free coding techniques described by Berg & Lune (2012). This included assigning words or phrases that seem to be repetitive in each interview into a coding category. Coding categories were then analyzed as themes emerged. Once the coding was completed, an ethnographic analysis was used to help with the data analysis. An ethnographic analysis was able to help identify some patterns and themes that came up in each of the interviews (Berg & Lune, 2012). Data was then compared against research regarding successful interventions with ASD children to determine commonalities and differences when applying interventions within the Hmong community.

Results and Findings

Due to the small sample size used in this research, it is important to carefully consider the findings in this section. Further discussions regarding the strengths and limitations of this research will be noted in depth later on.

Based on the coding from each of the audio transcriptions, there were five similarities that this researcher found which were also repeatedly mentioned in each interviews. Five categories emerged: The type of Hmong families that are currently in therapy, the cultural and traditional beliefs regarding therapy, the different techniques used among Hmong ASD children, barriers to therapy services, and finally, where referrals come from.

Years of Practices

One of the questions asked was, “How long have you provided therapy to Hmong families with children diagnosed with ASD?” Interviewer 2 stated that she is relatively new to her position, which she held for almost a year. However, she has been working with children with ASD for the last five years. Both interviewee 1 and 3 had been practicing in this field for 18 years or longer. Interviewer 1 and 2 had worked in other organizations prior to coming to the organization they are currently working at. However, interviewee 3 stated that she completed her undergrad internships with this organizations, got hired, and have been with the organization ever since. While at the organization, she has had the opportunity to work in other areas at which all the positions were within the ASD program. All interviewees stated that they not only provide therapy to children with ASD but also sees children with other forms of mental illness as well as children diagnosed with developmental disabilities. Only Interviewee 2 has had

experiences working with Hmong children with ASD at her previous jobs. However, at the time of the interview all worked with Hmong children.

When asked, “How many Hmong children with ASD do you normally see?” The answers ranged from one family per year to sometimes three to four at two of the organizations. However at another organization, interviewee 3 stated that they could see sometimes up to ten Hmong families at a time.

Hmong Families and Therapy

Based on the findings from the snowball sampling questions, all eight of the providers who responded back also affirmed that although they have but are not currently serving any Hmong children with ASD acknowledged however that they were providing therapy to Somali children. However, as mentioned earlier, those eight providers could not be accounted for due to the purpose of this research study. This research was designed to only interview mental health professionals who are currently seeing Hmong ASD children.

Based on the findings, overwhelmingly there are a lot more Somali children with ASD who are currently in therapy than there are Hmong children. Both interviewee 1 and 3 confirmed that there are a lot more Somali clients than there are Hmong. When comparing how many Hmong in comparison to other minority groups, Interviewee 3 stated,

“I can tell you that by far, our largest group of minorities are Somali families and then Spanish speaking families. Hmong families are probably our third if not fourth.”

Interviewee 3 also point out that there is a strong Somali advocacy group who really tries hard to collaborate services with ASD providers due to the high numbers of children diagnosed with ASD within the Somali community. Interviewee 3 stated,

“I would have to say that we haven’t had the same collaboration...with umm...with Hmong groups as we have with the Somali groups. There is a really vocal Somali groups that are contacting us, and collaborating with us. They have a really nice parent support group that they have had for quite some time. I think it’s just the awareness is so high because the number of ASD children are pretty high in that community. We haven’t had as much with the Hmong...I guess more like an ‘organized group.’ And that goes the same as the Spanish-speaking clients as well.”

All three of the interviewees mentioned working with young Hmong children with ASD. However interviewees 1 and 2 were not specific about the ages of the individuals they have worked or currently working with. Interviewee 3 affirmed that most Hmong children who are coming into therapy ranges from age 3 – 12 years old, however, they do serve older Hmong individuals as well.

Based on the findings in this research, it was found that most of ASD Hmong children comes from parents who are fairly fluent in English already. There are a few Hmong parents who do require an interpreter for both the assessment as well as the therapy sessions. However, research found the majority of Hmong parent’s overall are pretty fluent in English.

Interviewee 1 stated,

“I am not sure if my colleagues have other Hmong families that are not fluent in English, but I have not had to use any interpreters for any of the clients that I see.”

Interviewee 1 also affirmed,

“The parents speak English. Typically the parents are younger. Those normally are the parents that comes, do what is suggested...Those are the children who makes the most progress, is when parents are involve.”

All interviewees agreed that younger Hmong parents are coming in with a “broader knowledge base” as interviewee 3 stated, regarding their child’s ASD. Therefore it makes this process run a lot smoother because interviewees are not having to explain a whole lot about their child’s ASD, the benefits of therapy, and/or why they are doing what you are do. Interviewee 2 echoes the same thing. However she shared a little more insight as what she is seeing among the younger Hmong parents compared to the older Hmong generations of parents. Interviewee 2 stated,

“Kuv pum has tas cov nam txiv hluas (I see that the young parents) knows how to seek out resources and really do try to find additional services for puab cov miv nyuam (their children). They are not just dependent on what their child gets in school. I think it’s because they are young...puab paub moog nrhav (they know how to look for) resources. Cov hluas naag nuav (the young parents now days) knows what Autism is. I think cov naam txiv Hmoob kws laug zog (the older Hmong parents) still has the mentality that there is nothing wrong with their child. That puab tug miv nyuas (their child) txhoj txhoj puab (naughty) xw lossi nwg ruam ruam xwb (or he/she is just dumb) and have a hard time accepting or

understanding their child's disability or the severity of puab tug miv nyuam's (their child's) cognitive development"

Interviewee 3 stated that although majority of the Hmong families they serve are younger and fluent in English, they do have a few non-English speaking Hmong families who do require an interpreter. As she went on to share about both younger and older Hmong parents, she sees that the younger Hmong parents are a lot more involved in coming to the therapy sessions. However, they do provide a pretty extensive day treatment program where the therapist goes into the home and works on skills with the whole family. Interviewee 3 stated,

"We try to incorporate skills that the grandparents can do with the child. We understand that Hmong families lives in...ummm... sometimes multi-generational household and it is important for us to meet the family where they are at. We really try hard individualized our therapy to meet the child as well as the family's needs. It really does take a village to raise a child."

Since all the interviewees mentioned that because the majority of the Hmong parents spoke English, and only one of the interviewees mentioned having use of interpreters, it led the research to ask if interpreters were available and/or provided if needed. All responded "yes" to providing interpreters. Interviewee 1 stated,

"In fact, many of the Somali clients use interpreters. I believe one of the therapist here uses a Hmong interpreter for one of her families. But I'm not a hundred percent sure. I don't know if the family I'm thinking of is Hmong or not. I'll have to ask her."

Interviewee 1 also stated that she sometimes will use a family member, who is more fluent in English to do the interpreting for the family and that seems to work as well.

Culture, Beliefs, and Traditions

Although only one of the therapist touched upon this subject very briefly and believes that culture may play a part in why not a lot of Hmong families seek out therapy for their children, the other interviewees gave more specific insights into what they have experienced working with Hmong families. Interviewee 2 explained a little bit about older Hmong parents believing that maybe they've done something wrong in their past life, therefore has been cursed with this child. Interviewee 2 stated,

“Cov naam txiv Hmoob kws laug zog, (the older Hmong parents) still has a hard time believing lossis (or) understanding that there is something wrong with puab tug miv nyuam (their child). Sometimes parent will say..umm..“Tej zag thaum ub...yug lub neej yug lug tsi zoo..umm..es yug txhaj le muaj txujkev npam es yug txhaj le muaj tug miv nyuam zoo le nuav. (Meaning, maybe sometimes in my past I've done something wrong/bad, that that is why I've been cursed with this child.)

Interviewee 2 later in the interview goes on to explain that Hmong parents, especially the older generation still has a hard time linking their child's ASD to a disability because it's not visual. However, that is not the case with the younger Hmong parents she has worked with. Interviewee 2 explains that sometimes living in multi-generational household, there can be times where one's spiritual beliefs can be pushed upon younger's parents decisions to not seek outside resources, such as therapy.

“Cov nam txiv hluas (the younger generations) are more educated and resourceful. They seek out opportunities to get their child additional services. However...yeah...sometimes, especially if...umm...yog puab tseem nrug puab nam puab txiv nyob (if they are still living with their in-laws/parents) there are

always cultural conflict or beliefs about their child's disability and that they should ua neeb lossi hu nplig (do a spiritual call or spiritual sacrificial offering). Tabsis cov hlus nag nuav (the young generations) don't believe in the whole spiritual thing like their parents do."

Interviewee 2 stated that she is always respectful of the parents' beliefs and always encourages the families to do what they need to do, whether it is a spirit calling or a sacrificial offering to their ancestors. She also encourages them to seek out speech therapy for their child as well. She stated,

"I tell the parents, I think that's a wonderful idea. You should make the sacrificial offering to your ancestors. But bring your child to speech therapy as well, so that the child gets double the help. Help from your ancestors and help from the speech therapist."

However, Interviewee 3 stated that although she believes culture, traditions and spiritual beliefs do come into play, they are not seeing it in the Hmong families as they do in the Somali community. She also emphasized that it is not only the Hmong community but all families of different ethnic and socioeconomics groups who ask questions and want to know why and how their child got ASD.

Interviewee 3 said,

"It is not up to us to decide where it came from. Because we have...all families who will say it's because of the immunizations or I knew from day one that something was different or he was fine until he got the shots or something to do with spirituality. There's so many belief systems so the approach we take is, it's really not up to us to figure out where it came from. We can spend a lot of time

and energy talking about that or we can spend our time on how to help. We know that sometimes it's really important...a need that they have to find out where it came from. And that is typically when we refer them back to the community."

Techniques Used

What was found in this research is there is not one specific therapeutic technique the therapist uses that is deemed as the "magical solution" to keeping their Hmong clientele or to any other individuals with ASD. Interviewee 1 stated,

"All of the therapies are very individualize to the child's needs, and is different among each child. Even when I was working with the two (Hmong) brothers, both of them had very specific skills that they were working on."

All three providers have some kind of home program that they use with families.

Interviewee 1 stated,

"We offer skills and teach the parents different strategies to work on at home with their child. However, not all the parents follow our suggestions. There are some parents who comes, participates, follow the suggestions and those are the children we sees making the most progress."

Interviewee 2 shared that sharing different techniques or skills with the older Hmong parents to work on at home with their child can be a challenge. Not so much with "some" of the young Hmong parents. However, interviewee 2 stated,

"Many of them (young Hmong parents) still lives with their parents (in-laws) and each generations has different values and ideas on how to raise kids."

However, as mentioned earlier, only one of the organization provide an “in-home day treatment’ where the therapist actually goes into the family’s home and work with the whole family. This is also the provider that serves sometimes up to 10 Hmong families at any given moment.

“These kids have so much to get out and it’s on us to help get it out...umm...as of all kids, but these kids in particular. I think they have so much strength that are so quickly overseen...cause sometimes you have to work really hard to get it out. But when you do, it’s quite rewarding.”

~ Interviewee 3

What research found in this study is that there are a lot more success stories than there are unsuccessful stories. All three interviewees shared examples of their struggles and the challenges they encounter while working with ASD children overall and not specifically to the Hmong children. However, the reward of watching a child, who comes into the program with no or very limited skills and now able to participate in activities, learn how to perform certain task either independently or with very little assistance, and to see the excitement and smile on the parent’s faces is priceless. As interviewee 3 points out, that although we as a society have come a long way there are still misperceptions of what ASD children are capable of doing and disregard what they can accomplish.

All three interviewees shared that, like all parents from different racial ethnicities, there are parents who are very involved and then there are those who are not so much. The involved parents come to their children’s therapy sessions. They use and work on the skills outside of the therapy sessions and are always very easy to work with. Then there are the parents who are not so involved. Interviewee 1 stated,

“Some families are very good at taking the suggestions you give them and are using them in the Home Program and are very good about using the Home Program with the child, and those are the children who makes the most change...the most progress. And then there are those that are like, ‘Oh yeah, I didn’t have time to do that’ or ‘My life is too busy’.”

However, interviewee 3 observed that the Hmong parents are always very involved, based on her overall experiences. The younger Hmong parents normally are bringing their child to the office for therapy, whereas the older Hmong parents are more like to participate in the Day Treatment Program. Either way, interviewee 3 sees that there are a lot of involvement from parents and even grandparents in both settings (the office and the day treatment program). Similarly to what Interviewee 3 observed, Interviewee 2 also sees that the younger Hmong parents are much more involved with their child. However, Interviewee 2 also sees that the older Hmong parents have a harder time with some of the suggestions given by the therapist. Often times the older Hmong parents sees certain therapeutic techniques as simply just “playing” with the child therefore, then they do not value the techniques or therapy itself. Interviewee 2 stated,

“Cov nam txiv Hmoob (older Hmong parents)...umm...I think has a hard time adjusting to how puab cov miv nyuam (their children) are raised in the Western world. Therapy yog ib yam nyuaj rua puab (is hard for them) because ib txwm peb Hmong 9the Hmong has always)...has never really played with our children. So, sometime nwg yeej nyuaj for parents to follow some of the therapeutic techniques you give them. Rua qhov puab txuj kev xaav (because their mentality) is still very different and they see it as not therapeutic but ‘nkim sib hawm coj tug mivnyuam tuaj (it’s a waste of time bringing their child), because we’re just

'playing with the child.' Another thing is, they have a hard time following a routine or understanding the importance of routine for cov (the) ASD children nuav (here)."

When asked if there are a high percentage of Hmong families dropping out of therapy, all interviewees said no. This researcher asked why Hmong families would dropped out of therapy, and it is found that it is mainly due to schedule (time). Interviewee 1 stated,

"We have had families that stopped coming simply because of daycare. Example: one of the family had 6 kids and two of the children has ASD. They have lots of deficits, language wise. Both boys were coming but mom just wasn't able to manage their schedule and stopped therapy all together. So, it was primarily about the schedule and not about the therapy itself. This family took a break for a while but then came back. They tend to have big families and it's a huge commitment to get them here."

It was found that the unsuccessful stories are not so much the therapeutic techniques that are used but more due to scheduling conflicts and parents not following through with the suggestions.

On the other hand, all three interviewee talked about the success stories they have witness through the years working with Hmong ASD children. A pretty compelling and an example of a success story was shared by interviewee 3, who talked about a young Hmong girl who came to them at age 11 or 12 (she couldn't remember for sure). This little girl has ASD but on top of that also has other pretty severe disabilities. Mom was non-English speaking and had no knowledge of what additional services or resources was out there. Therefore, the mother lacked support from the community, friends and/or family member and thus was quite isolated. By the time this

little girl came to them, the therapist assisted this family by connecting her with other providers and assist in putting a team together. The team consisted of a County social worker, PCAs, teachers, and other providers. Together as a team, they were able to provide mom and this little girl with not only therapy but other services that this provider was not able to do alone.

“The whole concept of, ‘It takes a village to raise a child’ was put into play and it was quite an amazing thing to watch...umm...to watch a team of professionals come together for the benefit of one child.”

Barriers to Services

“These kids have so much to get out and it’s on us to help get it out...umm...as of all kids, but these kids in particular. I think they have so much strength that are so quickly overseen...cause sometimes you have to work really hard to get it out. But when you do, it’s quite rewarding.”

~ Interviewee 3

Three key words that kept coming up when interviewees talked about “barriers to services” included time, language barrier, and lack of support and involvement from parents and community. Under lack of support, there also seems to be an echo from each of the interviewees regarding parent’s lack of understanding the importance of therapy.

There is a phrase that goes, “Time is of the essence.” Time is important to everyone. Interviewee 3 acknowledging how important time is to parents with disabled children, in particular with parents who have more than one child with a disability. Interviewee 3 stated,

“Especially if you are a mother of 5 children and all of them have some form of disability. Who has time to juggle therapy for all 5 children? This mom was just trying to survive.”

Over and over, it was echo that time played a key factor as one of the barrier in services.

Sometimes families will pull their child from therapy due to scheduling conflict, which again has to do with time.

This finding matches what was found in the literature review, where parents often commented on the amount of work therapy involves and the countless hours of therapy their child has to attend to each week (Howling, 1998; Shyu, Tsai, & Tsai, 2010). There are parents who will say they are, “just too busy” or that they “just don’t have time.” Although in the study done by Shyu, Tsai & Tsai (2010), Taiwanese parents mentioned nothing about “time.” They did express how exhausted they were due to having to attend all the different treatments their child had to attend.

When asked if there are a high percentage of Hmong families dropping out of therapy, all interviewees said no. This researcher asked why Hmong families would drop out of therapy, and it is found that it is mainly due to schedule conflicts (or lack of time). Interviewee 1 stated,

“We have had families that stopped coming simply because of daycare. Example: one of the family had 6 kids and two of the children has ASD. They have lots of deficits, language wise. Both boys were coming but mom just wasn’t able to manage their schedule and stopped therapy all together. So, it was primarily about the schedule and not about the therapy itself. This family took a break for a while but then came back. They tend to have big families and it’s a huge commitment to get them here.”

It was found that the it is not so much the therapeutic techniques that are used but more due to scheduling conflicts and parents not following through with the suggestions.

Language is another barrier to services, according to what was found in this research. As mentioned earlier, all interviewees affirmed that majority of the ASD Hmong children come from younger Hmong parents who speaks English fluently. They come with a “broader knowledge”, are more resourceful, and know how to access information and resources for their child.

Concepts in one language is also hard to interpret into another language, especially medical terminology, such as ASD. From this research, Interviewee 2 and 3 acknowledge and appreciate the complexity of languages among the different minority children they see. They understand and recognize that when language becomes a barrier and an interpreter is used, one cannot interpret “word for word” but instead need to interpret the meaning and/or the concept. As seen in earlier sections, there are concepts that are not translatable and the value of the meanings are lost in translation. There are also no words for “Autism” in the Hmong language, as well as in the Somali and Spanish language. Therefore, it makes it even harder for non-English speaking Hmong parents to understand the complexity and severity of their child’s disability. As Interviewee 2 points out, if parents cannot understand the complexity and/or severity of their child’s disability (especially if it is not visual like Down Syndromes) it makes it even harder for parents to appreciate the therapy.

All three interviewees shared examples of their struggles and the challenges they encounter while working with all ASD children overall and not just specifically to the Hmong children when there is a lack of involvement from parents. The reward of watching a child, who comes into the program with no or very limited skills and now is able to participate in activities,

learn how to perform certain task either independently or with very little assistance, and to see the excitement and smile on the parent's faces is priceless. As interviewee 3 points out that although we as a society have come a long way there are still misperceptions of what ASD children are capable of doing and disregard what they can accomplish.

All three interviewees shared that, like all parents from different racial ethnicities, there are parents who are very involved and then there are those who are not so involved. The involved parents come to their children's therapy sessions. They use and work on the skills outside of the therapy sessions and are always very easy to work with. Interviewee 1 stated,

“Some families are very good at taking the suggestions you give them and are using them in the Home Program and are very good about using the Home Program with the child, and those are the children who makes the most change...the most progress. And then there are those that are like, ‘Oh yeah, I didn't have time to do that’ or ‘My life is too busy’.”

However, interviewee 3 observed that the Hmong parents are always very involved, based on her overall experiences. The younger Hmong parents normally are bringing their child to the office for therapy, whereas the older Hmong parents are more likely to participate in the Day Treatment Program. Either way, interviewee 3 sees that there are a lot of involvement from parents and even grandparents in both settings (the office and the day treatment program). Similarly to what Interviewee 3 observed, Interviewee 2 also sees that the younger Hmong parents are much more involved with their child. However, Interviewee 2 also sees that the older Hmong parents have a harder time with some of the suggestions given by the therapist. Often times the older Hmong parents sees certain therapeutic techniques as simply just “playing” with the child therefore they do not value the techniques or therapy itself. Interviewee 2 stated,

“Cov nam txiv Hmoob (older Hmong parents)...umm...I think has a hard time adjusting to how puab cov miv nyuam (their children) are raised in the Western world. Therapy yog ib yam nyuaj rua puab (is hard for them) because ib txwm peb Hmong (the Hmong has always)...has never really played with our children. So, sometime nwg yeej nyuaj (it is difficult) for parents to follow some of the therapeutic techniques you give them. Rua qhov puab txuj kev xaav (because their mentality) is still very different and they see it as not therapeutic but ‘nkim sib hawm coj tug mivnyuam tuaj (it’s a waste of time bringing their child), because we’re just ‘playing with the child.’ Another thing is, they have a hard time following a routine or understanding the importance of routine for cov (the) ASD children nuav (here).”

All three interviewee talked about the successful stories of what they have witnessed through the years in working with Hmong ASD children. A pretty compelling and an example of a success story was shared by interviewee 3, who talked about a young Hmong girl who came to them at age 11 or 12. This little girl had ASD as well severe cognitive disabilities. The mother of this girl did not speak English and had no knowledge of what additional services or resources was out there. Therefore, the mother lacked support from the community, friends and/or family member and thus was quite isolated. By the time this little girl came for services, the therapist assisted this family by connecting her with other providers and put together a support team. The team consisted of a County social worker, PCAs, teachers, and other providers. Together as a team, they were able to provide mom and this little girl with not only therapy but other services that this provider was not able to do alone.

“The whole concept of, ‘It takes a village to raise a child’ was put into play and it was quite an amazing thing to watch...umm...to watch a team of professionals come together for the benefit of one child.”

Where are Referrals coming from?

What this research shows is that parents are getting referrals from their child’s doctors and/or through school. All three interviewees agreed that if the child with Autism Spectrum Disorder (ASD) is higher functioning, doctors might not always identify it right away. Therefore, many times parents are not being referred until the child is in school and the teacher starts noticing certain behaviors. Sometimes parents refer other parents for services, especially if parents who are currently getting services see their child’s skills develop and are happy with the services. Interviewee 1 stated,

“I had a Somali mom who was so pleased with her son’s therapy what her son is now able to do...umm..that she started telling all her friends.”

However, as mentioned earlier, unlike the Somali community, the Hmong community does not have the same collaboration with providers. Therefore, awareness of the different kinds of services available are still very limited and referrals for mental health services are mainly through doctors and teachers.

Discussion and Implications

History of Therapy

According to Kanner (1943) who was quoted in an article by Campell, Schopler, Cueva and Hallin (1996), when autism was first identified, it was believed that this disorder was an unconscious decision this child was making due to him/her rejecting his/her mother. Therefore, according to Bettelheim (1967) (Campell, Schopler, Cueva, and Hallin, 1996), the treatment plan for ASD children back then was to place the child in residential treatment homes away from their parents (Campell, Schopler, Cueva, and Hallin, 1996). When the child was placed in residential treatment, parents had no involvement with the treatment plans whatsoever (Campell, Schopler, Cueva, and Hallin, 1996).

However, according to Schopler and Richler (1971), it was *the Department of Psychiatry, University of North Carolina at Chapel Hill*, (Campell, Schopler, Cueva, and Hallin, 1996, p. 135) that first developed a plan that enlisted parents to partake in their child's treatment plans by taking on the role as co-therapists (Campell, Schopler, Cueva, and Hallin, 1996). This plan, according to Reichler and Schople (1976) later on was implemented into a statewide, community-based program. This program involved parent's participations in the sessions and encouraged a team approach between parents and public school staffs in creating a treatment plan for the child (Campell, Schopler, Cueva, and Hallin, 1996, p. 135)

Findings and What is in Literature

Both interviewee 2 and 3 made a lot of comparisons between the younger generations of Hmong parents and the older Hmong generations' parents. Interviewee 2 stated,

“I think cov naam txiv Hmoob kws laug zog (the older Hmong parents) still has the mentality that there is nothing wrong with their child. Parents will say ‘Kuv tug miv nyuav yeej tsi muaj mob dlab tsi le os. Nwg tsuas yog txhoj txhoj pob xwb os.’” (Meaning, my child has no sickness, he/she is just naughty).

The findings of this research is consistent with that found in an article by Jacob, Gray, and Johnson (2011), who cited Lin & Cheung (1999) in saying that Asians believe that the body and mind are one unit. Therefore, they are more prone to talk about their physical sickness and not bring up the mental distress that they are experiencing. As mentioned by Lin & Cheung (1999), for Asian’s the approach to mental and physical health are much different than how the Western world sees or explains it (Jacob, Gray and Johnson, 2011). Older Hmong parents still have a hard time wrapping their head around their child’s cognitive development disability especially if their child’s ASD is not visible.

Researcher’s Interpretations

Base on the literature review, this researcher was not surprised by the findings of this research. Although, according to the 2010 Census, Minnesota holds the second highest Hmong population, the numbers of Hmong children with ASD who are currently in therapy are devastatingly low. This researcher also did not find it surprising that the majority of the ASD Hmong children come from younger Hmong parents and not so much from older Hmong. Some of the barriers in services, such as language barriers, was something this researcher assumed all along and the findings of this research confirmed this. Factors such as: Language barriers, lack of understanding of ASD, and mentality of mental health services, have always been a struggle in the Hmong community, as well as among other minority groups.

Language barrier – In a study by Hebert (2014), Hebert mentioned that normally after a child has been diagnosed with ASD, their physicians bombards them with a wide range of resources that include: brochures, websites, list of providers, and other reading material regarding their child’s diagnoses. Hebert (2014) also stated that often physicians will also suggest other providers for parents to follow-up with.

Being Hmong and having experienced working with the Hmong community, this researcher found that Hmong Parents who are non-English speakers may not always understand everything that is being communicated to them, even if there was an interpreter at the appointment. Once the parent leaves that setting, there may not be anyone at home to go through all the materials with them. Even if the materials are written in Hmong, not all Hmong individuals read in their native language. Therefore, all the important resources that was given to them by the child’s physicians/providers are no longer useful.

As noted, concepts are mentioned also hard to interpret from one language to another. Similar to what was found in this study. This researcher understands the complexity of interpreting and translating one language to another. This researcher believes that being fluent in a language does not make one a good interpreter or translator. There are words that are not translatable and meanings are often lost in translation or interpretation. Like many other terms, there are also no words for “Autism” in the Hmong language. Therefore, it makes it even harder for non-English speaking Hmong parents to understand the complexity and severity of their child’s disability.

To add to the complication of language, this researcher also sees that many older Hmong parents are computer illiterate. Therefore, some of the older Hmong parents may not possess the skills to look up resources on the computer. As Interviewee 3 stated,

“The language barrier is huge...let alone, just knowing where to start. You know that trying to get around the County system, even when English is your primary language, is hard. And then to add another language on top of that as you try to figure out services...umm...is even more challenging.”

Lack of understanding of ASD - ASD, unlike Downs Syndromes or Cerebral Palsy, do not have a visible disabilities or defect. Therefore, parents may believe that their child is really just “naughty” or “slower in their learning.” This researcher has hear Hmong parents say, “Miv nyuas, thaum miv tes yeej txhoj pob. Luj tes tsi txhoj lawm.” Meaning, “Children, when little are bound to be naughty. They will grow out of it as they get older.”

According to Hebert (2014), many parent’s idea and/or perceptions of ASD are strongly influenced by what they see and/or hear. Therefore, if parents have never encountered anyone with ASD or similar traits as their child, it makes it difficult for parents to understand their child’s disability (Hebert, 2014). This researchers as well as one of the interviewee, also witnessed the same thing as Herbert (2014) within the Hmong community. This makes therapy hard for some parents to accept, especially if it contradicts with their beliefs and/or value system.

Mentality of mental health services – Based on this researcher’s experience, mental health overall is such a taboo topic, regardless of what community the individual is from. But particularly within the Hmong community, mental health is still very hard for the older generation of Hmong parents to talk about. In an article by Park and Chesla (2010), they reported that the disparity among Asian Americans and mental health services are still pretty significant.

“For an immigrant community such as Asian Americans, the culture of their country of origin and the society in which they currently live in have a significant role in their belief and their approach toward seeking help.”

(Jacob, Gray, and Johnson, 2011, p. 180)

Jacob, Gray and Johnson (2011) gave a very concise picture to the mentality of Hmong individuals on how they go about seeking professional mental health services. Looking back to this researcher's own experiences growing up in the Hmong community, Hmong individuals will seek additional medical advice from their elders, family members and friends (who are NOT medically-trained professionals) before seeking professionals for medical attention. This help-seeking pattern decreases even more significantly for mental health services. From this researcher's own experience as a Hmong, often times, her parents and/or family members would suggest using alternative medicine or spiritual guidance before following up with what their primary doctor has suggested. As mentioned by Gee (2004), Goldsmith (2000) and Lin & Cheung (1999), Asians are more likely to converse with their doctors about their physical health rather than what is mentally concerning them (Jacob, Gray and Johnson, 2011)

Implication for Policies

According to the literature reviews, it is found that the sooner the child can partake in early intervention, the better the long-term results (National Research Council, 2001; Boyd, Odom, Humphreys & Sam, 2010). Therefore, it is crucial to identify signs of ASD in infants earlier rather than waiting until ages 2 to 3 (Boyd, Odom, Humphreys and Sam, 2010). Multiple researchers have shown that ASD is not represented fairly among all races, ethnicities and socioeconomic groups (Boyd, Odom, Humphreys, and Same, 2010; Mendal, Listerud, levy, &

Pino-Martin, 2002; Mendal, Novak, & Zubritsky, 2005; Mandel et al., 2009). There is still a huge discrepancy between when children from different races/ethnicities as well as lower socioeconomic groups are diagnosed compared to white children of higher socioeconomic groups (Mandel, Listerus, Levy, & Pinto-Martin, 2002; Levy et al., 2003; Landa, Tek, 2012; Thomas, Ellis, EcLaurin, Daniels, & Morrissey, 2007). Therefore, it is imperative that stronger policy be put in place for early diagnoses and intervention for all children, especially lower socioeconomic minority children.

Implication for Research

Based on the findings in this research the importance of parents' involvement has been supported in other studies. Research, such as Bristole and Schopler (1998) and Schopler and Reichler (1971), who was cited by (Campell, Schopler, Cueva, and Hallin, 1996), found the collaborations between the professionals and the child's parent is invaluable and necessary. According to Campell, Schopler, Cueva, and Hallin, (1996) there are four important components in regards to the collaborations that occur between the providers and parents as they work together to better assist this child. Those four components includes:

1. Having the parents take the role of the trainee as the therapist takes on the role of the trainer.
2. In situations where parents may have a better grasp and understanding of their child's needs, the roles of the provider and the parent then changes where the parent becomes the trainer and the provider learns from the parent.
3. The importance of building support for each other (both parents and provider) as they encounter frustrating circumstances

4. The importance of parents being an advocate for their child

(Campell, Schopler, Cueva, and Hallin, 1996, p. 135)

Although all providers encourage participations from parents, not all parents participate. It would be important to explore the Hmong parent's perspective regarding this issue in future research. As the saying goes, "There are always two sides to a story." It is essential that the parent's voices are heard so that appropriate steps can be put in place to support Hmong parents in getting services for their child with ASD.

Implication to Social Work Practice

Based on the finding in this research, it shows the importance social workers play in helping parents connect with outside resources. Regardless if you are a school social worker, county social worker or a clinic/hospital social worker, it is important to assist everyone, especially the non-English speaking families. Social workers must work to connect families with appropriate services so that they do not fall through the cracks. There needs to be a more aggressive effort from all social workers to ensure all children have access to the different services available to them.

Due to the high volume of cases each social worker has on their caseload, sometimes certain families fall off our radar. One thing this researcher always tells her clients are, "If there is no fire, I assume everything is okay." Yet, that is not always true because there are certain minority groups that simply do not share what they are really struggling with due to not wanting to "burden" you with their issues, or the fear that you would not understand and would not be able to help. Sometimes there is shame associated with that, so the individual or family does not share.

As social workers, we are not only here to help but also here to be a voice. Our role should not be to only look at the different kinds of services available and implement those services. Social workers need to also play the part of an advocate and an ally to those who have been forgotten or hurt by the system, and/or fell through the cracks. Because using an interpreter takes twice, if not three times as long, this researcher has often witnessed other social workers skipping over important information or leaving out explanation of certain services that would be beneficial to the individual simply because of language barriers and lack of time.

Strengths and Limitations

Qualitative research allows for an in-depth understanding and description of natural phenomenon through narrative analysis. However, results are tempered by a small non-random sample. Moreover, results will not necessarily be generalizable to a broader population, but will help begin to shed light on a topic of which research is non-existent.

One of the limitations of this research was the inability to interview all the providers who have had experience working with Hmong children with ASD. Due to how this study was set up, all the providers who responded back to the sampling questions were not currently serving Hmong children with ASD and thus were not able to be interviewed and/or accounted for. It would have been beneficial to talk to all providers who have had experienced working with Hmong ASD children to have a broader picture of this issue. It would have been important to know from all providers if the Hmong ASD children graduated from the program/therapy sessions or if they dropped out of therapy.

There was also no way of finding out from mental health professionals how to better understand some of the barriers in systems to support Hmong families and children in ASD and how to remove those barriers. Because the research was set up to only interview mental health

providers who are currently serving Hmong children with ASD and due to the research wanting to look more closely at what each agency is doing to retain their Hmong clientele, interviews were not set up with those other six providers. Further research is necessary in order to include all providers who have had and are currently working with Hmong children with ASD.

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Appendix A

CONSENT FORM ST. CATHERINE UNIVERSITY

Mental Health Professionals' perspectives on successful techniques and interventions used among Hmong children with ASD

I am conducting a study about the different techniques and intervention used among mental health professionals who work with children with ASD. I am especially interested in hearing from each mental health professionals who are working with ASD Hmong children and those who are not and weather the techniques and interventions used different or similar each other. The purpose of this study to better understand weather the techniques and interventions used among mental health professionals helps in retaining their Hmong clientele. The purpose of this research is to better understand why Hmong families are not choosing to keep their child in therapy when research have shown the benefit of early intervention and therapy and to help bridge the gap in services between mental health professionals and the Hmong community.

I invite you to participate in this research. You were selected as a possible participant because *you* were identified as a mental health professional is working in an agency that is working services to children with ASD. Please read this form and ask any questions you may have before agreeing to be in the study.

This study is being conducted by: Der Her, a MSW student at the University of St. Thomas, and Dr. Rajean Moone, professor for Social Work Practice Research summer class.

Background Information:

As mentioned above, the purpose of this study is: to better understand weather the techniques and interventions used among mental health professionals helps in retaining their Hmong clientele. The purpose of this research is to better understand why Hmong families are not choosing to keep their child in therapy when research have shown the benefit of early intervention and therapy and to help bridge the gap in services between mental health professionals and the Hmong community.

Procedures:

If you agree to be in this study, I will ask you to do the following things: Agree for a face-to-face interview. A time will be set up for you to be interviewed by Der Her. The interview will take place in a private setting and will last about 60 - 70 minutes. For this study, you will be audio recorded and later the audio recording will be transcribed. This will be a one-time interview only.

Risks and Benefits of Being in the Study:

Like any study, this study may have some risk that can impact you both emotionally and/or psychologically as the interviewee. Because this study is asking about different techniques and interventions used when working with Hmong children with ASD. It can trigger any emotions you may have had in your own life, especially if you have love ones who with ASD who are in therapy themselves. It can also trigger some emotions that you have encountered while working with the Hmong community.

The direct benefits you will receive for participating are: None

Compensation:

You will receive payment: None

Confidentiality:

The records of this study will be kept confidential. In any sort of report I publish, I will not include information that will make it possible to identify you in any way. The types of records I will create include audio recording, transcripts, computer records; which will all be destroyed after the study has been completed. During the time of the study, all audio recording, transcripts, computer records will be kept on private computer with protected password, which only student will have access to.

Voluntary Nature of the Study:

Your participation in this study is entirely voluntary. Your decision whether or not to participate will not affect your current or future relations with the St. Catherine University. If you decide to participate, you are free to withdraw at any time up to and until end of March 2015. Should you decide to withdraw data collected about you will not be used in any way in the study. You are also free to skip any questions I may ask.

Contacts and Questions

My name is Der Her. You may ask any questions you have now. If you have questions later, you may contact me at 612-242-1336. Dr. Rajean Moone, Chair for MSW Research Study, will be overseeing this study and he can be contacted at 651-235-0346. You may also contact the St. Catherine University Institutional Review Board, at (651) 690-7739 or jsschmitt@stkate.edu.

You will be given a copy of this form to keep for your records.

Statement of Consent:

I have read the above information. My questions have been answered to my satisfaction. I consent to participate in the study. I am at least 18 years of age. I also consent to being audio recording for the purpose of this study.

Signature of Study Participant

Date

Print Name of Study Participant

Signature of Researcher

Date

Appendix B

Schedule of Questions

Screening Question

1. Are you currently serving any Hmong children with ASD at your organization?

Survey Questions

1. Demographic Questions:
 - a. Can you please tell me a bit about your background – your degrees and licensures?
 - b. How long have you provided therapy to Hmong families with children with Autism?
 - i. What is the age range and average age of the Hmong children?
 - ii. How many Hmong children do you serve?
2. What therapeutic techniques do you use with your clients in general (not just Hmong clients)?
3. Can you describe successful techniques and interventions you use when working with Hmong children with ASD?
 - a. What makes these techniques and interventions successful?
 - b. Can you give an example of a scenario using the technique?
4. What are some techniques that are not successful when working with Hmong children with ASD?
 - a. What makes these techniques and interventions not successful?
 - b. Can you give an example of a scenario using a technique that did not work so well?

5. What alternative modalities such as acupuncture do your clients use in addition to the therapy you provide?